# ALADDIN: A home care system for the efficient monitoring of elderly people with dementia

## Speaker: Dr. Maria Haritou, session A2

Maria Haritou[1], Silke Cuno[2], Yuri Glickman[2], Aggelos Androulidakis[1], Andrej Baboshin[2]

[1]*Institute of Communication and Computer Systems, 9 Heroon Polytechniou str., 15773 Athens, Greece, Tel: +30 210 7723893, Fax: +30 210 7722431, Email: {mhari | androu}@biomed.ntua.gr*
[2]*Fraunhofer FOKUS, Kaiserin-Augusta-Allee 31, 10589 Berlin, Germany, Tel: +49 30 3463 7201, Fax: +49 30 3463 8000, Email: {silke.cuno | yury.glikman | andrej.baboshin}@fokus.fraunhofer.de*

**Abstract:** ALADDIN's objective is to develop a trustworthy and reliable system supporting patients with dementia and their informal carers in the management of the disease from home. Based on a set of monitoring parameters and measuring scales feeding the risk assessment component, the system aims to early detect symptoms that predict decline, avoid emergencies and secondary effects and, ultimately, prolong the period that patients can remain safely cared at home. Informal carers are also closely monitored by the system whereas additional features supporting networking, education and cognitive stimulation are also integrated along with decision support and patient management tools for the treating clinicians. The platform has been built based on credible methodologies for efficient patient follow-up, risk detection and adaptive care. It is an open, secure, interoperable, integrated IT-solution designed according to Service Oriented Architecture principles. The system has been developed in the framework of the ALADDIN project funded by the AAL Joint Programme and is currently evaluated through a pilot operation conducted in three AAL member states. This article reflects the presentation of ALADDIN system in the context of the A2 session of the AAL Forum 2011 in Lecce.

## 1. Introduction: Dementia - a leading cause of concern in the ageing society

A specific area of interest as regards chronic diseases is the one of patients with cognitive impairments and mental disorders, which draws increasing attention as the society gradually ages. Dementia is one of the leading causes of concern in the elderly. It comprises one of the most debilitating and stressful conditions that the patients and their carers can experience, manifesting itself through memory loss, impaired cognition, behavioural problems, loss of orientation in time and space, motor deficiency and at later stages even delusions, hallucinations, sleep disturbances and aggressive behaviour. On the personal level dementia reduces quality of life and independent living. On the socioeconomic level, it is one of the major causes of costs' increase in health care for the elderly population, with severely demented patients requiring constant supervision and medical care [1, 2]. People with dementia live in different types of care settings depending on the level of care they need (assisted living, day-centres, residential units). It is estimated that 40% of people with dementia reside in long-term care (institutional settings), whereas the largest proportion of the patients (60%) are living in the community, supported by carers or living alone. The role of the main carer is often assumed by an equally elderly spouse or another close relative. In turn, carers of demented people may themselves suffer from stress, over-work, depression, and be also physically hit.

Experts estimate that 35.6 million people worldwide suffered from Alzheimer's Disease (AD) alone in 2010, with the numbers nearly doubling every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 [3]. The World Health Organisation estimates that globally, the total Disability Adjusted Life Years (DALY) for AD and other dementias exceeded eleven million in 2005, with a projected 3.4% annual increase and accounting for 4.1% of total disease burden (DALY) among people aged 60 years and over, 11.3% of years lived with disability and 0.9% of years of life lost. According to a recent study by the European Commission regarding the state of Dementia in Europe, there are now more than 6 million people with dementia in the EU. In some countries, support from the State for people with dementia and carers (e.g. in the form of services, allowances and care structures) is quite well developed whereas in others, it is virtually inexistent [4, 5]. While there are many positive aspects of caring, carers of people with dementia are very likely to experience strain –significantly more than the strain manifested in other carer groups. It is reported that 40-75% of the carers develop significant psychological illnesses, and

15-32% of them are clinically diagnosed with major depression. There may also be physical health consequences -strained carers have impaired immunity and a higher mortality rate. Moreover, informal carers experience increased rates of absenteeism from work and also carry increased costs associated to the patient's care.

