Ethics, e-Inclusion and Ageing

SENIOR Discussion paper for the European Ministerial e-Inclusion Conference Vienna, 30 Nov- 2 Dec 2008

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Ethics, e-Inclusion and Ageing

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1 Executive Summary

In line with the objectives of the renewed *Lisbon strategy*[1], the *i2020 Strategic Framework* purports to create a "Single European Information Space" which includes "a common set of regulations that govern the supply of content and services and the operation of networks, regardless of the technology that is being used"[2]. In such a context, ethics play a vital role by providing the general frame to EU policies. The specificities of ethics and e-inclusion came into sharper focus at the workshop organised by the Commission in **Bled in May 2008**, which explored the dimensions of ethics and e-inclusion in different contexts. The SENIOR project contributed to the Bled Workshop with a discussion paper devoted to ethics of e-inclusion of older people. The points fixed by the "**Bled Discussion Paper**" constitute the basis of this second discussion paper, which is published for the **European Ministerial e-Inclusion Conference**. Four major areas for further discussion have been identified: (i) developing of a specific approach to ethical issues raised by ICT; (ii) describing in greater detail the age related digital divide in Europe; (iii) defining the legal framework for inclusion of the elderly in the digital society; (iv) identifying technology trends and emerging challenges. SENIOR proposes the following action points:

Action 1: Propose a set of actions to facilitate the development of communication lines between different EC services, agencies, and relevant expert committees on the issue of ICT ethics.
Action 2: Promote further research on the segmentation of the elderly population in Europe, on the way in which digital divide impacts on different segments, and to what extent the digital divide increases marginalisation in the most vulnerable segments of the older population.
Action 3: Indentify and target with specific policies the main threats to older citizens' dignity
Action 4: Develop an understanding of the wider legal and policy implications of anti-discrimination provisions on e-inclusion, in particular on ageing, by promoting research and debate on this subject and by involving relevant EU services and agencies (e.g., the FRA).
Action 5: Promote further reflection on privacy as a distinct concept from data protection and issue a comprehensive policy document on privacy as fundamental liberty right, particularly regarding older citizens.
Action 6: Develop specific guidance on data protection in elderly people, in particular in the context of ambient intelligence and assistive technology.
Action 7: Prevent anti-ageing technology from reinforcing ageism by carefully monitoring messages conveyed by industry and by promoting educational campaigns.
Action 8: Scrutinize the development of brain-machine interfaces (BMIs) and involve all stakeholders in an ongoing ethical review of the technology design.
Action 9: Promote more systematic analysis on specificities of biometric system design for older people with respect to their biological and cultural background.
Action 10: Adopt opportune regulatory measures in order to ensure that the implementation of biometric systems, notably large scale identification schemes, and questions of interoperability, encompass the requirements of the elderly.
Action 11: Support the production of inclusive design guidelines for ambient intelligence to avoid barriers, notably for elderly people, in the design.
Action 12: Promote ethical and legal reflection on surveillance practices on elderly people in order to issue specific guidance and regulation, also involving relevant EC services, agencies, and committees [e.g., the Article 29 Data Protection Working Party, European Data Protection Supervisor (EDPS), the European Group on Ethics and Science in New Technologies (EGE), the European Union Agency for Fundamental Rights (FRA)].
Action 13: Promote the development of corporate statements of social responsibility and codes of ethics in e-inclusion and implement EC Corporate Social Responsibility (CSR) policies in this field.
Action 14: Devote further research to collect and compare best practices at local and regional levels.
Action 15: Launch an initiative to monitor in real time ethical and privacy implications of emerging technology relevant to e-inclusion.
Action 16: Promote more structured exchanges between stakeholders by creating regular consultative mechanisms, platforms and fora.

[1] Kok, Wim, et al., *Facing The Challenge. The Lisbon strategy for growth and employment*, Report from the High Level Group chaired by Wim Kok [the Kok report], Office for Official Publications of the European Communities, November 2004.
[2] I2020: A European Information Society for Growth and Employment is a strategic framework to boost Europe's digital economy, and is a key part of the EU's renewed Lisbon strategy for growth and jobs. http://ec.europa.eu/i2010/

2 Introduction

Modern societies have witnessed an expansion of public initiative in private life. Several aspects of the life of the individual, such as health, work, family life and education, hitherto confined to the "shadowy realm of the household", are today matters of public concern.[3] We have learnt[4] how legal regulatory frameworks (and the demands for legal recognition and protection they are based on) affect several "spheres" of life, and how therein the separation between what is private (e.g., to live long) and public (e.g., to enjoy decent health services and a decent environment) is not always valid. The social has become political.

Policies on inclusion of the elderly in the digital age reflects this state of things. The combined effect of the "rise of the social" and the increased use of digital technologies in many spheres of life (health care, security, education, commerce, etc.) is mirrored in the European Union's e-inclusion (i2020) policy framework. In line with the objectives of the renewed Lisbon strategy[5], the i2020 Strategic Framework purports to create a "Single European Information Space" which includes "a common set of regulations that govern the supply of content and services and the operation of networks, regardless of the technology that is being used".[6] In such a context, ethics plays a vital role by providing the general framework for EU policies. This is explicitly acknowledged by the Riga Declaration[7] on "ICT for an inclusive society", which calls for increasing ethical awareness:

> *Particular attention must be paid to further improve user motivation towards ICT use, as well as trust and confidence through better security and privacy protection... Realising increased quality of life, autonomy and safety, while respecting privacy and ethical requirements.*

The Commission has continued to emphasise the importance of ethical issues in e-inclusion in its 2007 Communication on Ageing well in the Information Society[8], the associated Commission Staff Working Paper[9], and the "European i2010 initiative on e-Inclusion - To be part of the information society"[10]. More recently, it has spoken of the need for "extending the European values of inclusion and quality of life to the information society" in its i2010 Mid-Term Review[11] and in the Renewed Social Agenda[12], wherein it notes that "Digital technologies have already empowered millions of citizens and helped socially and geographically marginalised groups become more included and engaged." Finally the specificities of ethics and e-inclusion came into sharper focus at the workshop organised by the Commission in Bled in May 2008,[13] which explored the dimensions of ethics and e-inclusion in different contexts. Within this framework, the SENIOR dialogue roadmap is tasked with assessing the social, ethical and privacy issues involved in ICT and ageing, "to understand what lessons should be learned from current technological trends, and to plan strategies for governing future trends"[14].

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[3] Arendt, Hannah, *The human condition*, University of Chicago Press, Chicago, 1974.

[4] Along the traditional civic-political sphere occupied with political participation to the elaboration of general norms, there emerges a social one of interaction, networking between persons around common interests diverse as the whole fabric of human society; and a third one, conceived of as the porous circle of the individual seeking recognition beyond rigid group and role understandings such as name, sex, age, lifestyle. See Habermas, Jürgen, *The Structural Transformation of the Public Sphere: Inquiry into a Category of Bourgeois Society*, MIT Press, Cambridge, MA, 1989.

[5] Kok, Wim, et al., *Facing The Challenge: The Lisbon strategy for growth and employment*, Report from the High Level Group chaired by Wim Kok [The Kok report], Office for Official Publications of the European Communities, November 2004.

[6] I2020: A European Information Society for Growth and Employment is a strategic framework to boost Europe's digital economy, and is a key part of the EU's renewed Lisbon strategy for growth and jobs. http://ec.europa.eu/i2010/

[7] On 11-13 June 2006, the European Commission, together with the Latvian Government and the Austrian Presidency of the EU, organised a high-level conference on the theme "ICT for an inclusive society" in Riga. The conference included an informal meeting of Ministers, where Ministers of the EU Member States and accession and candidate countries, European Free Trade Area (EFTA) countries and other countries adopted a Declaration on e-Inclusion, commonly known as the "Riga Declaration". http://ec.europa.eu/information_society/activities/e-Inclusion/events/riga_2006/index_en.htm.

[8] Ageing well in the Information Society, Action Plan on Information and Communication Technologies and Ageing, An i2010 Initiative, COM(2007) 332 final, Brussels, 14 June 2007. http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52007DC0332:EN:NOT

[9] Commission Staff Working Document, SEC(2007) 811, Brussels, 14 June 2007.

[10] European i2010 initiative on e-Inclusion: "To be part of the information society", COM(2007) 694, Brussels, 8 Nov 2007. http://ec.europa.eu/information_society/activities/e-Inclusion/policy/i2010_initiative/index_en.htm

[11] Preparing Europe's digital future: i2010 Mid-Term Review, COM(2008) 199, Brussels, 17 Apr 2008.

[12] Towards a Renewed Social Agenda for Europe – Citizens' Well-being in the Information Society, Commission Staff Working Paper, SEC(2008) 2183, Brussels, 2 July 2008.

[13] Rogerson S., "Ethics and e-Inclusion: Exploration of Issues and Guidance on Ethics and e-Inclusion, Contribution to the European e-Inclusion Initiative", Report of the workshop, September 2008.

[14] SOCIAL, ETHICAL AND PRIVACY NEEDS IN ICT FOR OLDER PEOPLE: A DIALOGUE ROADMAP (SENIOR) is a 24-month support action which aims to provide a systematic assessment of the social, ethical and privacy issues involved in ICT and Ageing. For information about SENIOR see www.seniorproject.eu

3 The Bled Discussion Paper on Ethics and e-Inclusion

The SENIOR project contributed to the Bled Workshop with a discussion paper devoted to the ethics of e-inclusion of older people ("Bled Discussion Paper")[15]. That paper focussed on nine areas for further research and discussion:

1) Age definition and e-inclusion policies
2) Justice
3) Rights and discrimination
4) Participation and privacy
5) Dignity and body integrity
6) Somatic surveillance
7) Human experimentation in ICT for the elderly
8) Informed consent
9) Loneliness and isolation.

3.1 AGE DEFINITION AND E-INCLUSION POLICIES

While ageing is a biological process, age definition is largely a social construct that should reflect the fluid nature of today's population of senior citizens rather than a rigid category apt to create stereotypes and limitations. Applying the generic label of "elderly" to all citizens over the age of 60 or 65 glosses over the broad spectrum of conditions and situations faced by people placed within this category. The naissance of an extended middle age and the extension of life into the eighties, nineties and beyond have created third and fourth age groups whereby we can distinguish two distinct phases of later life. This extended middle age bridges the point of retirement with the fourth age, which is characterised by the oldest of the old, people in their eighties, nineties and above. People in these two periods of old age have also been referred to as "young elderly" and "older elderly".

Younger senior citizens are a heterogeneous population, which share physical and mental conditions that put them closer to the middle-aged than to the older senior citizens group. They are people who would be considered chronologically older according to a standard description, but who are actually biologically and psychologically middle-aged. Younger senior citizens are the main victims of the digital divide and could be consequently the main beneficiaries of measures for overcoming it. Older senior citizens are people in their eighties and nineties. They are often suffering from various negative changes in their physical and mental abilities. Gerontologists often refer to these changes as increasing frailty. The main goal of e-Inclusion in regard to older senior citizens should be containing frailty and promoting independent living by using assistive technologies[16], which have important ethical implications.

3.2 JUSTICE

Justice can be conceptualised as fairness, which includes: i) fair distribution (distributive justice), ii) fair and reliable procedures (procedural justice), iii) fair retribution for evil and good done (retributive justice), and iv) proper restoration of evil done (restorative justice).[17] The digital divide offends the principle of justice according to all four of these meanings. The principle of fair distribution tends to stress the commodity function of Information Communication Technologies (ICT), which is obviously important but not exhaustive. Digital technologies are goods, but not only goods. Digital technologies are also instruments to reach other goods; they are enabling technologies, which allow people to fulfil important material, social and human goals. In such a sense, the age-related digital divide contravenes the principle of procedural justice, which calls for the adoption of fair procedures. The age-related digital divide involves retributive justice too. It is morally untenable that senior citizens, who have contributed more to the growth and development of the whole polity, should be excluded from the benefits of the digital revolution. Finally, the age-related digital divide contravenes restorative justice.

[15] "Ethics of e-Inclusion of older people Discussion paper for the Workshop on Ethics and e-Inclusion, Senior Discussion Paper No. 2008/01, April 2008, www.seniorproject.eu

[16] Assistive technologies for older senior citizens include affective computing, memory assistance, robotics, ambient intelligence and sensors, ICT for physical and cognitive training, brain-computer interaction or more generally neuro-ICT interfacing, navigation systems, speech, sign and movement recognition, ICT for modelling and simulation of users and their interaction with devices (virtual user, virtual artefacts), ICT for social networking, automatic language translation, collaborative creativity, alternative communication environments and virtual worlds.

