



## Editorial

### SENIOR one year later - time to strike the balance !

SENIOR took up its work in January 2008. In January 2009 the balance sheet of the project is more than positive. The fact finding phase of the project has been fruitfully completed and the project is now ready to develop its second phase, concentrating on the roadmap for dialogue among the main stakeholders.

The activities performed by the Consortium in the first year focused on understanding the social meaning of ICT for ageing, on describing what ethical and privacy perspectives are currently applied to ICT for inclusion, and on promoting stakeholder dialogue. Finally a specific feature of the SENIOR project has been its active participation in the e-Inclusion 2008 initiatives, which have beat the time of the project through two major events, the workshop on ethics and e-Inclusion held in Bled during the Slovenian presidency of the EU (12 May 2008) and the Inter-Ministerial Conference on e-Inclusion of Vienna ( 30 Nov. - 2 Dec. 2008).

During the first three months of project activity, SENIOR hosted the Launching Workshop, which drew a wide range of people from different backgrounds including industries, social activists, academics and policy-makers. From 2 June – 3 June 2008 SENIOR organized a Socio-Anthropological Workshop on ICT and Ageing. Through expert presentations and open floor discussion, the workshop investigated various social and anthropological themes related to ICT and ageing, including human-ICT interaction within the context of ageing, techno-animism, and ICT in the home environment. One important conclusion drawn from this activity is that technology should function as a support, not as a replacement for care. The workshop also led to the conclusion that access to technology alone will not result in inclusion; in order to have true inclusion of the elderly in the digital society, we need better codes of ethics, standardization, and policies to promote ICT for inclusion.

During the first year, SENIOR also held 5 Expert Group Meetings and dissemination reports on the topics of Ubiquitous Computing, Ubiquitous Communication, Intelligent User Interface, Adaptive Software, and Assistive Technology. These meetings took place in Brussels between 8 September and 8 December, 2008 and consisted of expert panels and group discussions. The meetings were invaluable to understanding the current state of technology, the pros and cons of ICT solutions for the elderly, the need to establish industry guidelines for development of products, and the need to include the elderly in the design process.

After one year of activity, SENIOR can look back on two main scientific reports, a book, two policy papers and a series of technical reports. The latter include the launching and the socio-anthropological workshop reports, 5 expert meeting reports, as well as contractual activity and administrative reports for the European Commission. The two main scientific reports are the Environmental Scanning and the Text Analysis. The Environmental Scanning yielded a comprehensive survey of key themes that ran through 157 policy documents, projects and studies conducted by the European Union. The result was a greater awareness of the need to *Continued at page 2*

### Reflections: the Socio-Anthropological Workshop on ICT and Ageing of June 1-2, 2008

SENIOR's Socio-Anthropological Workshop on ICT and Ageing brought together social scientists to explore social and anthropological issues regarding ethical and privacy concerns of ICT and older users. The focus was on human-ICT interaction, techno-animism, and homeliness. Presentations on homeliness considered smart homes and monitoring, the very meaning of "home", issues in promoting independent living at home over institutional options, and concerns about substituting ICT for live people. In preparing to discuss homeliness, I realized that several related issues needed to be examined: (1) the difficulty of escaping ageism, even while working toward e-inclusion; (2) what constitutes independent living; (3) the invisible, yet profound impact of time as experienced by different stakeholders (ICT designers, older users, policy makers) in shaping e-solutions; and (4) the crucial need for accountability to older users. SENIOR has been working on developing an ethical and privacy roadmap to guide future policies to deploy ICT with older users. In working

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The "e-Inclusion: be part of it!" campaign is organised by the European Commission. More information on this action is available at [http://ec.europa.eu/information\\_society/einclusion](http://ec.europa.eu/information_society/einclusion). The European Commission bears no responsibility for, nor is it involved in, the events, documents or other manifestations associated or claiming to be associated with the campaign, unless indicated otherwise.

## What's new in Ethics and Privacy?

### Ethics and e-Inclusion Best Practices in Europe

The search is on for examples of good practice in e-inclusion. The issue of good practices was discussed at two meetings of experts on ethics and e-inclusion hosted by the European Commission and supported by SENIOR in Brussels on 16 March and 6 April. A third is to be held in October, the month before the SENIOR final conference. The aim of the three expert meetings is to identify criteria for selecting good practice cases and to identify about a dozen examples of good practices in e-inclusion and ethics, which would be the start of a library of good practices.

About 25 experts attended the first meeting, and a subset of about 15 the second. In the first, experts made presentations about what they have been doing of relevance to e-inclusion and their views on good practice.

The experts agreed that exchanging good practices is a way of helping to educate stakeholders.

