The European Older People's Platform
La Plate-forme européenne des Personnes âgées

Older people and Information and Communication Technologies[1]

---- An Ethical approach ----

13 November 2008

Information and Communication Technology (ICT) has pervaded people's lives not only in Europe but all over the world. For older people ICT can help them carry out daily activities as well as monitor their health, create social networks and increase participation in society and augment safety. The use of technology can also facilitate social inclusion, improve their professional participation and quality of life and ultimately enhance independent living. However, the use of ICT also raises many ethical questions.

Ethics is the result of our pursuit to systematically reflect on, analyse, and question the norms and values that guide human action.

Göran Hermerén, President of the European Group on Ethics (EGE)

The use of assistive technology to deliver care or enable the increasing numbers of dependent older people to continue living in their own homes, rather than in care homes or other institutional settings raises many challenges that have to be taken into consideration. There is a very fine line between technology that promotes independence and technology that threatens individual freedom. The question of risk, choice, as well as the need to respect human rights, must be a key consideration. As the technology

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develops, there is a need for a debate about the moral and ethical issues concerning the use of technology, including how to ensure that basic human rights are not compromised by the introduction of new technology.

In this context, it is worth noting some key ethical principles and tension areas that seems to govern both research and practice in this area:

- Autonomy and consent of the end-user
- Benefice to end-user – balancing risk tolerance and risk aversion – safety and independence (i.e. in areas like restraints)
- Achieving a balance between avoiding harm and respecting decisions, dignity, integrity and preferences
- Justice – treating the individual fairly and respecting its rights.

The individual at the centre of technology

For older people it is important that technology takes a "human centred approach" i.e. that older people's are involved in the technological research process, their voices are heard and their individual needs and requirements are met. Ethical questions arising from the usage of technology can only be discussed and debated by the people who are going to use them. Any product of service aimed at older people cannot be developed without them having their say. Consultation and real end user involvement in the process of development of technological products and services is essential.

Older people must fully understand their role and their contribution towards technological development. The procedure should be clearly described by researchers and informed consent must be obtained. Informed consent is keystone for older people in technological trials and usage. "Only persons able to freely understand and question should give consent" (Pauwels 2007 p.21). This includes language clarity[2], the feel of ownership, acceptance, choice, access, transparency as well as the right to "opt out" from information society. Adequate legal frameworks must be put in place to also guarantee

[2] The question of language and terminology in the Information Society is crucial is this respect with today's' globalisation and multi lingual communities there is so much opportunity for misunderstanding. To this extent further consideration must be given to this area of research and wide collaboration with the International Information Centre for terminology is in order. http://www.infoterm.info/

the participation of vulnerable people (e.g. fragile older people, mentally disabled people, injured patients, etc.).

Technology developers and service providers must understand older people's expectations enabling them to continue (or stop) using the products or services if they prove to be (un)successful for them. The question of cost in this respect is decisive. Technology can only be fully inclusive and benefit everyone if it is not only physically accessible but more importantly economically accessible. Economic and social ethics within technology development and service provision is an important question that needs to be tackled and reflected upon by all EU Member states in the coming years. Here a broad ethical question arises about the role of government (at national and EU level) in the development and distribution of these technologies. What is society willing to pay to provide wider access to these technologies? Further cross-cutting socio-economic studies to investigate these issues may be necessary.

Respect for the individual and protection of human rights

Technology must be geared towards the respect of the individual, protection and full realisation of human rights. Among these human rights principles are: universality and inalienability; indivisibility; interdependence and interrelatedness; non discrimination and equality; participation and inclusion; accountability and the rule of law. These are enshrined in various European[3] and International[4] human rights instruments and are important guides to ICT technology development.

[3] For example:
-Convention for the Protection of Human Rights and Fundamental Freedoms. Available from: http://conventions.coe.int/Treaty/en/Treaties/Word/005.doc
-European Charter of Fundamental Rights. Available from: http://www.europarl.europa.eu/charter/pdf/text_en.pdf
-Code of conduct for responsible nanosciences and nanotechnologies research ftp://ftp.cordis.europa.eu/pub/fp7/docs/nanocode-recommendation.pdf
- Directive 90/385/EEC of the European Parliament and of the Council of 20 June 1990 This relates to active implantable medical devices. Available from: http://europa.eu/eur-lex/en/consleg/pdf/1990/en_1990L0385_do_001.pdf
- Decision No 1982/2006/EC of the European Parliament and of the Council of 18 December 2006 This concerns the Seventh Framework Programme of the European Community for research, technological development and demonstration activities (2007-2013). Available from: http://eur-lex.europa.eu/LexUriServ/site/en/oj/2006/l_412/l_41220061230en00010041.pdf