[17] Tyler, T.R., and M.A. Belliveau, "Dealing with Tradeoffs Among Justice Principles: The Motivational Antecedents of Definitions of Fairness", in Barbara B. Bunker and Jeffrey Z. Rubin (eds.), *Conflict, Cooperation and Justice*, Jossey Bass Inc. Publishers, 1995, p. 291.

Senior people who are suffering from physical and mental limitations have been often damaged by polluted environments, unsafe working conditions, inadequate medical treatments and so on. They deserve a proper restoration for the evils suffered because of their active participation in the labour market.

3.3 RIGHTS AND DISCRIMINATION

Universal access to communication and information services can be considered a liberty right in the sense that digital technologies can empower people and free them from many constrictions and limitations. Most digital technologies have the potential to increase personal freedom (think of the Internet) and any lack of access to them may result in impairing individual liberty. Conceptualizing universal access to ICT in terms of a liberty right implies that the state's main obligations should be the removal of any legal conditions which may prevent senior citizens from accessing new technologies. Given the pervasive nature of ICT in today's society, any digital divide is also a form of indirect discrimination. The Council Directive on implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation[18] defines acts of indirect discrimination as:

> *an apparently neutral provision, criterion or practice that would put persons of a particular religion or belief, a particular disability, a particular age, or a particular sexual orientation at a particular disadvantage compared with other persons.*

Universal access to ICT can be also conceptualised as a (positive) claim right, which is a right to have something. Without entering into the various subtleties of claim rights theory[19], this notion logically implies that one person's possession of a right is equivalent to someone else's possession of a duty – a duty, moreover, with the same content. It implies that senior citizens have the right to claim accessibility to ICT, including financial support, educational programmes designed for them, special content, etc. In other words, as there are specific schemes to ensure universal health insurance, there should be similar schemes to ensure universal digital access.

3.4 PARTICIPATION AND PRIVACY

Participation is a key concept in e-inclusion, which includes things such as voting, contributing to democratic society by learning and/or teaching, and interacting with others. In its broadest sense, the right to participation refers to participation in public affairs, in what Habermas defined as the "public sphere"[20], which embraces activities of civic associations, neighbourhood groups, social movements and social clubs, as well as formal procedures of governments.

An important ethical problem, however, is the way in which e-inclusion is used in regard to the tension between public and private spheres. The notion of e-inclusion certainly underscores the importance of being included in families, groups, communities and networks but also emphasises the significance of being an independent individual, someone who has the possibility to "stand apart" from the intrusion of others. Indeed, among values accorded protection under European human rights law and together with the right to participation, there is the respect for private life and the protection of personal data[21]. Just as one has the right to participate in the public sphere, one also has the right to maintain one's privacy. Hence, social institutions must respect the private life of individuals and the protection of personal data. While the state must play an active role in data protection, the individual should have the possibility to control access to his or her personal information and to construct his or her own public persona.

3.5 DIGNITY AND BODY INTEGRITY

ICT should not impinge upon the rights of senior citizens, but rather should empower them to protect and pursue their rights. Among these rights is that of dignity, the importance of which is highlighted by the very first article of the European Charter of Fundamental Rights: "Human dignity is inviolable. It must be respected and protected." The principle of dignity affirms that any human being is priceless,

[18] COM(2008) 426 final

[19] E.g., Sreenivasan, Gopal, "A Hybrid Theory of Claim-Rights", *Oxford Journal of Legal Studies*, Vol. 25, No. 2, 2005, pp. 257-274. http://ojls.oxfordjournals.org/cgi/content/short/25/2/257

[20] Habermas, Jürgen, *The Structural Transformation of the Public Sphere: Inquiry into a Category of Bourgeois Society*, MIT Press, Cambridge, MA, 1989.

[21] Articles 7 and 8 of the Charter of Fundamental Rights of the European Union (2000/C 364/01) and Article 8 of the European Convention on Human Rights.

literally invaluable, independent of their age, gender, socio-economic condition, ethnicity, religion, etc. There is no utilitarian consideration that may ever justify the sacrifice of a single human being for whatever reason (be it ideology, religion, science, philosophy and so on). Dignity is an essential principle in e-inclusion.

According to the Charter, two of the chief aspects of dignity are (i) the right to life and (ii) the right to the integrity of the person, which also implies the right to the free and informed consent of the person. Older senior citizens are facing the last years of their lives. New technologies may offer a way to extend their lives in a more comfortable, more dignified condition. Yet it should be clear that there are some questions concerning life and death that do not admit a technical fix. The right to life should never be conceptualised in terms of an obligation to submit to any anti-ageing technology. The right to the integrity means that one's physical and psychological conditions should be respected and no one has the right to infringe upon them without explicit and informed permission. This principle holds true also for senior citizens and is vital when one considers assistive technologies destined to meet the needs of the older senior citizen.

3.6 SOMATIC SURVEILLANCE

Foucault's seminal intuition that "society exerts its control over individuals not only through conscience or ideology, but also in and with the body"[22] is particularly valid for older senior citizens. Examples already meriting the attention of researchers include behavioural pattern monitoring systems, in which behaviour patterns of elderly subjects are monitored and any changes detected are reported to care givers. Experts foresee that, within a decade, software efficient enough to spot early Parkinson's symptoms will be commercially available. Modern information technology has also increased the possibilities for supervision and surveillance of elderly people suffering from dementia. Relevant supervision technologies in the field of welfare services include sensors in exit doors warning about undesired movement and electronic tags for localisation of the elderly. While such technologies have undoubted benefits, they also pose serious questions. The bodies of senior citizens are invaded by microtechnologies, reconstructed as nodes in vast information networks, and controlled through automated responses or network commands. This trend requires a careful ethical scrutiny.

3.7 HUMAN EXPERIMENTATION IN ICT FOR ELDERLY

The EC has issued specific guidance for the ethical review of human experiments in ICT projects in the Seventh Framework Programme. There are, however, some important issues that still need to be addressed, such as (i) the definition of specific criteria for evaluating the vulnerability of senior citizens who take part in ICT research; (ii) the development of ethical guidelines tailored to the ICT context; (iii) clarification of the interplay between cares and cures, medical and social services, which are often blurred in the field of assistive technology experimentation.

3.8 INFORMED CONSENT

Senior citizens can be categorised in several ways which help to elucidate the issue of informed consent. Some senior citizens live independently in their own homes, while others require care by third parties, either from family members and/or professional care-givers. The latter category of senior citizens can be subdivided between those who require care, but live in their own homes and those who require care in a nursing home. Those who require care can be further subdivided between those who suffer from some physical disability and those suffering from mental impairment such as dementia or Alzheimer's disease. Each of these groups has different needs and should be informed differently. Indeed, the complexity of the issue is such that ethical guidelines and perhaps regulatory measures are appropriate. Such guidelines should be constructed on the basis of (brief) scenarios that illuminate the various permutations where informed consent is desirable and/or mandatory.

3.9 LONELINESS AND ISOLATION

The notion of solitude comprises at least two different concepts, loneliness and isolation. Loneliness and isolation are often confused; there are important differences between being emotionally isolated (loneliness) and being socially isolated (isolation). Despite stereotypes to the contrary, older senior citizens tend to feel isolation less distressful than younger people.[23] Many older senior citizens do not

[22] Foucault, Michel, "The Birth of Social Medicine", in James D. Faubion (ed.), *Essential Works of Michel Foucault 1954-1984*, Penguin, London, 2001, pp. 134-156.
[23] Rokach, Ami, "Loneliness and the life cycle", *Psychological Reports*, Vol. 86, No. 2, April 2000, pp. 629-642. http://www.ingentaconnect.com/content/docdel/000020031171/2000/86/2

view living alone as particularly distressful. Some deliberately seek to be alone as an expression of independence. For most older people, the main problem is isolation rather than loneliness. Here, however, the digital divide is critical. Very often, older senior citizens are precluded from using new communication tools, which could help them to overcome isolation, because of their digital illiteracy. Some scientists believe assistive robots are the answer. Yet being somehow forced to consider inanimate objects as the comprehensive universe of one's own social life may become degrading and may hurt self-respect. The issue at stake is that of emotional dignity, as Badcott proposes to call situations that could elicit profound feelings of personal humiliation.[24]

4 Going beyond the Bled Discussion Paper

The nine points fixed by the "Bled Discussion Paper" constitute the basis of this second discussion paper, which is published by the SENIOR project for the European Ministerial e-Inclusion Conference (Vienna, 30 Nov - 2 Dec 2008). Four major areas for further discussion have been identified: (i) developing a specific approach to ethical issues raised by ICT; (ii) describing in more detail the age-related digital divide in Europe; (iii) defining the legal framework for inclusion of the elderly in the digital society; (iv) identifying technology trends and emerging challenges. Corresponding action points are also proposed:

4.1 DEVELOPING A SPECIFIC APPROACH TO ETHICAL ISSUES RAISED BY ICT

Ethical questions about ICT have been debated since World War II. Western democracies have had more than 50 years of experience in addressing and organising the ethical, social and legal aspects (ESLA) of scientific and technological developments. However, this expertise, tradition and experience are not enough to manage the most urgent ethical and social issues and contemporary challenges linked to ICT. Therefore, a systematic and institutional organisation of social values in the context of modern ICT tools must be undertaken.

While bioethics and ICT ethics are not one and the same, the experience of shaping ESLA processes for biomedicine can help to develop an operational ESLA for ICT. One of the major lessons may be that ESLA is not the progressive accumulation of finalised insights and tools, but an ongoing process. Another major lesson is that the ESLA development is not the result of one single homogeneous and all encompassing process, but requires the development and strengthening of specific niche-related processes with strong interaction among the key stakeholders.[25]

4.1.1 Humanness

There is, undoubtedly, a growing convergence between biology and ICT tools, as exemplified by ICT implants that enhance brain function. With such implants, it is now possible to move artificial limbs through connections to the brain. Likewise, paraplegics can use them to control external devices like a computer cursor. Through such devices, ICT continues to encroach upon the human body and upon the image we hold of ourselves as human beings.

This image is not limited to the body alone. When we think about our own identity, we also include our personal history, what we do and what we did, how we organise our lives, and how we see the future. We include the type of work we do, and the way our achievements and actions are perceived by others. When we take account of these broader aspects of identity and current developments in the field of ICT, it becomes hard to see ICT as a merely neutral tool whose field of operation is in the solution of external problems. We must recognise the fact that ICT has become a powerful tool that can change and shape human identity.

While there are many benefits to be reaped by the convenience and connectedness that ICT affords, there are, again, many pitfalls to consider. At one extreme, some believe that current ICT developments will result in the final destruction of typical human features. This can perhaps most easy be conceptualised in light of neuro implants and prosthetic devices. The fear also exists that ICT does not

[24] Badcott, David, "The basis and relevance of emotional dignity", *Medicine, Health Care and Philosophy*, Vol. 6, No. 2, June 2003, pp. 123-131. http://www.ingentaconnect.com/content/klu/mhep/2003/00000006/00000002

[25] For example, the key researchers in Huntington's disease are in close contact with representatives of the HD league of patients, and are aware of the concerns of patients and their families. The patient organisations know the scientific leaders in their field and know the fundamental scientific context that scientists are developing.

enrich our human characteristics but rather replaces them by unnatural, technological characteristics, which are determined by scientists, the industry and the market. In addition, it has been argued that ICT does not multiply or enrich relationships among humans, but that ICT reduces the rich complexity of human contact to purely technical connections with distant or virtual contacts. Furthermore, many assert that ICT does not multiply the impact of our work by allowing us to send the results around or publish them on the Internet, but that it takes the achievements of our creative work away from us. The end result, arguably, is that ICTs have the ability to strip human beings of everything that makes them human, of each and every element that constitutes their rich internal human identity. Seen in this way, the development of ICT would be an assault on human dignity, on the humanness of human beings. Opponents of ICT underline that ICT *tampers* with human identity instead of enriching it, and that ICT should be prevented from doing so. Indeed, public policy must seriously evaluate the ethical aspects of ICT as they relate to the human being.

4.1.2 Public policy context

Near the end of the 20th century, public policy recognised ICT as a vital element in contemporary life. Proactive policy-makers promoted access to technologies as a priority of public policy. The e-inclusion initiative of the European Commission is a major contribution to this priority. Other policy initiatives include the promotion of adapted technologies for citizens with special needs (including the elderly), and the promotion of ICT technology as an asset to strengthen the economy. Here, the growing number of older people constitutes a growth market for ICT products and services.