Reflecting the importance of the demographic change and its consequences on the quality of life of the citizens, European governments intensively promote and finance research and development of successful concepts and technologies, which allow older people to lead an independent and responsible life for as long as possible - to strengthen the dignity and quality of life in their central living space: their own home. Home and family environments move in the centre of attention. To attain the goals, the homes have to be remodelled and equipped so that older people can cope with their daily lives in their familiar environment even if they are already dependent on additional support or care. The key to this is seen in age-appropriate assistive systems like AAL, based on modern, unobtrusive micro systems and advanced information and communication technologies. In this respect, a significant number of ICT-enabled systems and services, computational models, micro and nano sensors and devices, sensor networks with advanced processing capabilities, smart home implementations and many others have been developed and put forward to achieve the goal of prolonging the time that older people can remain self-managing at their own homes. However, in the specific case of older people suffering from dementia which is known to impose significant burden to the informal carers involved, it is important that the technological solutions proposed must take into account and provide for the well being of the carers as well. Therefore, apart from monitoring and assistive technologies, the elaboration of a novel care methodology is required for the home management of dementia, allowing for both, the delayed institutionalisation of the patients and the close monitoring and support of the informal carers in order to preserve their quality of life and relief their distress.

In the above complex context the objective of the ALADDIN-project [6] was to create a technology platform and a novel care methodology allowing for remote health and physical monitoring, cognitive and behavioural assessment, early detection of symptoms that predict decline, personalised care delivery and individualised treatment planning along with multi-level support services to all the actors involved in the caring of patients suffering from dementia.

The platform supports carers, patients, clinicians and other service providers in efficiently planning, managing and monitoring the patients' and carers' health status, primarily to avoid emergencies and secondary effects caused by a cognitive, psychological or behavioural decline of the patient, and secondarily to relieve the stress experienced by the carer so that the Quality of Life of both can be maintained and optimally supported. The term Quality of Life (QoL) is used to evaluate the general well-being of individuals and societies and it arose lately to a research topic of its own. Research units around it were built up and conceptual frameworks worked out, developing, evaluating and applying QoL measures within health related research, some of which are integrated also in the ALADDIN platform.

## 2. ALADDIN monitoring and supporting services

In conventional clinical practice the diagnosis of dementia and the assessment of disease progression are mainly based on a multitasking clinical approach including as first line the conductance of neuropsychological tests, with the Mini-Mental State Examination (MMSE) [7] being the most widely adopted. In the MMSE test, scores range from 0 to 30, with scores less than 24 typically associated with dementia. Other tests have also been developed enriching the clinician's arsenal in their diagnostic work and several scales are also largely used in clinical practice laterally to the MMSE, providing additional or supplementary assessment capabilities. The most frequently used of these neuropsychological assessment scales are the Memory and Behaviour Problem Checklist (MBPC) [8] and the Clinical Dementia Rating Scale (CDR) [9, 10].

In the ALADDIN monitoring system, a sub-set of questions from each one of these tests has been selected for integration into the ALADDIN patient questionnaire which, in its complete form, comprises of 32 questions –one of them is illustrated in figure 1. The questions are organised in clusters aiming to provide multiple-context patient assessment as regards (a) temporal and spatial orientation, (b) Psychiatric and Behavioural Symptoms (PBS) - further organised in

Cognition, Aggressiveness and Mood clusters - and (c) functional capacity in performing daily life tasks. Additionally to the above, there are also questions related to the drug therapy administered, the use of conventional healthcare resources (emergency calls or visits, contacts with the doctors, nursing staff, social workers, etc) and finally there is also a free-text option, allowing the carer to express any other concern that worries them with regard to their relative. Each question integrated in the test is associated to a specific numeric value depending on the answer given. In this way, scores are registered both at the level of individual questions, as well as at the level of clusters and of course of the whole questionnaire.
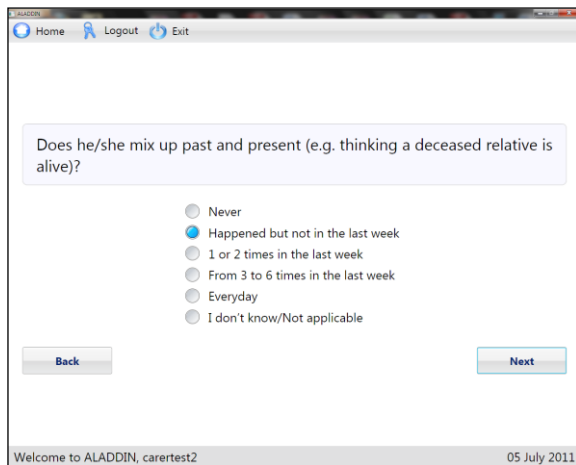


