Sharing: Quality of life in aging society

Innovative ICT Solutions for Patients with MCI and Dementias – A Romanian Success Story

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President of Ana Aslan International Foundation

“Moral technology, Inner Power, Together We Can”
18-19 January 2017
Faculty of Medicine, Naresuan University
Who we are?

Ana Aslan International Foundation (AAIF)

A Non-Profit International Organisation, established in 2000 in Bucharest

Expertise
* comprehensive, integrated approach of healthy and active ageing and longevity medicine
* Research,
* High-Profile Educational, and Predictive, Preventive and Personalized Medicine (3P Medicine).

Mission
* to integrate scientific progress into the original, holistic concept of predictive, preventive and personalized medicine
* to provide patients, medical and scientific community with the instrument to make brain aging medicine the longevity medicine.
AAIF’s Specific Profile

Medical services - The Centre for the Diagnosis and Treatment of Memory Impairment Diseases and Medical Rehabilitation (established by AAIF in 2003 in Bucharest)

- preventive, predictive and personalized medical services in the field of aging and ageing-related pathology,
- health management, especially of the cerebral cortical level,
- assistance of persons with special cognitive needs in acute care settings, day centre, or at home.

Research - Ana Aslan Academy of Aging – the R&D department of AAIF, founded in 2001,

- develops basic and applied research activities and clinical trials in areas such as epidemiology, risk factors and medication of dementia,
- publishes and transfers the obtained results into the practice of geriatric care,
- promotes the advanced technology-based (remote) long-term care of the elderly, as medical partner and end-user organization in more than 15 (AAL, FP6-IST and FP7- CIP-ICT-PSP) projects + EU or privately funded clinical trials.

Education

- mostly linked to the The Geriatrics, Gerontology and Old Age Psychiatry Chair of Carol Davila UMF, Bucharest
- designs and implements higher education and postgraduate programs,
- Coordinator of the SOP-HRD project BRAINAGING -1800 Romanian physicians and 2600 medical assistants were trained in the field of Brain Aging (between 2011 and 2013).
AAIF’s Specific Profile (2)
International cooperation:

★ EADC centre of excellence, (European Alzheimer’s Disease Consortium) [http://www.eadc.info/sito/pagine/home.php],

★ national coordinator of the Romanian representative of EPMA - The European Association for Predictive, Preventive & Personalised Medicine (www.epmanet.eu),

★ Founding member of 7 communities in EU Joint programmes EADC, AgeingWell, LiveWell, Confidence, BrainAging, E-NO Falls and INNOVAGE

★ medical (coordinator) /partner in 11 project consortia of EU FP7+AAL Mobile.Sage, MobileOld, Confidence, LiveWell, E-NO Falls, CarerSupport, StayActive, Revolution, SeniorTV, MyMate, TSBank

★ cooperative relationships with over 20 worldwide top universities and clinical institutions dealing with aging and related pathology.
Romania facts
In the past few years - an increasing trend in the number of single elderly, especially women rises more demands on health and social services for personal care.

The Romanian households are now foregrounding each family member self-sufficiency and the most affected are the elderly.

- Today they increasingly face isolation, abandonment and institutionalization.

The European population is currently suffering a second major trend: the emergence of a new age group entitled "the fourth age" ("the oldest of the old" of over 80 years) with a high rate continuously growing.

*According to the results of AMIGO "Ancheta fortei de munca in gospodarii" ("Survey on labor force in household"), the number of the economically active Romanian elderly (65 and over) was in 2011, of 388,000

- 3.9% of all active population
- 12.2% of the total population in the same age category.

The economically inactive elderly (65 and over) were 87.8% of the total number of people in this age group.

http://www.worldbank.org
The evolution of the demographic aging in Romania

Active ageing and solidarity between generations. A statistical portrait of the European Union 2012: “Romania is one of the most affected country by the phenomenon of ageing. In 2010, the Romanian population median age was 38.3 years, close to the EU average estimated at 40.9 years.”

PC utilization in Romania

According to the INSSE report on 2013, PC is used by more than half (54.0%) of the individuals aged 45-54 years, by 38.2% of people aged 55-64 years and only by 16.8% of individuals aged 65-74 years,

Table on Structure of Computer Use by Age groups in 2013

NGA technologies in Romania

NGA technologies are most widespread in Romania, Belgium, Lithuania and the Netherlands, where over 50% of lines are high-speed.

INTERNET utilization in Romania

During 2006 – 2012, the percentage of households with Internet access increased in the Member States;

⇒ in Romania: from 14 to 54%.

