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ISISEMD evaluation framework for impact assessment of ICT pilot services for elderly with mild dementia, living in the community and their relatives

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Abstract

With the demographic changes and the ageing population in the most of the European countries, currently we are witnessing emerging pilots with a different scale of e-care services for elderly. Before further investment for wide

deployment and uptake of ICT solutions in social care services, there is a need for drawing a baseline for arriving at solid and comparable evidence to facilitate policy decisions. While general rating scales for measuring quality of life of healthy adults are relatively widely used, suitable indicators and methodologies for evaluation of improving quality of life for elderly with mild dementia living in the community and their relatives using assistive technologies, are under discussions among researcher and social care providers who are involved in introducing ICT services for these user groups. One of the challenges is how to best measure the anticipated improved quality of life for the main user groups and the socio-economic benefits for the care systems in a scientifically acceptable way. To fill in this gap, ISISEMD project has worked towards proposing overall evaluation framework to assess the impact of introducing ICT services. This paper presents this framework with the suitable indicators, measurement methodologies and rating scales.

Key words – pre- and mild dementia, demand-driven services, personalisation, holistic approach, quality of life, burden of care, randomised controlled study, service validation.

1 Introduction

According to Eurostat, in 2005 there were around 81 million elderly people aged 65 and over in the EU-27, compared with 38 million in 1960. Today there is one elderly person for every four people of working age. Dementia affects only 1% of people aged 60–64 but 30%–50% of those older than 85. It is a syndrome (group of symptoms) associated with a progressive loss of memory and other intellectual functions that is serious enough to interfere with performing the tasks of daily life. The prevalence of dementia increases rapidly with age; it doubles every five years after age 60. The incidence of this pathology creates many interests around it and people who has it. ISISEMD project is involved in finding a method to improve these persons' quality of life [1].

ISISEMD, Intelligent System for Independent living and SELF-care of seniors with cognitive problems or Mild Dementia, is a European Project granted in the sphere of telemedicine diffusion and project for elderly. The aim of the ISISEMD project is to provide a pilot of innovative intelligent set of scalable services that will support the independent living of elderly people in general and in particular the group of elderly with cognitive problems or mild dementia and at the same time to support the formal and informal caregivers in their daily interaction with the elderly. To prove wide applicability in Europe, the operation will be validated, evaluated and tested in realistic conditions for

12-month period in four Member States regions which have extensive experience from innovative tele-homecare services for elderly – in Frederikshavn (Denmark), Lappeenranta (Finland), Belfast (UK) and Trikala (Greece). The target end-user groups are elderly persons with mild dementia (EP), formal caregivers (FCG) and informal caregivers (ICG). Based on these main user groups, the test groups with which the functionality of the scalable services will be evaluated and validated are divided in three test groups. Details about the user requirements, bundles of services, architecture of the platform are provided in [2].

To achieve its objectives, ISISEMD project mobilized an expert consortium of 12 partners for 30 months, built on public-private partnership and presenting the whole value chain for deploying the pilot service - the consortium has partners to conceive, develop, integrate, install, service the system as well as partners to use and benefit from it. In particular:

- Four end-user organizations representing the public community and the end-users (Municipality of Frederikshavn -Elderly Care, Denmark, Belfast Health and Social Care Trust, UK, Municipality of Trikala, Greece, Municipality of Lappeenranta - Health and Social Care, Finland)
- Two major industrial players with long successful history in equipment production, services delivery and global system integration (Alcatel-Lucent, Hewlett Packard)
- One public office with strong management experience (North of Denmark EU-Office)
- Three SME's including 1 providing service platform, 1 providing tele-medical equipment and 1 installation, manufacturing and maintenance company (Converge, Eltronic A/S, Socrate Medical)
- Two academic organizations (Aalborg University, National Technology University of Athens)

As conducting larger scale trials of innovative assistive services for elderly with mild dementia living in the community and their relatives under realistic conditions for a substantial time period is a relatively new activity, there is not enough research carried out for development of appropriate rating scales for measuring the outcome. In the review of new and existing technologies as feasible, successful, and worthwhile therapeutic interventions, only a handful articles mention computerized assessment tools and none were specific to dementia or to non-pharmacological interventions. [3, 4, 5].

On one hand, the most instruments for measuring improved quality of life (QoL) coming from use of assistive technology, are quite broad, and for healthy adults. On the other hand, the instruments that target elderly adults with

mild dementia, are developed for measuring effects of pharmacological interventions and not interventions from assistive technology. Moreover, for the same reason, there is a lack of rating scales to measure burden of care and quality of life within the group of informal carers caring for older adults with mild dementia. Furthermore, proving cost effectiveness and societal benefits is quite challenging because of the diversity of social care models and funding schemes for the care provision across Europe.

The contribution of this paper is **the proposal for adoption of a novel evaluation framework consisting of a set of very appropriate for the target end-user groups measuring indicators, evaluation methodologies and rating scales**, namely:

- Definition of strictly defined inclusion and exclusion criteria
- Proposal of controlled study design and practical considerations for its applicability
- Evaluation methodologies for user acceptance and satisfaction
- Rating scales for measuring quality of life improvement of main end user and reducing care burden for informal carers
- Parameters for functional and non-functional technical evaluation
- Indicators for measuring of gains in costs and social benefits
- Proposal of success criteria for the pilot evaluation

The goal of this proposed evaluation framework is to make possible comparison of future evaluations of similar services by relevant indicators and reliable measurement methodologies.

The paper continues as follows: Sect. 2 introduces the ISISEMD service platform and explains how the services are being validated. The main contribution of the paper is presented in Section 3 and 4 – namely the randomized controlled study, the overall evaluation framework and the measured indicators. Section 5 presents the methods for measuring costs and evaluating cost efficiency. Sect. 6 provides **the view of social care providers** for future exploitation of the services while Sect. 7 outlines business perspectives. Related work is presented in Sect. 8. The described work is discussed and concluded in Sect. 9.

2 ISEMD service platform and its validation

2.1 Overview of the ISEMD services

Challenge in such type of pilot projects for offering e-care services, is the multidisciplinary nature which involve representatives of actors from the main value chain, is to find a common language such as all partners reach a level that allows them to understand each others point of view with overall goal to increase the quality of life for patients with mild dementia and their informal caregivers. This has been successfully achieved in ISEMD and user-centered demand-driven innovative services have been defined as part of the platform [2].

In the services and interface design, ISEMD partners followed requirements for technology for people with dementia, as stated in other European projects such as Technology, Ethics, and Dementia Report [6]; ASTRID Report [7]; At Home with AT [8]; ENABLE Project [9]):

- Support the user's sense of autonomy
- Support decision-making
- Be a positive influence on the user's quality of life
- Support intact abilities while de-emphasizing a loss of function
- Support the end user's image of themselves as a person with abilities, not reinforce a disabled mentality
- Provide effective information that is visible and available
- Provide autonomous systems that require a minimum of learning and interaction with new information
- Multimodal interactions – audio, visual, speech and tactile
- Simple language
- Large font to balance macular degeneration
- Choice of suitable colors to prevent glare

The goal of the services is to improve the elderly ability for self-care by support for their basic daily activities in way that prevents health risks in their homes. The pilot services contain three different service bundles (basic services, intermediate and high level) that allow for escalation of the service provided to the end-users based on their needs and providing different pricing schemes. The platform also ensures highly personalised approach to selection of services per clients and customisation of a particular service. The services will also strengthen the daily interaction with their social sphere - partners and relatives, friends and care-givers, giving them the feeling of safety and preventing their social isolation. Last but not least, their cognitive training and activation will be strengthened.

In particular, the daily activities support is important for elderly that is granted by a domotic home-safety solution and reminders for daily actions. This is highly important for the caregivers, either formal or informal, because it guarantees urgent notification in case of a dangerous situation. Additionally, the multimedia services can help the elderly to prevent social isolation and maintain their mind active. From the informal caregiver point of view the most important service is notification and alarm service for out-of-normal activity pattern and to permit him/her a less stressed life.

For the formal caregiver it is important to reduce the time of intervention - many interventions can be made by video-telecommunication, and daily supervision of patients can reduce emergency situations.

The main interface with the ISEMD system is implemented through a portal which acts as a single point of reference for these services; the access is profile and role-based. The portal comprises the platform upon which the various services from different systems are integrated and inter-operate for achieving the required functionality.

For elderly side, the equipment depends on the house plan and the services selection. The complete equipment is composed by a touch-screen and home-safety equipment: set of sensors integrated with the portal. Moreover the elderly can be equipped with a portable device for the outdoor location service. The ISEMD services for elderly, such as reminders, video communication, request for assistance and cognitive stimulation are provided by means of a GUI on the touch screen with text, sound and speech modalities, which has been studied in order to be as simple as possible and to require minimum amount of input interaction with the end user. There are possibilities for selection from three levels of interaction of EP with the touch screen allowing suitable modalities for the dementia stage. If the cognitive level allows, only interaction required is the pressure of a few buttons on the screen for starting a video-communication, for providing feedback to reminders or for requesting assistance.