Figure 1: Example of how a question is displayed and answered through the ALADDIN software. This is the first question of the cognition cluster of the patients' questionnaire.
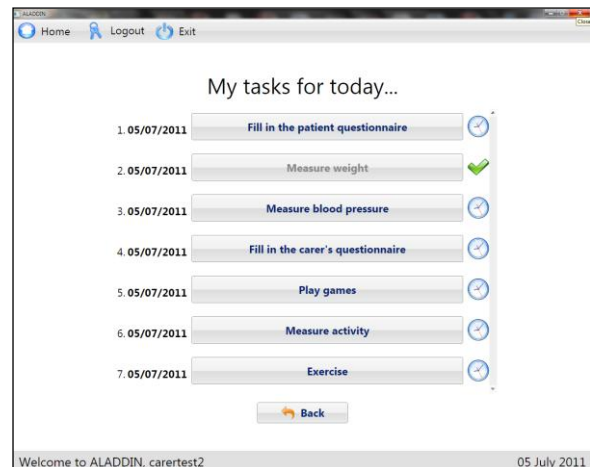
Figure 2: The list of tasks for today to be performed by the carer/patient in the ALADDIN application. In this example the task "Measure weight" is completed. Others are waiting to be performed.

Apart from the neuropsychological assessment questionnaire, the patient, either alone or assisted by the carer, performs some additional simple measurements of two physiological parameters of interest, namely blood pressure and body weight, and feeds the system with the measured values. Finally, an actigraphic device in the form of a wrist-band is worn by the patient throughout the day, providing indices of their activity levels during day and night and therefore some indications of anxiety, insomnia, apraxia etc, which can be estimated by this type of monitoring. The frequency of the controls is defined by the doctor, according to the specific needs of each individual patient. The clinician can also easily add or remove questions from the patient questionnaire, making individualised assessment tests tailored to the specific patient profile.

The scores registered by filling out the patient questionnaire along with the values of the other monitored parameters, are stored by the system and fed into the risk assessment and analysis component (RAAC) [11], which processes the specific patient recording against a set of pre-defined rules and thresholds set for the specific patient at the beginning of the systems' use. In case there are persistent deviations of the collected data compared to the ones obtained in previous patient recordings, an automatic warning is generated and stored, together with the patient's specific recording, triggering an evaluation from the treating clinician and a subsequent corrective action or medical intervention if necessary.

Similarly to the patient, a carer questionnaire has also been implemented and integrated into the ALADDIN system, comprising of 40 questions representing (a) the Zarit Burden Interview [12] for the assessment of work load, (b) a subset of the MMSE for mental status assessment and (c) the Quality of Life measuring scale [13]. Again, the frequency of filling out the carer questionnaire is defined and can be customised by the doctor. The list of tasks assigned to the patient and carer by their doctor is shown in Figure 2.