For households with broadband Internet access ⇒ in Romania: from 5 to 50%.

According to the INSSE/2013, in Romania the Internet is used:

by more than half (51.3%) of individuals aged 45-54 years,
by 34.3% of people aged 55-64 years,
and only by 13.9% of people aged 65-74 years.

INTERNET utilization in Romania

Eurostat Statistics in 2012 shows that in Romania,
★ 73% of users access the internet to read the news and newspapers online,
★ 8% use internet banking services,
★ 48% post messages on social networks,
★ 24% use services related to travel and
★ 9% need internet to create a website or a blog.

In 2013, the most commonly used devices for Internet accessing were:
★ mobile or smartphone - 61.8%, followed by
★ notebooks with a 47.5%.

The share of men who have accessed the Internet via mobile phone or smartphone was slightly higher than women (64.0% vs. 59.3%).

Type of connections (networks) used to access the Internet from other places than home or work,
★ The smartphone has the highest share per total (78.2%) as well as and by residence (77.2%-urban and 81.2%-rural).

Among those who have used the notebook, the most commonly type of network technology was Wireless (62.5%).

ICT packages utilization in Romania

In mid-2012 in Romania, there were 5.5 million users of electronic communications services packages (integrated and related services),

\[\downarrow\]

an increasing of 68.8% comparing to the same period of 2011.
The coverage ratio regarding the packages of electronic communication services in 100 households has reached to 77.6%.

According to the last report of the National Regulatory Authority for Communications (ANRC)

ICT research spending in Romania

Research spending increased slightly despite budget constraints.
Public investments in research and development in ICT grew with

1.8% or 122 million EUR to 6.9 billion EUR in 2012;
The private investment in research and development in ICT have also increased.
The increase of 2.7 % was not enough to offset the 2011 decline.

## Quantification of the market

**In Romania – Main morbidity data in elderly people**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>31.80%</td>
</tr>
<tr>
<td>Neurodegenerative (dementias)</td>
<td>24.44%</td>
</tr>
<tr>
<td>Respiratory</td>
<td>6.17%</td>
</tr>
<tr>
<td>Gastroenterology</td>
<td>4%</td>
</tr>
<tr>
<td>Endocrine</td>
<td>2.94%</td>
</tr>
<tr>
<td>ENT</td>
<td>1.77%</td>
</tr>
<tr>
<td>Urinary tract</td>
<td>1.42%</td>
</tr>
<tr>
<td>Other</td>
<td>0.99%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Founding year</th>
<th>Theme</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>AgeingWell</td>
<td>2012</td>
<td>* improving the life of older persons by promoting the market uptake of ICT solutions for Ageing Well;</td>
<td><a href="http://www.ict-ageingwell.net">www.ict-ageingwell.net</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>* a reference point for key stakeholders in the ICT &amp; Ageing Sector</td>
<td></td>
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<tr>
<td>LiveWell</td>
<td>2012</td>
<td>* a web-based tool for Parkinson patients, their caregivers and health professionals, with training contents, exercises and information packages;</td>
<td><a href="http://www.livewell-community.eu">www.livewell-community.eu</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>* a social community for Parkinson Patients, Caregivers and Health and Medical professionals</td>
<td></td>
</tr>
<tr>
<td>E-No Falls</td>
<td>2013</td>
<td>* a consensus on action plans, standards and specifications ensuring the widest future replication and co-deployment of innovative solutions;</td>
<td><a href="http://www.e-nofalls.eu">www.e-nofalls.eu</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>* brings together knowledge, experiences and best practices in the area of fall prevention, intervention and safety.</td>
<td></td>
</tr>
<tr>
<td>Confidence</td>
<td>2011</td>
<td>* a community (family members, staff of home care agencies and/or trusted volunteers) - enabling mobility safeguarding assistance service that combines “assistive technologies” with “personal help” in supporting patients with Mild to Moderate Dementia</td>
<td><a href="http://www.salzburgresearch.at/en/projekt/confidence_en">www.salzburgresearch.at/en/projekt/confidence_en</a></td>
</tr>
</tbody>
</table>
### AAIF - founder member of European consensus ICT initiatives & EU AAL Joint Programmes (II)