2.2 Selection of individual services per client

Quality of life (QoL) for the aging population is associated with the ability of the people to live independently, with dignity, without needing to be attached to their children, grand-children or any other person whose help would they need for their daily life and social behavior. For elderly adults suffering from dementia, the symptoms are very individual, depending on the type of dementia, previous lifestyle and occupation, etc; hence the requirement for individual selection of needed services. One way of determining the level of care needed, as well as the stage of dementia, is by having an Occupational Therapist (OT) evaluate the client. These professionals are trained to notice the ease of

movement, retention of directions, and ability to carry out a task safely and successfully. Basic activities of daily living (ADLs) and instrumental activities of daily living (IADLs) are statistically correlated with QoL for the end user and reported caregiver burden in ICG. ADLs consist of self-care tasks - bathing, dressing, toileting, transferring, continence, and feeding. ADLs are assessed with Katz's ADL Scale [10]. IADLs are not necessary for fundamental functioning, but enable the individual to live independently within a community. IADLs are evaluated using Lawton and Brody's IADL Scale [11]. The exact parameters which will be measured include: ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, medication responsibility, and ability to handle finances.

In order to better equip the trial homes with appropriate intervention services, an accurate account of physical functional abilities is needed. Rather than using only ADLs and IADLs rating scales for the client, the selection of the individual services per client will be fine-tuned with the help of self-reports and semi-structured interviews with informal carers who can mention user needs for which they compensate. ICGs are presented list of IADLs and asked to report which they assist with and approximate time spent assisting the care receiver. All these assessments help the services providers accurately to fine-tune the services to the end users specific needs. **It should be emphasized that although both parameters of physical functioning are measured, ISISEMD is mainly providing services and solutions to aid IADLs (secondary effects may aid ADLs, but not as the purposed goal).**

2.3 Validation of the services

Validation of the services is carried out in real-life settings for one year trial in the four regions with the three groups of end-users and evaluated with a controlled study. To work with a representative sample of the elderly, the recruitment of ISISEMD trial participants for the pilot services follows strongly defined inclusion and exclusion criteria.

More specifically, the test participants from EP group are elderly over 60 years of age diagnosed with stage two (Age Associated Memory Impairment) to four (Mild Dementia), according to The Global Deterioration Scale (GDS) [12]. The controlled study is randomized, involving 80 elderly (20 per test site), equally split in intervention and control groups. The study complies with high ethical standards and for this, the regional partners have obtained approvals from regional Ethical Committees (if necessary) and from data protection agencies. All trial participants sign "Informed consent form".

Trial objectives are evaluation the effects and the efficiency of ISISEMD services, find out how success/failure is correlated with a certain

group of the users, identify the most successful and most preferable service, find out which parameters are most important for user satisfaction/acceptance, and find out what should be improved in the services for future application and research. The evaluation framework includes specific rating scales suitable for the end-user groups and specifically designed ISISEMD questionnaires.

Cognitive decline is accessed with the help of MMSE rating scale (Mini-Mental State Examination) [13] or Montreal Cognitive Assessment (MoCA) [14], which is assumed to be more sensitive for the early dementia stages. The main inclusion criterion for the primary users is the stage of disease (level of cognitive decline). More details about the evaluation framework are presented in Section 3 and 4.

2.4 Success Criteria for the ISISEMD Platform of e-care services

Based on the expected positive outcome of the piloted services, overall success criteria have been defined for the controlled study. Table 1 presents examples of evaluation questions and such success criteria.

| Parameters | Example of questions | Success Criteria |
|-------------------------------------|---|---|
| Elderly Perceptions | - Were elderly satisfied with the homecare service compared to the alternative(s)? | 70-75% of the elderly feel satisfied using the system |
| Caregiver Perceptions | - Were attending and/or consulting caregivers satisfied with the homecare application compared to the alternative(s)? | 75% of the caregivers feel satisfied using the system |
| Relatives perceptions | - Were relatives satisfied with the homecare service compared to the alternative(s)? | 75% of the relatives feel satisfied using the system |
| Quality of Care and Health Outcomes | - What were the effects of the homecare application on the care process of care compared to the alternative care options? - What were the effects of the homecare application on immediate, intermediate, or long-term health outcomes compared to the alternative(s)? | 70-75% of the test subjects feel positive effects |

| | | |
|--|---|--|
| Access to Care | - Did homecare affect the use of services or the level or appropriateness of care compared to the alternative(s)? - Did the services affect the timeliness of care or the burden of obtaining care compared to the alternative(s)? | Increase of access to care with 20-30% |
| Home Care Costs and Cost-Effectiveness | - What were the costs of the homecare application for participating care providers or compared to the alternative(s)? - What were the costs of the homecare application for elderly and families compared to the alternative(s)? - What were the costs for society overall compared to the alternative(s)? - How did the cost of the system relate to the benefits of the homecare application compared to the alternative(s)? | 10-20 % decrease in costs for elderly and families |

Table 1: Overall success criteria for the controlled study

3 ISISEMD evaluation framework

An overall evaluation framework can easily become multifaceted as a comprehensive understanding of how and in which ways the system works. However, for this particular project, older adults with cognitive impairment are one of the target end user groups, and this must be taken into consideration when developing the assessment structure. Furthermore, secondary end users (FCG and ICG) may not be as familiar with using technology in home care, and especially at this scale. At the beginning of the project, thorough end user requirements were gathered for and by all three end user groups, supported by professional staff (professional caregivers, medical doctors, aging specialists, and technical partners). These user requirements became the basis for modeling our technology and services as well as serve for a platform for assessing the project.

The study is expected to lead to positive conclusions for all parties involved – meaning all types of organizations representing the value chain in providing the services in order to reach conclusive evidence for its positive outcomes. Some of the main challenges to draw relevant evaluation framework comes from the complexity of the controlled study because diverse aspects must be evaluated. Another challenge is identifying relevant measuring instruments for the target user groups of the service platform. A third challenge is to define suitable methods of evaluation for the two end-user groups considering ethical aspects and their health status – for example it will not be meaningful to ask older adults with mild dementia to fill in self-evaluation questionnaires while this can be applied to their relatives.

The uniqueness of ISISEMD overall evaluation framework is that it evaluates the e-care pilot services from four complementary perspectives, described in the following subsections:

- User acceptance and satisfaction
- Improving quality of life of EP and reducing care burden for ICG
- Functional and non-functional technical evaluation
- Economic, societal and business aspects

Overall, an explorative approach is used in the evaluation of user acceptance, satisfaction and quality of life –before, during and after the pilot trail. Many of the primary users do not see themselves as impaired; either they do not see their difficulties in their daily life or they are embarrassed and try to hide them. Having dementia, and the difficulties derived from that condition are often tabooed, so getting into the issue can be difficult both to the elderly person but also to the data collector. Due to different understandings and views on one's own condition, one method has different applicability on different demented persons. Therefore, it is necessary to approach the participants from different angles to gain the best understanding of the actual situation. The philosophy is that each of the methods reveals different aspects of the same reality thus, by applying them all to the same participant; they piece together an image closer to objective reality. Therefore, **a triangulation of methods** is used to approach the users of the system from different angles. Besides questionnaires, two quantitative methodologies are applied in the analytical work: semi-structured interviews and participation observations.

3.1 Design of randomized controlled study

The controlled study started in the beginning of May 2010 and will run for one year in the four regional sites. The characteristics of the study to be carried are outlined below:

Main hypothesis: The personalised services offered by the ISISEMD platform based on each client's specific needs, level of dementia, hobbies and lifestyle will have a positive impact on QoL, feeling of safety and ability for independent living in their home environment. The services supporting the informal carers will reduce their burden of care and will also have a positive impact on their QoL, in particular increased feeling of safety and reduced rates of stress levels. The regional care providers will be able to offer social services to these groups of clients which are currently not supported by the traditional care model thus increasing the access and quality of social care.

Objectives: To evaluate the efficiency and the sustainability of the service platform as a whole and for individual services. To demonstrate the feasibility of this service model across European countries. To demonstrate that clients can independently live longer in their home environment. To demonstrate reduced burden of care by evaluating multidimensional aspects such as rates of stress symptoms among family caregivers, daily demands and overload over time.

