

Senior citizens and the ethics of e-inclusion

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Abstract The ageing society poses significant challenges to Europe's economy and society. In coming to grips with these issues, we must be aware of their ethical dimensions. Values are the heart of the European Union, as Article 1a of the Lisbon Treaty makes clear: "The Union is founded on the values of respect for human dignity...". The notion of Europe as a community of values has various important implications, including the development of inclusion policies. A special case of exclusion concerns the gap between those people with effective access to digital and information technology and those without access to it, the "digital divide", which in Europe is chiefly age-related. Policies to overcome the digital divide and, more generally speaking, e-inclusion policies addressing the ageing population raise some ethical problems. Among younger senior citizens, say those between 65 and 80 years old, the main issues are likely to be universal access to ICT and e-participation.

Among the older senior citizens, say those more than 80 years old, the main issues are mental and physical deterioration and assistive technology. An approach geared towards the protection of human rights could match the different needs of senior citizens and provide concrete guidance to evaluate information technologies for them.

Keywords Digital divides · E-inclusion · Informed consent · Right to dignity · Senior citizens

Introduction: values and EU policies

In an article in *The New York Review of Books*, Alain Finkielkraut, the French essayist, responded to the question "What is Europe?" by saying that Europe embodies "a certain idea of culture, which can be best defined by the

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words: autonomy of the spirit”.¹ This definition, which was written in 1985—well before the fall of the Berlin Wall, the rapid growth of globalisation, the enlargement of the Union, 9/11—not only is still valid, but also grounds the normative cohesion of European construction and the European identity as a unified subject. The EU Committee of the Regions (CoR) elaborated somewhat this idea as follows:

European identity is founded on the values contained in its Declaration for Europe, adopted at the extraordinary CoR plenary session held in Rome on 23 March 2007; these values include respect for human beings, their freedoms, rights and dignity; the principles of solidarity and responsibility; the rule of law and equality before the law; cultural diversity; the consolidation of the European social model; and the development of local and regional autonomy and civil society. These values, which are non-negotiable and valid for all who reside in the Union, lay the foundations for a bond of trust between the Union, its different levels of governance and its citizens, and establish the key features of a common European identity.²

The notion of Europe as a community of values has various important implications, not the least of which are those that concern European growth and economic development and the construction of the European Research Area. In January 2006, following a decision taken at the Hampton Court Summit during the UK presidency, an Independent Expert Group on R&D and Innovation produced a report on how to fully integrate research into the strategic plan of the EU with regard to economic growth and economic development.³ The Group, chaired by Esko Aho, former Prime Minister of Finland, provided a comprehensive analysis of the fundamental steps to take to put research into the core of economic development, from an investment in research and development of 3% of GDP to the creation of innovation-friendly markets, from financial mobility and venture capital to mobility in organisations and knowledge.

In addition to its economic considerations, the Aho Report advocated reinforcing European values as integral to an effective EU growth policy. Such values also need economic growth in some cases to be affordable to EU societies. Equality, health, social cohesion and common security are therefore indicated as elements that facilitate innovation though they are not sufficient by themselves to ensure sustainability. “Equality, solidarity, justice” are all

elements that belong to the set of shared values contained in the European Charter of Fundamental Rights and that contribute to the notion of Europe as a value community. Furthermore, ethics are embedded and legally binding in the Sixth and Seventh Framework Programmes (FP6, FP7) and, as such, characterise research and development policy within the EU and beyond.⁴

Both public perception of and respect for fundamental rights are key elements conducive to the promotion not only of responsible science as set out in FP7 but also of industrial and research applications of ICT consistent with societal goods and values.

Recent political decisions have reinforced this need. At the European Council of 13 December 2007, the EU Heads of State and Government signed the EU Reform Treaty in Lisbon. The Reform Treaty (now more generally known as the Lisbon Treaty) clearly indicates a set of European values, such as human dignity, freedom, democracy, human right protection, pluralism, non-discrimination, tolerance, justice, solidarity and gender equality.⁵ These values are stated in the Charter of Fundamental Rights of the European Union,⁶ proclaimed by the Presidents of the three EU institutions (Council, Commission and European Parliament) on 12 December 2000 and constitute the key frame for design and implementation of EU policies, from research to security, from immigration to energy and climate change. The presupposition that EU policies have to be consistent with the fundamental rights as stated in the European Charter implies that ICT research activities and policies also need to address these new dimensions. More specifically, this means that all European policies—beyond their obvious and explicit targets—have the general goal to promote and pursue European ethical principles worldwide, as clearly stated in the Commission’s Green Paper on the European Research Area.⁷

European research policy ... should experiment with new ways of involving society at large in the definition, implementation and evaluation of research agendas and of promoting responsible scientific and technological progress, within a framework of common basic ethical principles and on the basis of agreed practices that can inspire the rest of the world.

Article 6 of the Seventh Framework Programme requires EU-funded activities not to contravene fundamental values.

¹ Finkielkraut 1985.

² EU Committee of the Regions 2007.

³ European Commission 2006.

⁴ European Commission 2000.

⁵ <http://eurlex.europa.eu/JOHtml.do?uri=OJ:C:2007:306:SOM:EN:HTML>.

⁶ http://www.europarl.europa.eu/charter/pdf/text_en.pdf.

⁷ European Commission 2007b.

FP7 provided specific guidance for ethics in ICT.⁸ The main issues mentioned in this guidance include:

- privacy and informed consent,
- use of animals in ICT research,
- ICT implants and wearable computing,
- e-health and genetics,
- ICT and bio- and nano-electronics.

In parallel with FP7, various EC Communications (e.g. on RFID, e-inclusion, privacy-enhancing technologies, i-2010) have advocated the need to promote ICT oriented to social goods and consistent with EU fundamental values, another area which needs proper analysis.

The FP7 guidance is underpinned by the Commission's Science and Society Action Plan, published in December 2001,⁹ which said it is "necessary to strengthen the ethical basis of scientific and technological activities, to detect and assess the risks inherent in progress, and to manage them responsibly on the basis of past experience". Actions 30 and 31 of the Science and Society Action Plan specifically address the need to study the ethical implications of new technologies:

Action 30: An open dialogue will be established between NGOs, industry, the scientific community, religions, cultural groups, philosophical schools and interested groups, stimulating an exchange of views and ideas on a range of critical issues, such as the ethical impact of new technologies on future generations, human dignity and integrity, 'info ethics' and sustainability. A variety of mechanisms will be used (focus groups, polling exercise, e-debates, workshops or institutional forums, etc.).

Action 31: The level of awareness among researchers of the ethical dimension of their activities is rather uneven in Europe. Actions to raise awareness of good scientific practices, including the ethical dimension, research integrity and the key elements of European legislation, conventions and codes of conduct should be encouraged.

Two Opinions of the European Group on Ethics in Science and New Technologies (EGE)¹⁰ have also advocated the embedding of ethics and societal considerations in ICT policy design and implementation as well as opening debates on the societal implications.

⁸ <ftp://ftp.cordis.europa.eu/pub/fp7/docs/guidelines-annex5ict.pdf>.

⁹ http://ec.europa.eu/research/science-society/pdf/ss_ap_en.pdf.

¹⁰ European Group on Ethics in Science and New Technologies (EGE) 1999, European Group on Ethics in Science and New Technologies (EGE) 2005.

Inclusion, e-inclusion and ethics

In the social sciences, inclusion refers to a process, de facto and/or de jure, of including people in a given social structure, most often, in society at large. Conversely, social exclusion describes "the inability of our society to keep all groups and individuals within reach of what we expect as a society...[or] to realise their full potential".¹¹

Since the time of the Greek philosophers, ethics have been evoked to mitigate the tension between individuals and community.¹² However, social bonds can be justified without resorting to ethical categories. For instance, according to Thomas Scheff,¹³ individualist societies have institutionalised two major defences against the loss of social bonds. One, he says, is the "myth of individualism, and the denial and repression of the emotions", and the second follows from this: a simplification of human nature and social order by the exclusion of social feelings, solidarity, for instance, and, in general, emotions. One should include individuals in the society chiefly because they can contribute to the common wealth and can receive from this common wealth accordingly. We should also open up the market to previously marginalised sectors of the society in order to enlarge markets. In the extreme version of this theory, only people who can remain active, either as producers or consumers, are worth being included.

Although an echo of a pure economic theory can be traced in EU policies on e-inclusion (e.g., the emphasis accorded to the need to promote "active" living), it is indisputable that the EU approach to e-inclusion is based on a different vision. Ethics are an integral part of the EU concept of e-inclusion: "e-Inclusion is necessary for social justice, ensuring equity in the knowledge society".¹⁴

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".¹⁵ The Riga Declaration explicitly calls for increasing ethical awareness:

¹¹ Power and Wilson 2000.