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<th>Name</th>
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<th>Theme</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>EADC</td>
<td>2001</td>
<td>• a fully functional network of European centres of excellence working in the field of Alzheimer's Disease.</td>
<td><a href="http://www.eadc.info">www.eadc.info</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• it provides a setting in which to increase the scientific understanding of and to develop ways to prevent, delay, slow, or ameliorate the primary and secondary symptoms of Alzheimer's Disease.</td>
<td></td>
</tr>
<tr>
<td>EPMA</td>
<td>2008</td>
<td>• is the European Coordinator in the field of Predictive, Preventive &amp; Personalised Medicine</td>
<td><a href="http://www.epmanet.eu">www.epmanet.eu</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• solves the accumulating problems in healthcare and the concomitant economical burden that societies across the globe are facing more and more</td>
<td></td>
</tr>
<tr>
<td>BrainAging</td>
<td>2011</td>
<td>• Professional Training on New Medical Technologies Related to Brain Aging, for the Specialized Medical Doctors and Nurses</td>
<td><a href="http://www.brainaging.ro">www.brainaging.ro</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• promotes healthy Brain-Aging as the capital component of healthy and active aging</td>
<td></td>
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<tr>
<td>INNOVAGE CARERS</td>
<td>2013</td>
<td>a web-based support services with a platform accessible in 2015 in 24 EU official languages with common and national-specific contents for carers, care professionals and employers of working family carers from EU-27.</td>
<td><a href="http://www.innovage.group.shef.a">www.innovage.group.shef.a</a></td>
</tr>
</tbody>
</table>
Categories of stakeholders involved by AAIF in AALs

User Organization: 54%
Public Authority: 20%
Other: 3%
EU project: 3%
Industry: 3%
R&D organization: 7%
ICT solutions provider: 10%
AAIF – The Romanian Pilot Site of E-Health Platforms Evaluation and Validation for Ambient Assisted Living projects (AAL)
WHAT CAN WE GAIN FROM AAL PROJECTS?

★ **Smart assistive devices and apps - valuable solutions for:**

- integral bio-psycho-social therapy and rehabilitation assessment
- disability support for maximum independence
- integration of people with disabilities within their social environment and within the society at large
- improvement of personal security as well as personal and family care
- a better quality of life for caregivers

★ **Services and products - great diversity of “high tech” solutions related to:**

- mobility and prosthetics
- physical assessment, treatment and rehabilitation
- support of daily living activities
- urban accessibility, transport and architecture
- accessibility in the work place
- sensorial impairments (visual and hearing)
- cognitive disability, including affective and social issues
- access to information and alternative communication
CONFIDENCE: Mobility Safeguarding Assistance Service with Community Functionality for People with Dementia

- based on clouding computing and Smartphone technology
- applications for dementia patients with two components:
  - a personal assistant on the smart phone – to enhance indoor-outdoor mobility of the dementia patient
    - services: outdoor orientation and tracking, medication and appointments reminder, weather information, navigation, security alarms with “just in time” help
    - provides different levels of assistance that can be adapted, depending on the situational needs of the patient and the degree of orientation loss
  - a community web portal to facilitate:
    - carers’ action and interaction for assisting the dementia patient’s needs
    - integration and expansion of the existing social network for the elderly
- CONFIDENCE was awarded the AAL Awards (both jury and public award) in 2014.
CONFIDENCE was awarded the AAL Awards (both jury and public award) in 2014
RESIDENTIAL & OUTDOOR SERVICES ADVANCING THE MOBILITY OF OLDER PERSONS

★ highly customized personal assistant service for seniors and their caregivers

★ multimodal Via: smart phone + tablet + TV

★ provides services to support indoor and outdoor mobility:
  ▪ trip planning, outdoor orientation,
  ▪ tracking and traffic info,
  ▪ weather info,
  ▪ physical mobility training,
  ▪ mental mobility training (quiz),
  ▪ daily life support (check lists, reminders)
MobileSage – Situated Adaptive Guidance for the Mobile Elderly

Smartphone application – assists elderly in using new technologies

Provides:

★ context-sensitive, personalized and location-sensitive tools, in order to carry out and solve everyday tasks and problems “just-in-time”

★ written, audio or video information for supporting:
  ▪ indoor mobility (clear user manuals for household appliances, weather and other info)
  ▪ outdoor mobility (find my way, tracking and trip info – ATM or ticket machine way of use etc.)
Almost all the old people in the end-users group proved interested in the Mobile.Old virtual companion.