Characteristics of the sample: To work with a representative sample of the primary end-users, the recruitment of ISISEMD trial participants for the pilot services follows strongly defined inclusion and exclusion criteria. The World Health Organisation (2007) International Classification of Diseases (ICD-10) [15] is used to classify dementia type and used in conjunction with the MMSE [13] to determine cognitive decline. Alternatively, MoCA [14] can be also administered by specially trained personnel. The main inclusion criterion for primary users is the stage of disease (level of cognitive decline). The GDS [12] is used as a classification standard. GDS is broken down into 7 different stages. Stages 1-3 are pre-dementia stages and stages 4-7 are dementia stages. People classified as stage 5 or greater are unable to live without assistance. The main inclusion criteria for participants in the controlled study are defined as: **elderly over 60 years of age diagnosed with stage two (Age Associated Memory Impairment) to four (Mild Dementia), according to the GDS and living in their own home.**

Number of participants: 80 elderly patients with mild cognitive impairment (MCI) or mild dementia (MD) across four regions - 20 per trial site (10 intervention and 10 control) with 5 formal caregivers per site and respective number of informal caregivers. **The selection of subjects in the group of EP will be random.**

Methods: Validation of the services is carried out in two stages – small-scale and large-scale validation. The services are first tested in a smaller scale, with a few end-users at each regional site for 2 months, in order to identify if major problems exist before large scale testing with all users during the rest of the testing period.

Target variables and expected results: a) increased QoL and feeling of safety, reduced burden of care, maintained cognitive ability, assessed by rating scales; b) user acceptance and satisfaction, assessed by specifically designed ISISEMD questionnaire; c) positive economical analysis.

3.2 Hypotheses for the study

The main hypothesis of the study was presented in the section above, namely - ICT services will have a positive effect on QoL for the elderly with MD and their caregivers. The supporting hypotheses are:

- Quality of Life
 - ICT services will increase QOL for 50% of EPs in the intervention group
 - ICT services will increase QOL for 70% of ICGs in the intervention group
- Burden of care for the informal caregivers
 - ICT services will reduce the burden of care by 60%
- Feeling of Safety
 - Intervention group EPs and ICGs will report a higher feeling of safety (30% higher) in their daily life than the control group.
- Social Benefits (Effectiveness and Economic Impact/Costs)
 - ICT services will allow for the transfer of care giving tasks from FCGs to ICGs (more efficient for FCG daily tasks, time, and travel)
 - Intervention group ICGs can remain employed outside the home longer due to reduced need in time spent in the care giving role
- Accessibility (to care/services offered by the care provider)
 - There will be a 25% increase in access to care offered to the public in intervention group participants
- Acceptability/Satisfaction
 - Intervention group participants will report 75% higher acceptance of ICT systems for home care than the control group
 - 75% of participants in the intervention group will use the ICT services regularly

- 75% of ICGs in the intervention group will report acceptance of ICT services as support in their care for EP (desire to continue utilizing ICT services)
- 75% of intervention group participants will report satisfaction of ICT services

In the following subsections, the evaluation methods and rating instruments are presented.

3.3 User acceptance and satisfaction

In this study, user acceptance both from a technology perspective and from a human perspective is investigated.

User Acceptance by elderly subjects and their relatives

Acceptance of remote support and monitoring by elderly and their relatives is by far one of the most important parameters in ISISEMD evaluation. If clients and their relatives are not comfortable with the technology, or feel that they do not have control over the system, they may avoid using it, thereby precluding other benefits of self-care and remote monitoring.

User Acceptance by professional caregivers

Acceptance of home-care services by caregivers and other healthcare professionals is important in home-care evaluation. If care professionals are not comfortable with the technology or judge that the technology decreases their control over clients, they may avoid using it, thereby precluding other benefits of home-care. Clinical acceptance of a home-care application may depend on the degree of confidence which the caregivers and medical staff have in their work tasks from using the application as well as the caregiver's satisfaction with the encounter in the absence of proximate interaction with the client.

User Acceptance from a technology perspective

Dillon and Morris [16] define **user acceptance** *in trials such as this as “the demonstratable willingness within a user group to employ information technology for the tasks it is designed to support.”*

Innovation diffusion theory is a paramount theoretical perspective on technology acceptance and it aims to provide a description of the mode in which technological innovation moves from invention to pervasive utilization. It applies five characteristics of innovations that affect their diffusion:

- Relative advantage (the extent to which a technology offers improvements over currently available tools)

- Compatibility (its consistency with social practices and norms among its users)
- Complexity (its ease of use and learning)
- Trialability (the opportunity to try an innovation before committing to use it)
- Observability (the extent to which the technology's outputs and gains are clear to see)

User Acceptance from a human perspective

Acceptance has also been conceptualized as an outcome variable in psychological processes that users go through in making decisions about technology [16]. Theory of Planned Behavior, or TPB [17] holds that attitudes, subjective standards and perceived behavioral control are immediate determinants of objectives, which in turn influence behavior. The Technology Acceptance Model (TAM), developed by Davis [18] predicts user acceptance of technology is influenced by perceived value and perceived ease of use. Theoretical work in social and cognitive psychology and sociology also study user acceptance, and this is particularly applicable for ISISEMD use where acceptance is subjectively evaluated and empirically measured. Relationships between beliefs, attitudes, norms, intentions and behavior shape subjective norms, and all are of great significance in shaping human behavior in exercising choice. The field of human-computer interaction (HCI) and Man-Machine-Interaction (MMI) calls for user-centered technology and current textbooks cover basic psychology and social impact, associating social science and engineering research to develop more useable and acceptable systems.

Method for assessing user acceptance for the ISISEMD services

Acceptance and use of the technological intervention by elderly and their caregivers is an important parameter in ISISEMD evaluation. Clinical acceptance of a home-care intervention will depend on, at least, the degree of confidence which the ICG and FCG have in their work tasks using the application and performance satisfaction. If trial participants are not comfortable with the technology, or if the service does not work as they expect from the very first times, they are more likely to avoid using it. Additional risk factor for user acceptance from EP aspect is that they may forget the purpose of the equipment installed in their home and thus feel confused by its presence. For such situations, a special explanation brochure has been designed by the care provider partners where the services are explained in a very simple language and with simple instructions to contact their ICG in case of a need. Another risk factor is that in the early stages of the illness, the patient sometimes does not

confess their cognitive or memory decline and thus may resist (in general) that they need ICT support for their independent daily living.

User acceptance is assessed by utilizing **Choice Modeling methodology**. Choice modeling is held to be the most accurate and general purpose tool currently available for making probabilistic predictions about human decision making behavior in a particular situation. As opposed to utilizing a poll or survey, Choice Modeling predictions are applicable over large numbers of scenarios within a context and it is considered the most appropriate method for assessing consumer willingness to pay for quality enhancements in multiple dimensions. To assess user acceptance, ISISEMD partners will use questionnaires and interviews with the users to determine their acceptance with the ISISEMD services. Caregivers (CGs) will be asked to determine how much they would be willing to sacrifice, pay or exchange to use a particular service/intervention. For example, an ICG will be asked to estimate how much they are willing to pay for an intervention or a FCG will be asked how much work time they would exchange for a service.

User Satisfaction

As the primary user group of elderly people shows a general resistance to technology, User Satisfaction is considered as one of the central measurements of the ISISEMD success. If the user is comfortable with a service, its aiding abilities are higher. In the ISISEMD project, ***user satisfaction can be defined as a user's critical evaluation of several aspects of the service.*** This evaluation is believed to be influenced by the user's expectations, perceptions, attitudes and personal values. Accordingly, **satisfaction is considered as a multidimensional concept** where different aspects should be considered and tuned to fulfill the user expectations and needs and thereby heighten the impact of the service. Therefore, user satisfaction will also be a central parameter in the improvement of the services during the pilot trail.

Method for assessing user satisfaction from the use of ISISEMD services

Similarly to assessing user acceptance, we will use questionnaires, interviews and perform observations with the users to determine their satisfaction with the ISISEMD-services. The **Quebec User Evaluation of Satisfaction with Assistive Technology** (QUEST 2.0) is inspiring to this action [19, 20]. QUEST is a method to assess how satisfied a person is with the use of an Assistive Technological Device (ATD) without considering how well the aid device is performing. To make a QUEST-analysis 12 items are evaluated; 8 items on the physical device or service and 4 on the service that is provided for

the maintenance of the device or service. QUEST is targeting all types of users of ATD.

Even though ISISEMD services cannot be fully considered as a single ATD, our evaluation is based on QUEST as a method to evaluate user satisfaction. Relevant updates and additions have been made in the parameters to be evaluated. It has been further decided that ISISEMD platform and services will be both evaluated as a whole and per service type. Aspects of the value added services from ISISEMD platform to be assessed are:

- Easily managed, transparent and comprehensive user interaction
- Feelings of safety and security in the home
- Satisfaction in the ability to self-care and extend independence
- Enhanced social interaction
- Ability to locate EP in- and outdoors
- Ability to communicate remotely with EP
- Reduction in care burden for ICG
- Memory support

Another questionnaire that evaluates how people use technology in their everyday tasks is ETUQ - Everyday Technology Use [21]. The target group for ETUQ are people with dementia. The ETUQ is developed to map out perceived relevance and competence in the use of everyday technology among older adults with MCI or mild dementia and it evaluates commonly used technology devices for personal care, household, data and telecommunications, shopping and transportation [21].