¹² E.g., most virtues listed by Aristotle are actually attitudes such as friendship, honesty, trustfulness, solidarity, etc., which are essential to overcome the conflict between the individual and the community.

¹³ Scheff 1990.

¹⁴ European Commission 2007e.

¹⁵ http://ec.europa.eu/information_society/activities/e-Inclusion/events/riga_2006/index_en.htm.

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. Furthermore, greater gender balance in the information society remains a key objective.

and

Realising increased quality of life, autonomy and safety, while respecting privacy and ethical requirements.

The centrality of ethical issues in e-inclusion has been further reasserted by the Communication on Ageing well in the Information Society.¹⁶

Solutions can only bring benefits if users have access to basic ICT facilities, have the appropriate education and motivation, and ethical and psychological issues are properly addressed. There is no specific reference point for ethics in ICT for ageing, for example, in safeguarding human dignity and autonomy where solutions require a degree of monitoring and intervention.

The concept is also affirmed in the associated Commission Staff Working Paper¹⁷:

With the emergence of ICT and ageing new ethical questions are being raised. These questions find their origin in the vulnerability of the user, the changing characteristics of the user population (e.g. more people surviving at high age but also the trend towards more educated and empowered users), economic constraints such as public budgets that are at tension with serving all fully in health and social care and the constant renewal of science and technology.

Still more specifically, the recent Communication “European i2010 initiative on e-Inclusion—To be part of the information society”¹⁸ says that “It is also important to raise awareness of the risks involved in processing personal data through ICT networks and educate users in this field, e.g. risks of identity theft, discriminatory profiling or continuous surveillance.”

Yet until the Seventh Framework Programme, there have been few systematic, co-ordinated initiatives on ethics and e-inclusion.¹⁹

Ageing and e-inclusion

The digital divide is a special case of social exclusion

Social exclusion may take various forms, one of which is the gap between those people with effective access to digital and information technology and those without such access, otherwise known as the “digital divide”. Reflection on the digital divide started in the 1990s, some years after industry, governments and academia began talking about an “information highway” linking all citizens to the internet. The opening lecture of the first Information Superhighway Summit, in January 1994, clarified the high ambitions of this highway. “We have a dream for ... an *information superhighway* that can save lives, create jobs and give every American, young and old, the chance for the best education available to anyone, anywhere.” The speaker was Al Gore, then Vice President of the US.

The summit was enthusiastic about the growing Internet and Web. It underlined that growth alone is not enough but that access to the Internet could play a vital role in empowering individuals and promoting their quality of life. It also underlined the need to promote universal access to the Internet. In the mid-1990s, the phrase “digital divide” was coined. This “digital divide” was not merely perceived as a neutral parameter describing some normal characteristics of society. It was seen as an indicator of a shortcoming of the information highway and as an appeal to society to solve this problem.

In the EU, policies emanating from DG Employment and Social Affairs²⁰ address active inclusion (linked to the labour market and better access to promote the integration of the most disadvantaged people), decent housing and homelessness (in order to minimise poverty and social exclusion), inclusion of vulnerable groups (including people with disabilities, migrants and ethnic minorities, homeless people, ex-prisoners, drug addicts, people with alcohol problems, isolated older people and children). DG Information Society and Media has also focused on the digital divide, especially in ICT terms.

The DG Information Society and Media adopted the notion of e-inclusion which “refers to the actions to realise an inclusive information society, that is, an information society for all”. The main goal of e-inclusion is improving ICT access for disadvantaged groups and populations, particularly for people with disabilities and senior citizens. The EC’s RTD Framework Programmes, including the Competitiveness & Innovation Framework Programme

¹⁶ European Commission 2007c.

¹⁷ European Commission 2007d.

¹⁸ European Commission 2007c.

¹⁹ In the Sixth Framework Programme, the European Commission provided funding for quite a few projects dealing with e-inclusion and senior citizens. Several of these projects mention privacy and ethics, but only a few devote more than some short paragraphs to the issues.

²⁰ http://ec.europa.eu/employment_social/spsi/poverty_social_exclusion_en.htm.

(CIP), have been the main instruments used by the EC to develop its policy on e-inclusion.²¹

The age-related digital divide

In Europe, the digital divide is primarily age-related. According to the European Commission's 2005 Benchmarking Report, 38% of EU citizens were regular users of the Internet, but only 8% of people over 65 were regular users.²² There are several reasons why this is the case. A joint report in 2002 from the European Commission and the Council, entitled "Increasing labour-force participation and promoting active ageing", said that raising participation of older people in the labour market will not be easy, partly because it will depend on changes in cultural and socio-psychological factors, in particular attitudes to older people.²³ Although Article 21 of the European Charter of Fundamental Rights²⁴ expressly prohibits "Any discrimination based on any ground such as ... [inter alia] age" and although Member States have introduced age-discrimination legislation or information campaigns,²⁵ discrimination

²¹ Additionally, at the EU level, the major initiative dealing with active ageing is the Ambient Assisted Living Joint Programme, established on the basis of Article 169 of the European Treaty. Member States are co-operating within a European framework for implementation of active ageing programmes and reduction of fragmentation of resources. The AAL strategy is aimed at the needs of the ageing population, to increase autonomy and to facilitate all activities of daily living by the use of remote services and intelligent products. All EU Members States are promoting national initiatives for inclusion of the elderly, the majority of which have several initiatives dealing with issues such as:

- accessibility to public services websites,
- specific content for senior citizens using new media,
- measures to avoid inhibitions to the use of ICTs by senior citizens,
- joint events for grandparents and grandchildren,
- networks of computer centres for senior citizens,
- courses for senior citizens on how to use PCs and the Internet, sometimes with the support of younger students.

The governance of e-inclusion policies is delegated in some countries (Czech Republic, Austria, Finland, among others) to ad hoc agencies such as councils for the elderly and/or associations of senior citizens.

²² The Pew Research Center has found a similar situation in the US: "An even more intractable part of the [digital] 'divide' relates to age. There is a pronounced "gray gap" as young people go online and seniors shun the Internet. Those who do not use the Internet often do not feel any need to try it, some are wary of the technology, and others are unhappy about what they hear about the online world." http://www.pewinternet.org/report_display.asp?r=21.

²³ http://ec.europa.eu/employment_social/employment_strategy/key_en.htm#4. See p. 13.

²⁴ http://www.europarl.europa.eu/charter/default_en.htm.

²⁵ See, for example, the Stop Discrimination website, launched 2003: <http://www.stop-discrimination.info>.

remains a challenge to overcome, as the Commission pointed out in its Social Agenda.²⁶

The biggest obstacle, experts say, is that most companies are reluctant to retain or hire older workers. In one survey, one-fourth of companies said they were not inclined to hire older workers. In an industry survey, a majority of technology companies candidly said they would not hire anyone over 40.²⁷

The digital divide cannot be characterised solely as a consequence of socio-economic variables nor can it be conceptualised solely in terms of socio-economic priorities. Social dynamics, personal motivations and cultural elements are as important as economic factors. Digital inclusion, in practice, implies changes affecting all these threads of the social fabric and promises benefits to society including economic development, health care improvements and enhanced levels of social inclusion.

From a technological perspective, these changes may range from the development of lower-cost, highly accessible technologies to the creation of applications that engage and motivate individuals to interact with ICT because it enhances their personal lives and their roles within family and community. Given that the digital gap is highly impacted by factors related to age and levels of education,²⁸ much of the work of closing this gap is contingent upon providing technologies and solutions that particularly address the physical needs of senior citizens as well as those who may be less educated and uncomfortable or unfamiliar with the traditional desktop computing environment which has become the hallmark of current day ICT.

Access to communications networks continues to improve slowly through decreases in cost and increased geographical availability of broadband networks. A great deal of research and development effort has been, and continues to be, focused upon assistive technologies, wherein the human interface with ICT is made more effective in dealing with physical constraints that may affect senior citizens and/or the disabled. However, most of these changes tend to focus upon providing new methods to access the same traditional ICT delivery mechanisms that have been in place for decades. Beyond this, innovations are being realised to bring about what was envisioned by researchers in the late 1980s as ubiquitous computing, where computers would be invisibly embedded within one's environment and which would focus upon interfaces that connected humans to each other, rather than ones that connected humans with computers.²⁹

²⁶ European Commission 2005.

²⁷ Lohr 2008.