Main results & Lessons learned from the Romanian trials at AAIF

NEXT slides
The Mobile.Old app:

- the previous trials (with 73 seniors, 35 males and 38 females) showed that the acceptance of the Mobile.Old app, (i.e. a complex set of ten services), is high, despite the myth that older people are more reluctant to advanced technology apps.
- almost all the old people in the end-users group proved interested in the Mobile.Old virtual companion.
- almost 2 third of the end-users were interested in buying various bundles of the services, according to their needs;
- only four participants would like to buy the services as one single application.
- the most preferred services were:

<table>
<thead>
<tr>
<th>for bundling</th>
<th>For the other six services</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Mobile.Compass” (prefered by 34 from the 73 end-users)</td>
<td>“Mobile.Activity” (28),</td>
</tr>
<tr>
<td>“Mobile.News” (33),</td>
<td>“Mobile.Aid” (28),</td>
</tr>
<tr>
<td>“Mobile.Trip” (32)</td>
<td>“Mobile.Security” (23),</td>
</tr>
<tr>
<td>“Mobile.Training” (31).</td>
<td>“Mobile.Checklist” (20),</td>
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<tr>
<td></td>
<td>“Mobile.Insight” (20),</td>
</tr>
<tr>
<td></td>
<td>“Mobile.Quiz” (12).</td>
</tr>
</tbody>
</table>
The MobileSage app:

There was a general agreement on the high utility and the most preferred were:

- the video-audio and text provided information;
- the appearance of the most frequently used function (Scan. Search, Travel) in the upper part of phone screen;
- the Help function and Phone settings (Font size and Language selection, Information type selection and Screen brightness);
- the QR code scanning highly appreciated as very useful and easy to use;
- the NFC (near Frequency Communication) code scanning required the user to find the proper position for accomplish the scanning half of them are lesser prone to use this function;

Especially the old end-user needs previous assisted training and personal exercise to easily and successfully use them;

Especially the participants with mild cognitive impairment underlined that the app and services are highly useful indoor and outdoor.
MobileSage

Many older people, including those with vision, mobility and memory impairments, wish to remain active and travel, even if they may be unconfident about finding their way around unfamiliar transport systems and with using new ticketing technologies.

The MobileSage project, which ran between July 2011 and March 2014, has provided older people with context-sensitive, personalised and location-sensitive guidance to allow them to carry out and solve every day travel tasks at the point they are needed, ‘just-in-time’. The MobileSage project was funded by EU Ambient Assisted Living (AAL) and involved the University of Ulster with partners from Norway, Romania and Spain.

The MobileSage services are installed on a mobile phone and employ geographical positioning system (GPS) data, wireless communication (WLAN), mobile phone communication (GSM/GPRS), Near Field Communication (NFC) and Quick Response barcode (QR) codes to identify context relevant information in the locality.

Cloud storage of the user profile ensures information is presented when required, in the language and format required, as well as supporting the storage and application of content relating to geography and help guidance. These are brought together for personalised presentation to the user on the mobile phone.

Examples of how this service might be used by an individual include searching for information on local landmarks or buildings, such as the Eiffel Tower, and having a spoken description delivered in the user’s preferred language. Guidance can be provided on the nearest underground station and on the line required to reach a destination.

Technologies such as NFC can be used to scan the ticketing technologies in use by the transport system to enable the system to select the appropriate ‘help’ content, such as a video guide on how to use the machine.

Following evaluation and design improvements carried out in 2013 a second version of the MobileSage Help-on-Demand service was released and trialled in 2013. Beta versions of the service, for Samsung and Android smart phones, and the content management system (CMS) have been made available for download from the project website. The website also provides video clips demonstrating how the system works, and reports on the range of activities undertaken by the project, such as establishing users’ requirements for the system.

The project was nominated as one of the three finalists for EU AAL 2013 Award. The MobileSage partners have undertaken business modelling activity but there is no information currently on how the partners wish to exploit the learning and services developed through the project.
The Confidence app:

- Confidence app can be **a valuable instrument for the long term care of Mi-Mo NCD people** especially **when using it beside other remote, biosensors-based monitoring systems**.
- The services provided are not very complicated,
- The interfaces and functions are intuitive enough,
- The two devices (Nexus 5 and Xcover2) are light enough to be permanently kept nearby,
- The five **Confidence services** were considered as very useful virtual companion for old people with special needs,
- The “SOS”, “Help”, “Map” and “Weather” functions were considered rather easy, while the “Calendar” and Find My Way functions seem a bit more complicated for the primary end-users (Mi-Mo NCD people) in terms of new entries creation and reminder setting.
- It would be better if the app could be run on various types of smart phones, depending on user’s preference.
- **For Mi-Mo NCD people, the initial, patient training with a human assistant will be of capital importance for the acceptance of the app** and its fully profitable use.
Strengthening Self-Management of Stress in Older Workers through Advanced Technology Apps:

A three step solution for detecting and managing the stress related symptoms in older adults working in an office or factory

System components: a set of biosensors, a Personal Agent installed on a smart phone, a clouding web portal

STRESS LEVEL DETECTION - biosensors (for heart rate, breath rate, skin temperature and moisture), and user’s movement tracking, this service detects user’s stress state and signalizes it to the Web portal component and to the end user.