The ESLA analysis of the many action lines involved requires the gradual development of a large variety of processes and networks of actors involved. While several pioneering initiatives are, or have been, operational, the real work still has to begin. In Western democracies, it is quite normal for ministries or departments in charge of health care to maintain a host of ethical committees and support ESLA work. Health care officials have structural communication lines with patients and captains of pharmaceutical industries. Public policy in charge of technology, ICT, and its many uses, recognise the need for such structural communication and, whenever possible, the need to talk to other stakeholders. At present, open and structural communication lines are not developed. Clearly, this must change.

4.2 A CLOSER LOOK AT THE ELDERLY

As was established at the Bled Conference, placing the elderly in a generic category based upon age does not provide an accurate image or assessment of the vast conditions and experiences found within this segment of the population. In order to understand more fully the challenge of including senior citizens in the Information Age, it is necessary to look at a variety of groups within the classically defined "elderly" population. To have a clearer understanding of the dynamics of such groupings, Bled participants considered Internet use by those over 60 years of age within specific groups: gender, married, single, immigrant, rural, urban and regional differences within the EU.

Action 1: Propose a set of actions to facilitate the development of communication lines between different EC services, agencies and relevant expert committees on the issue of ICT ethics.

4.2.1 Gender

The life expectancy rate for women in the EU is generally three years more than that for men. Women make up 59 % of people aged 65+ and the proportion of women increases with age, e.g., 64 % of those aged 75+ are women, while 71 % of those aged 85+ are women. Among those over the age of 60, twice as many men as women use the Internet. Among those women who do access the Web, only 3 % consider themselves as having strong Internet skills.[26] The age-related digital divide, therefore,

[26] For the age group above 60, 18 % of men compared to 9 % of women use the Internet (Eurostat, *The Life of Men and Women in Europe: A Statistical Portrait*, Brussels, 2008). For the age group 55-74, 31 % men and 19 % women use the Internet (European Commission, *Women in ICT: Status and the Way Ahead*, 2008).

particularly affects elderly women, who live longer and often alone. Elderly women, especially those in the "older elderly" group, are at a higher risk of being excluded from the Information Society.

More elderly women might use computers and the Internet, if they were part of their existing social activities. They could be offered free ICT training at local community centres and libraries. As elderly women are likely to live alone, ICT training should be presented as an opportunity for socialising; in this way, women will gain both valuable skills and social networks. [27]

4.2.2 Marital status

Data from a labour force survey (2005) shows that 30% of women and 13% of men over 65 live alone. There are regional variations, of course; for example, in Spain, Portugal and Malta approximately 22% of women over 65 live alone, compared to 37% in the Czech Republic, Estonia, Hungary and Finland. Overall, the percentage of women living alone increases as they grow older. Thus, roughly 52% of women aged 75 + live alone compared to only 21% of men of the same age.[28] These figures are obviously influenced by the fact that women in general live longer than men. The fact that more elderly women than men live alone and that elderly women use computers and the Internet less than men suggests that households with married couples are more likely to use a computer and the Internet.

However, there have been no significant studies undertaken that reveal differences in ICT use between married and single/widowed elderly people. This requires investigation. From the few studies that have been carried out, we know that, while 31% of men, and 19% of women between the ages of 55 and 74 use the Internet, only 8 % of single households in the age group 60+ have broadband Internet access. This suggests a wider digital divide for the single elderly than for those who are married.

4.2.3 Immigrants

In Europe (as in most parts of the world), immigrants are often among the most socially excluded and disadvantaged groups. Factors such as language barriers, low education levels, low rates of employment and employment in low skill jobs reinforce their exclusion. Many people become acquainted with computers and the Internet via their jobs; however, many immigrants have not had this opportunity due to their type of employment (or unemployment).[29] Consequently, many immigrants enter retirement without ICT skills. This lack of skill is arguably most prevalent among those immigrants (usually women) who remain in the home rather than participating in the workforce.

While elderly immigrants are generally more digitally excluded than native citizens, addressing this exclusion is also more challenging. Language barriers and cultural customs call for greater sensitivity when interacting with these elderly. ICT training courses should be offered in multiple languages and take cultural differences into account. People may refrain from ICT training courses if they perceive insensitivity to their religion. For example, mixed gender ICT courses may effectively hinder some Muslim women from participating; women-only courses should, therefore, be available.

Such solutions require a greater level of awareness regarding individual needs which won't happen if we look at the elderly as a single amorphous group.[30] Inclusion of the elderly in the Information Society is critical to their overall inclusion into European society. Without inclusion, we cannot form a cohesive Union based upon social solidarity and values.

4.2.4 Urban versus rural

Across Europe, there is a notable difference in the use of computers and Internet between urban and rural areas, with broadband penetration being significantly lower in rural areas.[31] This clearly increases the issue of a digital divide for those elderly living in rural Europe, which in turn relates to furthering a sense of isolation experienced by many elderly in these areas. Many inhabitants of rural areas are already isolated by factors such as distance and poor modes of public transportation. As such, this is arguably the group who would benefit most from broadband coverage and Internet access, which

[27] Eurostat, *The Life of Men and Women in Europe: A Statistical Portrait*, Brussels, 2008. http://epp.eurostat.ec.europa.eu/portal/page?_pageid=1073,46587259&_dad=portal&_schema=PORTAL&p_product_code=KS-80-07-135

[28] Ibid.

[29] http://ec.europa.eu/enterprise/ict/policy/ict-skills/es-br.pdf

[30] SEC(2007) 1469] [SEC(2007) 1470

would allow them to communicate with family and friends in far away places and interact with peers via social networking groups. However, if broadband coverage is poor, this segment of the elderly population will not be able to participate in the Information Society. As such, extending coverage to rural areas should be made a priority.
While coverage is not typically a problem in urban areas, urban seniors run the risk of being isolated or alienated by too much ICT. If visits by care givers or family members are substituted with cell phone calls or emails, the elderly can become isolated even in the most populated areas. In addition, social interaction in urban areas tends to be more anonymous, meaning that the elderly could feel alone even when surrounded by people. Thus, it is imperative that a delicate balance is struck between closing the digital divide and closing seniors in a virtual prison.

4.2.5 Regional differences within Europe

Just as there are differences between rural and urban areas in general in relation to the use of computers, the Internet and access to broadband internet connection, so there are similar differences between different regions in Europe. We thus see notable differences between old and new Member States. For example, in the EU15 approximately 52% of all households have internet access at home, while only 33% have access in NMS12. However, these figures continue to increase, in particular several new Member States (e.g. Czech Republic, Cyprus and Slovenia) have had a significant increase in the number of households with internet access at home.[32]

In relation to broadband access a similar trend is clear: broadband access is less prevalent in new Member States where just under 25% of households have access. Particularly in new Member States the penetration of broadband technologies is significantly higher in urban and metropolitan areas than in rural areas. This gap is less wide in new Member States.[33]
Taking these regional differences in Europe into account, Europe's elderly population is also at different levels in relation to their risk of exclusion. The age related digital divide cannot be understood, nor combated, in isolation. The entire population of new Member States is at greater risk of exclusion in the Information Society due to the basic unequal level of access to computers and the Internet. It is useful, however, to focus on age because across Europe the population is growing older. This makes it impossible for governments, policy makers, ICT developers, the market etc. to ignore the seriousness of the age related digital divide, which is of particular concern in new Member States. At the same time, it is important to highlight that the elderly constitute a very heterogeneous group with different needs, attitudes and social background that face different barriers to e-Inclusion. Although it is clear that overall elderly people in Europe are at risk of exclusion, the degree of risk is interdependent on other factors, such as country of residence, immigrant status, rural/urban residency, gender, and marital status, to name but a few. These differences present a variety of challenges to policy makers and government leaders aimed at e-Inclusion.

Action 2: Promote further research on the segmentation of the elderly population in Europe, on the way in which digital divide impacts on different segments of older European citizens, and to what extent the digital divide increases marginalization in the most vulnerable segments of the older population.

5 The legal framework for inclusion of the elderly in the digital society

5.1 THE EU CHARTER

The first chapter of the 1996 EC Green Paper on "Living and Working in the Information Society: People First" affirmed that, "*The way we develop the Information Society, the most fundamental change of our time, must reflect the ideas and values upon which the European Union is shaped. These ideas and values should be transparent in order to gain and deserve the broad support of European*

32 e-Communications Household Survey, Eurobarometer, 2008
33 e-Communications Household Survey, Eurobarometer, 2008

citizens"[34]. The 2000 EU Charter of fundamental rights provides now a solid value framework to guide the development of the Information society and notably the process of e-inclusion of the elderly.[35] It contains explicit rights on the elderly, together with rights on human dignity, equality, privacy and data protection. The relevance of these rights enshrined in the EU Charter for the elderly and for their inclusion in the digital age is evident. They can be summarised under three main headings:

1) Dignity and Liberty
2) Discrimination and Equality

5.2 DIGNITY AND LIBERTY

Human dignity is inherent to the universal acknowledgment of fundamental rights. A full description of all fundamental rights derived from a concept of human dignity could be debated. Yet there is a main trend in the normative texts of International and Constitutional Laws, which include also the EU Charter, to set the foundations of dignity on autonomy. Human dignity involves a complex notion of the individual. It includes recognition of a distinct personal identity, reflecting individual autonomy and responsibility. It also embraces a recognition that the individual self is a part of larger collectivities and that they, too, must be considered in the meaning of the inherent dignity of the person. There is an implication to be drawn from the recognition of human dignity as a "source" of human rights. Drawing upon the conception of human dignity and the intrinsic worth of every person, we can extend and strengthen human rights by formulating new rights or construing existing rights to apply to new situations. The conception of respect for dignity suggested above can also be applied to eInclusion. Indeed, nothing so clearly violates the dignity of persons as social exclusion that demeans or humiliates them. Put in positive terms, respect for the intrinsic worth of a person requires a recognition that the person is always entitled to participate in social and community life notwithstanding her age, disability, and health conditions.

The Moniteur Belge case: the right not to be forced into inclusion

In the "Moniteur Belge" case (ECJ, C-303/06, *S. Coleman v. Attridge Law and Steve Law* , 17 July 2008) a non discrimination complaint was brought against a law which limited the publication in paper format of the Belgium Official Journal (*le Moniteur Belge)*, to three copies, and opened up public consultation via an on-line service and database. The Court recognized the objectives pursued by the law as "objective and reasonable" (economic, environmental) and in line with the social evolution towards e-communication. The Court went on to analyse the requirement of proportionality. Judges found that, notwithstanding compensatory measures (the intention of the legislator to equip public libraries with the necessary IT support to access the "Moniteur Belge", and the possibility to obtain a hard copy upon request within twenty-four hours), the law violated the general principle of non-discrimination and had to be annulled. The law discriminated againt those who did not have access to the Internet or enough skills to consult, without excessive effort, the official gazette online as they were used to do on paper.

The relevance of the Moniteur Belge for e-inclusion is the importance attributed by the Court to the capacities prevalent in a community, notably those of non-mainstream groups. The Court made a strong point for the legal equality of individual capacities and stated that, individual capacities being equal, the right to non-discrimination is to ensure that members of society have equal access to goods or services, such as access to rights and duties setting laws, deemed most important in society. The case should not be read with a short-sided attitude of anti-modernistic or anti-technological stance. The Moniteur Belge indicates that access to goods or services deemed crucial in a democratic society should not be hampered; hence, as technology spreads in society, technological artefacts which have an important public interest dimension should be designed to accommodate all capacities of the public.

5.2.1 Human dignity

Article 25 of the EU Charter recognizing fundamental rights for the elderly (see below) puts forward the central idea that elderly have a right "to lead a life of dignity and independence and to participate in social and cultural life". As pointed out by Stefano Rodotà[36], article 25 is not an isolated statement.