²⁸ Demunter 2005.

²⁹ Weiser et al. 1999.

These innovations are more likely to be seen today as individual applications and products. Although they have yet to achieve a truly pervasive level, they are positioned to provide services to a broader range of users than the typical desktop computing system. Combined with the ever-expanding scope of wireless communications technology, ambient devices or sensors embedded within a building, a room, in clothing, on the pavement or on one's body require little or no knowledge of technology on the part of the individual. Once such technologies are embedded within an environment, they do not usually give the user an opportunity to decide whether or not to make use of it. A sensor affixed to one's skin is collecting and transmitting data to one's doctor continuously; a sensor in a doorway will monitor one's passage from room to room; a load sensor in the floor might determine one's weight, whether or not this is information one wishes to share with the recipients of the data.³⁰ These technological changes will alter where, when, how and how often each individual interacts with ICT. However, closing the gap is also a function of change from the perspective of the individual, and other key factors driving closure of this gap, particularly within the community of senior citizens, are likely to include:

- *Demographics*—As the current work force ages, will an infusion of more technology-savvy retirees into a community encourage greater dialogue about ICT? Will such a dialogue lead to an increased use of ICT for services, information and support?
- *Globalisation and migration*—Will the physical distance between families sufficiently motivate senior citizens to take up use of e-mail or video conferencing to keep in touch with their grandchildren?
- *Viral applications*—Once engaged in the use of ICT for one purpose, will the natural curiosity of the individual cause him or her to seek out new uses of ICT to enhance their social interactions and support their daily activities?
- *Financial opportunity*—Will the prospect of reaching a growing marketplace encourage enterprises to innovate and develop more services and products targeted to better meet the needs of an underserved market segment?

These are some of the forces that are slowly but surely beginning to drive uptake of ICT towards the “tipping point”. To close this gap effectively, the desire or need for ICT-based services from the user's perspective must accelerate its convergence with the applications and services

being offered by technology, service, communications and content providers to create an efficient market in which they can deliver on the promise of a socially inclusive environment.

Ethics of e-inclusion of senior citizens

Who are the senior citizens?

Although ageing is a biological process, age definition chiefly results from cultural and societal conventions.³¹ Our passage through time is made up by a series of age-graded roles that we fulfil both simultaneously and sequentially. Each role has its own social clock for adjudging the age-appropriateness of various role performances, such as the “right” time for going through school, getting married, starting a family, “peaking” in one's career, retiring and so on. Societies not only differ in how they value age, but in how they categorise age.³²

The difficulty of defining senior citizens as a homogeneous class of persons in need of protection without making reference to context and personal conditions has consequences for the implementation of e-inclusion policies. In particular, it has consequences for the forging of an ethics capable of guiding, protecting and promoting the participation of senior citizens in particular and of people in general to the functioning of the (information and communication) society. The categorisation of senior citizens, as a result of socio-cultural determinism, emerges critically as one proceeds to identify and overcome the obstacles and satisfy the needs of senior citizens for ICT.

Contemporary societies are only roughly described as “ageing societies” but the general trend is more complex. Two events characterise current ageing processes: the naissance of an extended middle age applying to the post-65 age group (which could be called the “third age”) and the creation of a “fourth age” (older senior citizens). A different way of categorising people, one perhaps more closely reflecting reality, is in terms of their health and cognitive functioning. Hence, instead of demarcating society by age (especially from retirement age), policy-makers could distinguish

³¹ Biologically speaking, there are only three life periods: (1) embryogenesis, i.e., the period in which the embryo is formed and develops; (2) growth, which starts with the fetus and continues until puberty when the body becomes capable of reproduction; and (3) senescence, the state or process of ageing which starts after puberty, which includes middle and old age, and ends with death.

³² Retirement can be regarded as a social convention shaped by various socio-economic factors which set the frame for minimum and maximum retirement age. As these socio-economic factors change, so do retirement structures. This in turn affects prevailing ideas and perceptions of age; of what it means to be old and when one is old. See also, e.g., Banner 2001.

³⁰ While these ambient technologies may overcome many of the accessibility-related issues of ICT, they themselves give rise to a host of ethical questions which are addressed later in this paper.

between (relatively) healthy people and those who are vulnerable, rather than some artificial age-related imposition (those between 65 and 75 and those who are 76 and older). While vulnerability is generally age-related, policy-makers should recognise that not all younger senior citizens are free from vulnerability and not all older senior citizens have serious health problems, marked cognitive decline, etc. Another approach refers to the “stages of life”, rather than the “ages”, and uses the economic status of citizenry, i.e., before, during and after paid work.³³

The term “middle age” was a concept popularised in the 1960s to indicate a grey area between adulthood (30–40 years old) and retirement (affecting those 65 years and older). “Extended middle age” is now the term commonly used to indicate a continuation of this period including a change in circumstances (e.g., retirement). During extended middle age, the main physical and mental abilities remain unaltered though the person is ageing and gradually forced into the role of the senior citizen. As such, he or she is better profiled in terms of desired activity patterns, job opportunities, desired life habits, desired conditions rather than medical and social needs.

The “fourth age” is applied to senior citizens who show substantial losses in physical mobility and cognitive functioning. Such losses can occur to the young-old senior citizens as well as the “old-old” senior citizens,³⁴ but are rather more common in people in their eighties and nineties.³⁵ Furthermore, with advanced age, people often express fewer positive emotions and a sense of loneliness. The fourth age, as used here, can be regarded as akin to the “oldest old” category introduced by Matilda Riley.³⁶

Breda and Schoenmaekers, among others, have pointed to the dangers of categorising people by age:

Age limits presuppose that age groups are homogeneous, which older people certainly are not. Indeed, senior citizens have exceptionally diverse interests, experiences, needs and desires, so that clearly their

³³ For an interesting discussion on this and, especially, the merits and difficulties of making social policy decisions on the basis of people’s social rather than chronological status, see Midwinter 2005.

³⁴ Bernice Neugarten coined the distinction between the “young-old” and the “old-old” senior citizens. See Neugarten 1974.

³⁵ See, for example, Breda and Schoenmaekers 2006, p. 541: “There are fewer disabled persons aged 20–65 years than older, and the share of all people with disabilities who are elderly will continue to rise.” The authors refer to Bestuursdirectie van de Uitkeringen aan Personen met een handicap (BUP) [Agency for Cash Benefits for Disabled People], *Jaarverslag 2000* [Annual Report 2000], BUP, Brussels, 2002. Much research has examined the well-known relationship between age and disability. As another example, see McMullin and Shuey 2006: “There is a strong relationship between age and disability among those of working age”.

³⁶ Riley, Matilda, and Richard Suzman. (1985). “Introducing the ‘Oldest Old’”, *Milbank Memorial Fund Quarterly*, 63(2), 175–186.

common age is an ineffective discriminating criterion ... ageing is a continuous process and no cut-off point distinguishes older people from the non-elderly. Imposing a threshold may create substantial differences in the treatment of two people whose ages differ little (even by only a day). Age limits are also rigid: many do not change in line with the social context. The most conspicuous example is the ‘official’ retirement age: the prescribed ages have remained unchanged for many decades (at least for men), while life expectancy has gradually increased. Since the state retirement age was introduced, average life expectancy has increased by 15–20 years. Social conditions can change so much that a rule created to provide protection may degenerate into a curtailment. Another disadvantage of age limits is that they contribute to the stereotyping of older people as poor, passive and care-dependent.³⁷

This scenario explains why most current statistics and demographic studies addressing ICT and senior citizens run the risk of being misleading. Most available studies, including the most recent Eurobarometer surveys, do not clearly differentiate between younger and older senior citizens and tend to lump together everyone over 65. Instead, at least as far as ICT is concerned, one can distinguish two different demographic groups.

Among the younger senior citizens, the digital divide is more likely to be an issue of concern. They need to defend themselves against ageist prejudice, which can constrain their rights and inhibit or prevent access to new technologies. The main e-inclusion goals in regard to this group are the first two mentioned in the Ageing Well Action Plan:

- *Ageing well at work or ‘active ageing at work’*: staying active and productive for longer, with better quality of work and work-life balance with the help of easy-to-access ICT, innovative practices for adaptable, flexible workplaces, ICT skills and competencies and IT-enhanced learning (e-skills and e-learning),
- *Ageing well in the community*: staying socially active and creative, through ICT solutions for social networking, as well as access to public and commercial services, thus improving quality of life and reducing social isolation.