RECOMMENDED ACTIVITIES - This service will recommend various activities (e.g. take a break, read an article, watch a short video, listen to music, play a relaxation game) in the form of audio, video, images/slides and text based on the stress level detected.

HYSTORY - The service will show the current relaxation (or stress) level and also statistics about user’s daily/weekly activity.

STRESS WIZARD - This service will provide the user with various, highly personalized game-like and other activities, for helping him to break the action of the stressor and avoid its disturbing effects.
CarerSupport
Platform for informal carers’ training and collaboration

★ development and operation of a sustainable pan-European ICT-based ecosystem for:
  o training
  o orientation
  o support of informal carers

★ Integrated ICT platform to manage training and psychological support programs for carers and stakeholders’:
  o e-learning sessions
  o computer based training sessions
  o tele-consultation sessions
  o psychological support
  o collaboration and interaction between stakeholders
REaltime VOLunteering solution

- based on a new, very flexible way to **plan and support help services brought to older adults on a voluntary basis**;

- simple and effective real-time scheduling of short-term assistance:
  - driving services
  - shopping
  - help at home
MY MATE - GAMIFIED COLLABORATIVE PLATFORM FOR THE
PROMOTION OF SUSTAINABLE CARE AND INDEPENDENT
ASSISTED LIVING

ICT based platform and content management system
for fostering and monitoring user centred “care in the
community” services

Connecting
★ FORMAL CARE CENTERS with
★ SENIOR VOLUNTEER INFORMAL CARERS and
★ ELDERLY in need of assistance

Enabling FORMAL CARE CENTERS to:
★ identify and monitor elderly care needs
★ recruit and train senior volunteers (+ 65 y.o.) to provide community informal care services: (conversation and accompaniment, visits, bio-physical data collection, medication schedules, leisure activities and physical exercise)
★ match care needs with volunteers’ experience and profile
★ monitor volunteers’ activity in real time
★ reward volunteers based on a point accumulation system
★ establish models of community care
MyMate – primary users
MyMate - volunteers
SeniorTV - PROVIDING ICT-BASED FORMAL AND INFORMAL CARE AT HOME

- holistic system that integrates IT applications for formal and informal social care services to older adults that live alone
- delivered via Interactive, simple to use, TV - as the central element of the system
- focused on active prevention + maintenance of relationships with friends, family, and the community
- using: education content, rehabilitation content, games, content targeted at older adults and caregivers, social networks)
Senior-TV –
FORMAL AND INFORMAL HOME CARE
WITH THE HELP OF ITC
PROJECT REALIZED BY A MULTINATIONAL CONSORTIUM

Cyprus Neuroscience and Technology Institute (Coordinator)
WHAT IS SENIOR TV?

- TELEVIZOR ITELIGENT
- FUNCTIILE UNUI TELEVIZOR + UNELE FUNCTII ALE CALCULATORULUI
- ADAPTAT PENTRU PERSOANE DE VARSTA A TREIA
- USOR DE UTILIZAT
- COMOD SI CONFORTABIL
ORIENTED TO PREVENT PHYSICAL AND COGNITIVE DETERIORATION

IT WILL SUPPORT SENIOR PERSONS TO TAKE CARE BY THEMSELVES

IT WILL FACILITATE THE COMMUNICATION WITH THE FAMILY MEMBERS, FRIENDS AND THE COMMUNITY
OPEN SYSTEM

FUNCTIONS ON VARIOUS PLATFORMS:

TV+TABLET+SMARTPHONE
an online platform that promotes active aging

encourages the elderly to volunteer their skills and time to perform work on a set of areas:

- tourism: helping tourists visiting his/her town; provide information to the tourist via the internet (e.g. best places to visit, suggested local tours, etc.), serve as guide and do a local tour, etc
- sitting over short periods of time for: children, pets, older family members,
- Consultancy or tutoring in their area of expertise

connects elderly with the people looking for support

simple, easy to use design- taking into account the limitations of the elderly users
E-NOFALLS

What?
★ a portal that integrates international knowledge, experiences, guidelines and best practices in the area of fall prevention, intervention and safety
★ multiple dimensions knowledge: medical, scientific, operational, technological, socioeconomic

