

Salón de Actos. Edificio C Escuela Técnica Superior de Ingenieros de Telecomunicación (ETSIT) Avenida Complutense 30 UPM -Ciudad Universitaria s/n 28040 Madrid



#### Madrid, 17 January 2018 - 09.00-14.00 – Universidad Politécnica de Madrid

#### A workshop organised by the IN LIFE project consortium

On average people in Europe live longer than just one generation ago. The challenge for Europe is to make sure that older adults live those additional years in the best possible condition. For most of them, this means living in own homes or at least in community settings, supported on an "as needs"-basis by informal and formal caregivers. If introduced appropriately in real life, technology can be a precious ally in making the life experience while ageing of higher quality compared to a situation without technology: more independent, safer, socially connected and with better and sustainable integrated care. This

holds true in particular for persons with mild cognitive impairment and initial stage dementia. The IN LIFE project has developed strategies and tools in different areas of independence for older adults with mild cognitive impairment and different stages of dementia. The project has aimed to prolong and support their independent living through interoperable, open, personalised and seamless ICT solutions that support

home activities, communication, health maintenance, travel, mobility and socialisation tasks. In this workshop, the Consortium will present the results and discuss the outcomes of the project with representative stakeholders: older adults, informal caregivers, service providers, clinicians, industry, policy makers and researchers. Demos of the developed systems and services will be available.

#### Final programme

- 8.30 Registration desk open
- 9.00 Welcome and Opening Luis Salgado (ETSIT -UPM Vice-dean Internat. Relations & Corporate Partnership) & Katerina Mavrou (President-elect Association for the Advancement of Assistive Technology in Europe)
- 9.30 The challenges of integrated care for older adults *Leo Lewis (AAATE & Integrated Care Foundation)*
- 9.50 The IN LIFE approach Maria Fernanda Cabrera (UPM project co-ordinator)
- 10.20 Examples of IN LIFE technologies and services and their piloting

Organisation: Universidad Politécnica de Madrid, CRTM & AAATE

- The IN LIFE Application Centre and the Matchmaker. Nikolaos Kaklanis & Stefanos Stavrotheodoros (CERTH/ITI)
- Combining tools and technologies for assessing elderly drivers Mary Panou (CERTH/HIT)
- Easing the use of technology for daily living: Daily Function Assistant Miguel Páramo (UPM)
- Intelligent Assistant Carer for Active Ageing: Fall detection & eDoorman Jani Bizjak (Jozef Stefan Institute)
- 11.20 Break
- 11.50 End user involvement: IN LIFE lessons learned Arlene Astell (University of Reading)
- 12.05 Exploitation and business models: IN LIFE lessons learned Paul Davis (Dublin City University)
- 12.20 "Challenges for the advancement of eHealth "-panel session with Peter Cudd (University of Sheffield), Jon Arambarri Basanez (Virtualware), Francisco Lupiáñez-Villanueva (Open Evidence), Christian Galinski (Infoterm), Maite Ferrando (ProACT Consortium). Moderater: Evert-Jan Hoogerwerf (AAATE)
- 13.00 Visit to demo set ups
- 14.00 End of workshop

#### Registration is required: please click here

The official language of the workshop is English, but translation into Spanish is provided. Programme updates will be regularly posted on the project website <u>http://www.inlife-project.eu/</u>





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# Ageing better IN real LIFE – <u>Summary report</u> from the 2<sup>nd</sup> IN LIFE workshop, discussing technology enabled strategies and tools for supporting older adults living in the community

On 17 January 2018, 60 European health professionals, researchers, physicians and members of the IN LIFE project consortium came together in Madrid, to look at results and conclusions from the 3 year IN LIFE project. The participants were then invited to brainstorm about putting the developed products and services into practice as well as think about how to concretely make use of the gained insights: who to tell, what to share and when to do so.

**María Fernanda Cabrera-Umpiérrez** kicked off the workshop with a few words about the essence of the IN LIFE project: how technology can support the ageing population, in particular those facing onsets of dementia. She was followed by **Luis Salgado**, Vice-Dean for International Relations and Corporate Partnership at the Universidad Politécnica de Madrid, who kindly hosted the workshop, and **Katerina Mavrou**, president elect of AAATE, co-organising the workshop, who both welcomed the audience and speakers and highlighted the importance of the project for their organisations.