With older senior citizens, it makes less sense to focus only on discrimination and ageism. Although these issues

³⁷ Breda and Schoenmaekers, op. cit., pp. 532–533. Many other researchers have made similar points. See, for example Bowling et al. 2005: “Any categorisation of chronological age obscures the physiological, psychological and social diversity of older people.” Walker contends that “public policy has played (and continues to do so) a major role in determining the meaning of old age and, therefore, the extent of age integration and segregation.” Walker 2000.

remain important and need to be addressed in the context of this group too (especially because some senior citizens at the age of 90 are more agile, physically and mentally, than others at the age of 60), it is worth focusing more on the assistive role of ICT. In this group of senior citizens, the lack of universal access to ICT might lead to a loss of independence and to an overall degradation in quality of life. The main e-inclusion goal with many of these people is the third mentioned in the Ageing Well Action Plan:

- *Ageing well at home*: enjoying a healthier and higher quality of daily life for longer, assisted by technology, while maintaining a high degree of independence, autonomy and dignity.

Needless to say, these demographic groups overlap (some people age and deteriorate faster than others or, to put it differently, some people remain active and healthier longer than others). Even so, one can distinguish different needs and different ethical implications. With the caveat that we consider our two groupings as a tool for organising arguments, we can categorise e-inclusion ethical issues involving senior citizens in two major clusters: first are those issues arising from e-inclusion of younger senior citizens and, second, those issues arising from the e-inclusion of older senior citizens.

Younger senior citizens

The existing group of younger senior citizens are the main victims of the digital divide and could be consequently the main beneficiaries of measures for overcoming it. Younger senior citizens are a heterogeneous population, which includes very different subgroups according to socio-economic, cultural and geographical variables.³⁸ Their actual physical and mental conditions put them closer to the middle-aged than to the older senior citizens group. The dramatic demographic change, with an increase of 10 or 20 years in life expectancy, achieved in the last few decades, has largely outpaced cultural and societal conventions about ageing and notions about who are the aged. People who would be considered chronologically older according to a standard description are actually biologically and psychologically middle-aged. Consequently, younger senior citizens face a twofold challenge. First, they have to deal with a change in their social status (e.g., as a retiree, grandfather or whatever) which is not consistent with their actual physical and mental conditions. Second, they have to face age-related exclusion, i.e., they have to prevent their being socially marginalised due to their age.

³⁸ For instance, in Europe, the digital divide is also geographically determined; it is more important in the south than in northern Europe.

Existing younger senior citizens grew up in the 1940s and 50s, in a pre-digital age, and they suffer from various limitations that impair their embrace of digital technologies.³⁹ Although the majority of Europeans aged 65 and over are open-minded towards new technologies and many have already gained hands-on experience with a computer, their full acquaintance with these technologies is limited by factors that prevent accessibility to ICT resources.⁴⁰

The importance of overcoming the age-related digital divide in this group of senior citizens goes beyond the obvious need to prevent marginalisation of a large number of EU citizens who could still remain active and contribute fruitfully to European growth and development. Though this objective might be laudable, it cannot be the core argument if one takes seriously the definition of Europe as a community of values. Allowing an age-related digital divide to continue does not make economic sense and, in any event, it is an ethical offence.

Justice due

An age-related digital divide is an offence to the principle of justice, which should be the cornerstone of any well regulated polity. Justice is the foundation of trust. Society members trust authorities if they think that authorities are just, that is, when they perceive that they are treated honestly, openly and with consideration. When principles of justice operate ineffectively, confidence in society's institutions is undermined. Citizens or group members may feel alienated and withdraw their commitment to institutions perceived as unjust. EU institutions, like others, have often been accused of suffering from a democratic gap (In this case, the accusation is that it is an unelected body—the European Commission—that initiates policy, while the elected European Parliament can only react to policy initiatives).

Justice can be conceptualised as fairness (at least, for purposes of this paper), which includes fair distribution (distributive justice), fair and reliable procedures (procedural justice), fair retribution for evil and good done (retributive justice), and proper restoration of evil done (restorative justice).⁴¹ The age-related digital divide offends the principle of distributive justice. Senior citizens expect to receive their share of a crucial common good such as digital technologies. It is important, however, to emphasise that the principle of fair distribution tends to stress the commodity function of ICT, which is obviously

³⁹ The next younger generation of senior citizens will comprise the baby boomers, who are already very familiar with technology, a fact which is likely to produce a very different scenario.

⁴⁰ Demunter 2006.

⁴¹ Tyler and Belliveau 1995, p. 291.

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 them 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. A society in which senior citizens are excluded from digital technologies is a society in which democratic participation is impaired. In other words, digital literacy not only opens the possibility to participate by all those who run the risk of being excluded, but also is a building block in the decision-making processes in modern states (e-government). If senior citizens cannot fully participate in democratic procedures, this jeopardises democracy. 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. Senior people who are suffering from physical and mental limitations have often been damaged by unhealthy foods and habits (which have often been promoted by the market), 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 and their adoption of society-induced life styles. If ICT can contribute to this restoration, by addressing the limitations suffered by senior citizens, it would be unjust not to offer them such a restoration.

The notion of justice applied to the age-related digital divide raises a number of challenging political issues which deserve further in-depth enquiry taking into account the different definitions of justice, all of which are applicable to the e-inclusion of senior citizens.

Human rights and ageism

When we consider the ethical issues that arise from the development and proliferation of new technologies, especially in the context of the inclusion or exclusion of senior citizens, such consideration must always be underpinned by the recognition of human rights and any legal implications, either positive or negative. This means that the diffusion and application of technologies must not impair fundamental human rights and should contribute to the values they embody.

The European Charter of Fundamental Rights includes non-discrimination principles. Specific rights are mentioned for senior citizens (“The Union recognizes and respects the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life”) and for persons

with disabilities (“The Union recognizes 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”).

Universal access to communications and information services could also be characterised as an essential human right guaranteed to senior citizens. Universal access to digital technologies could be conceptualised both as a liberty right and a claim right. This poses some interesting issues about what should be assured and who is obliged to fulfil the right, as mentioned above.

Liberty rights are those rights which can be described as being free from something. 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. Conceptualising 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. Of course, at least in Europe, it would not make sense to speak of legislation that directly prevents access to ICT by senior citizens. Yet, it would be true if one considers legislation that indirectly impairs access. For instance, a lack of policies that facilitate the development of an ICT infrastructure accessible to senior citizens, such as computers, networks, broadband or software, or the lack of considering seniors’ needs in setting ICT standards, such as senior-friendly human-machine interfaces, can be seen as examples of indirect ageism. In other words, e-inclusion policies should target discrimination against senior citizens and promote affirmative actions, but there might not be a positive obligation to address senior citizens’ ICT needs by actively offering services.

The digital divide is an ethical problem that needs to be addressed by public policy. The underlying assumption is that the Internet should not simply be compared with so many other technologies and gadgets which society accepts as being distributed unequally among the population. Access to the opportunities of the Internet now is regarded as an essential element in our society and economy, just like access to food or clean air and water or health care.

At least some of the information that can be found on the Web and some of the possibilities of the Internet can be seen and defended as vital elements of modern individual and social life. At the social level, a central role is played by the understanding that our modern society is a Knowledge Society and that its social welfare and economic growth depend on the availability of knowledge and the

innovative creation and use of new knowledge. The Internet is essential to this process. At the individual level, the Internet greatly enhances transparency. The Internet promotes a decentralisation of knowledge and breaks the monopoly on information controlled by those in power.

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,⁴² 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. To this end, the Commission announced in early 2009 that it would spend €1 billion with the aim of achieving 100% high-speed Internet coverage for all citizens by 2010.⁴³

Participation and privacy

Participation is a key concept in e-inclusion, particularly in regard to the age-related digital divide. Participation 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”,⁴⁴ which embraces activities of civic associations, neighbourhood groups, social movements and social clubs, as well as formal procedures of governments. In other words, the domain of action of the public sphere should not be restricted to political institutions but should also include a vast array of social activities and networks. Two fundamental instruments define the right to public participation: the 1948 Universal Declaration of Human Rights and the 1976 International Covenant on Civil and Political Rights. The Declaration is a statement of general principles. The right to participate is spelled out in similar language in Article 21 of the Declaration and Article 25 of the Covenant. Article 25 of the Covenant states:

Every citizen shall have the right and the opportunity, without ... unreasonable restrictions:

(a) To take part in the conduct of public affairs, directly or through freely chosen representatives.