Why?
★ to identify potential areas for: research, develop, pilot, evaluate and deploy ICT solutions
★ to support co-deployment of innovative solutions (with special emphasis on ICT-based ones)
★ to enable collaboration and exchange of information and experience among stakeholders

FOR WHOM?
★ Addressed to a wide range of stakeholders: industry, users organizations, informal and, formal care providers, public authorities, investors, housing and insurance companies and service providers
LiveWell

Grundtvig initiative under the Lifelong Learning Program

Promoting Healthy Living and Well-being for Parkinson Patients through Social Network and ICT Training

- an innovative Web-based Training and Social Community System
- addressed to Parkinson patients, Caregivers and Health Professionals

TWO MAIN FEATURES/AREAS:

- **training**: offering both Parkinson Patients and Caregivers interactive training contents, exercises and information packages about the disease and how to deal with patients and contribute to their active ageing

- **social community**: allowing interaction between Parkinson patients, Caregivers and Health Professionals
AgeingWell
Network for the Market uptake of ICT for Ageing Well

European network focused on improving the quality of life of Elderly People by promoting the market uptake of ICT solutions for Ageing Well

- develop guidelines for deployment and sharing of best practice between key competence centers;
- build an ICT for ageing knowledge center to share relevant information and results with the AgeingWell community;
- develop an ICT for ageing society strategic agenda to provide a study on options for future structure and implementation of EU innovation funding;
- promote the European innovation reinforcement between innovative ICT & ageing and the investment community;
INNOVAGE

★ developing, testing, surveying and cataloguing social innovations that will have a solid impact on improving the quality of life and well-being of older people

★ implemented by a multidisciplinary consortium

★ consolidates a network of public, private and third sectors

★ built on the partnership with end users and stakeholders, including older people

★ key outputs: 4 new major social innovations in different EU countries and a new European platform to promote the sustainable implementation of social innovations to promote well-being in later life
AAIF Publications & research papers on AAL


- Assistive Technology (AT) development: A capital response to population aging. The European model. L Spiru, I. Turcu, C. Ghita; Gerontechnology; ISSN 1569-1101; 2010;9(2):333;

- Normal versus pathological cognitive aging. Variability as a constraint of patients profiling for AmI design, Luiza Spiru, C Ghita, I Turcu, L Stefan, Ulises Cortes, Proceedings of The International Work Conference on Artificial Neural Networks, Salamanca, Junie 10-12th, 2009, Lecture Notes in Computer Science (LNCS), ISSN: 1867-8211, Springer Verlag, 2009

- Legal concerns regarding AmI Assisted Living in the elderly, worldwide and in Romania, Luiza Spiru, L Stefan, I Turcu, C Ghita, Ulises Cortes, Proceedings of The International Work Conference on Artificial Neural Networks, Salamanca, Junie 10-12th, 2009, Lecture Notes in Computer Science (LNCS), ISSN: 1867-8211, Springer Verlag, 2009


Legal Concerns Regarding AmI Assisted Living in the Elderly, Worldwide and in Romania

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2 Universidad Politècnica de Catalonia, Jordi Girona 1, 08034 Barcelona, Spain
3 Fondazione Santa Lucia, Via Ardeatina 354, Rome, Italy

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Abstract. The recent concepts developed in order to meet the specific technology-related needs of older people are “Ambient Intelligence” and “Ambient Assisted Living”. The major aim of AmI is to prolong the time older people can live decently in their own homes with an increased autonomy and self-confidence. One category of patients that would necessarily require intelligent ambient assistance devices in the future is the old one, characterized by a high incidence of co-morbid conditions and diseases, cognitive and/or physical impairments.

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Abstract. Ambient assisted living can greatly assist seniors in pursuing an active and healthy lifestyle. MobileSage is an Ambient Assisted Living Joint Programme supported project that develops a cloud enabled smartphone based help-on-demand service for seniors providing appropriate “just-in-time” assistance through an individualized adaptive and multimodal user interface. This paper details the results from a user needs analysis conducted with seniors to help determine the design of MobileSage. Six focus groups in three countries were held to elicit the information. The user input is structured under the following themes: Multimodality: Input & Output; Navigation (wayfinding); Personalization; Help material – content; help-on-demand; and Privacy, trust and security concerns. The MobileSage system will have its first iteration of user testing late Fall 2012.

Keywords: user needs analysis; help-on-demand; seniors;

The participating countries are Norway, Spain, Romania and the UK.

MS involves the development of a cloud enabled smartphone based HOD service for seniors providing appropriate “just-in-time” assistance through an individualized adaptive and multimodal user interface. The front end consists of an application (app) installed on an Android phone. Advanced software on a server including a database populated with the HOD media in the form of text and multimedia files comprise the back end of the system. The content in the database is generated through a Content Management System (CMS). An overview of the MS architecture is provided in Figure 1.