**Leo Lewis**, senior fellow at the Integrated Care Foundation, then guided the audience into the core discussions by outlaying the lessons learned so far in regards to integrated care for older adults. She started off, with a very much needed definition of what is understand under the term "integrated care". In Leo's words, integrated care is above all person-centered and builds on a person's:



Dementia is a complex condition which combines features of chronic neurological disease, mental illness and physical frailty. Integrated care aims at "integrating" and coordinating the different aspects of formal/informal care and treatment that people with dementia receive from a range of health and social care services.





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This is in line with the definition by WHO, which says: "Integrated people-centred health services means putting the comprehensive needs of people and communities, not only diseases, at the centre of health systems, and empowering people to have a more active role in their own health."

Leo Lewis summarized her experiences with trying to introduce this new concept of integrated care over the past years, in the following stepping stones:

- find a common cause with all stakeholders and develop a shared narrative, building on the local environment and reflecting people's specific needs;
- show stakeholders what is in it for them and why they should want to co-design and co-deliver integrated care;
- one size does not fit all and the introduction of integrated care needs to follow discovery and learning rather than a pre-defined design;
- bottom-up alignment and top-down support are primordial;
- try to understand how dementia impacts on physical, emotional and psychological wellbeing, then
  invest in supporting and empowering people to look after themselves with appropriate digital tools
  and information sharing;
- learn about the availability of help, applicability of digital health solutions, and where to go for more information.

Sometimes, Lewis said, the move towards integrated care can come out of a crisis, like the closing down of a care center. The need to find alternative solutions can be a powerful push towards introducing a novel concept and the great benefit of integrated care is that it wants to enable people with dementia and other chronic conditions to live longer in their own homes.

For this to work, we need to increase the support for self-management and this is where digital health solutions can help to delay deterioration, maintain health and wellbeing and enhance coping. "We have the luxury of now being able to introduce ICT and digital health solutions in early stages of dementia which can make them more meaningful to the older users, but we also need to be realistic about who can and wants to accept these technologies", she said. For one, we have a whole range of solutions on the different levels of our health and care systems – some involve the individual and their families, some are system oriented. Indeed, we often do not see the penetration of ICT solutions that could be expected based on their potential, because healthcare professionals cannot adopt different systems targeted to different population segments.

Secondly, we should be realistic about who we target with digital health solutions. Right now, it might be better to focus on the age group of around 75 year olds, rather than the very old population. And then of course, all the technology used on individual level needs to be personalized, tailored to the specific needs and wants of the person supposed to be using it.

Many mistakes are made in projects around health and care systems because they are based on the notion that the systems are set in stone. However, if we want to cater appropriately to the needs of our ageing populations, we will need to be iterative and change direction when and wherever necessary. This includes





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reconfiguring workforce roles in the social and health care sectors, stimulated by information sharing via ICT tools, like for example the transfer of simple diagnostics and tests from the hospitals to the community.



We have many different levels of integrated care and many different digital health solutions, but what we are missing is the glue, the connection that brings it all together - Leo Lewis, Integrated Care Foundation

Integrated care is a journey and everyone who thinks that it can be achieved in 12 months or shorter is fooling themselves. Integrated care can only work if it is planned long-term and when we learn and adjust simultaneously in all aspects. Finally, we need to move away from considering integrated care only for older people with complex health and social care needs. As citizens, we should all experience care that is integrated. Lewis pointed out that most barriers to wider technology uptake in care are not of financial or technological nature but relate to human issues.

Following this train of thought, the IN LIFE project looked at what users need in terms of specific support in specific situations, then identified and employed appropriate ICT tools. Therefore, after setting the stage with some numbers and statistics, **María Fernanda Cabrera Umpiérrez** from the Universidad Politécnica de Madrid (UPM) and coordinator of the IN LIFE project, outlined concrete examples of how older individuals with mild cognitive impairment can interact with technology and ICT solutions.

The challenge is evident: we have to cater for an increasing ageing population, with predictions of 151 million of people aged 65+ in Europe alone by 2060 (as compared to 81 million aged 65+ in 2008). Combined with the fact that dementia mainly affects older people and that there are, according to the World Alzheimer Report 2015, 9.9 million new cases of dementia registered each year worldwide. In addition, our social and healthcare systems are under economic strain and we see a reduction of personnel in this field as well as fewer specialists.

Technology will not be the miracle solution, but it can help and provide support. IN LIFE in particular aimed at prolonging and supporting the independent living of seniors with cognitive impairments, through interoperable, open, personalized and seamless ICT solutions that support home activities, communication,





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health maintenance, travel, mobility and socialization tasks, with novel, scalable and viable business models, based on feedback from large-scale and multi-country pilot applications.