Apart from the purely medical monitoring that comprises the core of ALADDIN platform, a number of additional features in the form of external services have also been linked and integrated into the system, providing means for networking, education, as well as cognitive and physical exercising. Through these functionalities, patients and carers can access their personal discussion forums, allowing them to exchange and share their concerns and ideas with their

counterparts, away the one from the other. They can also access educational material and other relevant information selected by the clinicians, or they can engage in executing a cognitive stimulation exercise or physical exercise assigned to them by their doctor for the specific day. Figure 3 shows the home page of the patient/carer application through which they can access the different system features.
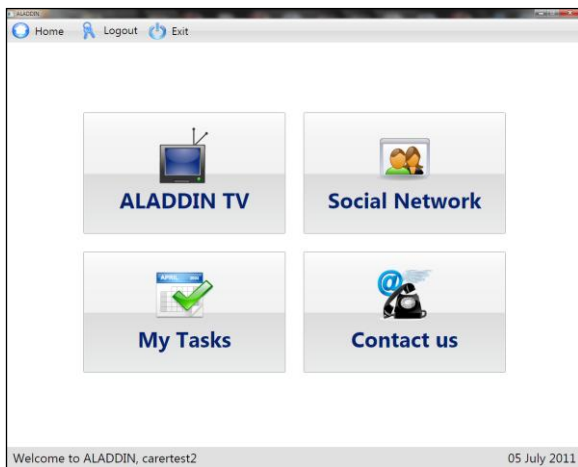


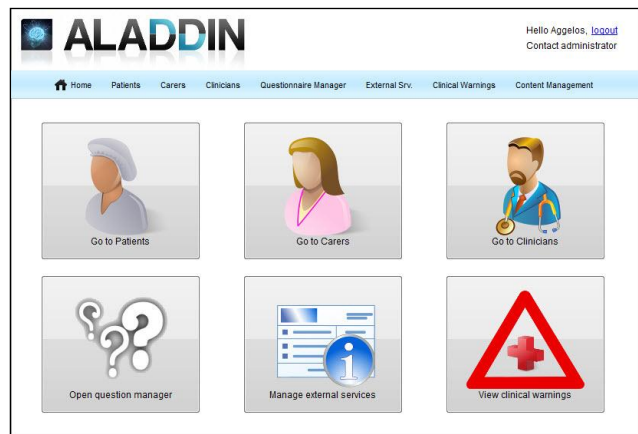Figure 3: The main menu of the ALADDIN application.



Figure 4: The ALADDIN portal for clinicians

In summary, the control parameters integrated in the platform are:

- Evaluation of the quality of sleep and physical activity of the patient
- Evaluation of general health aspects and the nutritional state of the patient
- Monitoring of the patient's cognitive functions and provision of cognitive stimulation exercises
- Detection and control of psychiatric and behavioural symptoms (PBS) of the patient
- Monitoring performance in daily physical and social activities of the patient
- Control of side effects and adherence to pharmacological treatment of the patient
- Registering the use of resources by the patient or the carer
- Control and monitoring of the carer workload
- Monitoring of the quality of life of the carer
- Monitoring of the mental health of the carer

The infrastructure that is required to be installed at the patient's home in order to operate the system consists of the following parts: 1) A blood pressure meter, a weighting scale and a wearable actigraphic sensor, 2) a tablet PC with the ALADDIN software for: (a) administering the neuropsychological examination, (b) providing access to the ALADDIN social networking environment and the ALADDIN TV for additional educational, physical and cognitive exercising features, (c) generating manual warning to the clinician and 3) a network connection through which the collected data can be transmitted to the ALADDIN server where they are stored, processed, analysed and displayed to the clinicians in a structured manner.

The clinicians' interface to the system is a web-based application, so they can access the system from wherever they are through a web-browser. The home page of the clinician's application, as presented in Figure 4, provides them access to all the functions and operations they can do through the system: they can view, sort and filter the list of their patients, or carers or fellow doctors and nursing staff, they can manage the questionnaires by adding or removing questions in a way tailored to the individual patient's and carer's profile, they can assign tasks to their patients / carers for the specific day or plan their tasks e.g. for the week, they can check the individual recordings of their patients and their recorded measurements, they can manage the external services and select material appropriate for their patients, and they can see at a glance all the warnings that have been generated by the system, and sort them by patient name, carer name, date, type, importance, cause, etc. Therefore, ALADDIN system is a useful tool for efficient patient management, providing effective follow-up and decision support capabilities to the treating clinicians and a feeling of reassurance to the carers.