The system can be applied to an abundance of situations and contexts in which seniors require assistance to conduct everyday tasks. Two brief examples will suffice.


COLLECTING USER REQUIREMENTS FOR ELECTRONIC ASSISTANCE FOR PEOPLE WITH DEMENTIA: A CASE STUDY IN THREE COUNTRIES

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Abstract. Collecting user needs for a personal digital assistant for people with dementia and their personal environment is a demanding task. If these people are coming from more than one country with different cultural and socio-economic backgrounds, a tailored approach which can be customized has to be applied. Therefore in the Confidence project an adaptable iterative approach to collect user requirements for a system supporting people with dementia has been applied and validated.
IMPORTANT ASPECTS REGARDING VALIDATION AND EVALUATION OF NEW TECHNOLOGIES
Assessment Battery for measuring the impact of new developed ICT services on end-users’ psychological, cognitive, functional and behavioral state

PRIMARY AND SECONDARY END-USERS TRAINING – performed repetitively – educational stereotypy:
★ 2 meetings inside the clinical department: one group + one individual meeting
★ 1 individual meeting at home with each end-user and the medical team

END-USER EVALUATION :
★ For dementia diagnostic: DSM-V, ICD-10 and NINCDS-ADRDA.
★ Cognitive and functional tests:
  - MMSE – for cognitive evaluation;
  - GDS – dementia severity;
  - GBS – functional assessment;
  - IADL – for instrumental functional assessment;
  - NPI (Neuro-Psychiatric Inventory) – for behavioral changes;
  - Tinetti static & Tinetti dynamic – for motor status evaluation;
  - Yessavage geriatric depression scale – for depression detection;
  - Zarit scale for caregiver’s burden

* agreed by the European Alzheimer’s Disease Consortium (EADC) as assessment tools for dementia in Alzheimer Centres across Europe, http://www.eadc.info
HOW TO EVALUATE IMPACT ON END-USER

★ improvement in scores of cognitive, functional, behavioral and mobility proposed tests (comparison between the baseline and the final end-users assessment);
★ end-users’ subjective feedback reflected by a specific questionnaire on services quality;
★ validated scales for behavioral issues on their social, psychological, physical and environmental wellbeing and engagement in their health management;
★ caregiver’s feedback (improvement of Zarit scale scores and questionnaire)
★ questionnaire addressed to the secondary and tertiary end users: health professionals, specific organizations of patients/caregivers, ICT providers or other stakeholders.
The ethical aspects of AAL projects
Extracts from the *Pilots Ethical Manual*
elaborated by AAIF and currently under publication

The pilot testing sessions must take into account the national legislation and local regulations. The recruitment of old voluntary end-users is based on previously established inclusion-exclusion criteria.

**Ethical rules** concern:
- end-users recruitment and involvement,
- informed consent as a standard procedure,
- participation in prototypes testing and validation protocol,
- precise information on how the end users can withdraw from the project at any time – the exit rights for individual end-users
- possible compensations provided for participating (expenses or fees paid, etc.),
- the possibility to contact the project coordinator for ethical issues and related questions,

**Protection of personal data:**
- information and data management,
- confidentiality of communications
- storage and transmission of personally identifiable information,
- macro level distributive ethics (justice, equality of access, choice etc.).

Even if the informed consent and other ethical issues do not raise special challenges in people with MCI, the practical application of ethical related principles (e.g. obtaining informed consent, use of assistive technology etc.) and the impact on individuals in terms of respect for personhood, autonomy and dignity, are under debate.
The anticipated impact of AALs expected by AAIF for the Romanian society (I)

New innovative interventions

- intent to cover as much of the elderly user's various needs, based on the principles of a novel domain such as **Participatory Medicine**: the patient - an active participant and a decision maker to the health and social caregiving act,
- self-management interventions and mutual assistance community services advance a more independent living for elderly
- easing the elderly’s access to medical biofeedback means, thus enabling them to monitor themselves and to act as a proactive self-carer.

Information derived from the studies

- may indicate levels of clinical change in symptoms
- could serve as the basis for personalized care interventions
- may provide an overview of the progression of the symptoms and related caregiver burden.
The anticipated impact of AALs expected by AAIF for the Romanian society (II)

Related to the **secondary end-users – SEUs**: medical and social professionals and formal or informal caregivers, the AAL services provided
- are equally able to ease the family, caregiver and professionals burden,
- facilitate communication between the various professionals.