In practice, this turned into some of the following use cases:

- Supporting home activities: Patricia, 77 years old, who lived with her husband Mario, 80 years old, in Madrid, noticed that her memory started to fail in activities of daily living (ADL). Advised by her doctor, she registered on the IN LIFE platform and started using a mental training tool. This tool comprised cognitive exercises and games, based on the frequent ADL functions that Patricia needed to remember.
- Supporting health maintenance: Carol, 82 years old, lived alone at home. She stayed seated for long periods, while watching TV for example. Her doctor advised her to do some exercises to remain physically fit, but due to her mild cognitive impairment, she often didn't remember which exercises she was supposed to do. Registering on the IN LIFE platform, she got access to the Physical Exercise application which showed her in short videos what to do.
- Supporting socialization and communication: Jose was 69 years old and in the first stages of dementia. He lived with his wife, Maria, 65 years old, in their own home. Maria was worried about the progression of Jose's dementia and wanted to help him. She found on the IN LIFE platform a tool to train Jose's communication skills. The tool was a virtual game, providing stimulation to carry out cognitive related tasks based on the opportunities of neural development. Jose's task was to name the objects in the pictures, training his verbal comprehension and production.
- Supporting the care givers: John, 37 years old, worked in a senior residence, attending people with different degrees of cognitive impairments. He used the reminder and scheduling app on the IN LIFE platform which supported him in sorting the treatment for his patients.



One of the most interesting aspects of the #INLIFE project are the large pilots implemented in six European countries with almost 2000 participants, Maria Fernanda Cabrera (project co-ordinator) at IN LIFE workshop in Madrid.





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While Maria's presentation focused on the users and how appropriate ICT tools were found to respond to their specific needs, the four following speakers explained in detail how the these tools were developed and deployed.

**Stefanos Stavrotheodoros** from the Greek Centre for Research and Technology (CERTH) explained the background and workings of the IN LIFE Application Centre and the Matchmaker tool.

The underlying concept for the IN LIFE Application Centre is the recognition that cognitively impaired elderly people have various needs that can be summarized as 1) need for general and personalized information, 2) need for support with regard to cognitive decline symptoms, 3) need for social contact and company, and 4) need for health monitoring and perceived safety. The main purpose of the IN LIFE platform is to monitor user activities and preferences in an unobtrusive way, to support elderly people with cognitive impairments in a variety of indoor and outdoor activities by providing easy and personalized access to the IN LIFE services and applications, to support care givers and to allow service and application providers to register their services or products on the IN LIFE platform so that users get access to these additional offerings in a transparent way.



Caregivers can monitor their connected elderly patients via the IN LIFE platform, are informed about alerts and can use the offered AAL solutions with their patients - Stefanos Stavrotheodoros of @HitCerth

Important components of the IN LIFE platform are the Matchmaker and the Application Centre. The Matchmaker provides personalized services to the elderly end-users based on their user profile and also serves to resolve emergency cases, in case someone has fallen for example. The Matchmaker combines rule-based and statistical outcomes and gives the user recommendations in terms of the most proper set of services to be used, in case there is an alarm notification that indicates an emergency for the user, or the most suitable tools for the user to be displayed when he/she accesses the IN LIFE platform.

Depending on what kind of role the user has in the system – whether he/she is an elderly person, a care giver, a service provider etc., and based on the user profile which gives an indication about the person's health,





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mental and activity status, the user will see different tools and services displayed when logging onto the platform.

The statistical component of the Matchmaker serves to improve the usefulness and accuracy of recommendations through the creation of likeminded users, whereas the users are filtered based on their usage of tools and their demographic data, including socio-economic status, country, education level, etc. The Application Centre then is the main interface of the IN LIFE platform through which both elderly users with cognitive impairment as well as care givers can access the AAL services registered in the IN LIFE platform, connect with other users and browse additional services and applications by third party providers. Additionally, the Application Centre offers a personalized dashboard with an accessible and user-friendly interface, alarm notifications, and is available in 9 languages.

One of the tools available via the IN LIFE platform – a driving assessment tool – was presented by **Mary Panou**, also from the Greek Centre for Research and Technology CERTH. Science shows that driving is an important aspect in independent living. The care giver or clinician can use the tool to assess the driving capability of the elderly and the system informs the user whether he/she is still capable of driving and/or if he/she needs driving aids (additional mirrors etc.).

