



THE RATIONALE, DESIGN AND METHODS OF NEW STUDIES

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The project “understAID” – a platform that helps informal caregivers to understand and aid their demented relatives

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ABSTRACT

“UnderstAID” is a platform that helps informal caregivers to understand and aid their demented relatives. It is an international project initiated by Denmark, Poland and Spain.

The aim of the project is to design, and implement the multimedia platform “understAID” to support informal caregivers of dementia patients. The project was launched in April 2013 and is expected to end 36 months later. The project is divided into five tasks concerning the final aim. The aim of task 1 is the management of the project, as well as the exploitation and dissemination of gathered information. Task 2 is meant to define the contents and solutions of the CarePlatform based on the knowledge gained from real-case studies. Demented elderlies from each country (n = 40) suffering from different degrees of dementia were evaluated by formal caregivers and dementia professionals. The aim of task 3 is the development of the social learning interface. Task 4 focuses on the CarePlatform development and system integration. Finally, task 5 assumes testing and validation of the platform. The platform is devised to be available in two versions, namely the light one for mobile appliance and the premium version. Also different activities leading to the popularization of the platform are planned.

Keywords: dementia, caregivers, software, help, platform.

General information

The project “understAID” – a platform that helps informal caregivers to understand and aid their demented relatives was awarded in the 5th contest of the Ambient Assisted Living Joint Programme (AAL).

The members of the international Consortium (listed below) signed administrative bilateral Agreements on 11 April 2013 (effective date):

– Danish Agency for Science (Technology and Innovation) and Sekoia Assisted Living ApS;

- Danish Agency for Science (Technology and Innovation) and Faculty of Health Science, VIA University College;
- Danish Agency for Science (Technology and Innovation) and Danish Alzheimer Association;
- Danish Agency for Science (Technology and Innovation) and Skanderborg Municipality;
- National Institute of Health Carlos III – Instituto de Salud Carlos III and The Centre of Supercomputing of Galicia (CESGA);

- Ministry of Industry, Energy and Tourism/Ministerio de Industria, Energía y Turismo (MINETUR) and Balidea Consulting and Programming;
- Ministry of Industry, Energy and Tourism/Ministerio de Industria, Energía y Turismo (MINETUR) and Provincial Association of Pensioners and Retired People (UDP) from A Coruña/Asociación Provincial de Pensionistas y Jubilados de A Coruña (UDP A Coruña);
- Centre for Research and Development/Narodowe Centrum Badań i Rozwoju, Poland and Poznan University of Medical Sciences (PUMS); Centre for Research and Development/Narodowe Centrum Badań i Rozwoju, Poland and Wiktor Dega's Orthopaedic and Rehabilitation Clinical Hospital Poznan University of Medical Sciences (ORSK).

Management

The project management structure is designed in several bodies, the main are: Steering Committee and Consortium Management.

Steering Committees of the above partners are represented by: PUMS (Ewa Mojs, Włodzimierz Samborski, Michał Musielak); ORSK (Przemysław Lisiński, Agata Bednarek); VIA (Lars Kjeldsen); Sekoia (Morten Mathiesen); Cesga (Maria Malmierca); Balidea (Angel Otero); DAA (Nis Nissen); UDP (Ana Maseda); Skan (Lisbeth Hyldegaard).

Consortium Management Coordinator is Lars Peter Bech Kjeldsen as Coordinator supported by the Technical Manager Angel Piñeiro Otero from Balidea and the Exploitation and Dissemination Manager Morten Mathiesen from Sekoia.

Ethics

Bioethical Committee at Poznan University of Medical Sciences on 8th November, 2012 accepted all the project's protocols and forms (number 990/12).

Finance

The total value of the granted funds in Polish Zlotys is 479,983.80 for PUMS and 165,841.21 for ORSK. The total value of the project for all participants was 1526217 Euro. Funds were used to cover personal costs of the project's participants and the costs of promoting the project. Additionally, new equipment, tools and software were purchased.

Project objective and schedule

The aim of the project is to design, and implement the multimedia platform "understAID" to support informal caregivers of dementia patients. The project is divided into five tasks concerning the final aim (**Figure 1**).

Task 1. Project management, Exploitation and Dissemination

Activity type: management

Leader: Sekoia

Duration: 1–36 months

The aim of this task is to collect information from a variety of sources and convert it into a form which allows translating them into real applications and content of understAID. In order to be tested by its end-users in each participating country, this task also aims at translating the contents into Danish, Spanish and Polish.