Since neither of the above mentioned questionnaires exactly targets the user group which ISISEMD service platform will support – namely elderly adults with MCI or MD using innovative e-care services, none of them could be directly applied. However, in the ISISEMD evaluation framework, we have designed our special user acceptance/satisfaction questionnaires, inspired by QUEST 2.0 and ETUQ. The ISISEMD interview guides for user satisfaction and acceptance by primary end-users and the questionnaires for the informal caregivers have been based on them. User acceptance and satisfaction are so very important in the process of introducing ICT services to elderly and also people with cognitive problems that these aspects will be two of the crucial factors which will define the success of ISISEMD services. Therefore, in the evaluation of user acceptance and satisfaction, iterative process will be followed. The first evaluation will take place already after the first two months of the pilot trials, during the small-scale testing. There will be after that midterm and final evaluations. The issues identified from them will be immediately provided to the technical partners to improve the services customization.

Training to increase User Acceptance/Satisfaction

In order to facilitate the best possible conditions for user acceptance, a reasonable amount of time must be spent on training. The amount of time and type of training caregivers and primary participants require for them to feel competent and confident with using the technologies, will be different for each situation. Face-to-face training at the time of installation and extensive print material (in the form of user manuals) with specific instructions and demonstrative pictures (such as how to make settings for receiving an alarm messages for example or set up an appointment) will be vital in influencing user acceptance. More technologically experienced relatives and caregivers will require more advanced materials to allow them to modify the initial system settings to meet their personal needs, such as disabling door sensor alarms during high volume use. Training for the three main user groups is foreseen and will be carried out by technical partners before the start of the trials and during the first months of use.

3.4 Cognitive functioning, Quality of Life and Care Burden

In ISESEMD project, cognitive functioning, activities of daily living and patients' and relatives' quality of life will be assessed as part of the evaluation framework by brief self-administered instruments or questionnaires administered by health professionals. The assessment will be performed in 3 phases during the 12 month trial period: at a baseline level, after 6 months and after other 6 months. In this subsection, the instruments for measuring cognitive functioning, QoL and burden of care for the ISISEMD target user groups will be shortly presented.

For elderly adults with MCI and MD - Cognitive functioning for patients

Dementia is characterized by multiple cognitive deficits, which are evaluated through neuropsychological assessment. Brief cognitive tools are used as screening tools and in order to obtain a global index of cognitive functioning [22]. Mini Mental State Examination (MMSE), a screening tool developed for the assessment of cognitive performance of older adults is an instrument widely used in clinical practice and research. MMSE evaluates the performance in five areas of cognitive functioning: orientation, registration, attention and calculation, recall and language, with a maximum score of 30. A cut-off score of 23 is concerned to be an indicator of cognitive impairment [13]. Cut-off score in MMSE depended on the target population of a study. For example, cut-off score of 26 is preferred if the study targets people with MCI.

Administration of MMSE and Montreal Cognitive Assessment (MoCA) adds to the procedure by indicating memory/cognitive complaints and grading of cognitive impairment. MoCA is a 30-point instrument that was developed as a screening tool of Mild Cognitive Impairment (MCI). MoCa evaluates several cognitive domains: Visuospatial abilities, short term recall, attention, concentration, working memory, language, delayed recall, orientation to time and place. A score of 25 or lower indicates impairment [14]. The selection of the above brief cognitive tools in ISISEMD project will distinguish among different stages of dementia. Mild dementia patients and their relatives are the target population in this project. Mild dementia patients often appear normal to a casual observer. They have mild cognitive deficits and preserve social and conversational skills. Some patients are aware of their difficulties and sometimes they become depressed. Other patients deny the symptoms and they do not accept help from their relatives [23].

Quality of Life of patient – QoL- AD

The level of functionality influences patient's and caregiver's Quality of Life. QoL is not easily defined. Physical, psychological and social variables are included in this definition. In elderly with cognitive impairment, stage of disease is a dimension that influences QoL. At the early stages, QoL is perceived in a different way as in the late stages, when the safety of the patient becomes a priority.

QoL-AD, a 13-item questionnaire is developed to evaluate the patient's QoL. A patient's report and a caregiver's report are provided through this procedure. Score is ranging from 13 to 52. High score determines a high quality of life [24].

Droes et al [25] has conducted interviews, focus groups and literature study in order to investigate domains that are included in the definition of Quality of Life by people with dementia living in the community and in nursing homes. Their answers were compared with instruments that are widely used in QoL research. Domains that participants assessed as important were: affect, self-esteem/ image, social contact, attachment, physical and mental health, enjoyment of activities, sense of aesthetics, security/ personal privacy, sense of being useful. QoL- AD covers 4 of the above dimensions: affect, social contact, physical and mental health and financial situation.

ISISEMD project is willing to support people with mild dementia in all the aforementioned dimensions as it is depicted in the Table 2.

| Self-Reported Domains | Technological Intervention (ISISEMD) | Desired Outcome |
|----------------------------|---|---|
| Affect | Videophone; Functions monitoring | Positive impact on life; support feelings of independence; maintain emotional balance; fosters expression of happiness, agitation, depression, etc. |
| Self-Esteem/Image | Calendar; Reminders/Alerts; outdoor positioning; Intelligent medicine dosing system; Function monitoring | Support for the self-image of being a person with abilities; strengthened coping abilities |
| Social Contact | Calendar; outdoor positioning; Videophone; | Developing and maintaining social relationships; developing care relationship with caregivers; interactions with family, friends, society |
| Attachment | Calendar; Reminder/Alerts; outdoor positioning; Videophone; | Feeling of imbeddedness in surroundings; friendship and kinship bonds; participation in local community and networks |
| Physical and Mental Health | Calendar; Alarms; Reminders/Alerts; outdoor positioning; Intelligent medicine dosing system; Function monitoring; Home-safety equipment; | Not feel as a person with disabilities; freedom from barriers; documented behavioural and psychiatric symptoms; satisfaction with health care; promotes self-care abilities |
| Enjoyment of Activities | Calendar; Reminder/Alerts; outdoor positioning; Videophone; Intelligent medicine dosing; Home safety equipment; | Support the user in making choices; empower a person with a notoriously dehumanizing disease |
| Sense of | Calendar; | Remind user of previously |

| | | |
|---------------------------|---|---|
| Aesthetics | Videophone; | familiar situations; promote comfortable atmosphere conducive to reducing anxiety, agitation, etc.; stimulating qualities |
| Security/Personal Privacy | Calendar; Alarms; Reminders/Alerts; outdoor positioning; Videophone; Function monitoring; Home safety equipment; | Peace of mind that one does not need to worry about locked doors, fire hazards, etc. |
| Being Useful | Calendar; outdoor positioning; Intelligent medicine dosing system; Function monitoring; Home safety equipment; | Support for skills retained, de-emphasis on lost skills |

Table 2: Quality of Life domains and expected outcomes of assistive technology

For informal carers - QoL

Poor functionality is related with caregivers' burden and quality of life. Patients with dementia, especially in the late stage become dependent of their caregivers. Caregivers are experiencing changes in family, social and professional life. Informal caregivers of patients with chronic diseases report increased physical health problems, lower levels of cognitive functioning, impaired social life, higher rates of depression and anxiety when compared to non caregivers [26, 27].

There are few instruments measuring quality of life for caregivers of chronically ill patients [28]. In ISESEMD project, QoL of Informal Caregivers will be measured by Scale of Quality of Life of Caregivers (SQLC) [29]. Glzman et al [29] has developed an instrument for caregivers of Parkinson Disease patients, which covers 3 domains: professional activities, social and leisure activities and responsibilities of caregivers to help patients in everyday living. SQLC is an instrument that could be used in dementia as it explores domains similar with those that are affected by dementia. SQLC score provides 4 categories of Caregivers' adaptation: full psychosocial adaptation (141-145), mildly disturbed (100-140), moderately disturbed (86-99) and severely disturbed (<85).

For informal carers - Burden of Care

Informal Caregivers are experiencing changes in multiple domains of their life. Burden of care is a widely used term, which depicts psychological, social and financial dimensions of care. Caregivers' burden is discriminated in objective and subjective. Objective burden involves the actual demands of care giving role and subjective involves the distress that caregivers are experiencing. For a number of researchers, burden is considered to be an outcome variable, which is effected by stressors that the carer is experiencing. These stressors are filtered by carer's coping strategies. Increased burden is responsible for increased use of formal, paid care, earlier institutionalization of patient, high rate of infectious illnesses. [28]

In ISESEMD project burden of the Informal Caregivers will be measured by Zarit Burden Interview (ZBI) [30]. ZBI is a 22-item tool with questions on caregiver's health, psychological wellbeing, finances, social life, relationship between carer and patient. Score is ranging from 0 to 88 and describes 4 conditions: little / no burden (0-21), mild to moderate burden (22-40), moderate to severe (41-60) and severe burden (61-88) [30].