They also agreed that e-inclusion good practice cases should:

- involve users, seek their opinions, consult about their needs and understand their social context,
- involve a range of stakeholders, reflecting co-operation between industry, governments and other stakeholders, including academia,
- reflect the importance of design for all and accessibility in products and services,
- help prolong social interaction,
- consider the need for safeguards (e.g., protecting users' data),
- enable users to have access to their data, to know how their data are collected and used,
- consider proportionality early in the planning process and limit the amount of personal data processed to what is truly necessary,



- provide a follow-up, to see, for example, how many senior citizens are using a digital service say a year after introduction,
- avoid stigmatisation from products and services,
- respect values and personal options,
- avoid paternalism and discrimination,
- evaluate risks that may emerge from new technologies and services,
- train users and treat participants with respect at all times,
- ensure consent is truly informed and explicit and that choices about ICT are understandable and transparent,
- consider the economic sustainability of projects,
- build trust (e.g., through reliability, safety, maintainability, privacy and integrity).

The workshops also considered criteria for selecting good practices, including:

- effectiveness
- significance
- transparency
- efficiency
- reliability
- replicability and adaptability
- optimality
- acceptability
- legitimacy
- equity
- learnability.

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establish lifelong learning programs, to increase the visibility of policies aimed at ageing well in the Information Society, and to strengthen coordination among stakeholders. In the Text Analysis, the depiction of the elderly was analysed, as well as the depiction of their relation to ICT, in literature and the media through 12 popular movies (from "Indiana Jones" to "Jurassic Park" and "Blade Runner"). Through analyzing several films and works of literature, it was found that the elderly are seldom depicted as being technologically savvy and that the elderly are seldom the focal point of films or literature, but are usually minor players.

SENIOR conducted 28 world leading expert interviews and published them in book format with a foreword written by Commissioner Viviane Reding. The interviews were used to explore various aspects of ageing and ICT and were crucial to understanding the broader complexities of inclusion for the elderly. Experts were from the fields of e-Health, gerontology, technology, sociology, biomedical ethics, robotics, care giving, governance and the arts, coming from a multitude of countries, disciplines, and cultural backgrounds. "*The challenges posed by including the elderly in the Digital Society require a multidisciplinary and pluralistic approach. This book has been a contribution in that direction*" stated Emilio Mordini in the book's conclusion. Finally the SENIOR consortium actively participated in the eInclusion 2008 initiative of the Commission not only by being present at the main events and presenting the SENIOR project, but also by preparing two discussion policy papers (the first submitted to the Workshop on Ethics and eInclusion held in Bled on 12 May 2008; and the second submitted to the Inter-Ministerial Conference on eInclusion held in Vienna on 30 Nov. - 2 Dec. 2008).

The main outcome of the SENIOR project will be a "Dialogue towards a Roadmap" that is expected to drive future development and deployment of ICT for ageing in Europe. However, we must be prudent in our endeavours and look ahead at the possible social, ethical and privacy implications of technological advancements. The work completed in SENIOR's first year represents such prudence and has paved the way for the tasks lying ahead.

The SENIOR consortium

SENIOR partner Kush Wadhwa had compiled these criteria from good practice considerations in other domains. Participants agreed that these "criteria" could be viewed as guidelines rather than strict criteria for each candidate good practice case. SENIOR coordinator Emilio Mordini also reminded participants that we are working on ethics in e-inclusion, that we should have cases involving ethical issues, especially cases where there is some ambiguity in reaching a solution.

One participant observed that one way of empowering people is through the use of technology, but that we had to consider whether a particular solution to one problem creates negative consequences in some other area. For example, giving access to the Internet to some disadvantaged young people may lead to an increase in cyberbullying.

An important issue is how best to disseminate good practice cases and to whom. The workshops considered different approaches such as by means of a platform, a network and a clearinghouse.

Emilio chaired the first meeting with Silvia Bojinova from DG INFSO and Kush chaired the second meeting. David Wright from Trilateral Research & Consulting was the rapporteur for both meetings. For more information, contact him at

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**SENIOR presents its work to the Netcarity project**

As SENIOR's work has continued to progress over the past months in looking more intensely at issues related to good ethical and e-Inclusion practices, SENIOR partners have likewise continued to expand the dialogue. In May, SENIOR partners Kush Wadhwa (GSI – UK) and Guido Van Steendam (IFB – BE) participated in a two-day training event for the Netcarity project, focused upon ethical issues.