The right to participate implies three main elements: transparency (decisions should be taken in the clearest way), information (relevant information should be freely available) and reasoned decision (decisions should be justifiable).⁴⁵ At least two of these three elements, transparency and information, can be facilitated by adopting information and communication technologies. The role of ICT in promoting participation was first emphasised in the European Commission's seminal White Paper on Governance.⁴⁶

Information and communication technologies have an important role.... Providing more information and more effective communication are a pre-condition for generating a sense of belonging to Europe.

The principle was then reaffirmed by the e-participation preparatory action,⁴⁷ and eventually by the recent e-government programme.

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, together with the right to participate, there is respect for private life and the protection of personal data.⁴⁸

Alongside a negative right “to be left alone”, the right to privacy and data protection has evolved to include a positive function. The positive function is two-fold. The first function is connected to the obligation, falling upon third parties, such as state authorities or service providers, to enable the individual “to control access to information about him or herself”. Without such a positive element, the protection of individual private life would be not effective, merely formal. The other feature of privacy's positive function relates to the construction of the individual public sphere and to the importance of forging *individualised* relationships. This function's aim is to enable the individual to develop his own personality within a network of other private human beings. Anthropological studies and

⁴² See, for example, Sreenivasan 2005.

⁴³ European Commission 2009. The Commission claims that broadband Internet connection is expected to create 1 million jobs and boost the EU's economy by €850 billion between 2006 and 2015. The day after the Commission's announcement, the UK government made a similar announcement, that it plans broadband for all its citizens by 2012. Wray and Robinson 2009.

⁴⁴ Habermas 1989.

⁴⁵ See Söderman 2001.

⁴⁶ European Commission 2001.

⁴⁷ http://ec.europa.eu/information_society/activities/egovernment/implementation/prep_action/index_en.htm.

⁴⁸ 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.

available privacy literature have demonstrated that what an individual is able to perceive around him or her “exercises a restrictive and/or steering influence over him/her”.⁴⁹ The same is true for what an individual is not able to perceive. If one is prevented from exchanging private e-mails in the workplace,⁵⁰ or one receives only the news that fits one’s own profile,⁵¹ one’s perception of others and of the world is seriously restricted. Under these conditions, individual privacy is endangered. Unless they engage in social relationships, individuals run the risk of conforming to dominant views and, fearing reprisal, dissent is silenced. This would be detrimental to individual privacy as well as to diversity and pluralism which are pillars of the democratic constitutional state. Protection of privacy, therefore, must also consider “the right to establish and develop relationships with other human beings”⁵² and, consequently, create conditions conducive to that end.

European data protection and privacy law protects the ability of the individual to gain and maintain control over ICT and, in particular, over the flow of information that ICTs engender. Furthermore, the legal values and goods that the rights to privacy and data protection protect go beyond the sphere of the individual per se. With the storage, processing and data mining capabilities of modern technologies growing at a breath-taking pace, privacy and data protection can be seen as a constitutive value that safeguards participation and association in a free society. “Information privacy rules normatively, and defines multidimensional, informational territories that insulate personal data from observation by outside parties.”⁵³

From an ethical point of view, senior citizens should be shielded from the adverse consequences of pervasive ICT as they impinge upon the individual’s personal and social rights. ICT should empower them with the means to protect and pursue their rights. This, however, might not be enough. Modern technologies should also ensure that senior citizens are not insulated, but have a genuine access to other people or networks of people.

⁴⁹ De Hert and Gutwirth 2006, p. 73.

⁵⁰ “There appears, furthermore, to be 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 since it is, after all, in the course of their working lives that the majority of people have a significant, if not the greatest, opportunity of developing relationships with the outside world. This view is supported by the fact that, as was rightly pointed out by the Commission, it is not always possible to distinguish clearly which of an individual’s activities form part of his professional or business life and which do not.” See European Court of Human Rights 1992, Sect. 29.2.

⁵¹ “No one can read all the news that’s published every day, so why not set up your page to show you the stories that best represent your interests?” *Google News*, quoted in Sunstein 2007, p. viii.

⁵² European Court of Human Rights 1992, Sect. 29.1.

⁵³ Schwartz and Paul 2000, p. 762.

Put under this light, a legal and ethical analysis should investigate requirements and values such as choice, consistency, consent (see below), confinement, context, inspection, *ex post* user control, adoption, protection, transparency and so on in the context of meeting the specific needs of senior citizens.

Older senior citizens

By older senior citizens, we mean people in their eighties and nineties. This demographic group is rapidly increasing in all developed countries and in Europe as a whole. This group of senior citizens is often suffering from various negative changes in their physical and mental abilities. Gerontologists often refer to these changes as increasing frailty.⁵⁴ Those who live to an advanced age will probably face it soon or later. Frailty is not really a disease but rather a combination of the natural ageing process and a variety of medical and social problems. Frailty not only undermines the quality of life, but also is a reliable predictor of a general decline in health, capacity of life in the community and personal autonomy. Frail citizens face an immediate future of deteriorated physical and mental conditions, reduced mobility, increasing disability, lack of autonomy, hospitalisation and death. Consequently, the main goal of e-inclusion in regard to older senior citizens should be containing frailty and promoting independent living.

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. All these technologies have important ethical implications, which means ethics panels should track their development and deployment to ensure they are truly assistive rather than invidious to senior citizens’ well-being.

⁵⁴ According to gerontologists, a person should be considered frail when at least three of these factors are met:

- unintentional weight loss (5 kg or more in a year),
- general feeling of exhaustion,
- weakness (as measured by grip strength),
- slow walking speed,
- low levels of physical activity.

The right to dignity

Although the notion of dignity has been considered sometimes as too metaphysically compromised (i.e., would it ever be possible to ground it without making an appeal to transcendent values?), the idea of human dignity is still the cornerstone of the EU constitutional architecture. The European Charter of Fundamental Rights affirms this in Article 1: “Human dignity is inviolable. It must be respected and protected.”

The concept of dignity is a vital element of e-inclusion as well. The recent amendment to the Commission’s proposal to set up an Ambient Assisted Living (AAL) agency, approved by the European Parliament in March 2008⁵⁵ and the Council in June 2008,⁵⁶ states: “When selecting projects following calls for proposals launched under the programme the following criteria should be met in addition to scientific excellence: technology must be adapted to the needs of the elderly, services must respect the privacy and dignity of the elderly.”

The principle of dignity affirms that any human being is priceless, 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).

According to the Charter, dignity includes

- the right to life,
- the right to the integrity of the person, which also implies the right to the free and informed consent of the person concerned,
- prohibition of torture and inhuman or degrading treatment or punishment,
- prohibition of slavery and forced labour.

The rights to life and integrity are both relevant to ICT for older senior citizens.

The older senior citizen’s right to life

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. Underlying current approaches to anti-ageing technology, are two principal scientific theories, one called “compression of morbidity” and the other called “indefinite prolongation of life”.

The compression of morbidity theory affirms that it may be possible to reduce cumulative lifetime morbidity.⁵⁷

Since chronic illness and disability usually occur in late life, cumulative lifetime disability could be reduced if primary prevention measures postponed the onset of chronic illness. However, decreases in health risks may also increase average age at death. The hypothesis predicts that the age at the time of initial disability will increase more than the gain in longevity, resulting in fewer years of disability and a lower level of cumulative lifetime disability. In its extreme version,⁵⁸ the hypothesis states that we are moving towards a society in which everyone lives in good health up to their genetic limits and then quickly dies in a few days or weeks without becoming an economic burden for the society.

The hypothesis of the indefinite prolongation of life is even more optimistic. In this case, it is assumed that genetic limits can be overcome thanks to new biotechnologies (e.g., cloning, stem cells) and new nanomaterials (e.g., nanoprostheses, artificial body parts, enhancers, etc.) and that boundaries of human life can be pushed further, almost to immortality.⁵⁹

Both hypotheses raise ethical issues of great complexity and profound significance. Contemporary techno-science shows an inescapable tendency to deny human limits, senescence and death. Yet it should be clear that there are some questions concerning life and death that do not admit a technical fix. In his short story, “The Immortal”, Jorge Luis Borges equates immortality with oppressiveness, irrationality and horror. For Borges, immortality is the nonsense of an infinite repetition without difference, and the immortals are troglodytes incapable of speech. Beyond these literary metaphors, assistive technologies for senior citizens pose serious questions about our motivations: do we really intend to address the needs of senior citizens or do we use them as an interesting test case for evaluating our new powerful technologies?

The older senior citizen’s right to integrity

The right to integrity means that one’s physical and psychological conditions should be respected and no one has the right to infringe them without explicit and informed permission. This principle is affirmed in a number of international and regional documents. It is also stated in Article 3 of the Charter of Fundamental Rights of the European Union:

1. Everyone has the right to respect for his or her physical and mental integrity.
2. In the fields of medicine and biology, the following must be respected in particular:

⁵⁵ http://cordis.europa.eu/fp7/coordination/article169_en.html.

