Testing Innovative E-Health Solutions in Romania

Ana Aslan International Foundation

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AAL FORUM 2014

9-12 September 2014, Bucharest, Romania

Who we are?

Ana Aslan International Foundation (AAIF)

A Non-Profit International Organisation

- established in 2000 in Bucharest
- with special expertise in the comprehensive but integrated approach of healthy and active ageing and longevity medicine

Bio-medical and clinical research and knowledge transfer into practice,

High-Profile Educational programs,

and

Holistic-integrated clinical approach

Mission: to integrate scientific progress into the original, holistic concept of predictive, preventive and personalized medicine of Aging

- to give patients, medical and scientific community the instruments, pathways

  ➤to make brain aging medicine the longevity medicine.

Specific Profile (1)

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 diseases

- health management, individualized risk factors and early interventions in pathological aging and brain aging

- assistance of persons with special cognitive needs in acute care settings, day centre, or at home.

Research activity:

The 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 of aging, risk factors and early interventions in pathological early aging and brainaging.

- 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 20 (AAL, FP6-IST and FP7- CIP-ICT-PSP) projects + EU or privately funded clinical trials (NEXT slide).

Specific Profile (2)

International connections:

- is an EADC center of excellence, (European Alzheimer's Disease Consortium http://www.eadc.info/sito/pagine/home.php),

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

- is the founder member of 7 communities in EU Joint programmes EADC, AgeingWell, LiveWell, Confidence, BrainAging, E-No Falls and INNOVAGE

- is the medical coordinator/ partner in 8 project consortia of EU FP7+AAL Mobile.Sage, MobileOld, Confidence, LiveWell, E-NO Falls, CarerSupport, StayActive and Revolution

- sustains cooperative relationships with over 20 worldwide top universities and clinical institutions dealing with aging and related pathology.

Education activities:

- mostly linked to the *The Geriatrics, Gerontology and Old Age Psychiatry Chair of Carol Davila University of Medicine and Pharmacy from Bucharest*

- designs and implements integrated higher education and postgraduate training .

- Coordinator of the SOP-HRD project BRAINAGING ➔2800 Romanian physicians and 2600 medical assistants were trained in the field of Early Interventions in Brain Aging (between 2011 and 2013).

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AAIF – The Romanian Pilot Site of E-Health Platforms Evaluation and Validation

AAL projects

Confidence is based on clouding computing and aims to enhance the indoor-outdoor mobility of the dementia patient through:

* a personal assistant on the smart phone (services in the area of outdoor orientation and tracking, medication and appointments reminder, weather information, and security alarms with "just in time" help) ✚ a community web portal to facilitate the stakeholders action and interaction for assisting the dementia patient's needs www.salzburgresearch.at/en/projekt

MOBILE.OLD aims to develop a personal assistant service for seniors and their caregivers – a set of combined services provided on smart phone, tablet and TV multimodal and highly personalized, capable of supporting the crucial needs of seniors 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). www.mobiledotold.eu

StayActive focuses on developing a three step solution for detecting and managing the stress related symptoms in older adults working in an office or factory. The developed platform will provide services, such as: user context and activity recorder, stress patterns detection, biosensors monitoring (temperature, Hear Rate, Breath Rate, Galvanic Skin Response), blood indicators for determining high risk situations (*The Burnout Syndrome*) .

AAIF – The Romanian Pilot Site of E-Health Platforms Evaluation and Validation

AAL projects

Mobile Sage provides elderly people with context-sensitive, personalized and location-sensitive tools, in order to carry out and solve everyday tasks and problems in the self-serve society when and where they occur, "just-in-time". www.mobilesage.eu

Based on NFC tags and QR codes scanning, the **Mobile Sage personal assistant** installed on a smart phone and a clouding component can provide written, audio or video information for supporting senior's indoor mobility (clear user manuals for household appliances, weather and other info), and outdoor mobility (find my way, tracking and trip info – ATM or ticket machine way of use etc.)

CarerSupport
* aims the creation and operation of a sustainable pan-European ICT-based ecosystem for the training, orientation and support of informal carers
* to develop an ICT platform for carers and stakeholders, enabling the management of training and psychological support programmes including e-learning sessions, computer based training sessions and tele-consultation sessions.