[34] COM(96) 389
[35] Timmers P., "Human rights are the foundation, also for the ICT world (Charter of Fundamental rights)", presentation delivered at the Workshop on "Ethical Aspects of Inclusion in the Information Society", Bled, Slovenia, 12 May 2008. http://ec.europa.eu/information_society/activities/einclusion/events/workshop_ethics/workshop/index_en.htm
[36] Rodotà S., Senior Launching workshop, Opening Lecture, Brussels, 3 March 2008, p. 1

It contains an explicit reference to the principle and right of human dignity which opens the EU Charter in Article 1, " *Human dignity is inviolable. It must be respected and protected*". Article 1 draws on the Preamble to the Charter[37] as well as on the 1948 Universal Declaration of Human Rights[38]. Its position in the Charter indicates the centrality of the person in the policies of the European Union and the function of human dignity as the "real basis of fundamental rights".[39] Dignity must be interpreted as imposing "not only a static attitude ("respect"), but mainly an active obligation to intervene to make dignity effective ("promote"). The implications of the positive, affirmative character of dignity extend to all fundamental rights enshrined in the Charter, which must be enjoyed by all to attain a dignified life. Mention can be made, for instance, of article 3 "everyone has the right to respect for his or her physical and mental integrity" which commands a strong protection to health. Likewise, article 35 requires Member States to afford a high level of human health protection.

Central in the idea of dignity is the idea that there is a threshold below which nobody and no law can go. Even the use of fundamental rights by the individual need to respect the notion of dignity: "It results that none of the rights laid down in this Charter may be used to harm the dignity of another person, and that the dignity of the human person is part of the substance of the rights laid down in this Charter. It must therefore be respected, even where a right is restricted".[40] Dignity offers clear guidance about the goals that EU policymaking need to pursue. Considering the market phenomenon re ICT, especially the observed fact that many individuals give away privacy for convenience, there is a clear obligation for policy makers to safeguard the individual against rights erosion caused by market and other pressure.

Action 3: Indentify and target with specific policies the main threats to older citizens' dignity

5.3 DISCRIMINATION AND EQUALITY

We are equal in having certain equally inalienable rights, and these rights are somehow grounded in the fact that we are equally vulnerable and frail creatures. To be human means to be the kind of being that has these rights. That is, to be a human being means that your right to defend yourself cannot be abrogated without self-contradiction. It means that you cannot discriminate against a person because she is weaker or frailer than you. Fighting against discrimination and substantial equality are necessary conditions of respect for the intrinsic worth of the human person. Art. 13 of the Treaty of Lisbon explicitly states that " *(1) Without prejudice to the other provisions of this Treaty and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission and after consulting the European Parliament, may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation"* (our underscore).

5.3.1 Equality and non-discrimination

The principles of equality and non-discrimination[41] are well established in EU law.[42] According to a consolidated jurisprudence[43], a difference in treatment constitutes discrimination either when it lacks

[37] "The Union is founded on the indivisible, universal values of human dignity, freedom, equality and solidarity... It places the individual at the heart of its activities."
[38] "All human beings are born free and equal in dignity and rights."
[39] Draft Charter of fundamental rights of the European Union, 4473/00, Brussels, 11 October 2000.
[40] Council of the EU, *Charter of Fundamental Rights of the European Union: Explanations relating to the complete text of the Charter*, December 2000, p. 15
[41] *Article 20 (Equality before the law)- Everyone is equal before the law*
[42] Non discrimination can be regarded either as a principle which mediates between primary constitutional principles (to be applied in a non discriminatory manner) or a right, in the sense that its breach constitutes a violation of the law, be it a convention, a treaty or a law.
[43] Eur.Ct. HR, *Case relating to certain aspects of the laws on the use of languages in education in Belgium, (Belgian Linguistic Case),* Judgment of 14 July 1968, 1 EHRR 252, para 10. ECJ, Case C-203/86 *Kingdom of Spain v. Council of the European Communities* [1988] ECR 4563, para 25. ECJ, Case C-279/93 *Finanzamt Koeln-altstadt v. Roland Schumacker* [1995] ECR I-225;

"objective and reasonable" justification, or when there is no reasonable relationship or proportionality between the means employed and the legitimate aim sought to be realised.[44]

The cardinal provision in EU law on discrimination based on age is article 6 ("Justification of differences of treatment on grounds of age") of the Employment Equality Directive[45], whose legal basis is article 13 TEC. According to the case law of the European Court of Justice (ECJ), the principle of non-discrimination on the grounds of age must be regarded as a general principle of Community law[46].

Article 21[47] of the EU Charter proscribes discrimination based on certain forbidden grounds, including age[48]. All fundamental rights are general in scope. The right to health, for instance, is a general right. Some groups, however, might require special attention in law. The reference to age in article 21 and the ascription of article 25 regarding rights for the elderly under the heading "equality" signals awareness that certain groups, such as the elderly, are at risk of discrimination and are in need of special protection: for instance in terms of affordability and accessibility of ICT products and services, or in terms of protection of personal data in the domain of e-health.

The Coleman case and the right to have care and not only e-care

The public role of the right to non discrimination in the process of e-inclusion is also shown in the recent *Coleman* case concerning the right of family members to take care of their disabled closes. In this case, a preliminary question was put to the European Court of Justice asking whether the protection granted by the prohibition of discrimination based on disability "is contingent on the employee having a disability herself, or does it also include the situation where the employee is discriminated against on the basis of the disability of her child, for whom she is the primary carer?". Beginning 2005, Ms Coleman accepted voluntary redundancy that ended her employment at a law firm. On 30 August 2005, she brought a claim to the South London Employment Tribunal for constructive dismissal and disability discrimination against her former employer. It was alleged that she had been treated less favourably than other employees because she was the primary carer for her child. The Court found that "when the less favourable treatment of an employee is based on the disability of her child, whose care is provided primarily by that employee, such treatment is contrary to the prohibition of direct discrimination". The *Coleman* judgement indicates the flexibility of non-discrimination law to expand the proscription of direct or indirect discrimination to combat covert discriminatory practices in society.

Importantly, the Coleman case indicates the pivotal importance that an inclusive public sphere with inclusive rules plays in the process of inclusion.

This broad legal backing for the value of equality, both in terms of rights and general principles of Community law, guarantees a common definition of age discrimination and a uniform level of protection against age discrimination across the Member States. Also, it puts on public institutions a twofold obligation: 1. to remove legal provisions "intrinsically liable" to engender direct or indirect

[44] It is worth stressing the peculiarity of the European approach. In contrast, for instance, with the US approach, Europe detects discrimination whenever the *effect* of a measure or of a group of measures is discriminatory. The US approach looks at the *intent* to discriminate, thus reducing the scope of legitimate public intervention. The leading case is *Washington v. Davis,* 426 United States Reports 229, 1976. Where the Supreme Court held that the equal protection clause contained in the Fourteenth Amendment does not prohibit governmental action that has a foreseeable discriminatory on identifiable groups. Unless it can be shown that such action was undertaken with "discriminatory intent", it is not subject to constitutional challenge. See R.A. Sedler, *The role of 'intent' in discrimination analysis,* in T.Loenen & P.R. Rodrigues, *Non discrimination law: comparative perspectives*, Kluwer Law International, The Hague/London/Boston, 1999, pp. 91-107.

[45] Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation [2000] OJ L303

[46] European Court of Justice, *Mangold v. Rudiger Helm* C-144/04, para 75.

[47] *Article 21 (Non-discrimination)*

1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.

2. Within the scope of application of the Treaty establishing the European Community and of the Treaty on European Union, and without prejudice to the special provisions of those Treaties, any discrimination on grounds of nationality shall be prohibited.

[48] Along article 21 EU Charter, non discrimination is enshrined in article 14 of the European Convention of Human Rights (ECHR) and article 13 of the Treaty establishing the European Communities (art.10 of the of the EU treaties as amended by the treaty of Lisbon) Art. 10: "In defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation." See also article 3.2(b) where it is stated that; "[The Union] shall combat social exclusion and discrimination, and shall promote social justice and protection, equality between women and men, solidarity between generations and protection of the rights of the child". Available at http://www.statewatch.org/news/2008/jan/eu-lisbon-treaty-consilidated.pdf

discrimination[49]; and 2. to promote affirmative actions aimed at avoiding that conditions triggering discriminatory effects emerge in our societies.

The rights to equality and to non-discrimination mandate EU policy makers to pursue a policy of e-inclusion regarding the elderly. Although legally speaking, a certain result is not warranted, a considerable effort is asked for. It is commonly held that all second generation rights are not enforceable, but a more precise understanding of human rights law shows that the right to non-discrimination is wholly enforceable and that making no process with regard to second generation rights is equally prohibited. Article 25[50] demands that positive actions are taken to strengthen the independence of the elderly and their participation in social and cultural life. Combined with Article 15 (the right of all citizens to engage in work) broad affirmative actions are allowed for. Hence, equality and non-discrimination allow and oblige policy making initiatives in the area of e-inclusion of the elderly. Conversely, protection against age discrimination is tightly dependent on a strictly chronological approach to age, i.e., an age limit. Setting age limits responds to the need of any welfare state to streamline members of the society into socio-economic categories. This is necessary in order to allocate scarce resources and organise appropriate interventions. It follows that the application of non discrimination law is bound by such *de quo* limits. The further legal implications of anti-discrimination provisions on e-inclusion, in particular on the e-inclusion of the ageing, are not fully understood. Lessons can be drawn from recent the cases, *the Moniteur Belge* and *Coleman.* Both cases show the importance of the public sphere of e-inclusion.

Also the rights of family members could benefit from IT, for instance to continue pursuing one's own career[51]. On the other hand, there are obvious ethical limits to the use of technologies *in lieu* of human caregivers: "technologies can be part of a program of caring, not be transformed slowly into the program as a whole".[52] To avoid this scenario, assistive technologies should thus operate in a context where (the possibility for) social contacts is an integral part of the notion of "being independent". But this would require not only intervention at the "design-stage" of the technology but, more importantly, on the "public sphere", *i.e.* the community. The community should create conditions where informal caregivers are not forced to face dramatic choice between the right to pursue their careers and the care of their closes. Setting rules that allow a caregiver to take some time off from work without suffering prejudice, without being discriminated against would help, *inter alia*, promote the ethical use of assistive technologies.

Action 4: Develop understanding of the wider legal and policy implications of anti-discrimination provisions on e-Inclusion, in particular on ageing, by promoting research and debate on this subject and by involving relevant EU services and agencies (e.g., the FRA).

[49] Case C-237/94 *O'Flynn v. Adjudication Officer* [1996] ECR I-2417, para 20 and para 21. Where the ECJ found that "a provision of national law must be regarded as directly discriminatory if it is intrinsically liable to affect (the migrant worker[...]) and if there is a consequent risk that it will place the former at a particular disadvantage".

[50] *Article 25 (The rights of the elderly) - The Union recognises and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life. Article 26 (Integration of persons with disabilities) - The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community. Article 15 (Freedom to choose an occupation and right to engage in work) - 1. Everyone has the right to engage in work and to pursue a freely chosen or accepted occupation. 2. Every citizen of the Union has the freedom to seek employment, to work, to exercise the right of establishment and to provide services in any Member State*

[51] According to Madeleine Starr of Carers UK, those providing heavy end care are "twice as likely than the general population to be in poor health themselves, as a result of caring…[they also experience] significant financial disadvantages; very frequently people have to give up work and therefore give up their income…this affects not only their working lives but it also affects their ability to put into the pension system…[thereby] creating a situation where carers themselves might go into poverty in their own retirement." SENIOR, *D.1.5 WP 1 Report Final*, p. 97

[52] "SENIOR, *D.1.5 WP 1 Report Final*, p. 9.

5.4 DATA PROTECTION AND PRIVACY

The Convention on the Rights of the Child is the only International Convention that addresses the subject of Identity as a fundamental right of every human being. Articles 7 and 8 of the Convention explicitly refer to the Right to an Identity. These articles deal with subjects such as registration, name, nationality, and the preservation of identity[53]. Only few jurisdictions feature a constitutional Right of an Identity. One of these is the Portuguese Constitution, which, in its Article 26 states, *"(1) Everyone's right to his or her personal identity, civil capacity, citizenship, good name and reputation, image, the right to speak out, and the right to the protection of the intimacy of his or her private and family life is recognized. (2) The law establishes effective safeguards against the abusive use, or any use that is contrary to human dignity, of information concerning persons and families. (3) A person may be deprived of citizenship or subjected to restrictions on his or her civil capacity only in cases and under conditions laid down by law, and never on political grounds*". The Right to an Identity is, however, part of the common European ethos and it gives implicit foundation to privacy rights and data protection. John Locke's often quoted sentence "*[t]hough all the earth and all inferior creatures may be common to all men, yet every man has a 'property' in his own person*"[54] does not merely recognise the potential commercial value of every person's identity. It also – and foremost – acknowledges the dignity inherent in the concept of human identity. The individual's identity and private sphere do not allow intrusions by others without good reasons.