⁵⁶ European Commission 2008.

⁵⁷ Fries 1980.

⁵⁸ Vita et al. 1998.

⁵⁹ Moody 1994.

- the free and informed consent of the person concerned, according to the procedures laid down by law,
- the prohibition of eugenic practices, in particular those aiming at the selection of persons,
- the prohibition on making the human body and its parts as such a source of financial gain,
- the prohibition of the reproductive cloning of human beings.

This principle holds true also for senior citizens and is vital when one considers assistive technologies destined for the older senior citizen. The body of the older person lies at the heart of various technological strategies. The body of the senior citizen is increasingly technologically altered through prosthesis, pacemakers, artificial sensors, drug dispensers, etc., and primed to be followed and located on a permanent basis. This is the purpose of under-skin chips containing medical data and nanosensors for continuous monitoring of physiological parameters, or for surveillance of older citizens suffering from dementia. There are also important implications that concern somatic surveillance, human experimentation in ICT for senior citizens and informed consent.

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"⁶⁰ 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. Research to analyse changes in behavioural patterns over time to provide early warning of age-related diseases (such as Alzheimer's or Parkinson's) is already being undertaken. 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 (older) senior citizens. 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 ethical questions. What protocols should be followed when introducing technology for supervision? What guidelines should an ethical review board follow when they evaluate clinical trials in this field? What ethical frameworks should be constructed to protect

⁶⁰ Foucault 2001.

senior citizens from abuse by researchers? How can one ensure users' control over the systems? Sensitive data produced by ICT services may represent an invaluable source of information for marketing departments of many companies and they could be covertly generated, stored and commercialised. Moreover, ancillary information generated by the system can be used for discriminating against ethnic groups and other minority groups. Certain technologies are particularly suited for generating shadow data (e.g., age, gender, skin colour, style in clothes, etc.) that could be used for illicit ethnic or religious classification.

Somatic surveillance⁶¹ is a concern in the medical domain. Increasingly, consumerist strategies promise "eternal youth" by manipulating the body through bio, info and nanotechnologies. As a result, 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 ethical reflections on the concept of respect for bodily and mental integrity in advanced ages. An important ethical tenet is that sensitive data should not be required in return for essential services unless the information is essential for the proper execution of those services. This principle is clearly embedded in all relevant EU legislation.

Human experimentation in ICT for the elderly

More than ever, funding agencies and the EC require the ethical review of research protocols in the field of assistive technologies aimed at senior citizens. There are, however, some important issues that still need to be addressed such as the following:

- Although being old cannot per se be considered a condition of vulnerability, there is no doubt that many older senior citizens suffer from social, mental and physical limitations (the condition of frailty) that make them a highly vulnerable population. Given that vulnerable populations deserve special attention in experimentation, is it possible to define specific criteria for evaluating the vulnerability of senior citizens who take part in ICT research?⁶²
- Assistive technologies are often piloted in settings far from traditional medical settings, by actors who are not medical doctors, involving subjects who are not medical patients. This makes it very difficult to apply rules developed in the context of medical to ICT research (e.g., there are no local ethical committees where to apply, it is not clear what could be a "standard" risk or whether the

⁶¹ Monahan and Wall 2007.

⁶² We believe it is. Some researchers have already been examining this issue. See, for example, Grundy 2006, Schröder-Butterfill and Marianti 2006.

research is in the direct interest of the subject, etc.). Is it possible to develop more context-dependent guidance?

- Distinction between cares and cures, medical and social services are often blurred in the field of assistive technology experimentation. Moreover, different actors are involved, often posing double agent issues. Roles and responsibilities of different players need to be clarified for a more reliable ethical review.

Informed consent

Senior citizens can be categorised in several ways which helps 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 disabilities and those suffering from mental impairment such as dementia or Alzheimer's disease.

In the latter case, informed consent with regard to how ICTs are used to support them becomes more problematic, so much so that the deployment of technologies to track and monitor them may need to be subject to some guidelines and third-party oversight, for example, by family members and/or associations for the ageing and/or government inspectors.

With regard to the other categories of senior citizens, who are capable of understanding the benefits of the new technologies, they should be informed about how the technologies could or would be used and where there are potential privacy impacts or ethical concerns. While many senior citizens are undoubtedly willing to forego some potential loss of privacy in exchange for increased safety and security, nevertheless, they should be informed explicitly not only about the benefits, but also the risks and what measures will be taken to minimise the risks. Service providers who deploy such technologies, for example, in projects, may wish to have the participating senior citizens sign consent forms, which should explain why the technologies are to be used, the perceived benefits and risks and mitigating measures, for example, how their data will be protected, who will have access to those data (including any images or video or audio recordings), how long the data will be stored, how they might be processed and so on. Even if a consent form is signed, it should not obviate the supplier or service provider's liability.

In other instances, the initiative to deploy or use the technologies will not be taken by third parties, but will be taken by the senior citizens themselves. In such instances, senior citizens will be somewhat like the mainstream public who should be informed by service providers, manufacturers, suppliers and any other stakeholder putting products or services on the market. This obligation is like that imposed on pharmaceutical vendors who are required to supply information not only about what illness their product is designed to treat, but also about possible contraindications and what to do in the event that one or more of these contraindications arises.

The issue of what constitutes informed consent also needs to be considered, not only in the context of senior citizens, but more generally. Where there are information asymmetries between—i.e., between suppliers and consumers—there is a risk that the consent will not be truly informed or that the consumer who gives his or her consent does so reluctantly, for example, if one wants to use the product or service, one must agree to the terms and conditions, even though one does not agree with all of those terms and conditions. In many situations, the information supplied may be too complex or abstruse for the consumer to understand (the privacy policies of many suppliers have been criticised as being too long, detailed, complex or ambiguous) or the consumer may not be willing to spend the time trying to decipher the information supplied.

Other considerations may apply to the issue of informed consent, for example, where the consumer may suffer from some disability, e.g., visual or hearing impairment or impairment of physical dexterity. In such cases, technologies and/or services should be designed taking such considerations into account.

Third parties, including policy-makers and other government officials, may also need to give consideration to cases where the senior citizen is capable of understanding the benefits and risks of ICT, but chooses not to use a particular technology where nevertheless professionals believe that despite the senior citizen's not consenting, he or she should be subject to the technology. One can imagine senior citizens with personality disorders, for example, who might never have committed any wrongdoing or harm to themselves, wittingly or unwittingly, but whom social workers nevertheless believe should be monitored or tracked because they represent a risk either to themselves or to others.

Policy-makers, suppliers and technology designers may also need to consider mechanisms by means of which they can be assured that the consumer truly has been informed, that he or she understands to what they are consenting and whether the consumer is given choices, e.g., to be

able to opt out of some service without any negative repercussions.

The issue of informed consent with regard to the use of ICT involving senior citizens is not a simple one.⁶³ Indeed, its complexity 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.

Solitude, loneliness and social 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 (alone).⁶⁴ Loneliness is the subjective perception of being deprived of a connection with other people, of being excluded from the community, of feeling alone, but not wanting to be. Loneliness is a psychological state: one can be in the midst of lots of people and yet not feel connected to them. Loneliness reflects a dissatisfaction with social relationships that the person has or does not have. Loneliness may elicit feelings of aggression and a desire for revenge,⁶⁵ which in turn inhibit the person's ability to acquire and develop supportive relations and reconstruct his personal network. In other words, sooner or later, loneliness leads also to isolation. Isolation is the objective condition of having too few and too poor social ties, of not being in any relevant social network. Isolation is the concrete condition of living alone.

Both loneliness and isolation may be perceived in a positive way.⁶⁶ One may wish to be alone (either emotionally and/or socially) in order to devote oneself to the cure of something valued more than social ties. The Benedictine

motto "*Beata solitudo, sola beatitudo*" is an example of such a positive understanding of solitude. The idea of solitude as a positive condition is also implicit in the notion of (emotional or social) independence. Such independence suggests a capacity to survive, or even to flourish, when social and/or emotional ties are weak or absent.