REVOLUTION — Realtime Voluntary Occupation online
* is based on a new, very flexible way to plan and support help services brought to older adults on a voluntary basis;
* is focusing on simple and effective real-time scheduling of a short-term need for assistance in the context of driving services, shopping and help at home.

AAIF - founder member of European consensus ICT initiatives & EU AAL Joint Programmes

Stakeholders, virtual communities, networking

Name	Founding year	Theme	Website
AgeingWell	2012	* improving the life of older persons by promoting the market uptake of ICT solutions for Ageing Well; * a reference point for key stakeholders in the ICT & Ageing Sector	www.ict-ageingwell.net
LiveWell	2012	* a web-based tool for Parkinson patients, their caregivers and health professionals, with training contents, exercises and information packages; * a social community for Parkinson Patients, Caregivers and Health and Medical professionals	www.livewell-community.eu
Confidence	2011	* 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	www.salzburgresearch.at/en/ projekt/confidence_en
E-No Falls	2013	* a consensus on action plans, standards and specifications ensuring the widest future replication and co-deployment of innovative solutions; * brings together knowledge, experiences and best practices in the area of fall prevention, intervention and safety.	www.e-nofalls.eu
INNOVAGE CARERS	2013	*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.	www.innovage.group.shef.ac.uk

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Specific tasks accomplished by AAIF in AALs

Confidence
AAL 4
EU Joint programme
	Mobility Safeguarding Assistance Service with Community Functionality for People with Dementia
	• has founded the local community able to substantially contribute to the absorption on the market of the ICT-based solutions that can enhance the quality of life of the Mi-Mo-NCD persons and their caregivers
	• has elaborated the Clinical Evaluation Protocol of the Primary and Secondary End-Users
	• has elaborated the Ethical and Legislation manual and control instruments related to the field trials with human subjects, with Mild-to-Moderate NCD
		• has provided test persons and test sites for the Romanian pilot activities and trials
		• has shared its expertise of medical partner for
		   - the target group definition,
		   - the use-cases and scenarios definition,
		   - the services design, interfaces design and refinement,
		• has coordinated and run the local field trials with PEUs and SEUs
		• has run dissemination* activities and contribute to results exploitation
		   * presentations to local and international scientific events, scientific publications (in Slide 15), workshops with stakeholders and local mass-media

Mobile.Old AAL 4	Home and on-the-go services advancing the MOBility of OLDer Persons has elaborated the Ethical and Legislation manual and control instruments related to the field trials with human subjects, elderly with or without disabilities	
MobileSage AAL 3	Situated Adaptive Guidance for the Mobile Elderly has applied its expertise in issues related to testing and evaluation methods and user research ethics	

Assessment Battery for measuring the impact of new developed ICT services on end-users' psychological, cognitive, functional and behavioral state

The primary and secondary end-users training is essential to be done repetitively – the educational stereotypy:

- 2 meetings inside the clinical department: one group meeting and another individual meeting with each end-user and the medical instructor;
- 1 individual meeting at home with each end-user and the medical team (including voluntary students at medicine).

After a week of testing the platform with the end-users, each of the end-user will be clinically evaluated, following the below protocol.

The NCD diagnostic- the clinicians use DSM-V, ICD -10 and NINCDS-ADRDA   Criterias.

For detecting the people at risk (project target group), we use a battery of relevant cognitive and functional tests:*

MMSE - for cognitive evaluation; Clock Drawing Test, VF, Rey,'s F

GDS– to discern dementia severity;

GBS– for 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

Progression showed by the end-users at the end of the trials on new ICT platform testing will be described by:

- 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;
- specific questionnaires for behavioral issues on their social, psychological, physical and environmental wellbeing (such as WHO QoL) and engagement in their health management;
- caregiver's feedback (improvement of Zarit scale scores and questionnaire)
- a questionnaire addressed to the secondary and tertiary end users: health professionals, specific organizations of patients/caregivers, ICT providers or other stakeholders.

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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:
- the end-users recruitment and involvement,
- the informed consent as a standard procedure,
- the protocol of their participation in prototypes testing and validation,
- the precise information on how the end users can withdraw from the project at any time – the exit rights for individual end-users
- the possible compensations provided to them for participating (expenses or fees paid, etc.),
- the possibility to contact the project coordinator for ethical issues and related questions,
- the protection of personal data:
    - information and data management,
    - confidentiality of communications
    - the storage and transmission of personally identifiable information,
    - the 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.