Kush Wadhwa presented to the group about the work of the SENIOR consortium, as part of a training programme that focused upon taking ethics from a theoretical discussion to one of practical implementation in real-world scenarios, empowering the attendees, who are responsible for the deployment of Netcarity solutions to recognise and address ethical issues within the projects' boundaries. In addition to lecture and workshops on specific ethical issues, the training included a discussion of the results that have thus far been yielded from the SENIOR project, including the key recommendations for e-Inclusion that have come from the early workshops on socio-anthropological issues and emerging technologies. The training also provided insights from the most recent work of the SENIOR consortium in evaluating good practices for e-Inclusion. The Netcarity project is researching how new and existing technologies can be used to enhance independent living at home, developing multiple applications and testing them in real-world environments. The project is expected to enhance communication, health, safety, and welfare and includes participants from diverse backgrounds, including academics, industry/technology organisations, caregivers, professionals from the fields of psychology and sociology, and regional authorities involved in delivery of services.

**Partners responsible: GSI (UK) and IFB (BE)**

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toward that goal, let us remember that information solutions, however beneficial and cost-efficient for an ageing Europe, *are pre-selected imposed solutions to which older users will be forced to adjust*. We must appreciate the difficulty many older persons already have navigating their world and their additional fears of using ICT as we work to develop our ethical roadmap. To maximize inclusivity as we move forward, let us ask: *How can we include the voices of older stakeholders who have the most to gain – and to lose – in deliberations? How can we best embrace their views so they can help shape their own futures?*

In his book *What are Old People Good For?* geriatrician William Thomas pushes us to define the value of older people in a changing ageist world. How, we might add does ICT, alter the perceived value of older people? In a Europe struggling to accommodate its citizens' diverse needs, there are strong incentives to discourage elder dependence and a drain on resources. Within this context, we could well respond to Thomas that old people are good for their economic contributions and ability to function. Once these are gone, they lose their social value unless it is replaced by non-economic value. In a non-secular, pre-Information age, elders were the holders of social memory, but in a secularized Information Society, where knowledge is accessible through other means, their value may be seen as having run its course. *We cannot afford to disregard the stark implications of this condition.*

There are ethical problems with policies demanding adaptation by elders, while ignoring unequal structural conditions and ageist processes of social exclusion. Distinguishing technologies that promote independence and engagement from those designed for integrated care might temporarily avert ageism, but ultimately serves to polarize healthy active citizens from less fortunate ones, reinforcing ageism. To avoid this, *we must embrace the continuum of variation - from vitality to frailty - among older people, and within any person over the life course*. Acknowledging our mortality and its meaning as we approach the closure of death is vital, but hard in a body-and-health-obsessed society that rejects death and decline.

In the meantime, we shall try to maximize life quality and growth and minimize disability and frailty. E-inclusion, as recognized by SENIOR, hopes to contain frailty and promote independent living. The central concept of "independent living," however, must be examined. The WHO (World Health Organization) adopts a *functional* definition -- performing functions of daily living (ADLs) with little or no help. It emphasizes active living, preventing disability and maintaining independence. An alternative *normative* definition, adopted by the TRIL Centre, Dublin, views independent living not as living alone, but as living "normally" from day to day. However one chooses to define that. As we age or become disabled, our ability to control daily activities may decline. Still, this view is more compatible with the view of older persons with disabilities, who emphasize freedom and choice (of what, when, where and with whom) and using ICT to support community residence and inclusion over institutionalization. A third *relational* approach of bioethicist George Agich challenges the very idea of absolute independence, arguing that people are fundamentally inter-dependent on each other; even our relations with technology depend on systems involving other people. *A critical life or health event can disrupt that inter-dependence, but also help us regain our bearings*. Functional, and to a lesser extent, normative views, of independent living reinforce the current obsession with personal responsibility for a healthy body and an ideology of independence that leads to unnecessary suffering and an ultimate sense of failure in many older persons. Since functional views are easier to grasp and measure, they offer pragmatic advantages to a rationalized economy. But they restrict understanding of what ageing "independently" actually entails and promote narrow solutions and bi-polar views of ageing.

A less apparent, yet significant issue concerns the cultural construct of time, and how competing experiences of time by different stakeholders shape options and experiences of older users. The natural relaxed "lived time" of the private home conflicts with the artificial, mechanistic, "clock" (or "computer") time of the work place. Those who shape policy or design ICT may experience a different time reality from elders whose lives they are affecting. The fast tech-savvy tempo of young ICT designers, may be worlds apart from the slower rhythms and practices of older users. ICT has too often been developed without taking into account experiential time of older users. Equally significant are the clashes between the way time is construed and structured in the home, the work place and institutional care setting. When the work site is the home, these clashes affect care delivery and life quality and should shape policy.