Despite stereotypes to the contrary, older senior citizens tend to find isolation less distressful than younger people.⁶⁷ Many older senior citizens do not view living alone as particularly distressful. Some deliberately seek to be alone as an expression of independence. Be that as it may, any prolonged solitude, emotional or social, is likely to impair people's physical and mental conditions, as countless medical and psychological studies have shown.⁶⁸ Researchers have demonstrated that both isolation and loneliness tend to accelerate the rate of physiological decline with age. This is particularly true of the frail older senior citizens, who are already physiologically and emotionally distressed.⁶⁹

New technologies address both isolation and loneliness. Trends in family structures (e.g., declining birth rates, smaller families, single parent families, childless, rather than extended, families, etc.) and in mobility (increasing physical distance between generations of a family) have resulted in increasing social isolation. On the other hand, new forms of communication—from phone calls to e-mails, instant messaging, Web meetings, social networking, wireless personal area networks and so on—help to alleviate, if not overcome, isolation. 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, which may stem from several factors (lack of user friendly interfaces, appropriate education, familiarity with computer jargon, financial resources, etc.), as mentioned above.

New digital technologies can also address loneliness. Sites such as Eons, Rezoom, Multiply, Maya's Mom, Boomj and Boomertown are all examples of websites aimed at senior citizens. Although it is unlikely most older senior citizens could fully exploit these new social media, the second generation of the World Wide Web (Web 2.0) may increase social networking and interaction among older seniors. In the near future, virtual friends may play an important role in the lives of senior citizens. Robotic pets for senior citizens are already a reality and they have proven to be as useful as real animals for senior citizens suffering from dementia.⁷⁰ Japanese hospitals and senior

⁶³ Although it does not cover all of the permutations mentioned in this section, the definition of informed consent in the European Directive on clinical trials forms a useful starting point: "A decision, which must be written, dated and signed, to take part in a clinical trial, taken freely after being duly informed of its nature, significance, implications and risks and appropriately documented, by any person capable of giving consent or, where the person is not capable of giving consent, by his or her legal representative; if the person concerned is unable to write, oral consent in the presence of at least one witness may be given in exceptional cases, as provided for in national legislation." Directive 2001/20/EC of the European Parliament and the Council 2001.

⁶⁴ In his book, *Old and alone: A sociological study of old people* Jeremy Tunstall conceptually distinguished "living alone", "social isolation", "loneliness", and "anomie". The first three concepts bear a close relationship to the distinctions made here. Anomie signifies in individuals an erosion or absence of accepted social standards or values.

⁶⁵ Stevens and van Tilburg 2000.

⁶⁶ Long et al. 2003.

⁶⁷ Rokach 2000.

⁶⁸ Cacioppo and Hawkley 2003.

⁶⁹ Gibson 2000.

⁷⁰ Sakairi 2004.

citizens homes have been experimenting with robot therapy sessions.⁷¹ Some scientists believe robots are the answer to caring for ageing societies where the young might otherwise be overwhelmed by the surging population of senior citizens. These robots look like puppies and have built-in sensors enabling them to respond to both contact and a user's voice, with either motion or speech. At the same time, these robots can be used to monitor the safety of older senior citizens because the interaction between them and their owners can be recorded and accessed remotely. A few robot companions are already in use—such as the “dogs” AIBO and SPARKY—and many others are in development.

The new communication technologies and robot companions do, however, raise ethical issues, ranging from privacy issues (older senior citizens are less likely to be able to defend themselves from informational intrusiveness) to more substantial objections (are we giving machines and virtual contacts to people who ask for warm human contacts?). Moreover, new communication technologies may diminish the interest in going outside the home, which would only compound the reduction in face-to-face contacts. All these issues could be categorised under the common heading of threats to the notion of self-respect. Being somehow forced to consider digital media and inanimate objects as the comprehensive universe of one's own social life may become humiliating and may hurt self-respect. In other words, the issue at stake is that of emotional dignity, as Badcott proposes to call situations that could elicit profound feelings of personal humiliation.⁷²

Preparing for the future

European society is ageing, life expectancies are increasing and the end of this process is not in sight. With this trend in mind, in this paper, we have explored some of the ethical issues relevant to senior citizens and ICT. We have reviewed the European path to e-inclusion, the politics of overcoming the digital divide, and the opportunities and risks in doing so.

An ethics of digitalisation which relies exclusively on the right to privacy, the right to data protection and the informed consent of the individual, while important and even vital, do not satisfy the ethical, social and privacy needs in ICT for senior citizens. We need a flexible and dynamic ethics of digitalisation which takes into account not only the need to protect individuals from unlawful intrusions, but also the enabling side of privacy and data

protection, i.e., enabling individuals, with different capabilities, to forge relationships, to stay authentically active in society, to express and share their views. If ICT systems, as the German Constitutional Court recently explained, appeal to a system of protection that is significant in terms of basic rights, the ethical and legal approach to ICT could be broadened to include self-determination as a limit and guideline to the development, use and presence of information and communication technologies in society.

The mixture of different levels in education, personal stories, skills and capabilities prevalent among older individuals (as well as among the general public) suggests that we eschew single instrument thinking. An approach geared towards the protection of human rights could instead match the different needs of senior citizens and provide concrete guidance to evaluate technologies for them. To assist decision-makers in deciding how and when a given innovation is better, it might be worthwhile considering the following principles:

- As technology embodies and reinforces values, evaluation requires making values explicit.
- As innovations can perform effectively only as part of socio-technical networks that embody multiple needs and expectations, the shielding and enabling effects of technology need to be articulated in relation to both current and potential practice.
- As technology, in particular assistive and health care technology, is a public-private good open to public policy interventions, reflexive science is produced within socio-political projects. Feedback should be sought when a given technology is introduced in a given context, for instance, in nursing homes.
- As the framing of policy is vital, civil society should be made a pivotal locus of transparent and public deliberations when the interests of senior citizens are at stake.
- As industry develops technology largely on the basis of its own logic, the role of the private sector within publicly funded systems, such as health care systems, needs to be made explicit.⁷³

Finally, we recommend that future agendas make room for the careful monitoring of these emerging areas:

- social technologies, robots and virtual friends for senior citizens,
- anti-ageing technologies and body enhancement,
- neuro-cognitive technologies and surveillance technologies for mentally impaired senior citizens.

⁷¹ Tamura 2004.

⁷² Badcott 2003.

⁷³ Adapted from Hyysalo 2007.