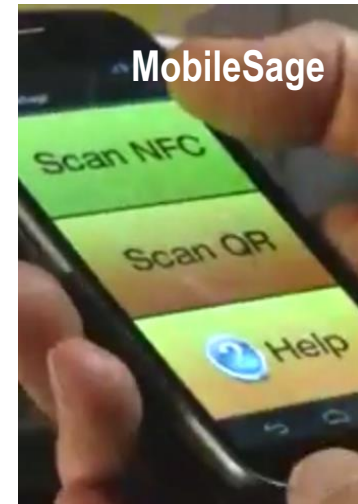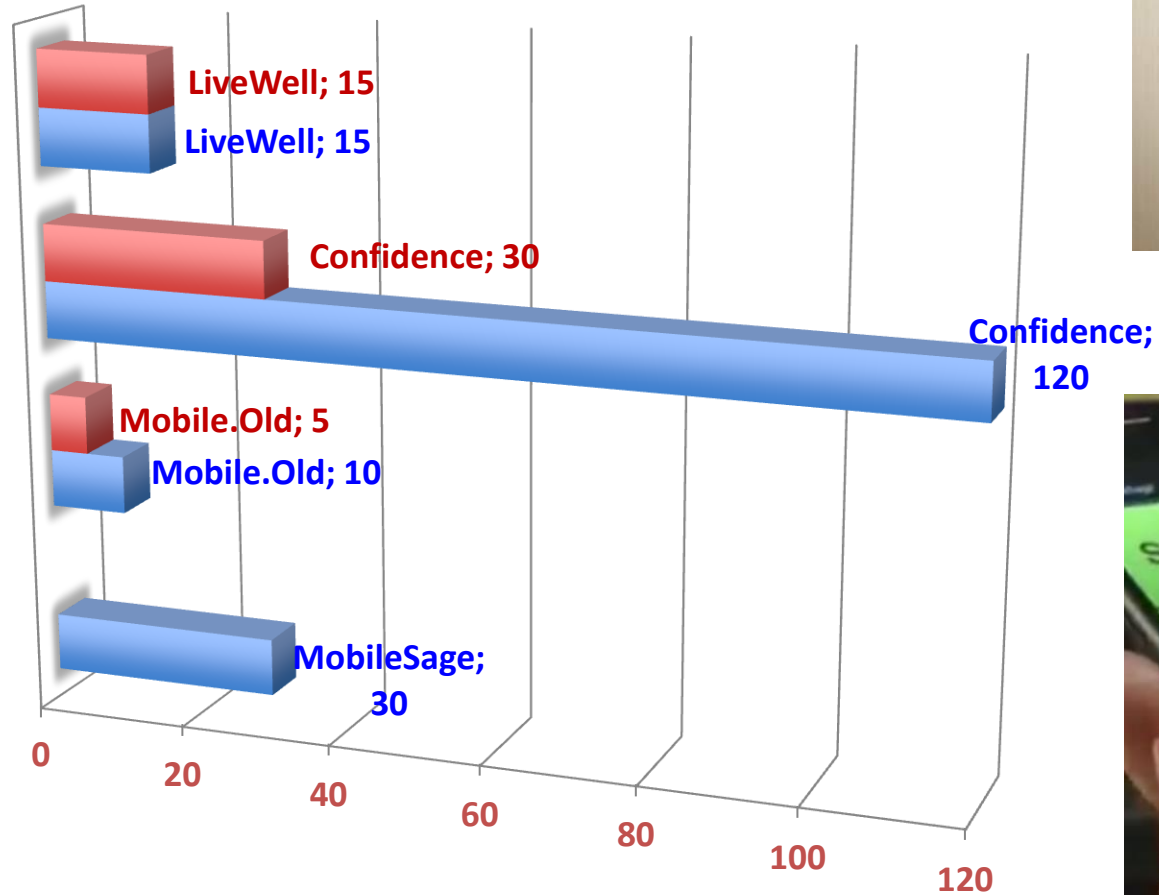# Platforms Evaluation and Validation at AAIF