[4] For example:
-The UN International Action Plan on ageing. Available from:
http://www.un.org/esa/socdev/ageing/madrid_intlplanaction.html
-The Universal Declaration of Human Rights, International covenant on civil and political rights. Available from:
http://www2.ohchr.org/english/law/ccpr.htm

The protection of an individual's privacy is clearly reflected in the European Convention on Human Rights (Article 8) and Universal Declaration on Human Rights and Fundamental Freedoms (Article 12) and other legal documents. However, with the development of assistive technology product and services for older people's independent living (e.g. tele-monitoring systems, electronic aids to support care and daily activities) it becomes difficult to define what is the limit of an individual's privacy and if it can be overridden to ensure the health, safety and independence of that person, its relatives and/or friends and diminish the cost of health and social care services. This is particularly true with regards to delivering telecare through digital television; the use of urine sensors; dementia tagging, falls monitors, closed-circuit television devices and monitoring eating or sleeping habits. "For decision-makers in state and local authorities the saving of economic means by introducing ICT in welfare services maybe an important motivation. This is understandable and not necessarily unethical. However, when the introduction of information technology reduces the quality of welfare services, the matter is different. Technology is not a substitute of care and human contact[5]" (Norwegian Board of Technology 2000 p. 11) it is only an enabler.

Evidence tends to suggest that older people would consider the installation of certain types of assistive/smart technology[6] in their own homes but some applications are preferred than others. This depends on the contextual environment such as the level of frailty of the individual and the perceived need which is not surprising as older people are a heterogeneous and disparate group. The contextual environment of where a person lives such as culture, adaptability to certain types of technology, literacy among others are all factors that impact in the take up or not of this type of technology.

- International covenant on economic, social and cultural rights. Available from: http://www.unhchr.ch/html/menu3/b/a_cescr.htm
- World Medical Association Declaration of Helsinki -Ethical Principles for Medical Research Involving Human Subjects. Available from: http://www.wma.net/e/policy/b3.htm
-Universal Declaration on Bioethics and Human Rights. Available from: http://portal.unesco.org/shs/en/ev.php-URL_ID=1883&URL_DO=DO_TOPIC&URL_SECTION=201.html

[5] Norwegian Board of Technology (2000) ICT for elderly people. Final report from the consensus of the Norwegian Board Technology.

[6] e.g. bed sensors are perceived as useful especially during the nights for the carer and for the person in care
e.g. motion sensors can provide an ease of mind from detecting intruders
e.g. video sensors are beneficial for health emergencies (falls)

However, one should also be aware that there are methodological challenges in measuring the true impact of assistive technology. There is a need to bring forward system-wide frameworks for the cost-benefits analysis of assistive technology solutions that are evidence-based to support policy development. In many cases gains are in the area of quality of life improvements or compensations for impairments - "dependency is not eliminated but is redistributed among people [family, friends, neighbours, health services, etc.] and technology[7]"

Directly linked to privacy is data protection of an individual as technology evolves and has the capacity to storage an immense amount of personal data. The European Directive 95/46/EC[8] protects individuals with regards to the processing of personal and free movement of data. Article 6 of the aforementioned Directive outlines eight enforceable principles;
Data must be: 1- Fairly and lawfully processed; 2- Processed for limited purposes; 3- Adequate, relevant and not excessive; 4- Accurate; 5- Not kept longer than necessary; 6- Processed in accordance with data subject's rights; 7- Secure; 8- Not transferred to other countries without adequate protection. Members States must ensure the protection of its citizen's data and fully respect the letter and spirit of the law.

The future of Technology development

As the world of technology continues to progress the impact on the lives of older people seems undeniable. More and more ethical questions will arise from the development and usage of different types of technological products and services. Current ethics check lists and ethical reviews or guidelines[9] will have to be updated to keep up with progress. "As technology becomes embedded in everyday objects and in the environment, functional and interaction aspects of technological artefacts may become subordinated to

[7] P. Richard and Van Hemel Susan (2004) Technology for adaptive Aging.
[8] Available from: http://www.cdt.org/privacy/eudirective/EU_Directive_.html
[9] See ethics review for the 7th research framework programme. Available from: http://cordis.europa.eu/fp7/ethics_en.html Additional information regarding ethics and ICT http://cordis.europa.eu/fp7/ethics-ict_en.html

other personal factors of choice. (…) In this respect new challenges arise concerning how a person will be able to know when and what type of personal information is recorded, by whom, and for what use in a technological environment where personal information is continuously collected by numerous invisible receptors"[10].

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[10] Emiliani and Stephanidis (2005 p. 612). Universal access to ambient intelligence environments: Opportunities and challenges for people with disabilities. Available from http://www.research.ibm.com/journal/sj/443/emiliani.pdf