References

- Badcott, D. (2003). The basis and relevance of emotional dignity. *Medicine, Health Care and Philosophy*, 6(2), 123–131. <http://www.ingentaconnect.com/content/klu/mhep/2003/00000006/00000002>.
- Banner, L. W. (2001). Coming of age: A cultural studies approach to aging. *Journal of Women's History*, 12(4), 212–214. http://muse.jhu.edu/login?uri=/journals/journal_of_womens_history/v012/12.4banner.html.
- Bowling, A., et al. (2005). Attributes of age-identity. *Ageing & Society*, 25, 479–500.
- Breda, J., & Schoenmaekers, D. (2006). Age: A dubious criterion in legislation. *Ageing & Society*, 26, 529–547.
- Cacioppo, J. T., & Hawkley, L. C. (2003). Social isolation and health, with an emphasis on underlying mechanisms. *Perspectives in Biology and Medicine*, 46(3), S39–S52. http://muse.uq.edu.au/journals/perspectives_in_biology_and_medicine/toc/pbm46.3x.html.
- De Hert, P., & Gutwirth, S. (2006). Privacy, data protection and law enforcement: Opacity of the individual and transparency of power. In E. Claes, A. Duff, & S. Gutwirth (Eds.), *Privacy and the criminal law*. Antwerpen, Oxford: Intersentia.
- Demunter, C. (2005). The digital divide in Europe. *Statistics in focus*, 38/2005, Eurostat. http://epp.eurostat.ec.europa.eu/cache/ITY_OFFPUB/KS-NP-05-038/EN/KS-NP-05-038-EN.PDF.
- Demunter, C. (2006). *How skilled are Europeans in using computers and the Internet?* Eurostat. http://ec.europa.eu/information_society/newsroom/cf/news.cfm?redirection=1&item_type=library&tpa_id=40.
- EU Committee of the Regions. (2007). *Conclusions of the Conference-debate of the Commission for Constitutional Affairs, European Governance and the Area of Freedom, Security and Justice*. Münster, 2 May 2007. http://cor.ip.lu/COR_cms/ui/ViewDocument.aspx?siteid=default&contentID=571cbb4a-376f-4ed9-9214-aa2883e2a765.
- European Commission. (2000). Towards a European research area, Communication from the Commission to the Council, the European Parliament, the Economic and Social Committee and the Committee of the Regions, COM(2000) 6 final, Brussels, 18 Jan 2000. http://ec.europa.eu/research/era/era-history_en.html.
- European Commission. (2001) European Governance: A white paper, COM(2001) 428 final, Brussels, 25 July 2001. http://ec.europa.eu/governance/white_paper/en.pdf.
- European Commission. (2005). *Communication from the Commission on the Social Agenda*. COM(2005) 33 final, Brussels, 9 Feb 2005.
- European Commission. (2006). *Creating an innovative Europe: Report of the independent expert group on R&D and innovation appointed following the Hampton Court Summit and chaired by Mr. Esko Aho*, Office for Official Publications of the European Communities, Luxembourg. http://ec.europa.eu/invest-in-research/action/2006_ahogroup_en.htm.
- European Commission. (2007). *The European research area: New perspectives*. Green paper. COM(2007) 161 final. Brussels, 4 Apr 2007. http://ec.europa.eu/research/era/pdf/era_gp_final_en.pdf.
- European Commission. (2007). *Ageing well in the information society, action plan on information and communication technologies and ageing, an i2010 initiative*. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. COM(2007) 332 final. Brussels, 14 June 2007. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52007DC0332:EN:NOT>.
- European Commission. (2007). Commission Staff Working Document. Accompanying document to the Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. SEC(2007) 811, Brussels, 14 June 2007.
- European Commission. (2007). European i2010 initiative on e-Inclusion: “To be part of the information society”. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions. COM(2007) 694 final. Brussels, 8 Nov 2007.
- European Commission. (2008). “Ageing well”: European Commission unleashes €600m for development of new digital solutions for Europe’s elderly people. Press release IP/08/994, Brussels, 23 June 2008. <http://europa.eu/rapid/pressReleasesAction.do?reference=IP/08/994&format=HTML&aged=0&language=EN&guiLanguage=en>.
- European Commission. (2009). Commission earmarks €1bn for investment in broadband—frequently asked questions. Press release. MEMO/09/35. Brussels, 28 Jan 2009. <http://europa.eu/rapid/pressReleasesAction.do?reference=MEMO/09/35>.
- European Court of Human Rights. (1992). Case of *Niemietz v. Germany*. Judgment. Strasbourg, 16 Dec 1992.
- European Group on Ethics in Science and New Technologies (EGE). (1999). Ethical issues of healthcare in the information society, Opinion No. 13, 30 July 1999. http://ec.europa.eu/european_group_ethics/avis/index_en.htm.
- European Group on Ethics in Science and New Technologies (EGE). (2005). Ethical aspects of ICT Implants in the Human Body, Opinion No. 20, 16 March 2005. http://ec.europa.eu/european_group_ethics/avis/index_en.htm.
- European Parliament and the Council. (2001). Directive 2001/20/EC of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use, OJ L 121/34, Brussels, 1 May 2001. http://europa.eu/eur-lex/pri/en/oj/dat/2001/L_121/L_12120010501en00340044.pdf.
- Finkelkraut, A. (1985). What is Europe? *The New York review of books*, 32(19). http://www.nybooks.com/articles/article-preview?article_id=5274.
- Foucault, M. (2001). The birth of social medicine. In J. D. Faubion (Ed.), *Essential works of Michel Foucault 1954–1984*. London: Penguin.
- Fries, J. F. (1980). Aging, natural death and the compression of morbidity. *New England Journal of Medicine*, 303(3), 130–135. <http://content.nejm.org/cgi/content/abstract/303/3/130>.
- Gibson, H. B. (2000). *Loneliness in later life*. New York: St. Martin’s Press.
- Grundy, E. (2006). Ageing and vulnerable elderly people: European perspectives. *Ageing & Society*, 26, 105–134.
- Habermas, J. (1989). *The structural transformation of the public sphere: Inquiry into a category of Bourgeois society*. Cambridge, MA: MIT Press.
- Hyysalo, S. (2007). “Review of Pascale Lehoux, *The problem of health technology—policy implications for modern health care systems*”, [Routledge, London, 2006], in *EASST Review*, 26(2). <http://www.easst.net/review/july2007/hyysalo>.
- Lohr, S. (2008). For a good retirement, find work. Good Luck. *The New York Times*. 22. <http://www.nytimes.com/2008/06/22/weekinreview/22lohr.html>.
- Long, C. R., Seburn, M., Averill, J. R., & More, T. A. (2003). Solitude experiences: Varieties, settings, and individual differences. *Personality and Social Psychology Bulletin*, 29(5), 578–583. <http://psp.sagepub.com/content/vol29/issue5/>.
- McMullin, J. A., & Shuey, K. M. (2006). Ageing, disability and workplace accommodations. *Ageing & Society*, 26, 831–847.

- Midwinter, E. (2005). How many people are there in the third age? *Ageing & Society*, 25, 9–18.
- Monahan, T., & Wall, T. (2007). Somatic surveillance. *Surveillance and Society*, 4(3), 154–173. [http://www.surveillance-and-society.org/articles4\(3\)/somatic.pdf](http://www.surveillance-and-society.org/articles4(3)/somatic.pdf).
- Moody, H. R. (1994). Four scenarios for an aging society. *The Hastings Center Report*, 24(5), 32–35. <http://www.jstor.org/pss/3563497>.
- Neugarten, B. (1974). Age groups in American society and the rise of the young-old. *Annals of the American Academy of Political and Social Science*, 415, 187–198.
- Power, A., & Wilson, W. J. (2000). *Social exclusion and the future of cities*. London: Centre for Analysis of Social Exclusion, London School of Economics.
- Rokach, A. (2000). Loneliness and the life cycle. *Psychological Reports*, 86(2), 629–642. <http://www.ingentaconnect.com/content/docdel/000020031171/2000/86/2>.
- Sakairi, K. (2004). Research of robot-assisted activity for the elderly with senile dementia in a group home. *SICE 2004 Annual Conference*, Vol. 3, Aug 2004, pp. 2092–2094. http://ieeexplore.ieee.org/xpl/freeabs_all.jsp?arnumber=1491788.
- Scheff, T. (1990). *Microsociology: Discourse, emotion and social structure*. Chicago: University of Chicago Press.
- Schröder-Butterfill, E., & Mariani, R. (2006). A framework for understanding old-age vulnerabilities. *Ageing & Society*, 26, 9–35.
- Schwartz, P. M. (2000). Beyond Lessig's code for Internet privacy: Cyberspace filters, privacy-control, and fair information practices. *Wisconsin Law Review*, 2000(4), 743–788.
- Söderman, J. (2001). Transparency as a fundamental principle of the European union. European Ombudsman. <http://www.euro-ombudsman.eu.int/speeches/en/2001-06-19.htm>.
- Sreenivasan, G. (2005). A hybrid theory of claim-rights. *Oxford Journal of Legal Studies*, 25(2), 257–274. <http://ojls.oxfordjournals.org/cgi/content/short/25/2/257>.
- Stevens, N., & van Tilburg, T.V. (2000). Stimulating friendship in later life: A strategy for reducing loneliness among older women. *Educational Gerontology*, 26(1), 15–35. <http://www.ingentaconnect.com/content/routledg/uedg/2000/00000026/00000001;jsessionid=4etb1mboasbi6.victoria>.
- Sunstein, C. R. (2007). *Republic.com 2.0*. Princeton and Oxford: Princeton University Press.
- Tamura, T., et al. (2004). Is an entertainment robot useful in the care of elderly people with severe dementia? *Journal of Gerontology: Medical Sciences*, 59(1), M83–M85. <http://biomed.gerontologyjournals.org/content/vol59/issue1/>.
- Tunstall, J. (1966). *Old and alone: A sociological study of old people*. London: Routledge and Kegan Paul.
- Tyler, T. R., & Belliveau, M. A. (1995). Dealing with tradeoffs among justice principles: The motivational antecedents of definitions of fairness. In B. B. Bunker and J. Z. Rubin (Ed.), *Conflict, cooperation and justice*. San Francisco: Jossey Bass Inc. Publishers.
- Vita, A. J., Terry, R. B., Hubert, H. B., & Fries, J. F. (1998). Aging, health risks, and cumulative disability. *New England Journal of Medicine*, 338(15), 1035–1041.
- Walker, A. (2000). Public policy and the construction of old age in Europe. *The Gerontologist*, 40(3), 304–308.
- Weiser, M., Gold, R., & Brown, J. S. (1999). The origins of ubiquitous computing research at PARC in the late 1980s. *IBM Systems Journal*, 38(4). <http://www.research.ibm.com/journal/sj/384/weiser.html>.
- Wray, R., & Robinson, J. (2009). Digital Britain report set to push broadband for all by 2012. *The Guardian*. <http://www.guardian.co.uk/media/2009/jan/28/digital-britain-broadband>.