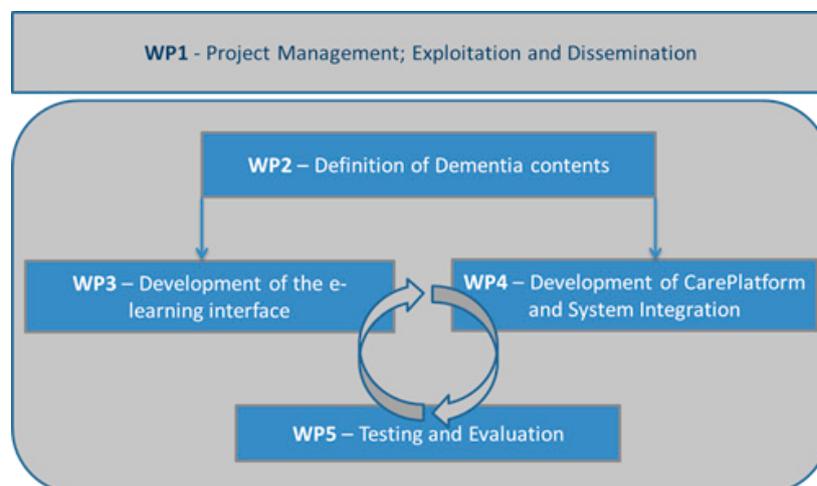


Figure 1. Project tasks

Detailed objectives:

1. Ensure effective communication and management of the project.
2. Enable robust transfer of expertise and knowledge to each of the Consortium members.
3. Ensure timely and correct delivery of all milestones and deliverables.
4. Provide objective mediation of conflicts.
5. Ensure that all project results are formulated and compiled into a protectable form.
6. Dissemination of technology and knowledge beyond the Consortium to technological and market stakeholders.
7. Enable exploitation through knowledge sharing and documentation.
8. Engaging a market access provider to partnership with the Consortium for taking products to market in the post-project period.
9. Use socioeconomic impact to influence end-users' investment decisions and to create awareness around the novel CarePlatform.

Task 2. Definition of contents and solutions for the CarePlatform

Activity type: research

The objective of this work package is to define the contents, the data and the solutions for the CarePlatform in order to support informal caregivers in the most efficient way. The knowledge about what the informal caregiver needs in different situations has to be extracted from a variety of sources, including published scientific literature, "gray literature", knowledge possessed by individuals and organizations that work with informal caregivers and by professional health staff who work with dementia patients in practice. The aim of this task is therefore to collect this information from a variety of sources and convert it into a form that the other tasks can translate into real applications in the CarePlatform.

Task 3. Development of the social learning interface

The objective of this task is to define specifications of the platform, preparation of the state-of-the-art review for e-learning interfaces and to define the e-learning model.

Task 4. Development of the CarePlatform and System Integration

The aim of this tasks is to apply specifications, design and programming. Subsequently, the development of

the online CarePlatform server solution and integration of the system is also planned.

Task 5. Testing and validation

The main objective of task 5 is to test the CarePlatform in all its aspects and to evaluate its ongoing development. This work package will be an iterative process to constantly evaluate, validate and improve the platform in order to fulfil end-users' needs.

Detailed description of the tasks

Task 1

Task 1.1. Overall management and risk contingency planning

The Coordinator is responsible for the continuous verification of consistency with the project tasks and deliverables before transmitting them to the AAL Association. Any minor deviations from the project plan is reported to the Steering Committee (SC) which considers problems and, where appropriate, makes recommendations for implementing the contingency plan(s). Where alternative contingency plans are needed, the Coordinator together with the Technical Manager and other relevant persons drafts them. The Coordinator ensures that conclusions are communicated to all members and included in the project plan.

Task 1.2. Formal responsibilities of the Coordinator

The Coordinator directs the technical progress during the project ensuring that the schedule is met. This means reviewing all reports and project progress, solving potential partnership problems and mediating in case of conflict, planning and organizing the regular meetings.

Task 1.3. Formal administration

The Coordinator's administrative tasks include: collation of deliverables, milestone reports, final report; administration of the financial funding and distribution of shares to partners; submission and organization of cost statements and Consortium agreements; keeping records and financial accounts; resolution of any administrative or contractual issues.

Task 1.4. Protection of project results

The appointed Exploitation and Dissemination Manager (EDM) is responsible for identifying and assessing the project results and reporting his findings to the Coordinator and the Steering Committee (SC). The

EDM will discuss with the partners and make recommendations concerning the need for protection of each output and the SC will decide on the appropriate protection strategy.

Task 1.5. Dissemination of project results

The Coordinator will establish, in dialogue with all Consortium members, how best to disseminate project results. The EDM will prepare a comprehensive dissemination plan with the input from all partners and subjected to the Consortium approval. Dissemination activities will include attending conferences and meetings, presentations, fair trades, and active engagement in contacts with customers, investors, academia and regulators/policy-makers.