The assessment is done via initial questionnaires, a neuropsychological assessment and a road test. This has an advantage over the standard driving capability tests that follow a purely clinical approach and generally focus on visual acuity only, however are not able to recognize cognitive decline which can be linked to the driving problems. It also allows to take into account the greater experience of elderly drivers which often enables them to compensate their deficits.

In her presentation, Mary made the case that fitness to drive should be viewed as a public health related issue rather than merely a road safety issue. Car driving is synonymous to independence and an active life in our society and the car assessment tool developed in the context of the IN LIFE project promotes the right to mobility.



Driving is an important aspect of independence, hence another ICT tool developed and deployed in the IN LFIE project: a driving assessment system - presented by Mary Panou of @HitCerth





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In the following, **Miguel Paramo Castrillo**, from the technical university of Madrid (UPM), presented the Daily Function Assistant by relating Maria's story. Maria was 72 years old and living in a senior center. She started to perceive small changes in her visual, motor, communicative and cognitive capabilities. She always thought that technology was hard to use but wanted to keep in touch with her family, feel safe, and have support in her daily routines.

The Daily Function Assistant supported her with phone and call management, alternative and augmentative communication, the handling of house appliances, media control, voice mail box and reminders. NFC tags were recorded with the smartphone and triggered actions from the user when they were scanned. The NFC tags can be attached to any object in the user's environment.



The Daily Function Assistant supports users like 72 year old Maria with phone & call management, AAC, house appliances, media control, voice mail box and reminders - Miguel Paramo Castrillo.

The use and test of the Daily Function Assistant with users like Maria showed that some tasks can be atomized, the app is easy to use and there are no security issues. However, people with mild cognitive impairment need a variety of training on how to use the technology.

**Jani Bizjak** from the Slovenian Josef Stefan Institute continued by sharing their experience with introducing a fall detection and eDoorman service. They worked with 150 in nursing and sheltered homes to which they distributed Smart watches that worked as fall detection systems. Their pilot rollout showed that the first week was crucial for the adoption of the technology – if the watch was carried consistently in the first week, it was continued to be carried later on, otherwise it often ended up unused in a drawer.

Users overall felt safer when using the Smart watch and felt that their independence improved. One user even dared taking up bike rides again since he felt safe that the watch would alert someone for help should he fall. Occasional false alarms were not considered an issue. On the contrary, they reassured the users that the system worked. Complaints centered around the ergonomics of the watch, battery life, the fact that it was not waterproof in its first edition...





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Interesting side-effect: families of elderly users testing the Smart watch and fall detection system wanted to also use the system for their children or when going mountain climbing for example – Jani Bizjak from the Slovenian Josef Stefan Institute

Another application developed in combination with the fall detection system on the Smart watch was the eDoorman, a virtual doorman monitoring the entries to and exits from the house and alerting the user if he/she left the house without their Smart watch. However, users found the interaction with the eDoorman via touchscreen on a tablet difficult and also experienced the system as akin to "Big Brother".

Pulling together the experiences from the six pilot sites on which the IN LIFE services and technologies were tested with over 1,100 patients with mild cognitive impairment and/or early onset of dementia, around 740 formal and informal caregivers as well as 26 other stakeholders, **Arlene Astell** from the University of Reading presented a synthesis of the lessons learned.

First of all, it is important to see the users of technology as the experts – what is important to them? How do they want to find out about technology and access it? What influences their decisions about technology and whether to accept or reject it? What training and support do they require? We cannot expect to successfully introduce technology and see it used if we do not answer these questions first.

The test of the 19 IN LIFE services, providing support for independent living, travel, socialization and communication, as well as support to caregivers, brought to light a few common issues:

- overall, much more training was needed for both professionals and end users as initially expected
- there was a need for one-to-one training and constant support
- re-training has to be factored in when software companies rollout updates that change the user interface
- the basic infrastructure was often not given, with glitchy Wi-Fi and lacking computer literacy of older adults, staff and informal caregivers
- the consent process of the older persons with mild cognitive impairment as well as the formal evaluations of the technologies tested through the users was difficult
- some complaints from users centered around the size of screens and usability of devices





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It also made a difference if the use of the app or service was recommended in a hospital setting or a care home where the users were more familiar with the staff, or if family recommended the use of it.