5.4.1 Privacy

In light of the large scale use of information and communication technologies which underpin e-inclusion, critical weight must be attributed to the fundamental rights to privacy and to data protection.[55] The fundamental right to privacy and the fundamental right to data protection are enshrined, respectively, in article 7 and article 8 of the EU Charter.[56] The rights guaranteed in Article 7 correspond to those guaranteed by Article 8 of the 1950 European Convention on Human Rights (ECHR). To take account of developments in technology the word 'correspondence' has been replaced by 'communications'. In accordance with Article 52(3) of the EU Charter, the meaning and scope of this right are the same as those of the corresponding Article of the ECHR. Consequently, the meaning is the same and the limitations which may legitimately be imposed on this right are the same as those allowed by Article 8 of the ECHR:

> *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.'*

The meaning of privacy as autonomy of the individual entails recognition not only of the right to be left alone[57] but also of "the claim of individuals to determine for themselves when, how, and to what extent information about them is communicated to others"[58]. Hence, and according to an evolution in the last decades, well-fitting with the dual nature of the right to identity, privacy is not only concerned with the right to be left alone but also with the right to keep control over one's own information and determine the manner of building up one's own private sphere"[59] and with "the right to choose one's life"[60].

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[53] *Article 7 1. The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality and. as far as possible, the right to know and be cared for by his or her parents. 2. States Parties shall ensure the implementation of these rights in accordance with their national law and their obligations under the relevant international instruments in this field, in particular where the child would otherwise be stateless. Article 8 1. States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference. 2. Where a child is illegally deprived of some or all of the elements of his or her identity, States Parties shall provide appropriate assistance and protection, with a view to re-establishing speedily his or her identity.*

[54] Locke, John, "An essay concerning the true original extent and end of civil government", in *Two Treatises of Civil Government*, Book 2, Chapter 7, section 27.

[55] The latter will be dealt with more in detail in a next paragraph.

[56] *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.* In the following analysis, we will refer to the archetype of art.7 & 8 EU Charter, article 8 of the European Convention of Human Rights.

[57] Warren, Samuel, and Louis Brandeis, "The right to privacy", *Harvard Law Review*, Vol. 4, 1890, pp. 193-220.

[58] Westin, Alan F. , *Privacy and Freedom*, Atheneum, New York, NY, 1967.

[59] Rodotà, S., *Tecnologie e diritti,* Il Mulino, Bologna, 1995, p. 122

Individual, elderly included, constantly negotiate their relations with the outside world[61]. Privacy (and data protection) grants them control rights when doing this.

The case law of European Court of Human Rights re. article 8 ECHR show a progressive evolution in the understanding of what privacy is about, *i.e.* what privacy protects and promotes. In its case-law, the Court has shown awareness of the mutually consecrative function of the private sphere and public sphere. *Malone*[62] and *Klass*[63] extend privacy protection to against unlawful interference, by the state and by third private parties, in the private home and correspondence, and, later, email and internet. Progressively the protection of privacy moved beyond the "shadowy realm of the household" to embrace in, *Niemietz* and *Halford*[64], the workplace. In *Niemietz,* it was found that there was "no reason of principle why this understanding of the notion of 'private life' should be taken to exclude activities of a professional or business nature"[65]. As a result, sending private emails from workplace is, unlike for instance in the US, "personal". With *Peck v. UK*[66], disclosure by private data retained by a public institution is protected. Similarly, in *Amann v. Switzerland,* the Court pointed out that the term 'private life' must not be interpreted restrictively and that respect for private life comprises the right to establish and develop relationships with other human beings[67].

In the same case, the Court held that the storing of data relating to the private life of an individual amounts to an interference within the meaning of Article 8 ECHR, regardless of the subsequent use of the stored information.[68] For the Court, it is also irrelevant as to whether the information gathered on the applicant was sensitive or not, or as to whether the applicant had been inconvenienced in any way. It is sufficient to find that data relating to the private life of an individual was stored to conclude that, in the instant case, the creation and storing of the impugned card amounted to interference, within the meaning of Article 8, with the applicant's right to respect for his private life.[69] In itself, this does not mean that the act of storing data is prohibited. It only means that the second paragraph of article 8 ECHR applies and that the inference needs to be based on a law, to serve legitimate interests and to respect the proportionality requirement ('necessary in a democratic society'). Crucial when assessing the existence of a right to privacy and the proportionality requirement is the idea of reasonable expectations of privacy.[70]

When there is no evidence to the contrary citizens, including elderly citizens, can develop expectations of privacy that, when reasonable, are legally protected. This notion of reasonable expectations has the potential of being a solid ethical and legal guideline for further developments with regard to e-inclusion. Without becoming merely subjective, it departs from the expectations of the persons most concerned with inclusion, in this case, the elderly.

Positive obligations on the State are inherent in the right to effective respect for private life under Article 8 ECHR.[71] These obligations may involve the adoption of measures even in the sphere of the relations of individuals between themselves. While the choice of the means to secure compliance with Article 8 in the sphere of protection against acts of individuals is in principle within the State's margin

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[60] Rigaux, F. , *La protection de la vie privée et des autres biens de la personnalité,* Bruylant, Bruxelles-Paris, 1990, p. 167 ; see also Gutwirth, Serge, *Privacy and the information age,* Rowman & Littlefield Publishers, Lanham, 2002.

[61] Marx, Gary T., "Murky conceptual waters: The public and the private", *Ethics and Information Technology*, Vol. 3, No. 3, 2001, pp. 157–169.

[62] ECtHR, *Malone v. the United Kingdom* judgment of 2 August 1984, Series A no. 82, p. 30, para. 64.

[63] ECtHR, *Klass v. Germany* judgment of *September 6 1978*, (1979-80) 2 *EHRR* 214

[64] ECtHR, *Halford v. UK*, judgment of 25 June 1997, §44; *Niemietz v. Germany*, judgment of 16 December 1992, § 32. It is clear from these cases that telephone calls made from business premises as well as from the home may be covered by the notions of "private life" and "correspondence".

[65] ECtHR, *Niemietz v. Germany*,para. 29.2.

[66] ECtHR, *Peck v. UK*, Judgement of 28 January 2003 §85

[67] ECtHR, *Amann v. Switzerland*, judgement of 16 February 2000, § 65-67

[68] ECtHR, *Amann v. Switzerland*, judgement of 16 February 2000, § 69

[69] ECtHR, *Amann v. Switzerland*, judgement of 16 February 2000, § 70.

[70] ECtHR, *Halford v. UK*, judgment of 25 June 1997, §45: "There is no evidence of any warning having been given to Ms Halford, as a user of the internal telecommunications system operated at the Merseyside police headquarters, that calls made on that system would be liable to interception. She would, the Court considers, have had a reasonable expectation of privacy for such calls, which expectation was moreover reinforced by a number of factors. As Assistant Chief Constable she had sole use of her office where there were two telephones, one of which was specifically designated for her private use. Furthermore, she had been given the assurance, in response to a memorandum, that she could use her office telephones for the purposes of her sex-discrimination case".

[71] ECtHR, *M.C. v. Bulgaria,* Judgement of 4 December 2003, Application no. 39272/98, § 150 with reference to *X and Y v. the Netherlands*, judgment of 26 March 1985, Series A no. 91, pp. 11-13, §§ 23-24 and 27, and *August v. the United Kingdom* (dec.), no. 36505/02, 21 January 2003.

of appreciation, effective deterrence against grave acts, where fundamental values and essential aspects of private life are at stake, requires efficient criminal-law provisions. "Children and other vulnerable individuals, in particular, are entitled to effective protection".[72]

5.4.2 Privacy equally demands a right to be connected in the Information Society

Progressively, a strong tendency has emerged toward imposing on European states not only "respect" for privacy, but also the promotion of privacy…in public: that is the promotion of the realisation of private life in all places, such as hospitals, care homes, beaches, parks et cetera...where the individual, through contacts with its peers, realise its personality, autonomy, *Selbstbestimmung*. In this sense, the *Botta v. Italy*[73] case can be regarded as a landmark decision. Mr Botta, a physically disabled person, while on holiday at the seaside resort of Lido degli Estensi (Comacchio, Ferrara province) in August 1990, found out that the bathing establishments were not equipped with the facilities to allow people with disabilities to access the beach and the sea. Specifically, the resort lacked special access ramps, lavatories, and washrooms in breach of Italian legislation. In March 1991, Mr. Botta asked the mayor of Comacchio to remedy these shortcomings. When he returned to Lido degli Estensi later in 1991, he found no changes. Whilst the claim itself was unsuccessful, the Court's decision reveals a far more sophisticated understanding of the realities which deprive so many disabled people of their ability to enjoy the same rights as Europe's non-disabled citizens. Most significantly, the Court ruled that article 8 imposes positive obligations on the state to facilitate disabled people's access to essential economic and social activities. In *Botta*, therefore, the Court held that the notion of "private life" had to be expanded to "ensure the development, without outside interference, of the personality of each individual"[74].

In the *Kutzner v Germany* case[75], the Court stated that article 8 ECHR creates obligations upon states to provide support to disabled parents in order to maintain their right to a 'family life'. Other positive measures required by the ECHR included facilitating access by service users[76] or by their carers[77] to social service files.
Inclusion is not just warranted by the value of equality. Stepping outside and meeting others is essential to the development of the personality of the citizen and therefore also warranted by the European understanding of privacy.

Action 5: Promote further reflection on privacy as a distinct concept from data protection and issue a comprehensive policy document on privacy as a fundamental liberty right, in particular for older citizens.

5.4.3 Data Protection

Since the beginning of the eighties[78] European states have started to develop a vast body of data protection law in response to the perceived threat of ICT systems to the individual right to privacy. Data protection is today well anchored in European law through the fundamental right to data protection (article 8 EU Charter[79]), Article 16 of the Lisbon Treaty on the Functioning of the Union[80], and a number of EU/EEA directives[81]. European data protection rules affirm the principle of the free

[72] Ibid.
[73] ECtHR, *Botta v. Italy* 1998 26 EHRR 241.
[74] *Ibid.*
[75] ECtHR, *Kutzner v. Germany* (2002) *E.H.R.R.* 653
[76] ECtHR, *Gaskin v. UK* [1989] 12 EHRR 36.
[77] *R (S) v. Plymouth City Council* [2002] 5 CCLR 251.
[78] 1981 Council of Europe Convention for the Protection of Individuals with regard to the Automatic Processing of Personal Data (in force October 1985).
[79] *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.*

[80] Art.16 par. 1: "Everyone has the right to the protection of personal data concerning them".
[81] Directive 95/46/EC Protection of Individuals with regard to the Processing of Personal Data and on the Free

flow of personal data but attach to it eight conditions, or principles. These consist in "various specific procedural safeguards to protect individuals' privacy and in promoting accountability by government and private record-holders[82]. In detail, they are: the fairness obtaining and processing principle, which includes consent; purpose specification; non disclosure of personal information unless compatible with the fair processing; data must be safe and secure; accurate, and up-to-date; the processing must be proportional, not excessive; the detention period must not exceed the period of time necessary for the processing; the data subject has right to access the data; an independent supervisory authority is established in each member state and can hear complaints about compliance with data protection directives.

Individuals have thus been endorsed with rights as data subjects: the right to fairness when giving information, to have a copy of their personal data (right to access); the right to correct data or to have data deleted; the right to opt out of direct marketing; the right not to be subjected to automatic decision making and the right to complain to the Data Protection Authority. Furthermore, European law applies a broad understanding of personal data. In opinion 4/2007 the Article 29 Working Party confirmed the definition provided in Directive 95/46/EC as any information relating to an identified or identifiable natural person, the data subject. An identifiable person is "*a person who can be identified, directly or indirectly, in particular by reference to an identification number or to one or more factors specific to his physical, physiological, mental, economic, cultural or social identity*." Processing of personal data enjoys a wide definition too as it "*shall mean any operation or set of operations which is performed upon personal data, whether or not by automatic means, such as collection, recording, organization, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, blocking, erasure or destruction*" (article 2, 95/46/EC).

In order for the processing to be lawful, the data subject must have given his/her consent unambiguously (article 7, 95/46/EC). Regarding the processing of special categories of data "*the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject's giving his consent*". Such data are personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life. Consent is defined as "*any freely given specific and informed indication of his wishes by which the data subject signifies his agreement to personal data relating to him being processed*."