Finally, how do we achieve an ethics of e-inclusion and accountability for a diverse group of senior citizens? The varying and changing needs of the older population for e-access and/or protection over their life course necessitates different ethical requirements at different times. Access to ICT holds vast promise, but poses ethical and privacy risks. Thus, at minimum, a 2-prong Roadmap should incorporate a positive rights-based ethics to promote e-inclusion, and a negative case-based ethics to protect against violations of privacy and monitoring abuses. Ethical requirements will develop as particular issues arise in the deployment of ICT with older persons. Through careful documentation and systematic analysis of specific cases, general guidelines will evolve, along with a taxonomy of cases, giving shape to the 2020 Roadmap. A vehicle could be developed to catalogue anticipated and actual cases that arise, along with an ongoing discussion forum (SENIOR's dialogue tool) to explore emergent issues. Whatever the process, it is essential that the primary stakeholders be meaningfully incorporated in the dialogue and determinations, as they are the ones who will be directly affected by the outcomes.

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## AARP 2009

**SENIOR presented to the 2009 AARP sponsored conference on “The Power of Inclusion”**

SENIOR partner GSI (UK), represented by Nancy Baker, presented the work of the SENIOR project at the 2009 AARP-sponsored “Diversity and Aging in the 21<sup>st</sup> Century: The Power of Inclusion” Conference. Held in Chicago on 8-10 June, this marked the first opportunity to feature the work of SENIOR to a US-based audience. The conference, with attendance exceeding 500, was open to the public and attracted experts in the fields of diversity and ageing, including social workers, health professionals, policy makers, advocacy groups, and others. The work of SENIOR, the key findings to date, including the preliminary work accomplished in identifying criteria for good practices in e-Inclusion, were presented as part of a panel focusing upon technology and accommodation issues related to the elderly and disabled. The work of SENIOR was well received, and the majority of the follow-on questions at the conclusion focused upon the lack of similar studies in the US, as well as discussions of some innovative projects taking place to enhance digital inclusion of the elderly, including simple, low-cost add-ins to tailor standard PC interfaces to respond to how elderly users intuitively make use of the PC and novel approaches to PC training for the elderly.

Partner responsible: GSI (UK)

**IAHSA 8th International Conference**

IAHSA (International Association of Homes and Services for the Ageing) will be holding its 8th International Conference in London, UK from 20–22 July 2009. The conference programme offers three days of education and networking opportunities that will bring the conference theme - *Leadership Beyond Borders* - alive! Each day a wide array of educational sessions will be offered that will expose the participants to international perspectives on common challenges and opportunities in the ageing services sector. One of the Plenary Sessions will be on the topic “Technology and Older Persons” - Mr. Eric Dishman from Intel Fellow will discuss Intel’s partnership with the government of Ireland to open the Technology Research for Independent Living Center (TRIL) in Dublin, to invent and test independent-living technologies in the households of hundreds of older people to help them age in place wherever they choose to live. There will also be Symposia directly related to the topic of ethics and ageing, for example a session on “Quality of Life and Moral Value: An Evidence-Based Model of Dementia Care for People Living in Care Homes” held by Wendy Moyle from Griffith University in Australia.



Further information can be found at: <http://www.iahsa.net/london/>

**AAATE 2009 Conference**

The 10th AAATE (Association for the Advancement of Assistive Technology in Europe) 2009 Conference will be held in Florence, Italy from 31 August to 2 September 2009.



The leading theme is “Inclusion between past and future: Assistive Technologies from adapted equipment to inclusive environments”. As technology develops rapidly the concept of Assistive Technology seems to be moving away from adopting the most appropriate devices to the design and set up of the total environment in which people live. At present, these two perspectives are deeply intertwined, from both a technological and a social point of view. The aim of the Conference is to bridge the gap between these two complementary approaches, by providing an opportunity to clarify the differences and the common points between them and to better define a way for the future.

Further information can be found at: <http://www.aaate2009.eu/>

**External Events**

- ⇒ Life and Death Matters: Disability Rights and Incapacity - Symposium - London, UK, 2 July 2009
- ⇒ IAGG World Congress of Gerontology and Geriatrics - Paris, France, 5-9 July 2009
- ⇒ IAHSA 8th International Conference - London, UK, 20-22 July 2009
- ⇒ 10<sup>th</sup> AAATE 2009 conference - Florence, Italy, 31 August-2 September 2009
- ⇒ 9<sup>th</sup> European Sociological Association Conference – Lisbon, Portugal, 2-5 September 2009
- ⇒ European Seating Symposium incorporating Assistive Technology - Dublin, 14-17 September 2009
- ⇒ The European Ambient Assisted Living Forum 09- Vienna, Austria , 29 Sep-1 Oct 2009
- ⇒ REHACARE International 2009 – Dusseldorf, Germany, 14-17 October 2009
- ⇒ Telehealth and Assistive Technology 2009 – Massachusetts, USA, 4-6 November 2009
- ⇒ USAB 2009 - Usability & HCI for elclusion at the University of Linz, Austria , 9-10 November 2009

**Senior Consortium**

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