Primary end-users

Target group	Project	Service(s)	End users amount in Romania	No of trials - Romanian pilot site	Status of the Trials in Romania	Other participant countries
People with **Parkinson Disease**	**LiveWell**	Web-based system with adaptative learning contents with interactive exercises + social learning	15	1	completed in 08.2014	UK, Portugal, Spain, Iceland, Slovenia
People suffering from **mild to moderate NCD**	**Confidence**	Professional portal with voice-video call for assistance and tracking services, SOS and HELP: calling/being; called; Find my way; Weather; Calendar + Community portal	120	4	completed in 2013 and 2014	Austria and Switzerland
Elderly users **with mild or moderate disabilities** (visual, motoric, dyslectics)	**MobileSage**	A smartphone app with help-on-demand service independence and mobility in the daily life, including in particular transportation and travel	30	3	completed in 2012 and 2013	Norway and Spain
Elderly users	**Mobile.Old**	"Mobile.Compass" "Mobile.News" "Mobile.Trip" "Mobile.Training" "Mobile.Activity" "Mobile.Aid" "Mobile.Security" "Mobile.Checklist" "Mobile.Insight" "Mobile.Quiz"	10	4	completed in 2013 and 2014	Austria, The Netherlands, Spain

Platforms Evaluation and Validation at AAIF

Secondary end-users

Target group	Project	Service(s)	End users amount in Romania	No of trials -Romanian pilot site	Status of the Trials in Romania	Other participant countries
Formal and informal caregivers	LiveWell	Web-based system with information packages and audiovisual contents + Social learning	9	1	completed in 2014	UK, Portugal, Spain, Iceland, Slovenia
Health professionals in Parkinson Dis.	LiveWell	The ability to remotely and continuously monitor the patient´s participation in the training activities and chat rooms + Social learning	6	1	completed in 2014	UK, Portugal, Spain, Iceland, Slovenia
Formal and informal caregivers + nurses	Confidence	Professional portal with voice-video call for assistance HELP: being; called; Calendar + Community portal	30	4	completed in 2013 and 2014	Austria and Switzerland
Formal and informal caregivers	Mobile.Old	"Mobile.Compass" "Mobile.News" "Mobile.Trip" "Mobile.Training" "Mobile.Activity" "Mobile.Aid" "Mobile.Security" "Mobile.Checklist" "Mobile.Insight" "Mobile.Quiz"	5	4	completed in 2013 and 2014	Austria, The Netherlands, Spain

No of **PEUs** and **SEUs** involved in testing session at AAIF & interfaces

LiveWell; 15
LiveWell; 15

Confidence; 30

Confidence; 120

Mobile.Old; 5
Mobile.Old; 10

MobileSage; 30

0   20   40   60   80   100   120

A researcher demonstrates the MobileSage app to a PEU

Almost all the old people in the end-users group proved interested in the Mobile.Old virtual companion

Testing the Mobile.Old app with PEUs and SEUs

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 :

for bundling	For the other six services
"Mobile.Compass" (prefered by 34 from the 73 end-users) "Mobile.News" (33), "Mobile.Trip"(32) "Mobile.Training"(31).	"Mobile.Activity"(28), "Mobile.Aid"(28), "Mobile.Security"(23), "Mobile.Checklist"(20), "Mobile.Insight"(20) "Mobile.Quiz"(12).

The MobileSage app:

There was a general agreement on the <u>high utility</u> 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.

Research and development work relating to assistive technology

2013-14

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.

Insert your travel card in the slot indicated,
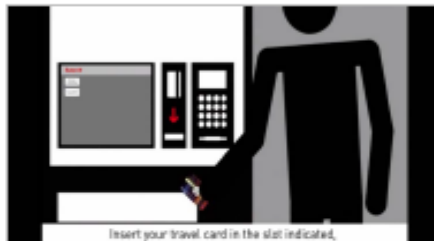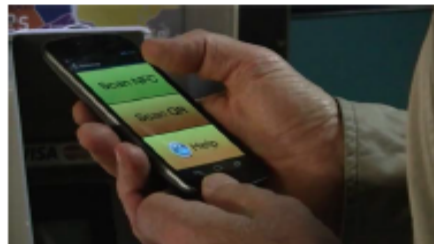
Scanning the barcode on a poster about an exhibition can enable the presentation of information on the show. Carers can also contribute help content that is personalised and locally relevant content for an individual.

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.