Is the data protection framework enough to ensure, not substantial justice, but procedural justice in the data processing involved in technologies for the elderly? As suggested in SENIOR deliverable D.1.5 "arguably, the privacy and data protection requirements of senior citizens are somewhat different from those of the rest of the population – or maybe not."[83] SENIOR correctly indicates a gap in understanding the privacy impacts of ICT on senior citizens. One of the reasons is that data protection gives rights to data subjects and data subjects are all equal, but in diversity.[84] Likewise, as pointed out above, the socio-economic category of the elderly differs widely within. While it appears that the use of ICT always involves some surrender of privacy, what rises concern are the limits of the requirement of consent for vulnerable groups' sharing of their personal data. The personalisation of ICT services[85], the mushrooming of social networks where sensitive health data are happily transferred[86], might well compress individual privacy in favour of a collective understanding of the right to privacy which puts

Movement of such Data; Directive 2002/58/EC Privacy and Electronic Communications

[82] P. De Hert & S. Gutwirth, op. cit., p. 77.

[83] SENIOR, D.1.5, op. cit., p. 35.

[84] "For instance, what privacy protection is enjoyed by a married, middle-aged ethnic-minority male working in a managerial post in a small town, and accustomed to buying many goods and services over the Internet? Is it equal to, or different from, that of everyone else in the same society? Are his movements less likely to be monitored in public places by legally-unregulated surveillance cameras than those of, say, his teenage, football-fan son? Or more likely than those of a member of the ethnic majority?" In the eyes of the law, these persons are all – equal - data subjects which come under the purview of the same rules if they are exposed to a similar information processing systems. "Yet" – "whether through compulsion, choice, or simply the differentiated circumstances of life, these different persons and categories differ in terms of the extent and frequency of their exposure of to information-processing systems", Colin J. Bennett and Charles D. Raab, *The governance of privacy: Policy instruments in global perspectives,* Ashgate, Hampshire, UK, 2003, p. 35.

[85] "Personalising citizen services goes behind convenience. We can use them to confront the problems of inequality, an ageing population, greater competition and global security with ideas, innovation and opportunity" quoted by C.D. Raab, in S. Fischer-Hulbner, P. Duquenoy, A. Zuccato, L. Martucci, *The future of identity in the information society*, p. 13, footnote 33 and sorced from www.govx.org.uk/communities/spaces/citizenservice/.

[86] *New Scientist*, "La santé passé au Web 2.0", October 2008.

emphasis on the public interest in personal data to guide inclusion policies. Applications involving continuous monitoring at a distance are particularly worrisome. Herein, technologies entail changes in the environment, which become populated with sensors-actuators and with objects which communicate ubiquitously, and also changes in the body, for instance by inserting microchips.

In its opinion on ICT implants[87], the *European Group on Ethics in Science and New Technologies* stressed that society should take care that such systems, where they are permitted, should not become systems of untenable restriction or even negation of basic rights, particularly when ICT Implant systems become part of health systems in which data is permanently or occasionally transmitted to other parties. In addition, the opinion suggests that interventions on the body and on the environment should strictly conform to the principles of necessity and proportionality and not be allowed when there are viable alternatives; that interventions should be as less invasive as possible; that all control devices could be removed without risk of dangers on the individual's life; that data collection and treatment should be strictly regulated, including non sensitive data; that people must keep the power of accessing and controlling their personal information and take part in the decision making process starting from them.

The reference to "society" which "should take care that such systems, where they are permitted, should not become systems of untenable restriction or even negation of basic rights" is very important. It reflects the decision in *Botta* where the Court considered the contextual conditions, linked them to personal development and called for positive actions. Similarly, in *Odièvre v. France*[88], the Court of Strasbourg discussed personal identity as "matters of relevance" to personal development. It also tallies well with the "circular" conception of human dignity adopted in this paper: human dignity as a legitimate source of fundamental rights elicits community intervention to guarantee the enjoyment of those entitlements necessary to realise a life of human dignity[89]. The automatic processing of personal data, most notably in ubiquitous environments, puts *eo ipso* the ceaseless exercise of informational borders negotiation at risk. For this reason, privacy has a fundamental interest that the automatic processing of personal information be regulated. Europe enjoys a consistent body of data protection law, culminated with the insertion of the right to data protection enshrined in article 8 of the EU Charter. But the right to privacy has assumed another meaning. Through the case law of the European Court of Human Rights, article 8 has been interpreted as ensuring the development, without outside interference, of the personality of each individual. Privacy therefore should be understood as a broadly conceived concept of autonomy and information autonomy of the individual[90].

In the landmark case *Botta v. Italy,* the Court used the right to private life to embrace the environmental realities which deprive disabled people of their ability to enjoy the same rights as Europe's non-disabled citizens. It is worth noting that *Botta* took the case to Court on the basis of article 8 (privacy) and article 14 (non discrimination). As for non-discrimination, the Court ruled that article 8 imposes positive obligations on state to facilitate disabled people's access to essential economic and social activities. In the foregoing we gave an account of the evolution of the right to privacy and of the implications of the right to privacy for the e-inclusion of the elderly. We argue that the European data protection apparatus is altogether well-equipped to guide the application of ICT for the elderly. But also that under certain circumstances the data protection framework might be insufficient. When data protection law is insufficient, for instance in cases of constant monitoring of the environment and of the body, the principle of human dignity and the "spirit" of the right to privacy as interpreted in *Botta*, as well as that of the right to equality and non-discrimination recommend that the community takes it on.

Action 6: Develop specific guidance on data protection for elderly people, in particular in the context of ambient intelligence and assistive technology.

[87] EGE group, Opinion 20, Ethical aspects of ICT implants in the human body (16/3/2005)
[88] ECtHR, *Odièvre v. France,* judgement of 13 February 2003
[89] Martha C. Nussbaum, Frontiers of Justice. Disability, Nationality, Species Membership, The Belknap Press of Harvard University Press, Cambridge (MA), London (England), 2007, p. 33.
[90] De Hert, P., and S. Gutwirth, "Privacy, data protection and law enforcement. Opacity of the individual and transparency of power", in E. Claes, A. Duff and S. Gutwirth (eds.), *Privacy and the criminal law,* Intersentia, Antwerpen-Oxford, 2006, p. 61.

6 Technology trends and emerging challenges

Technology affects older people in at least two major senses. First, technology may target the elderly by aiming to improve and prolong their life. By increasing elders' capacity to stay longer and more safely in work places, communities, and homes, technology may improve older people's living conditions and – together with modern biomedicine - may help the elderly to be healthy and vigorous until late age. Yet, this raises a serious anthropological issue as most older people die, and increasingly will die, after a period of protracted debility and feeble dementia stretching on average for some seven to ten years[91]. In other words the price to be paid for the assistive technology revolution seems to be a protracted period of considerable misery in the last years of life. In addition, thanks to medicine and technology's success in forestalling death, there is the risk that we have produced a culture in which death is even more unacceptable and more feared than ever before. This is a perfect example of the ever-expanding character of human desire, in which we are now doing better but feeling worse[92]. The corollary of this is that the failure to do everything possible to prolong active life is now regarded as morally culpable.

Second, technology concerns older people in a more general sense. As ICT is playing an important role in enabling older people to live independently for longer and in supporting their needs, it is important to ensure that general technology products are usable by this age group as well as to develop products specifically targeting the older population. The most immediate problem concerns accessibility in its broader sense, including physical accessibility, as older people are often irritated with devices and technologies that are fiddly to use, and linguistic accessibility, as this is also due to the kind of language that is used to explain technologies, what they can do for people, and how much they cost people. The older age groups feel particularly frustrated when it comes to understanding information they are given about technologies. Finally, economic accessibility is also an important issue, as many elderly feel that they cannot take up the opportunities new technologies have to offer because the prices are still too high for them.

Three main technology revolutions are affecting the elderly in the two senses sketched above (technology targeted on older people, and general technology). They are:

1) The Augmentation Revolution
2) The Biometric Revolution
3) The Wireless Revolution

6.1 AUGMENTATION

Technology will be used to restore normal performance and will advance performance. These techniques will come via implants, brain interfaces, genetic selection and nerve to prosthesis applications. Technologies for endowing humans with physical or psychological skills which restore lost capabilities, or even enhance them beyond a level previously experienced, strengthening brain or motor capacities, is becoming more prevalent, and more subject to scientific and ethical debate. Through bionic prostheses, bio-implants, and bio-chips, technological artefacts can be already integrated into the human organism and this trend is expected to progress. In the next few years nano implants in the brain might allow the development of treatment for neurodegenerative diseases but also to develop devices enhancing information storage and retrieval, and mood enhancers. The possibility to supplement, modify or replace biological components with technology components - also within the brain - and to network it with external machines and computer networks forms the current background for discussions among those who study technology trends.[93]

Drawing the line between necessary therapy and discretionary enhancement is genuinely difficult. Augmentation technologies will increasingly blur the border between alleviating the effect of disabilities and "human enhancing".[94] Indeed a pure "technical fix" of disability (age or not age related)

[91] Andrew, M.K., A.B. Mitnitski and K. Rockwood, Social Vulnerability, Frailty and Mortality in Elderly People. PLoS ONE 3(5): e2232, (2008). doi:10.1371/journal.pone.0002232

[92] Nowotny, H., 2004, *Wish Fulfilment and its Discontents - On the Uneasy Relationship Between the Life Sciences and the Humanities*. In European Union Advisory Group on Life Sciences (eds): "Modern Biology & Visions of Humanity", Multi-Science Publishing Co. Ltd.: Brentwood Essex

[93] Wreye, S., "Neuroethical Considerations: Cognitive Liberty and Converging Technologies for Improving Human Cognition", Ann. N.Y. Acad. Sci., No. 1013, 2004, pp. 221–228.

[94] COM (2004) 338.

is ethically problematic, because any disability is always the result of concurring physical, environmental and social conditions.[95] For improving impaired human performance it is necessary to define the intertwined concepts of normality, disease, disability, and defect. Who decides what is disability or disease or defect? Who establishes what is normal? This point is critical in ageing processes. Actually we have not yet understood whether ageing per se is a physiological process. Some scholars[96] have tried to identify ageing as a process which is universal, progressive, intrinsic and deleterious. There is no doubt that a degree of physiological deterioration will occur in all major organ systems with advancing age. Yet more recent studies have tended to cast doubt on the view that physiological deterioration is a characteristic of normal ageing[97]. Some have argued that the lifespan, old age and death of an individual can never be physiologically normal and that senescence should be always viewed as a disease[98]. As a matter of fact "*the identities of many older people are defined in relation to issues of abnormality and normality. The 'cut off' point were an old individual is or is not deemed to be 'frail' is in no sense clearly defined and variations in levels of assessment is of increasing concern for care managers. In a climate of resource constraints, distance from the norm has become valued amongst older people who do not conform to discourses of 'slow' and 'deterioration'* "[99]

An analysis of achievable results and concretely feasible applications of augmentation technologies, requires to consider an ethical monitoring, to protect fundamental rights of persons, against the potential risk of threats for the respect of human dignity, autonomy, and personal identity, to assess these potential risks and comparing them with the opportunities for dignity promotion and personal identity development, which are made possible by these devices through the restoration of lost functionalities and the chance of recovering effective interactions with the external environment. [100] It is particularly important that augmentation technology is not conceptualized as a pure anti-ageing technology. In such a case there would be the unavoidable risk to stigmatize those who fail – for many different reasons –to prevent ageing or rejuvenation. In other words the human augmentation revolution may reinforce ageism by increasingly devaluating the status of those who, notwithstanding technology, become older.

The most challenging sector in the field of human augmentation is the area of Brain Machine Interfaces (BMIs). BMIs are adaptive systems made of artificial components, which interface with biological organisms and establish a new kind of human-machine integration. BMIs are usually designed to restore lost motor and sensory functions and to overcome damages in the nervous pathway, directly connected to central nervous system, in order to bypass damaged neural areas and restore lost perceptual and motor functions. Examples of the types of systems emerging for widespread use in the near future include:

- stimulation devices for chronic pain therapy
- limb prostheses for anatomical compensation of damaged neural pathways
- implantable neurostimulation devices
- cochlear and retinal implants[101].