## 3. Some conclusive remarks from ALADDIN experience

Standard telemedicine and home-care systems have been established and tested for a variety of chronic health conditions, and a significant number of high-tech products are now available in the market to support these implementations. Our experience, however, from implementing the ALADDIN project, has been that the most important requirement for home care systems dedicated to dementia management, is simplicity. Systems of this kind have to be designed to be as simple and user-friendly as possible, if they are to actually make the lives of the patients and the carers easier, instead of putting an additional burden on them. Low cost is the other most important requirement, especially in the current environment of the economic crisis. Home care solutions have to be first of all affordable by the users, and this parameter must be given a high priority by the developers when it comes to chose between components, parts and devices that are necessary to build their systems. The implementation of fully automated systems is also an open question as regards the benefits to the users when compared to solutions that allow an increased level of self-involvement to the disease management process.

At the moment of preparation of this paper, ALADDIN system is being tested and evaluated in a pilot study conducted by 3 clinical sites in Spain, Greece and UK involving more than 30 patients. The results of the pilot operation are expected to provide an initial confirmation as regards the anticipated benefits of using the system, in a quantitative manner. While the anticipated benefits remain to be proven, it is worth sharing the feedback provided by our colleague in the project, Prof. Jahanshahi, who is in charge of the pilot running at the National Hospital of Neurology and Neurosurgery in London, in her own words:

*[...] We have all been amazed at how 'desperate' and stressed most of the carers are and feel we have opened up the door to an area of real need, which is not adequately covered by existing services as it lies in the no man's land between medical and social services  [...]*

## References

[1]     Allain H, Neuman E, Malbezin M, Salzman V, Guez D, Wesnes K, et al. Bridging study of S12024 in 53 in-patients with Alzheimer's disease. J Am Geriatr Soc 1997;45:125–6.

[2]     McKeith IG, Ayre GA. Consensus criteria for the clinical diagnosis of dementia with Lewy bodies. In: Iqbal K, Winblad B, Nishimura T, Takeda M, Wisnieswski HM, editors. Alzheimer's disease: biology, diagnosis and therapeutics. New York: Wiley; 1997. p. 167–78.

[3]     Alzheimer's Disease International, World Alzheimer Report 2009, Editors Prof Martin Prince, Institute of  psychiatry, King's College London, Mr Jim Jackso

[4]     Todd, S., Passmore, P.: Alzheimers disease, the importance of early detection. European Neurological Review (2009)

[5]     http://www.alzheimer-europe.org/Policy-in-Practice/European-Alzheimer-s-Alliance/Alliance-Activities/December-2008-The-rising-cost-of-dementia

[6]     See ALADDIN-project: http://www.aladdin-project.eu/

[7]     Folstein MF, Folstein SE, Mc Hugh PR. Mini Mental State: a practical method for grading the cognitive state of outpatients for the clinician. The Journal of Psychiatric research. 1975; 12: 189-198.

[8]     Teri, Linda, Truax, Paula, Logsdon, Rebecca, Uomoto, Jay, Zarit, Steven, Vitaliano, Peter P., Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. Psychology and Aging, 0882-7974, 1992, Vol. 7, Issue 4

[9]     Morris, J.C. (1993) The Clinical Dementia Rating (CDR): current version and scoring rules. Neurology, 43, 2412-4.

[10]    Hughes CP, Berg L, Danzinger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. Br J Psychiatry. 1982 Jun; 140: 566-72.

[11]    Stefanos Xefteris, Aggelos Androulidakis, Maria Haritou, Andrey Baboshin, Yuri Glickman, Francesco D'Andria, Konstantinos Tserpes, Theodora Varvarigou, «Enabling Risk Assessment and Analysis by Event Detection in Dementia Patients Using a Reconfigurable Rule Set», The 4th International Conference on PErvasive Technologies Related to Assistive Environments (PETRA2011), Crete, Greece, 25-27 June 2011.

[12]    Zarit S.H., Rever K.E., Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20:649-655.

[13]    Burckhardt CS, Woods SL, Schultz AA, Ziebarth DM (1989). Quality of life of adults with chronic illness: A psychometric study. Research in Nursing and Health, 12, 347-354.