Apart from SQLC and ZBI, Caregiver Activity Survey (CAS), a 13 item instrument, will be administered in order to measure the illness's impact on the time of caregivers spent looking after the person with dementia. CAS is an objective measure of caregiver's burden and estimates the amount of time that caregiver spends to help patient to basic and instrumental activities of daily living [31].

The following Table 3 summarises the rating instruments selected for the ISISEMD evaluation framework.

| Evaluation aspect | Assessment tool | End user involved | Time demand | Assessment method |
|---|---------------------|-------------------|-----------------------|----------------------------------|
| Assessing QOL of primary end-user | QOL-AD | EP | 3x 10 minutes | Questionnaire with support staff |
| Assessing care burden of informal caregiver | ZBI | ICG | 3x 15 minutes | Questionnaire self administered |
| Assessing QOL of informal caregiver | SQLC and CAS | ICG | 3x 10-15 minutes each | Questionnaire self administered |
| Assessing cognitive | MMSE/ MoCA | EP | For MoCA - | Questionnaire with |

| | | | | |
|--|---------------------------------------|--------------|--|--|
| decline for primary end-user | | | 3x 10-15 minutes For MMSE - 3x 30 minutes | professional (Certified for MMSE /MoCA) |
| Assessing activity of daily living | ADL/ IADL | EP | 3x 15 minutes | Questionnaire with occupational therapist |
| User acceptance of assistive technology or service and User satisfaction | User Satisfaction / Acceptance | EP, ICG, FCG | 3x 30 minutes | Structured interviews with ISISEMD personnel from the care providers |

Table 3: Matrix of the evaluation methods and instruments

3.5 Applicability of the evaluation framework

ISISEMD project is 30 month project. During the first 12 months (M1-M11), the services have been integrated in the ISISEMD platform and preliminary tested by the partners. The service validation and evaluation will be done during the second 12 months of the project (M12-M24) in realistic conditions and with selected test participants. The evaluation framework will be applied as follows - M13-M24, the pilots will be used by the test users under realistic conditions – older adults in their homes; the professional caregivers in their work tasks, performing their daily work to care for the elderly; the informal caregivers/family, also in their everyday activities to care for the seniors. The services will be first tested in a smaller scale, with a few end-users at each site for 2 months (M13-M14), in order to identify if some major problems exist before the large scale testing with all users during the rest of the testing period until M24. The pilot sites will be maintained and serviced during this second phase by the technical partners.

In some cases, the illness may progress fast; therefore the process of cognitive assessment for the stage of dementia (test MoCA/MMSE) will be done immediately before starting the test period – in M12. For the same reason, MoCA/MMSE tests will be again carried out after 6 month period. This is also necessary, because if during the first 6-month period, more cognitive problems appeared for the elderly person, they may need advanced service level. This

testing of the cognitive decline in the middle of the 12-month test period will ensure that the correct service level is provided to the client. At last, in the end of the testing period, MoCA/MMSE test will be carried out again. This will be done because part of the test participants, who have been in dementia stage 4 during the test period, may have progressed to dementia stage 5, thus making the use of some of the services inappropriate for them.

QoL evaluation will be carried out in the beginning (M13) and the end (M24) of the test period using standard questionnaires. Similarly, assessing IADL will be carried out at the same time. QoL-AD will be administered for the test group of EP, while SQLC, ZBI and CAS will be administered to their relatives, in order to measure the baseline for their quality of life and care burden. These tests will be carried out also in the middle of the pilot period, in order to access the level to which EP and ICG rely on the assistive services after the initial months when they are not very used to use the services.

To evaluate the user acceptance and satisfaction from using ISISEMD services, iterative process of periodically receiving user feedback will be applied with overall goal of constantly improving the services in the life time of the project. The first evaluation for this aspect will be carried out in the second half of M14, after the smaller scale testing with a few test participants. The main goal of this will be to identify some major flaws in the design of the services which will be avoided with the full scale testing. Then, mid-term and final evaluation for user acceptance and satisfaction will be done in M18 and M24 respectively. At the end, based on feedback of this evaluation, identification of possible weaknesses in the design will be presented to the technical partners and recommendations for improvements will be given.

Figure 1 depicts the evaluation plan for the pilots.

3.6 Practical considerations

It must be underlined though that all these rating scales which have been talked about in the previous sections (MMSE, MoCA, QoL-AD and SQLC, CAS) are initially published in English. They need not only to be translated to the local language of the four regional care providers (English, Danish, Finish and Greek) but also to be adapted to the respective country. This is to avoid different understandings in the formulations, leading to inaccurate results, coming from some cultural difference in different countries. For the tests for which translations already existed in Greek, Danish and Finish, they were obtained from MAPI Institute in France, specialized in rating scale translations. For the tests that do not have translation, the regional partners were in contact with their scientific dementia advisors who help them with the translations.

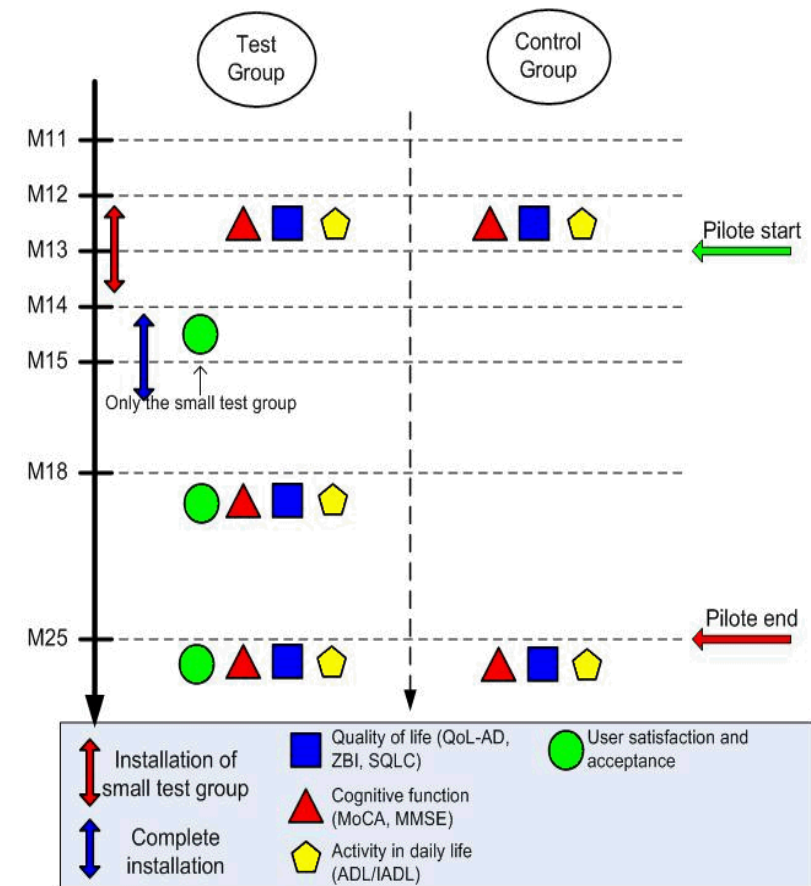


Figure 1: Work plan of the pilots and instruments to be administered

In addition to that, there could be small differences in the range of the scores in the countries; therefore, the need for tests validation and standardization. However, validation of these tests requires running of the tests in each country with many subjects, usually more than 100 patients per country.

This is a process which cannot be done in the framework of the project and usually is done by some authorized organization.

Moreover, in order to be used for research purposes by the project partners, who are the care provider organizations, permissions for use were obtained by the authors by each regional partner. In the same way, instructions on how to carry out the tests were also obtained by the authors.

3.7 Technical evaluation

In the ISISEMD evaluation framework, technical aspect is also included. There is a division of the technical evaluation on functional and non-functional evaluation. While the functional evaluation is rather trivial, including testing of all functions of the platform as defined by the user requirements to reach expected outcomes, the non-functional evaluation targets “soft characteristics” of the ISISEMD platform, such as level of personalisation and customisation, positive user experience, scalability, reliability, availability, response time, ensuring required security and privacy. In this paper, more details will be provided about the non-functional evaluation.

Functional Evaluation

The main objective in the functional pilot evaluation is to evaluate whether each of the function in each of the services is working properly. Therefore the evaluation method covers a way to log the successful and failure operation or execution of certain function in each service.