As BMIs emerge, it is important to contemplate how they affect:

1. Personal identity and autonomy -- In brain-machine interfaces, a technological device is connected to the brain, the main material substrate of human mental activity. How and to what extent does BMI interaction with the central nervous system modify mental activity? Which modifications are sustainable from an ethical point of view, with respect to the protection of dignity, personal identity, autonomy and potential alteration of a human being's perception of her/his strength and limitations? Which changes of one's actions control are tolerable from an ethical point of view?
2. Alteration of self-perception and modification of subject-environment interaction -- BMIs that are designed to overcome interruptions in the neural signal transmission bring about physical or psychological alterations to restore both perceptual transmission and motor transmission. The auditory brainstem implant is a prosthesis designed to restore hearing in people with injured auditory nerves through stimulation of the cochlear nucleus in the brainstem. Cortical visual

[95] EGE, Ehical aspects of ICT implants in the human body , Avis n. 20, 2005.
[96] Strehler, B. L., *Time, cells and aging,* 2nd ed., Academic Press, New York, 1977.
[97] Kohn, R. R., "Causes of death in very old people", *JAMA,* No. 247, 1982, pp. 2793-2797.
[98] Anton, B, L. Vitetta et al., "Can We Delay Aging? The Biology and Science of Aging", Ann. N.Y. Acad. Sci. 1057, 2006, pp. 525-535.
[99] Powell, J., Rethinking Gerontology: Foucault, Surveillance and the Positioning of Old Age, 2004. http://sincronia.cucsh.udg.mx/verano04.htm
[100] Lucivero, Federica, and Guglielmo Tamburrini, "An Ethical Monitoring of Brain-Machine Interfaces", 2007.
[101] For an in-depth study on these devices, see Lucivero, 2007.

implants send codified images, recorded by a tiny digital camera, to electrodes implanted in the visual cortex. These bionic systems for functional restoration may bring about alterations of perceptual capacities and may affect the human being's interaction with the external world.

3. Social identity and fairness -- Auditory implant applications may illustrate the impact of BMIs on the elderly as a member of a social community and the difficulties of re-adapting after a bionic operation. A reflection of these potential alterations of the identity of persons within a social environment is therefore needed.
4. Shared control: restrictions of individual autonomy -- Where BMIs are used to restore motor functions, the human being and the robotic artificial system cooperate in the action, selection, and execution. How is action control shared between the human being and the machine, and is it still possible to claim that the human is still fully responsible for the execution of the action? Is the human being still autonomous?

Action 7: Prevent that anti-ageing technology reinforces ageism by carefully monitoring messages conveyed by industry and by promoting educational campaigns.

Action 8: Scrutinize the development of Brain Machine Interfaces (BMIs) and involve all stakeholders in an ongoing ethical review of the technology design.

6.2 BIOMETRICS

The e-inclusion goal to assist the elderly to retain their independence for as long as possible chiefly focuses on e-services. This type of policy carries with it the urgent need for reliable remote identification of elderly individuals. The recent explosion and deployment of biometric technologies have emerged from the realm of science fiction books and movies into the mainstream of daily activities such as travel, shopping, personal identification, banking, access to public services, voter identification, and many others. With this growth, researchers continue to look for new methods of utilising many different characteristics of the human body to find the ultimate biometric identifier, which provides a high level of accuracy (i.e., uniqueness), and which is non-invasive/privacy-enhancing, inclusive, and relatively easy and cheap to collect and validate. Current biometric methods for human identification now include fingerprints, ultrasound fingerprinting, iris scans, hand geometry, facial recognition, ear shape, body shape, voice verification, computer keystroke dynamics, skin patterns. Emerging biometrics (2nd generation biometrics) include DNA analysis, neural wave analysis, ECG analysis, skin luminescence, remote iris scan, advanced facial recognition, body odour, and others. Multimodal systems, which match different identification technologies, are also rapidly progressing, as well as multiple biometrics, which consist of different types of biometrics used in combination. Also behavioral biometrics - which measure behavioral characteristics such as signature, voice, keystroke pattern and gait - are becoming more and more important.

A biometric system consists of some basic modules. The sensor module measures the biometric characteristic presented to the system. The aliveness detection module measures the person's physiological signs of life in order to avoid being cheated by artificial attributes. The quality checker performs a quality check on raw measurements and indicates whether the characteristic should be sensed again. The feature-generator module extracts the set of discriminatory features from the raw measurements and generates a digital representation of the biometric features, which is called "live template". The matcher module compares the live template against one or more templates previously stored. The decision module takes the final decision about identity according to the system threshold for acceptable matching.[102] Biometrics is likely to affect the lives of more people more quickly than

[102] When only two set of templates are confronted (the live template and stored templates), we speak of authentication, which aims to verify an identity claim, authentication answers the question "are you who you say you are?". Instead when the live template is compared against a large number of set of templates stored in a database, with the aim to find a set matching, we speak of (positive) identification. In positive identification, the person presented to the system does not explicitly claim an identity, and the question answered is "who are you?". Finally when the live template is compared against a limited number of stored set of templates, with the aim to check whether a person belongs to a watch-list, we speak of negative identification or screening. The negative identification process intends to answer the question "are you who you say you are not?" Both positive

any other current technology and the possibility of social exclusion resulting from the use of biometric systems has not yet been fully explored[103]. As a matter of fact, biometrics systems deal with people who fall within the range defined as ''normal'' by the individual system's commissioners, designers and administrators. It is very difficult to design a system that works well for the whole range of physical and behavioral characteristics expressed by humans, notably with elderly and disable people. Older people are sometimes less dexterous and slower to process through enrolment and verification steps. Sensory and motor impairments (e.g., poor eyesight, arthritic hands, poor memory, etc) may also create particular problems. Observations from field trials and literature show that biometric systems are normally designed for the "average" (young) person. The elderly user can be unjustly rejected by the system because their biometric features are not distinct enough (e.g., fingerprint) or they cannot be sufficiently protected against identity theft in case the system threshold for acceptable matching is set too low. If one considers that the new biometrics services being established by governments are essentially compulsory for citizens (e.g., biometric passports, e-government, e-health, etc.) and that very large scale commercial services based on biometric authentication are in progress (also in order to obviate the need to remember lots of PINs and passwords, which can be an advantage for older persons) one can easily guess the dimension of impact of the biometric revolution on elderly life.

1. **Technological Barriers for the Elderly.** Despite some good research, there is still a lack of detailed understanding about how biometric data and biometric templates behave with aging, especially specifically within an elderly population. Many human features change with age, and current biometric technologies have not been able to overcome some of these impacts to date. Accuracy of facial recognition technologies, which are the primary biometrics in use for travel/border security applications, does not hold up well over time. Fingerprint biometrics, which are inexpensive and fast to implement, and which are broadly deployed (e.g., payment systems, logical access to computer systems), have very high failure rates for older persons, whose fingerprints have become worn over a lifetime (also an issue for manual laborers, no matter their age)[104]. In addition, where biometric applications are designed to rely upon a particular physical characteristic for identification, they will result in exclusion of those individuals who may, due to injury or disability, not possess such a characteristic (e.g., injuries to eyes, fingers, limbs, etc.). Usually, systems are designed to offer fallback alternatives, but these are often time-consuming to pursue and can create some perception of stigma at "failing" the system. A 2005 trial for biometric passports held in the UK found that individuals over the age of 60 had more difficulty in enrolling in biometrics than their younger counterparts[105]. A suggested approach to remedy these issues is multimodality, which uses more than one personal trait or characteristic to identify a person. If one sample does not register, such as a scarred or faded fingerprint, another sample could be used, such as facial or signature recognition, which would lessen false rejection rates[106]. In addition, researchers continue to look for different biometrics which may be more reliable, unique, and non-invasive, including such options as human tissue, evoked brain signals, and heart sound.[107]
2. **Technology-Based Fear.** Concerns over privacy issues as they relate to biometrics are not unique to the elderly, but can be amplified by more generalized apprehension about technology borne out of a lack of knowledge, and ultimately cause individuals to wish to opt out of participation in some aspects of society. Identity theft is a significant concern to the elderly and biometrics aims to reduce the chance of this occurring[108], but many users also fear that violent acts, such as cutting a finger off, may be committed in order to acquire information[109]. There are, however, a number of ways to mitigate these concerns. Vitality tests that guarantee a living person is giving the

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and negative identification require databases. Instead in authentication mode, the template could be stored in a portable media, retained by the user, and submitted at the time of transaction in order to allow the system to compare it against the live template.

[103] Jeremy Wickins J, 2007, *The ethics of biometrics: the risk of social exclusion from the widespread use of electronic identification*, Sci Eng Ethics 13:45–54,

[104] Modi, Shimon K. and Dr. Stephen J. Elliott, *Impact of Image Quality on Performance: Comparison of Young and Elderly Fingerprints*, Purdue University, 2006, p. 5.
http://www2.tech.purdue.edu/it/resources/biometrics/publications/proceedings/ModiRASC2006.pdf

[105] UK Passport Service, 'Biometrics Enrolment Trial Report', May 2005, p.8-9.

[106] Khan, Imran., "Multimodal Biometrics – Is Two Better Than One?", *Auto ID & Security*, 2006.
http://www.findbiometrics.com/Pages/multimodality.htm

[107] Phua, Kokson, etal. "Human identification using heart sound," *Pattern Recognition*, Volume 41, Issue 3, March 2008, Pages 906-919.

[108] Hunter, Jessica, "Will Biometrics Eradicate Identity Theft Completely?", *Biometrics and Identity Theft*, 2006.
http://www.identitytheftfixes.com/biometrics_and_identity_theft.html

[109] Patrick, Andrew S., *Usability and Acceptability of Biometric Security Systems*, National Research Council, 2004, pp. 2.
http://www.andrewpatrick.ca/biometrics/NATO-BiometricsAbstract.pdf

information can be used to avoid the fear of harm while using biometrics[110]. Over the past several years, vein-based (finger or palm) biometrics has advanced into the market, but remain, at this time, a costly alternative to fingerprint or hand geometry, and may be slow to be adopted.

3. **Health Concerns and Misuse of Biometric Data.** Most of the privacy concerns associated with biometrics have been focused upon the general issue that biometric data might be stolen and misused as easily as any other personally identifiable information, with the heightened problem that one cannot merely reset one's biometric traits. However, as the price of human genome sequencing rapidly and dramatically falls[111] it is foreseeable that DNA tests, routinely used by law enforcement in investigations, will be used in everyday settings, in which case, new concerns about privacy are certain to emerge. In particular, once such technologies advance sufficiently, how much information can be obtained about an individual's current and future health and what can the information be used for? How can such information be effectively protected? This is of particular concern to elderly citizens who may find that they are diagnosed as having the potential for Alzheimer's, diabetes, cancer, or some other chronic or life-threatening disease in the future. Such a diagnosis could negatively impact treatments, living arrangements, health insurance coverage, etc. Clearly, such a use would raise serious ethical concerns.

Action 9: Promote more systematic analysis on specificities of biometric system design for older people with respect to their biological and cultural background.

Action 10: Adopt opportune regulatory measures in order to ensure that the implementation of biometric systems, notably large scale identification schemes, and questions of interoperability, encompasses the requirements of the elderly.

6.3 WIRELESS REVOLUTION

The computing revolution was about information—digitizing documents, photographs and records so that they could more easily be manipulated and stored. The wireless-communications revolution is about making digital information about anything available anywhere at almost no cost. During the last 150 years, human communication has been transformed by the launch of wired technologies and now by wireless technologies, as shown by the take–up of ubiquitous technologies, in which devices interact seamlessly within the environment. Some devices (sensors) only provide for sensing: movement, physical health, temperature, pictures, etc; other devices (actuators) can take action, reacting to stimuli provided by the service, such as human interface devices, door openers, light switches, etc. The key innovation in this revolution is that these devices communicate directly with each other through invisible wireless networks. Ubiquitous communication technologies therefore create a wireless technological network environment where access to control devices is a key issue for the user.

The technologies of ubiquitous communication are particularly relevant in the e-Inclusion domain, especially in the context of Europe's ageing society. Wireless technology is the building block of most assistive technology for elderly, including home based health and wellness measurement and monitoring architecture, location technology, emergency calls/alarm systems, wearable computers and smart clothes, etc. Wireless brings countless benefits. Devices and objects can be monitored or controlled at a distance. Huge amounts of data that were once impossible or too expensive to collect will become the backbone of entirely new services. Yet an essential ethical problem with the use of wireless technologies concerns the notion of autonomy; these technologies may threaten people's autonomy in the sense that they generate a new type of dependency, and create a huge amount of personal data beyond the person's control. Issues to be considered are the following:

1. **Privacy and Data Protection.** The streams of data from devices and sensors are different in kind from what most people are used to: the information is "probabilistic" rather than definitive, and the

[110] Patrick, Andrew S., p. 2.