The joint support of informal caregivers and various professionals involved in elderly persons’ monitoring (general practitioners, specialists, physiotherapists, psychologists, nutritionists etc.), are also enabled through a better communication between them, as well as with their patients or with the patients’ family.

Particular categories of SEUs that can significantly benefit from new-implemented platform are the associations of volunteers and their trained members for whom efforts are carried out in reinforcing the community care.
The anticipated impact of AALs expected by AAIF for the Romanian society (III)

- The AAL services counteract, support or compensate PEU’s mild memory loss, stress, depression, physical impairment or social withdrawal,
- A better coordination of the healthcare systems
- A reduced burden of care by supporting family or caregivers as well.
- Through the know-how component ➔ a significant contribution is brought in smart platforms’ standardization for enhancing the ability for such technologies to be easily used by the direct consumers and various stakeholders in the field.
- Through their objectives and expected outcomes the AAL projects meet the requirements and recommendations of several European programmatic documents stringently needed to be implemented in Romania, such as:
  - Madrid International Plan of Action on Aging,
  - WHO’s ACTIVE AGEING: A POLICY FRAMEWORK
  - The Strategic Implementation Plan of the European Innovation Partnership on Active and Healthy Ageing
Conclusions and Recommendations
**AAIF’s Recommendations on AAL development in Romania (I)**

- Involve stakeholders in the PEUs and SEUs requirements process!
- Organize and execute *events for the attraction and the recruitment of PEUs and SEUs*
- Users’ attraction and mobilization modalities / project dissemination
  - **direct contacts with patients, formal and informal carers** affiliated to the consortium organizations/business networks
  - **publications and dissemination of projects objectives and results:**
- Exchange know-how with other partners!
- By involving a big number of end-users in the trials for platforms testing, we received important knowledge on their specific needs on AAL platforms design, functionality and apps interfaces.
Market implementation of new AAL developed platforms

the testing sessions with the end-users showed their interest on the provided services, but the successful implementation raises two issues:
★ financial support
★ end-users’ computer + technical literacy and reluctance against advanced technologies.

reluctance against advanced technologies – a consequence of:

▪ stigma and prejudice against people with dementia, which some of the platforms (e.g: CONFIDENCE) can actually counteract it!

▪ user’s age – another stigma that can be counteracted when the initial training is provided with patients and care!

★ Usually, the projects provide important data on various categories of decision-makers in the long term care of the elderly with or without physical or mental disabilities.
Conclusions

* in the field of the cognitive impaired persons and elderly assistance ➔ patients and caregivers empowerment and improvement of:
  - mobility and quality of life (daily tasks accomplishment, help in critical situations, long-term remote monitoring)
  - ability to respond in real time to situations upheld,
  - interactive communication patient-caregiver-family-health professional,
  - relationships within families,
  - prevention of
    - home accidents and injuries
    - immobility and marginalization

*Mobility has a major impact on mental health; its absence may often lead to social and relational withdrawal!

The management of its physical, cognitive, psychosocial, environmental, and financial determinants is essential for a healthy and active ageing.
Conclusions

- To design friendly interfaces adapted to the end-user profile and needs (user centered design);
- To carefully consider the end-user training - specific guidelines intending to contribute to the intelligent platforms’ standardization and allowing thus the ability for such technology to be easily used by consumers (patients, caregivers and families) and other stakeholders in the field;

friendly interfaces,
- easy access and navigation through various functions
- a good initial training with a human assistant

In terms of ethics the adoption of a standardized Pilots Ethical Manual (*elaborated by AAIF and currently under publication);
Conclusions

★ integrated services based on the Participatory Medicine principles ➔ to empower the patient as an active participant and decision maker of his assistance;

★ the concerted assistance of the patient-caregiver-family ➔ a functional entity within the caregiving process;

★ implementing current medicine guidelines and innovation ➔ refocusing the health system improvement based on two, complementary components:
  - human assistance (with health and social professionals)
  - non-human, advanced technology-based assistance

New AAL solutions may overcome constraints of national borders.

Romania seniors’ needs of long-term assistance, never fully covered, are huge challenges to which health system must adapt.

Advanced technologies already proved their potential to significantly contribute to this adaptation.
Instead of Conclusion:

My personal belief is that when it comes to healthy aging there is no “fountain-of-youth”, the only “true secret” for longevity resides in the correct and early AGE DIAGNOSTIC through an integrative medical approach, based on the latest developments of the medical know-how and with the use of innovative e-HEALTH solutions and smart technologies.
Thank you for attention

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