Below, two examples of log message are provided to exemplify functional evaluation. They are implemented in order to log or record the event related to the test functional of service:

- FunctionWorks – a log with time of event, which indicate that certain function in certain service is working upon the execution, e.g. reminder function works when it is called, alarm function works when it is called, etc
- FunctionFail – error log with time of event, showing that any function fails to execute

Non-functional Evaluation

The non-functional pilot technical evaluation covers the performance evaluation in terms of user experience, scalability, reliability, availability, response time, security and privacy, etc of the service platform. This sub-section provides some proposed methods, mainly in the form of log message at the portal or servers, in order to measure specific performance metrics. However, practically the whole performance metrics that have been defined would be very difficult to be

implemented, due to technical reason or time constrains in the project to implement, or even the performance parameters are rather subjective such that there is no model or any compact way of measuring the performance objectively. Therefore, in the following paragraph, a list of log messages will be outlined which try to depict the non-functional pilot evaluation as much as possible. On the other hand, the list is flexible, i.e. if it is not possible to be implemented, other alternatives can be found to achieve the goal of technical evaluation, or drop the evaluation plan in order to be more focused on fewer performance metrics.

Reliability and availability measures:

- ServerStart – verify that server is up and running at particular time
- ServerShutdown – determine when the server is down
- PowerShutdown – log the time when there is an electric power shutdown
- ServiceStart – verify that service is up and running in the server side at particular time
- ServiceShutdown – determines the down time of service in the server side

Security and privacy measures:

- AuthenticationError – determines that the authentication function is not working properly
- AuthenticationFail – determines that user can't be authenticated, e.g. wrong username & password. If the same user or IP address fails after making several attempts, then that particular user or IP can be blocked. Blocking can be released after further verification is done
- AccessFromUnprivilegeUser – a user has made an attempt to access, i.e. read, write, or delete, any information that is not under his privilege

Scalability measures:

- ServiceRequestError – the received service request from user cannot be processed, due to some errors, too many request to handle, etc
- ServiceResponseError – the response upon service request does not work properly, due to some errors, too many request to handle, etc
- NumberOfUsers – determine how many users are currently accessing the portal as well as each of the services. This information, together with other error log can determine how many users at most can be handled by the portal or by a service

Robustness:

- DeviceError – determine any error in the device, i.e. communication, broken hardware, no power, etc

Other required information that does not reside in the server:

- ServiceRequest on user side– determine the time when any particular service is requested/sent by user
- ServiceResponse on user side – determine the time when the response upon service request is received by user
- SMSreceived – determine the time when an SMS concerning user, service, etc is received

4 Evaluation indicators for impact assessment

In the previous section the evaluation aspects and the rating scales of the framework were introduced. Each of them is characterized with a set of indicators which are also very important for measuring positive outcome of the assistive technology for adults with MCI or MD. As part of the contributions presented in this paper, these indicators are also detailed here.

- Cognitive functioning for patients, activities of daily living (ADL) and instrumental activities of daily living (IADL)
- Quality of Life (QoL) of patient ,
- Quality of Life (QoL) of informal caregiver and burden of care

Indicators for user acceptance and satisfaction

User acceptance will be measured for the following domains:

- Relative advantage (the extent to which a technology offers improvements over currently available tools)
- Compatibility (its consistency with social practices and norms among its users)
- Complexity (its ease of use and learning)
- Trialability (the opportunity to try an innovation before committing to use it)
- Observability (the extent to which the technology's outputs and gains are clear to see)

User satisfaction will be measured for the following domains:

- User interaction with the platform
- Feelings of safety and security in the home
- The ability to self-care and extend independence

- Enhanced social interaction
- Ability to locate EP in- and outdoors
- Ability to communicate remotely with EP
- Reduction in care burden for ICG
- Memory support

Other relevant indicators

Objective parameters:

- Factors related to the person with dementia (education, profession, ethnicity, diagnosis and severity, other health issues, functioning abilities, acceptance of problem, ADLs and IADLs, etc.)
- Factors related to the caregiver (relationship to the person with dementia, the nature of the care giving role, living arrangement, employment status, perceptions of EP, expected outcomes of non-pharmaceutical intervention, etc.)
- Factors related to the environment (nature and extent of services provided, EP's home environment, etc.)
- Factors related to the assistive devices (design, function, reliability, etc.)

Subjective parameters

- If assistive technologies are useful to people with mild dementia and their caregivers.
- Potential outcomes depending on the type of problem addressed (e.g. falls at night, leaving the stove turned on, and better social interaction).
- Importance of the problem to EP, caregivers and society and how the(se) problem(s) affect them.

Further, the evaluation indicators from perspective of QoL, daily activities and care burden, are presented in the following Tables 4, 5, 6.

To conclude this section, we would like to explain that current status of the project activities is in the end of the small scale pilot in all four regions. The pilots have started with 2-3 clients in each pilot site and are running for 2 months. An activity that was not initially planned in the project, was installing the service platform in demo rooms in the premises of the care provider partners in three of the regional sites. The goal of these demo rooms was four-fold:

| Type of Rating Scale | Indicators |
|---|--|
| MoCA/ MMSE | Cognitive domains of Executive function, Visio-spatial function, New learning, Attention and concentration, Abstraction, Memory, Language, Conceptual thinking, Calculations and Orientation |
| Katz's Scale – ADL | Bathing; Dressing and undressing; Eating; Transferring from bed to chair, and back; Voluntarily control urinary and faecal discharge; Using the toilet; Walking (not bedridden) |
| Lawton and Brody's scales - IADL | Light housework; Taking medications; Shopping for groceries or clothes Using the telephone; Care of others (including selecting and supervising caregivers); Care of pets Child rearing; Communication device use; Community mobility; Financial management; Health management and maintenance; Meal preparation and clean-up; Safety procedures and emergency responses |
| Logsdon scale – QOL-AD | directly evaluates the person with dementia: social contact (family, friends); attachment (marriage); physical and mental health (physical health, energy, mood, memory) ; enjoyment of activities (leisure); financial situation (finances); being useful (ability to contribute) |

Table 4: Indicators to be evaluated per user group with the help of the different ratings scales – for end-user group of elderly persons with mild dementia

| Type of Rating Scale | Indicators |
|-----------------------------|---|
| Glozman scale - SQLC | Professional activity; Social and leisure activities; Responsibilities of the care-giver to help the patient in his everyday living |

| | |
|--|--|
| Zarit Burden Interview – ZBI | emotional strain, level of frustration, fulfilment, relational, caregiver uncertainty, mental, social, financial, support and physical domains |
| Caregiver activity survey - CAS | Measures the time which informal carer spends in caring for a person |

Table 5: Indicators to be evaluated per user group with the help of the different ratings scales – for end-user group of informal carers

| Type of Rating Scale | Indicators |
|---|--|
| Feeling of Safety – based on ISISEMD questionnaires | Each person's feeling of safety indirectly affects QOL |
| Access to services and care not offered with traditional public care | Number of extra services offered to the test groups - indirectly affects QOL |
| Everyday perspective of use of ICT services | How the offered ICT services fit in the everyday activities of end-users |

Table 6: Indicators to be evaluated per user group with the help of the different ratings scales – for both end-user groups

- Stress testing of the system in realistic conditions and fine-tuning of the settings of the service which depend on local settings – for example the service for cooker activity and the home safety services in general, which are more challenging in terms of settings.
- Opportunities to train the technical staff from the care provider organizations for more efficient installation of the home equipment and the system.
- Opportunities to demonstrate all services of the platform and recruit test participants.

- Opportunities to train in some short sessions the relatives and the formal care staff for using the service platform.

Future work is conducting the large scale pilot and services validation with the rest of the test participants for the next 10 month period. In the end, the overall evaluation will be carried out.

5 Measuring costs and efficiency gains for actors along the value chain

The economic aspects of new e-health and e-care applications are important because the cost of health care is rising and the need for prioritizing the limited resources is growing. This is relevant at the societal level, but also within the specific health care institutions who must decide whether or not to implement new technologies.

The economic aspects of an e-health or e-care application can be described in:

1. A societal economic evaluation comparing an application with other relevant alternatives in terms of both their costs and consequences.
2. An analysis of the expenditures and revenues for the care institutions using the application.

Whereas the first analysis can be made as a health economic evaluation, e.g. a **Cost efficiency analysis (CEA)**, the second can be made as a business case in which the return on investment (RoI) for the institution is estimated. CEA analysis will be performed as part of the **Health Technology Assessment (HTA)** of ISISEMD platform based on the outcomes of the QoL outcomes for patients and caregivers, compared with the costs, per intervention and control group.

Then, simple Willingness To Pay (WTP) analysis will be made to assess how affordable these billing schemes could be for the end-users. The goal will be to provide some realistic recommendations if the costs are acceptable for care provider organisation and for the clients.

Taking into account all the explained above, below is a summary of the economic aspects to be assessed:

- Costs of the services – cost of equipment, the installation, cost of service support, provided number of hours from formal care staff per region (for 10 homes); operational costs – electricity, internet, SMS;
- Willingness To Pay analysis
- CEA analysis and comparison with costs per month for dementia care homes for 10 persons

- Required education and training hours

For long term perspective, as expected longer term positive outcome, the partners who are the care-providers hope to be able to delay institutionalization in dementia care homes of the clients who are supported with ISISEMD services. However, it will be difficult to come up with hard-core data to support this hypothesis. Only some assumptions will be made.