The way we bring technology into the hands of elderly users is crucial for how and if it will be adopted. Nobody wants to feel stupid, so the training needs to be easy and smooth - Arlene Astell, @Positive\_Ageing

In terms of how to put insights from a project like IN LIFE into practice, **Paul Davis** from the Dublin City University, shared some key lessons. There are two kinds of deliverables that can come of such a project: the project outcome and the exploitation that comes afterwards. Not everyone targets a commercialization of the results in the end. Very often, project participants are only interested in the research and results that will support advancements in the subject area. However, if you want a business plan and a concrete roadmap on how to commercially use the results, this needs to be planned for and factored in from the very beginning of the project.

Important to consider in this context is that all the training on the pilot sites, the data gathered, the processes developed to rollout the technology to the pilot users.... all that is intellectual property and needs to be treated as such!





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In complex projects like INLIFE, we hardly talk about IP, we hardly think about recording it because we are focused on the research outcome. But that makes it difficult to commercialize afterwards. Beware of where you create intellectual property! Paul Davis from @DublinCityUni

Finally, Evert-Jan Hoogerwerf, new Secretary General of AAATE, chaired an expert panel to discuss the challenges for eHealth.



Challenges for eHealth – panel session with Jon Arambarri Basanez (Virtualware), Christian Galinski (Infoterm), Peter Cudd (University of Sheffield), Evert-Jan Hoogerwerf (AAATE), Maite Ferrando (ProACT), Francisco Lupiáñez-Villanueva (Open Evidence).

IN LIFE is a case in point for the need to involve users in the conception and planning of eHealth and digital health solutions. And yet, a lot of research is done without user involvement.

One difficulty is of course that it needs a very sizable user group to get information on what user groups really want and need. The paradigm in the tech sector has been and still is that you only need 5 people to test for usability. However, if the target audience is the old to very old population, this approach might fail. Yes, if we





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want to create appropriate solutions that users will accept and put into practice, their involvement is absolute key, **Peter Cudd** of the University of Sheffield insisted.

Experience in the IN LIFE project confirmed that a wide consultation of stakeholders and end users is crucial to the successful rollout of technology, also because the direct feedback can be fed back to the companies and help refine and improve the deployed software solutions, as mentioned by **Jon Arambarri Basanez** from Virtualware, who developed some of the gaming solutions to train elderly users and help prevent or delay further cognitive deterioration. IN LIFE consortium members looked at what was already published in the area of eHealth and digital health solutions and then involved end users from the very start.

In general however, we need to be careful about the story we tell to convince healthcare providers, formal and informal carers to use ICT solutions, warned **Francisco Lupiáñez-Villanueva** from Open Evidence. We need to avoid exaggerated economics and any pretense that technology can replace human care. Also, there are huge gaps between what some reports promise in terms of market and saving potential, and what reality will be able to offer. Solutions need to be designed within the constraints of our systems and we need to keep in mind that in many cases the "users" we need to target for adopting these solutions are the formal and informal caregivers, not forcibly the elderly end user. And in all these proposals, we need of course constantly prove the cost-effectiveness of the proposed solutions.

There are lot of elements that can motivate individuals to adopt or reject proposed ICT solutions, was pointed out by **Maite Ferrando**, who works on a transferability study of digital solutions in integrated care in the framework of the ProACT project. Cultural issues, individual motivation, appropriateness of technology, economic sustainability, interoperability and many more factors can be decisive for participation.

The integration and interoperability of any service or technology that is intended for large-scale rollout has to rely on standards, continued **Christian Galinski** from InfoTerm. Two of the deliverables of the IN LIFE project were therefore an overview of all currently relevant standards and *Recommendation 2016 concerning standards on eAccessibility and eInclusion*<sup>1</sup>.

If public healthcare providers should pay for ICT solutions, there will need to be some sort of certification, participants from the audience pointed out. Healthcare professionals want guidance on what ICT solutions to recommend to their patients. However, it will not be possible to have all eHealth apps certified, came the reply from the panel. Healthcare professionals will have to try and test ICT solutions, everyone contributing to building evidence on what works and what does not work.

The workshop concluded with the showcase of several of the services and apps developed and tested in the IN LIFE project.

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<sup>&</sup>lt;sup>1</sup> http://aaate.net/recommendation-2016-concerning-standards-on-eaccessibility-and-einclusion/



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Consortium members are happy with the results of the IN LIFE project: a good number of scientific publications, standards recommendations and plans for a commercial implementation of the IN LIFE platform. End-of-project factsheets summarizing the key findings for healthcare providers, researchers, policy makers, industry and patient organizations will soon be published.