Task 1.6. Exploitation of project results

The EDM in cooperation with the Coordinator will deliver a plan detailing how to exploit the project in terms of production, distribution and sales. In particular, they will survey and select, together with all partners, a strong market player in medical instrumentation/devices that can enable market access for post-project commercialization of the products developed.

Task 2

Task 2.1.

The aim of this task is to perform a strong and comprehensive report of the literature review which can be used by the experts responsible for building the learning models in task 3. In addition, a review paper in a peer-reviewed scientific journal based on the results is demanded to be published.

Task 2.2. Real-cases study

The aim of this task is to collect knowledge from real-case studies. Demented elderlies from each country (n = 40) suffering from different degrees of dementia will be analysed by formal caregivers and dementia professionals. The primary end-users, i.e. informal caregivers (mainly relatives) in charge will, in interviews, provide input on their day-to-day situation, describing the routines and behaviour of the elderly, the most stressful situations, the solutions most commonly employed and respective results. Questionnaires will also be sent online to other informal caregivers through the end-users' networks. Moreover, the burden of the caregivers will be measured using the Zarit Burden Scale for comparison at the end of the project to assess the impact of understAID.

Task 2.3. Definition and building of contents

The aim of this task is to find and define the most important problems as well as the possible solutions on the basis of the previously gathered information and then to build a database (text, audio and video contents).

The situations, behaviours and corresponding solutions will be ranked according to their importance and regularity as well as the predicted point in the progression of dementia.

A great amount of relevant situations is considered, e.g. leaving a building without being adequately dressed or at unsuitable times, getting lost, feeling confused and anxious, verbal or physical aggression, improper sexual behaviour, etc.

Task 2.4. Translation of contents into Danish, Spanish and Polish

The aim of this task is to translate the contents of the database into Danish, Spanish and Polish in order to allow effective testing and the accessibility of the understAID solutions to caregivers. The second aim is to peer-review these solutions by specialists in dementia, namely to test them in user trials within task 5.

Task 3

Task 3.1. Platform specifications

Two versions for the platform: "light" and "premium" are planned. The decision regarding the final content of each version will be defined considering the users' needs.

The "light" version is an application on multiple operating systems/platforms Android, iOS, Windows, Windows Mobile, Linux, etc. The functionality of the "light" version is thought to provide relevant content for the end-user, but limited when compared to the "premium" version.

The test of the "premium" version is planned to go ahead on Sekoia's web platform. The premium version will include a complete questionnaire to provide the most relevant content for each situation, communication channels with informal and formal caregivers (forums, chats, etc.), video content, audio content (chatbot), etc. The application from the "light" version is to be included in the "premium" solution, with additional functionality:

- easy upload of recorded instructional videos to the web platform,
- access to calendar,
- access to instructional videos,

- scanning of QR codes located in-house for access to instructions,
- receiving reminders.

The web platform is thought to supply an administration area with the following functionality:

- chat/forums,
- administration of medicine reminders,
- “drag and drop” calendar where everyday activities of daily life can be organized and visually presented,
- module for creating tutorial “video recipes” for the demented elderly on “how to do...”. This could be a “how to make coffee” video that the informal caregiver records in own surroundings and leaves to “play at a touch” for the care receiving person to use when in need. Elements/ tutorials can be also used in the “drag and drop” calendar in relation to activities,
- administration of QR codes for easy in-house access to instructions,
- access to the virtual dementia coach including access to videos.

Defining the light and premium versions is fundamental at this stage in order to establish the e-learning models for both versions. Despite the fact that a similar approach will be used for both versions, the premium version will be more complex, requiring an extensive and advanced questionnaire, a much more innovative and advanced e-learning interface, etc.

Task 3.2. Analyse current state-of-the-art e-learning for support of informal caregivers

This task aims at reviewing and identifying the most adequate existing state-of-the-art e-learning interfaces (such as LMS, CMS, SLI, MOOCs, Groupware, etc.) that can be used by adult individuals from all educational and cultural backgrounds to support informal learning and to build a learning network, as well as identifying their weaknesses. The aim is to find a model that helps adult caregivers learn collaboratively, connect to other learners in their network and obtain information needed quickly, while keeping the online interface as user-friendly as possible.

Task 3.3. Definition of e-learning model

This task is aimed at providing the best environment for informal caregivers to learn, find answers, and communicate with other caregivers, therapists and health care professionals. In order to do so, this task is considered to determine the best e-learning model to be used, based on user needs analysis results. As

a basis, some e-learning methodologies seem more adequate, such as connectivism, blended learning, user-centered design, all of them focused on the individual needs of an individual caregiver in combination with research-based knowledge rather than presenting large amounts of information and learning material to be browsed through and selected from. A precondition analysis component should provide online guidance and support to relatives/informal carers to help them make qualified choices in relation to choosing relevant e-learning materials, peers or deciding whether it would be more appropriate to seek guidance and support, in the virtual kin networks or from health care professionals respectively. Online communication tools should facilitate all sorts of connections and sharing among users, both asynchronous and synchronic, through text, audio and video resources. User entries into the application should allow the application to make the necessary analysis and selection of e-learning resources. Based on entries and user choices, the application will collect data in order to both improve future services targeted at the specific user and develop the application's content elements. This function could be described as a kind of Web 3.0 solution.