The same is valid for the expected outcome on disease progression. The services which could have positive impact on disease progression are the services which offer cognitive stimulation via showing pictures from personal life of patients and via cognitive games. The number of the EP across regions who will use these services will depend on their individual care needs.

ISISEMD will attempt to make some analytical assessment for the following.

- Efficiency to support the target user groups and prevention of institutionalization
- Impact on disease progression

The effect of using e-care and e-health on the use of time for the clinical/caregiver staff is also an important aspect in estimation of costs. If the description of the organisational aspects of an e-health/e-care application (in the organisational domain) reveals that a treatment can be produced with less use of labour or result in task shifting (e.g. from physician to nurse /caregiver) the related change in the costs should be reflected in the estimated cost per patient. So, also relevant for the overall assessment of ISISEMD services are the societal benefits expected to be achieved and to be evaluated are:

- Saving of personnel, time and travel for FCG, leading to reduced overall health and social care costs
- Possibility of reallocating responsibilities and tasks among FCGs in such a way that personnel with lower education levels can perform tasks when supported by ISISEMD
- Possibility to increase the number of patients one FCG is responsible for
- New business opportunities for European industries and SMEs

6 The view of social care providers

Seen from care provider organization's perspective, the fact that these organizations are facing a major demographic change means that they have to find new ways to provide care for the elderly and the growing group of people with dementia. They are facing increased costs in these areas while at the same time the working force will be reduced.

For a public care organization there are several reasons to participate in a project like ISISEMD. A Scandinavian project '*Technology and dementia in the North*' [32] concludes that it is typical that only some single problems related to dementia are being solved with assistive technology, and that is seldom enough for the elderly to feel safe and independent.

In the area of dementia there is a lack of knowledge for technology services and methods for revealing the needs related to cognitive problems. Often even care providers and doctors are not aware of the existence of the technology services that already exist on the market.

Only a few persons with dementia have been informed by the doctor or other public instances from the very beginning of the illness about the existence of technology services for cognitive support, even though it is very important to receive the assistive technology in the earlier stages of the illness as it takes time for the elderly with dementia to learn to use it. All these problems can be at least partially solved by the ISISEMD platform.

Depending on the outcome of the pilot, the ISISEMD platform might be ready to go into operation in public care organizations immediately after the end of the project. The care provider organizations from the consortium are looking forward to having the results of both the quality of life (QoL) tests and the activity of daily living (ADL) tests and instrumental activity of daily living (IADL). ADL and IADL have a strong correlation to QoL and the need for long-term care. QoL is rated lower where there is a decreased ability to carry out daily functions independently, and it might lead to need of institutional care if 24-hour assistance cannot be provided in the home. The ISISEMD assistive technology services are quite suitable according to this issue as the services are developed to support Activities of Daily Living. Facing increased costs in the area of care for elderly with dementia it is essential to improve the elderly's ability to undertake the tasks of daily living.

The services of the ISISEMD project have not been offered traditionally in the portfolio of services for the social care providers. Therefore there will be initial raise in the costs from the introduction of the ICT services in the elderly's homes related to costs for equipment, installation and maintenance of the system. However, the expectation is that in a long term elderly with dementia **will need less care because of the offered services, and their admission in care homes will be delayed**. These effects cannot be measured in the life-time of the project, although the regional partners are going to carry out cost-efficiency analysis that allows us to compare across different health programs and policies.

Few months into the clinical trials of the project the partners have begun to explore ideas about how the services could be supported in a longer

term and for payment schemes. One promising way for future exploitation, seen from the perspective of care provider, is **the ISISEMD platform to be offered by a single company as a complete service**. This means that the care provider organization, based on the identified needs of a client, presents list of needed services to such a company. Further, all practicalities for handling the services are taken care of the company – starting from buying the equipment, installing it in the clients home, providing technical support and maintenance, and even, depending if it is needed – connecting the system to a call centre for handling alarms. The provider of the ISISEMD platform will still be the public care organization **purchasing services** from the commercial company.

As the services in the ISISEMD platform are meant for people with mild dementia who are currently not receiving this type of social services, it might also be essential for the success of the platform that the relatives of the elderly person with dementia will be active regarding setting up reminders and following up on alarms and alerts instead of social care personnel. Otherwise care providers might risk increasing costs by offering public services to people who are not having home care today. Since ISISEMD platform also offers services for relatives, it is expected that it will increase QoL of the informal caregivers even more than they will increase QoL of the elderly with dementia. There might be a good chance that the care provider organisations can succeed in getting the relatives to participate actively in the management of the services.

In the view of the care provider organization it is also essential that the ISISEMD project will identify to which level it is appropriate to use assistive technology to support people with dementia and their formal and informal caregivers. The care provider organisations hope that this knowledge can be used for adjusting the services in the ISISEMD platform and for development of new care and treatments and support tomorrows citizens with dementia and their caregivers.

7 Business perspective of ISISEMD platform

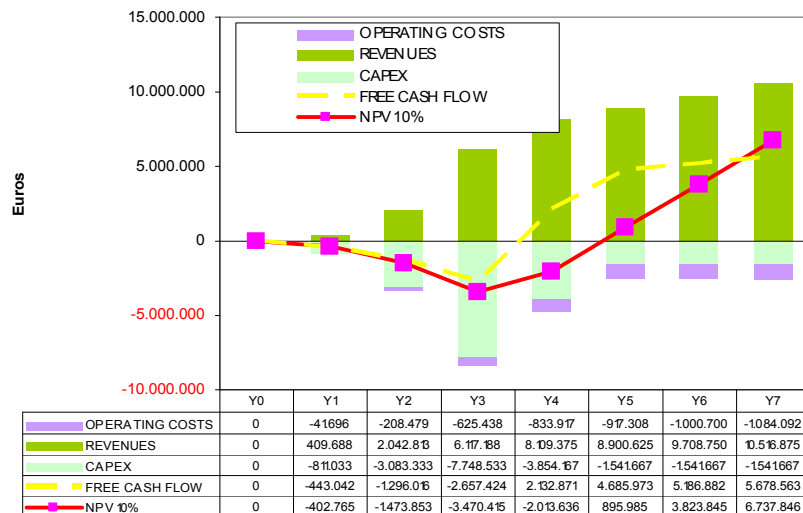
E-care and e-health offer major opportunities. These include the possibilities for improving the quality, efficiency and accessibility of care. Apart from opportunities there are also risks due to the initial lack of full maturity of the platforms and the fact that e- applications and the early systems may not be of a sufficient quality. Privacy and adequate data protection measures must be considered already in the design phase in order to prevent vulnerabilities and threats. The systems must be fault-free to prevent that errors in software and/or hardware have serious consequences. The cost of the current forms and future developments in e-health and in e-care, can also be significant as initial investments and the stakeholders may become reluctant to invest on them.

Many National Health systems have introduced cost threshold for the introduction of new health technologies. [33]

For business model, different components are identified with CATWOE (Customer, Actors, Transformation process, World view, Owner, Environmental constraints) analysis. The market analysis focuses on two aspects: demographic and motivation analyses [34].

The evidence is the increase of people over 65 years old and the resulting increase of chronic diseases and mental pathologies that cause the increase of national health system costs because of necessity of long-term assistance and domiciliary services. This is the most important application field for the ISISEMD service platform. Moreover, the costs of the National health systems are the most important motivation for tele-care service improvement. Especially, support to formal caregivers and remote support for patients are the most important areas of development. These are main market drivers, but also private market segments, as nursery, can be important. Well defined market drivers make it possible to elaborate an estimation of the market demand: 5000 user in 5 years of which 25% using a residential solution, with a cost for users of 2155€/year for 6-8 apartments, and 75% using an in-home solution, with cost of 1437€/year for 1-2 apartments [34].

Free Cash Flow Analysis



Free Cash Flow Analysis

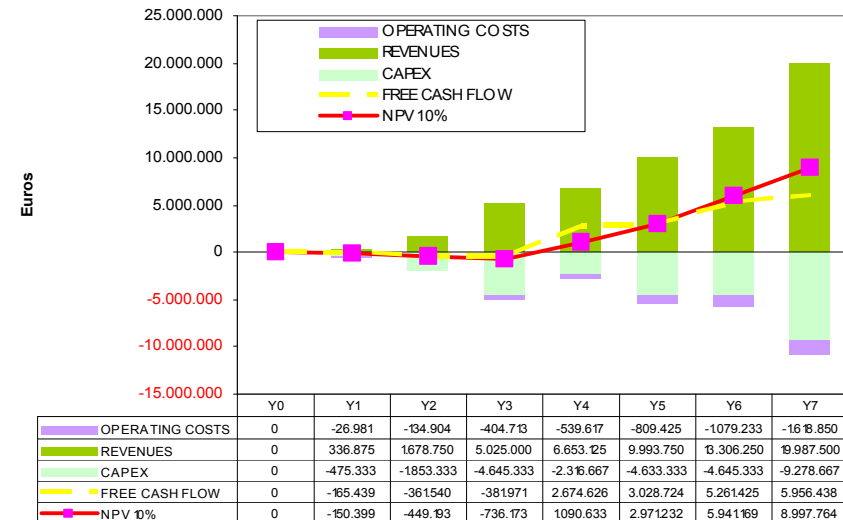


Figure 2: Business case solution. a) for all services b) for basic service.