[111] "Whole genome sequencing costs continue to fall: $300 million in 2003, $1 million 2007, $60,000 now, $5000 by year end," march 25, 2008. Http://nextbigfuture.com/2008/03/genome-sequencing-costs-continue-to.html

systems are vulnerable to being hacked into. Today's privacy rules presume a relationship between citizen and government or consumer and company. But the way in which information is generated and shared in wireless systems may involve so many parties that we have to change the way in which we look at privacy protection. Wireless communication may appear to be less intrusive because it is invisible and ever present, i.e. fully integrated in our daily lives, but the question remains as to who has access to control the system/devices, who has access to the personal data, how is data retrieved, interpreted and processed, how is data transmitted and to whom, how is the right to access determined and/or guaranteed, how is informed consent obtained, etc.

2. **Isolation and Exclusion.** A potential adverse impact of the deployment of wireless technology could be their impact on the senior's social surrounding: as long as an elder person is "attended" to by a wireless system, the risk exists that his family and friends feel less inclined to visit and spend time with the elderly user.
3. **Legal Status and Justice.** The legal status of wireless technologies at home (generally called AAL) pose the following questions: should they be considered as a "communication universal service" and as a "medically necessary prosthesis" and should they be included in the benefits provided under public insurance schemes? In other words, should such AAL systems be guaranteed to all elder persons in need of such systems, or conditioned to their ability to pay for it? What would be the economic impact of these systems on social security schemes?
4. **Autonomy and Surveillance.** Location and monitoring of people can be of vital importance for the security of some disabled and elderly users but these techniques are very intrusive. Devices can either prevent undesired wandering (e.g., automatically closing doors or gates to a house or community grounds to protect Alzheimer′s patients) or remind others to take corrective action (e.g., at night time when someone inappropriately leaves the bed). Some systems can detect cases of incontinence via special moisture sensors on bed sheets[112]. Other systems allow caretakers to detect periods of restlessness in the night by using sensors in the beds[113]. Computer vision techniques [114]can be used to determine asymmetries in gait patterns during visits to the doctor and consequently provide early warnings of the possible onset of a wide range of common neurological and musculoskeletal disorders such as stroke, Parkinson′s disease, and arthritis. Vision technology could also detect asymmetric tremors indicative of Parkinson′s disease and can be used to track the effectiveness of medication regimes to control the disease. Yet it is clear that wireless technology systems and devices are bringing society to an autonomous human-machine interaction. This may affects notions about autonomy, privacy, and informed consent, as well as the possibility of opting out of the ICT society. If technologies are ubiquitous, they are forever present and access to control becomes more central. Senior citizens who are less technologically savy, suffering from dementia or who simply have difficulty understanding the new environment profiles, risk losing their autonomy.

Action 12: Support the production of inclusive design guidelines for ambient intelligence to avoid the inclusion of barriers, notably for elderly people, in the design.

Action 13: Promote ethical and legal reflection on surveillance practices on elderly people in order to issue specific guidance and regulation, also involving relevant EC services, agencies, and committees (e.g., Art.29 WP, EDPS, EGE, FRA).

[112] Vigil Integrated Care Management SystemTM (http://www.vigil-inc.com/)
[113] For instance at Elite Care′s Oatfield Estates Cluster in Milwaukie, Oregon (http://www.elite-care.com)
[114] For instance at University of Rochester′s Center for Future Health (http://www.futurehealth.rochester.edu/)

7 Conclusions

The SENIOR project proposes a few points as main priorities for the policy agenda on ethics, e-Inclusion and ageing:

7.1 DEVELOPMENT OF COMPANY ETHICAL CODES ON E-INCLUSION

As advancements in technology allude, industry is a critical component of e-Inclusion. An important indicator of industry's participation in e-Inclusion initiatives and policy is seen thorough corporate statements of social responsibility and codes of ethics. At the European Council Summit in Lisbon, March 2000, the European Union set itself a new strategic goal for the next decade: to become the most competitive and dynamic knowledge-based economy in the world, capable of sustainable economic growth with more and better jobs and greater social cohesion. Underlining the important contribution of the private sector in achieving this goal, for the first time the European Council addressed businesses directly in "a special appeal to companies' corporate sense of social responsibility regarding best practices on lifelong learning, work organisation, equal opportunities, social inclusion and sustainable development". This was then reaffirmed by the 2001 Green paper on "*Promoting a European framework for corporate social responsibility*"[115]. In a further document in 2002[116], the Commission gave a description of Corporate Social Responsibility (CSR),

> *– CSR is behaviour by businesses over and above legal requirements, voluntarily adopted because businesses deem it to be in their long-term interest;*
> *– CSR is intrinsically linked to the concept of sustainable development: businesses need to integrate the economic, social and environmental impact in their operations;*
> *– CSR is not an optional "add-on" to business core activities - but about the way in which businesses are managed.*

and set a number of principles:

- *recognition of voluntary nature of CSR;*
- *need for credibility and transparency of CSR practices;*
- *focus on activities where Community involvement adds value;*
- *balanced and all-encompassing approach to CSR, including economic, social and environmental issues as well as consumer interests;*
- *attention to the needs and characteristics of SMEs;*
- *support and compatibility with existing international agreements and instruments (ILO core labour standards, OECD guidelines for multinational enterprises)*

Among various instruments to implement these principles, the Commission has identified codes of conducts, defined as "*innovative and important instruments for the promotion of fundamental human, labour and environmental rights, and anti-corruption practices especially in countries where public authorities fail to enforce minimum standards [...]The biggest challenge related to codes is to ensure that they are effectively implemented, monitored and verified*"[117] Finally in the 2006 Communication on "*Implementing the partnership for growth and jobs: Making Europe a pole of excellence on corporate social responsibility*"[118], the Commission stated that CSR can contribute to reach a "*more integrated labour markets and higher levels of social inclusion*". With this Communication, the Commission launched the *European Alliance for CSR* – an open partnership to make Europe a Pole of Excellence on CSR - whose priorities include *"Better responding to diversity and the challenge of equal opportunities taking into account the demographic changes alongside the rapid aging of the European population".*[119]

However corporate statements of social responsibility and codes of ethics are still rare in the ICT industry and notably in the field of e-Inclusion and ageing. Existing codes vary significantly from one corporation to another and are generally driven by needs such as:

- New markets and new market opportunities (which senior citizens can offer)
- Improvements in trust and confidence in their products and services
- Reductions in their administrative burden (which e-government services could provide)
- Reductions in regulatory hurdles and market barriers (say, harmonised legislation across the EU)

[115] COM(2001) 366 final
[116] COM(2002) 347 final
[117] COM(2002) 347 final
[118] COM(2006) 136 final
[119] COM(2006) 136 final

- A better understanding of senior citizens' ICT needs (which civil society organisations, the Commission, Member States and academia can provide)
- A better understanding of the most important determinants of ICT access and use and how ICT engagement develops over time
- Ethical guidance

Action 13: Promote the development of corporate statements of social responsibility and codes of ethics in e-Inclusion and implement EC CSR policies in this field.

7.2 COLLECTION OF LOCAL AND REGIONAL BEST PRACTICES

In the area of e-inclusion, work has already begun on compiling best practices. For example, the i2010 e-Inclusion subgroup has compiled a useful and interesting collection of national strategies for e-inclusion, aimed at assessing the status and exchanging practices of e-inclusion policy approaches across the EU. The subgroup is updating the collection as the national plans themselves are updated.[120] The Commission also sponsors the European Journal of e-Practice, a digital publication which promotes the sharing of good practices in e-government, e-health and e-inclusion.

The UK released a cluster of e-inclusion reports in late October, one of which provides results from the analysis of documents and contact with digital inclusion experts in 30 countries[121], while another summarises insights and experiences gained from community and third sector organisations involved in opening up digital technologies to excluded communities[122]. A critical success factor in these reports is the importance of engaging excluded communities. "For many excluded groups, support needs to be more pro-active and outreaching; it needs to come to the potential user, rather than wait for them to act."[123] Yet work has still to be done in order to compare local practices and to analyse regional diversities, in particular in the field of ageing.

Action 14: Devote further research to collect and compare best practices at local and regional level.

7.3 MONITORING TECHNOLOGY DEVELOPMENT IN REAL TIME

The pace of technological change has often challenged policy-makers. A new technology or application may reach the market before policy-makers are able to evaluate its ethical implications or impacts on privacy. Social networks such as Facebook and MySpace provide a good example. Each of these networks have well over 100 million users, making them among the most popular sites on the World Wide Web, yet it's only in the past year or so that policy-makers have begun scrutinising their services, and their popularity. Social websites can be said to empower citizens in a way different from most online applications of just a few short years ago. The social Web phenomenon shows great promise in helping to overcome digital exclusion.

[120] European Commission, i2010 e-Inclusion Subgroup National Reports, December 2007. http://www.epractice.eu/einclusion
[121] Foley, Prof. Paul, Cristiano Codagnone and David Osimo, *An Analysis of International Digital Strategies: Why develop a digital inclusion strategy and what should be the focus?*, Research Report, Department for Communities and Local Government, London, October 2008.
http://www.communities.gov.uk/publications/communities/internationaldigitalstrategies
[122] Office for Public Management Ltd (OPM), *Community Perspectives on Digital Inclusion: Qualitative Research to Support the Development of the Digital Inclusion Strategy - Research Report*, Department for Communities and Local Government, London, Oct 2008. http://www.communities.gov.uk/publications/communities/communitperspectives
[123] OPM, op. cit., p. 7.

However, there remains a need for ethicists and privacy experts to monitor the emergence of new technologies and to debate ethical issues at an early stage, before new applications have garnered millions of users. Many technologies raise ethical issues, which may not be easily resolved by reference to some prescriptive guidelines. Indeed, the application of many technologies may raise context-dependent issues, hence, there may well be a need for ongoing review by ethics experts to identify solutions. In addition, some oversight may be needed to ensure that the application of technology is ethically defensible and/or is in line with the foreseen ethical solutions. Monitoring the development of technologies can be done in various ways. One possible solution is via a web portal, like that launched by the Commission in June 2008 for exchanging broadband best practices. Another possibility is the establishment of an expert group tasked with preparing periodic working papers describing the most important new technologies. The Commission has convened many such expert groups in the past. An example is the Digital Literacy Expert Group, established in November 2007, to provide the Commission with inputs for a Digital Literacy Policy Review[124] and to contribute to guidelines on digital literacy actions.

Action 15: Launch an initiative to monitor in real time ethical and privacy implications of emerging technology relevant to e-Inclusion.

7.4 FACILITATING EXCHANGES BETWEEN THE MAIN ACTORS

The European Commission, Member States and other stakeholders have repeatedly and frequently spoken of the fragmentation of effort and the lack of co-ordination and collaboration in building an inclusive society in Europe and, in particular, an e-inclusive society that engages the growing population of senior citizens, a high percentage of whom are on the wrong side of the so-called digital divide.

In an attempt to remedy this fragmentation, the 2006 Riga Conference included EU Ministers, Commission members, members of civil society, and industry to work together with the European Commission, Member States and other countries to address the needs of the elderly population, thus creating new business opportunities. What the Declaration did not mention was *how* these stakeholders should work together, what mechanism should be used to stimulate collaboration. In the absence of such a mechanism, the Commission expressed its fears 18 months later that the Riga targets may not be met because of fragmentation of efforts and lack of collaboration.[125] It said the level of political and stakeholder commitment should be raised. One can envisage several different structural mechanisms for involving all stakeholders, like a pan-European platform[126] or a permanent stakeholder forum[127].

Action 16: Promote more structured exchanges between stakeholders by creating regular consultative mechanisms, platforms, and fora.

[124] http://ec.europa.eu/information_society/eeurope/i2010/studies/index_en.htm#literacy.
[125] COM(2007) 694 final
[126] The Bled workshop suggested a pan-European platform on ethics and e-inclusion clustering relevant stakeholders (industry, society, academia, ethicists, etc.) as a way of stimulating dialogue, sharing good practices and addressing the ethical, social and legal implications that may derive from the use of technology. Models for such pan-European platforms already exist. The information gathered and the activities of the platform should be the basis for awareness raising and education directed at both the stakeholders and the general public and take into consideration the international context.
[127] In the case of its e-health action plan, the Commission said a high level e-health forum should be established, the role of which would be to support the Commission services. The forum's task would be to follow up on the various roadmaps, and to iden**tify further actions including a strong evidence basis for the case for e-health.**

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