The model is thought to be designed to function both as a “Virtual Dementia Coach”, a “First Aid Kit” and a “Social forum for knowledge and experience sharing” for relatives/informal carers. The “Virtual Dementia Coach” should support the development of the learner's knowledge and skills by presenting factual, validated knowledge about dementia and information on how the learner can optimally support the demented person. It should also introduce e-learning programs that focus on supporting caregivers and develop their knowledge, skills and attitudes in relation to the specific challenges they are facing. If a caregiver has previously received formal instruction, then the application can work further to develop this knowledge and these skills by interacting with the content of the “Virtual Dementia Coach”.

The “First Aid Kit” can act as a “here and now” resource that can present on-the-spot suggestions for the resolution of some of the problems that caregivers usually meet in their daily dealings with the demented person.

Task 4

Task 4.1. E-learning application specifications

An extensive survey among end-users in the participating member-states will be performed to fully understand their needs and the expected output of the

applications. Requirements and specifications will be defined, namely the design, contents organization and structure, touch technology, etc.

When defining the e-learning application, state-of-the-art technologies and approaches will be taken into consideration and they will include:

- mobile learning, ubiquitous e-learning,
- Web 3.0, augmented intelligence,
- connectivity,
- usability and accessibility standards,
- open source technologies,
- cloud computing (SaaS).

Task 4.2. Design and programming of the e-learning application

The application is thought to be built on an open source heterogeneous software service in order to allow a smooth and error-free integration into the final platform (e.g. using CORBA, Web 3.0, ICE, or related technologies).

Task 4.3. Development of CarePlatform

The platform is meant to be based on cloud technologies in order to provide easy deployment of new contents, to have access from several devices (end-users will log in into the server and will have direct access to their profiles from any smartphone, tablet or computer), allow input and communication from end-users, etc. This demands open source heterogeneous software service that can be accessed by multiple platforms (Android, Linux, iOS, Windows, C, C++, Java, C#) e.g. using CORBA, W3C Web services, ICE, or related technologies.

Task 4.4. Integration of the system

This task focuses on the integration of the e-learning interface and dementia contents with the CarePlatform in the final version. This integration requires extensive hardware and software implementation tasks. The CarePlatform should be integrated in an iterative fashion, producing several prototypes: on principals in actions, on wireframes, on graphical user interface, on cloud based services, on individual application – before testing and implementing the final system version 1.0.

Task 5

Task 5.1. Testing the CarePlatform

The work should be carried out according to the implementation goals and objectives defined at the beginning of the project. The iterative process makes sure that testing goes on in close relation to implementa-

tion ideals, making testing the first part of commercialisation.

Task 5.2. Evaluation and validation

Evaluation is key to establishing a feasible market model that needs little customization in relation to the following marketing and commercialisation.

End-users assist in the evaluation process in relation to testing activities to follow the intention of developing closely in relation to end-user, buyer and other stakeholder needs.

Task 5.3. Documentation of how well the final CarePlatform product assists caregivers

In order to provide a sound business case, it is necessary to demonstrate that the final product has a positive effect on stress realized on caregivers and that caregivers in fact will continue to use the CarePlatform over longer periods.

The final validation consists of three parts. A quantitative study with the aim to address whether there is a perceived measurable effect on depression and perceived life quality. Additionally, qualitative interviews about how the CarePlatform has been used in everyday life is planned. Finally, a focus group of professional caregivers and representatives from the Alzheimer Association should present feedback on the platform as the final version.

The protocol for the quantitative and the qualitative study is inspired by the results found in the DAISY study. Hence, the inclusion criteria include patient diagnosis, time since the diagnosis was provided, age and gender of the caregiver, relation between the caregiver and patient, caregiver educational background, etc.

The quantitative data collection consists of a questionnaire that can be filled out online by the caregiver with or without support by the trained staff from VIA or PUMS. The questionnaire addresses questions about depression and perceived life quality, so the results are comparable with the DAISY study.

Expected results

Apart from building the final “understAID” platform in two versions, different activities popularizing the platform are planned. The aim is not only to circulate the knowledge but also to sell the software to the wide international audience.

Additionally, a review publication of end-users psychological condition, a review paper based on the results of the report of task 2 and a research study of

dementia patients and their caregivers are planned. Also, the results of these papers, as well as dementia patients and their caregivers' needs will be promoted at some conferences or meetings with specialists and politicians.

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