Revenues depend on the evaluation of how much the market can pay the service, and costs can be divided in capital (capex) and operational expenses (opex). Capex costs are divided in centralized costs for server and costs for home equipment. Opex is not fixed costs and are installation, manutention and maintenance costs apart from marketing and administrative costs.

Business case results can be calculated as difference between revenues and costs, and allow to quantify cash flow and payback time that is 4.7 years for all the services (Figure 2a). The same analysis made for basic configuration of services (Figure 2b) shows a payback time of 3.4 years [34].

From the analysis it can be concluded that a public and private market exist for the ISISEMD platform.

8 Related work

QoL is a broad, multidimensional construct, yet all of these domains can be influenced by technologies in the home. Virtual environments, mobile communication, and sensors have contributed to significant advances in home care technologies [34]. These fields, merging together and with others, have created new platforms for assistive technology (AT): enhancements in an environment that are sensitive enough to adapt and respond to users' needs and behaviors.

Robust, ad-hoc networks are formed through the use of mobile devices and wireless systems that are embedded, context aware, personalized, adaptive, and anticipatory [35]. AT emphasizes user experiences, which allows for feedback based on user interactions to anticipate and create adjustments in the environment. Through a user-centered design, devices serve as support for daily activities and tasks in an unobtrusive, natural way, enhancing functional capabilities while minimizing limitations. When appropriately integrated, context aware systems can improve the quality of life of persons using them by means of a direct impact on users' ADLs and domains of QoL. Other potential benefits for a home setting intervention include privacy, security, efficiency, convenience, and support for the end user, informal caregivers, and formal caregivers.

Current QoL assessments for dementia do not allow for technological interventions as a direct influence on parameters, nor has there been an assessment tool developed specifically to evaluate the QoL outcomes with AT. This demonstrates a significant gap in the verification between how AT is used and where high-quality evidence supports it. Although FLAIR 1 and FLAIR 2 [36][3][4] are computerized assessments, they are not designed for dementia nor specific to technological intervention. They only assess ADL functioning status as an indicator of QoL, but have laid the groundwork for future investigative endeavors. Further advances in dementia research and care methods warrant appropriate evaluation methods. In this respect, the assessor can more accurately gauge whether or not a therapeutic intervention, such as utilizing tele-health technologies, has succeeded in its purpose. Additionally, the proposed assessment has implications for further development for use in longitudinal studies. When an AT system is installed in the home for supported care for dementia, it would be extremely beneficial to regularly assess QoL to adjust technological interventions, non-pharmacological and medical therapies, and take a proactive role in bettering the individual life quality.

Another controlled study for increasing QoL using non-pharmacological intervention is described in [37] that targets adults with dementia and their relatives. Their approach is offering community occupational

therapy. The authors present their evaluation framework including MMSE, CIRS-G = geriatric rating scale that measures co-morbidity, RMBPC = for measuring memory and behavior problems; geriatric depression scale; AMPS = measures process skills; IDDD = measures need for assistance; SCQ = sense of competence questionnaire. The main difference with the proposed in our article evaluation is that it does not involve evaluation of assistive technologies.

Overall, in the mentioned related works, it is common for them that there is a lack of general evaluation framework for assessment of quality of life improvements and cost efficiency of service; platforms of innovative new technology services for older adults with mild dementia and their relatives. Only some evaluations of separate services are described in the literature [38, 39] – for digital family portraits and for ambient display for the home.

9 Discussions and Conclusions

In this paper we discussed ISISEMD service platform to support the dyad “older adults with mild dementia and their informal carers” and the expected positive outcome for increasing their quality of life and reducing care burden. Evaluation framework was proposed with the goal to assess the results in a comparable way for future similar studies and services. It is expected that the controlled study will demonstrate positive results in terms of costs gains and societal benefits.

Relevance of results

Comparison of the expected results will be difficult because of some of the challenges mentioned in Section 1. First of all, there is a lack of similar studies of long term pilot trials in realistic conditions. Second, the platform offers a broad range of services to be evaluated, while some existing publications mention evaluation of only one type of service of assistive technology. Third, references exist for interventions of type – occupational therapy or pharmacological but not from type assistive technology.

Difficulties in comparison of cost gains will come from the fact that these are innovative assistive technology services that are being introduced by care provider organizations during the trial, they are not offered traditionally. Direct comparison for the costs of introducing of such services with existing services is not possible as for example comparison of health monitoring services in which home monitoring system is offered instead of hospitalization. However, relevant indicators for theoretical comparison are proposed. One aspect of comparison for social benefit can be theoretical comparison of costs for living in a dementia house for the duration of delayed institutionalization – i.e. the period while the client is able to live independently at home using the service platform.

Strengths of the evaluation framework

The proposed study and evaluation framework are empirically robust because of the randomized controlled design and the fact that economic analysis from a societal perspective will be carried out.

Another strong point is the validation of these innovative services in a larger scale, across different European countries. Assessment will be made about how to accommodate the needs of different organizational structures of social care providers; the individual needs of the clients and their carers; different level of use of new technologies among clients and carers; different cultures of care for elderly, existence of internationally recognized rating scales specifically designed for measuring positive outcomes of use of AT for elderly adults with mild dementia.

Moreover, the study will run for a period of 12 months in each of the regions with all the clients from the intervention group, thus allowing them to get used to the technology and to experience positive feelings about the services.

The trial is being conducted under realistic conditions, giving possibility to assess how robust the system is and for technical evaluation.

The evaluation framework includes all aspects which are considered to be relevant for the type of the organizations participating in the value chain but the focus is on the improving quality of life of primary end-users and reducing care burden.

Weaknesses of the evaluation framework

The service platform will be evaluated as a whole. The set of offered services per client is unique, depending on the care needs of the dyad “older adult with mild dementia-informal carer”. Not all the clients in the intervention group will use all the services from the platform because not-needed services might confuse the patient and thus leading to less positive overall evaluation if they are used. That means that not all of the services will be evaluated with all 40 clients from the intervention group.

The applied evaluation instruments for measuring QoL are general-purpose, evaluating a number of indicators. ISISEMD intervention is based on assistive technology service and is expected to make positive influence on some of the indicators, therefore only leading to expected smaller incremental improvements.

Not all of the used self-evaluation instruments are validated for all of the four nationalities because validation in the lifetime of the project is not possible due to funding and time limitations.

Conclusions

Despite of the increasingly wider use of new technologies for access to e-services by the public, unfortunately, when it comes to older adults’ computer usage, they fall into the digital divide. Those with dementia certainly fall into the disability gap as well. Because technological advances are rapidly occurring, the gap is widening and significant endeavors are required in order to keep this consumer group involved in the market.

However, the good news is that the number of older adults becoming computer savvy and the growing adaptability of electronic technologies have reached a point where they can unite and work better together than separately. Although the use of technologies to develop non-pharmacological interventions for dementia care is a comparably new sphere of exploration, the wealth of information in all applicable domains is continuing to expand and ready to be applied. Previously, older adults, especially individuals with dementia, had been disregarded as secondary consumers of technology applications [40]. Only recently have systems been designed and marketed towards aging adults, and even more recently has the scientific community integrated this consumer group in their development methodology [41]. This is also the goal of ISISEMD service platform for e-care.

The uniqueness of ISISEMD approach is the holistic way in which services are offered. Rather than focusing on intended, static solutions, researchers and developers in ISISEMD are pushing to create flexible opportunities for innovation with intent. They are setting the parameters for development to fall within, while letting the entire process dictate the direction of product evolution. Agreeing with Astell [42], the developments obligate an understanding of the difficulties in addition to a comprehension of their influence, to be conscious of the implications of practical application and the resulting benefits, rather than unconsciously developing for the sake of new technology.

ISISEMD is aiming to adjust the personal environment to agree with intact functioning at the degree of impairment. Assistive devices and ambient technologies are implemented and utilized by older populations to enhance intact functioning, accommodate the level of decreasing functioning, and allow individuals to live in their own community safely. In various respects, the living environment is of utmost and personal importance; as life beyond the home becomes increasingly challenging, the surroundings contract and become more personalized, either enabling or hindering opportunities for a person to maintain and express aspects of their identity.

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Disclaimer

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