AAIF Publications & research papers on AAL

- Advanced technology services for supporting active seniors: The Mobile.Old project. L Spiru, I Karlhuber, I Turcu, N van der Vaart, S Schurz, JM Laperal, Med-e-Tel 2014 Proceedings (CD-ROM); Global Telemedicine and eHealth Updates: Knowledge Resources, Vol. 7, 2014. (in press)

- Smart technologies for seniors' mobility: The MobileSage project. L Spiru, I Solheim, I Turcu, J Rovira Simon, V Sanchez Martin, Med-e-Tel 2014 Proceedings (CD-ROM); Global Telemedicine and eHealth Updates: Knowledge Resources, Vol. 7, 2014. (in press)

- A user Centred approach to analyse user requirements for a system supporting people with Dementia. Schneider C, Willner V, Feichtenschlager M, Andrushevich A, Turcu I, Spiru L - In: Ammenwerth E, Hörbst A, Hayn D, Schreier G, eds. Proceedings of the eHealth2013. May 23-24; Vienna, Austria. OCG; 2013

- Collecting User Requirements for Electronic Assistance for People with Dementia; A Case Study in Three Countries. Schneider C, Willner V, Feichtenschlager M, Andrushevich A, Turcu I, Spiru L, In: Ammenwerth E, Hörbst A, Hayn D, Schreier G, eds. Proceedings of the eHealth2013. May 23-24; Vienna, Austria. OCG; 2013

- What Seniors Want in a Mobile Help-on-Demand Service. A user needs analysis in the MobileSage project; Dale O, Solheim I, Spiru L, Turcu I, Halbach T, Schulz T, [et al.]; eTELEMED 2013, The Fifth International Conference on eHealth, Telemedicine, and Social Medicine. (ISBN 978-1-61208-252-3). pp 96-101. 2013

- The ethical issues linked to the use of assistive technology in dementia care; Dianne Gove, Inger Hagen, Sirkkaliisa Heimonen, Stefánia Kapronczay, James and Maureen McKillop, Maria McManus, Alistair Niemeijer, Päivi Topo, Luiza Spiru, 2010. Alzheimer Europe Report: Luxembourg, 2010.

- 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, Iunie 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, Iunie 10-12th, 2009, Lecture Notes in Computer Science (LNCS), ISSN: 1867-8211, Springer Verlag, 2009

- E-Health and Assistive Technology (AT) as suitable answers to global aging; Luiza Spiru, Ileana Turcu, Ioana Ioancio, Roberta Annicchiarico, Ulises Cortes, David Riano; Alzheimer's & Dementia: The Journal of the Alzheimer's Association; ISSN: 1552-5260;Volume 5, Issue 4, Supplement , Page P241, July 2009;

- The Memory Impairment. Medical Ethics, L. Spiru-invited speaker, C. Ghita, I. Turcu, L. Stefan, 5th Romanian National Conference on Bioethics, Sovata, Romania. 2009.

- Intelligent ambiance for the cognitively and physically impaired elderly. The European model; Luiza Spiru, Ileana Turcu, Ioana Ioancio, Ulises Cortes; International Conference on Alzheimer's Disease, ICAD 2008, Chicago, Iulie 26-31, 2008; Alzheimer's & Dementia: The Journal of the Alzheimer's Association, ISSN: 1552-5260, Vol: 4, Issue: 4, Pages: T650-T650; Data: 2008-7

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Conclusions and Recommendations (1)

- in the field of the cognitive impaired persons and elderly assistance ➜ patients and caregivers empowerment and improvement of:

  - their mobility and quality of life (daily tasks accomplishment, help in critical situations, long-term remote monitoring)

  - their ability to respond in real time to situations upheld,

  - the interactive communication patient-caregiver-family-health professional,

  - the relationships within families,

  - the 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.

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Conclusions and Recommendations (2)

- To design as much as possible simplified algorithms on accessing various platform services ➔ 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, / well trained medical team

  are important prerequisites for the acceptance of a smart application by the seniors.

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Conclusions and Recommendations (3)

- integrated services based on t*he 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 ŧ improvement based on two, complementary components:

    - human assistance (with health and social professionals)

    - non-human, advanced technology-based assistance

    > the human-machine interaction

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

- New E-Health solutions may overcome constraints of national borders .
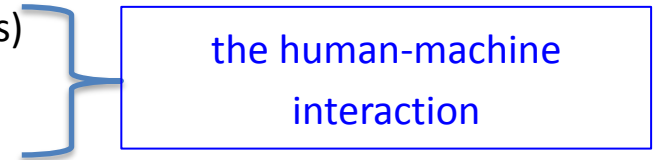
Thank you for attention.

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