

# ICT Services for Life Improvement for the Elderly

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**Abstract.** Integrated care ICT Platform to support patients, care-givers and health/social professionals in the care of dementia and Parkinson's disease with training, empowerment, sensor-based data analysis and cooperation services based on user-friendly interfaces.

**Keywords.** eHealth, Parkinson, Alzheimer, Dementia, Integrated Care

## 1. Introduction / Background

Almost 10 million Europeans live with dementia or Parkinson's disease today. As a result of ageing and life expectancy, the number of people affected by one of those conditions is forecasted to double by 2030, making them major health challenges for current societies. Those people want to live at their homes but they face difficulties in the daily lives both in managing their own care and in living independently because of their symptoms.

The increase of chronic patients has proven that nowadays acute health care systems are unable to tackle efficiently the current population needs. They were designed and organized to address acute care processes and not the continuous and life-long needs of chronic and multi-morbidity patients. Chronic care models are needed to address a person-centred perspective, coordinating care services to support long-term care.

Moreover, the World Health Organization (WHO) published in March 2015 the "WHO global strategy on people-centred and integrated health services" [1] to address the need for shifting the way health services are funded, managed and delivered. The suggested strategy supports the need for people-centred health services for patients, families and communities. According to this view, they would participate in their own care, provided in a context of integrated health services that would ensure the continuum of health promotion, prevention, diagnosis and treatment at the different levels of care.

However, the concept of integrated care cannot be limited to health services. The rising burden of chronic disease and of the number of people with complex care needs require delivery systems that bring together a range of professionals and skills from both the cure (healthcare) and care (long-term and social-care) sectors. The concept of integrated care seems particularly important to service provision to elderly, as elderly patients often are chronically ill and subjects to co-morbidities.

In Europe, the situation varies considerably across the countries not only because of the demographic differences but also because of health and social systems rooted in different histories and cultures.

European health systems are already moving away (but not at the same pace) from the treat and cure acute conditions culture to face the challenges posed by the demographic transition to an ageing society and the increasing burden of chronic diseases and related co-morbidities. Strategies at the country or regional level have been adopted dealing with organisational, financial, delivery and eHealth technology aspects.

This is the scenario where the project solutions aim to be implemented.

The project is a three-year project financed under Horizon2020. Its main objective is to create a Platform for Integrated Care to connect patients, families, health/social professionals and care-givers through user-friendly tools. Therefore, it is a solution focused on supporting patients suffering neurological chronic diseases, considering its impact as a health challenge. The project includes the perspective of integrated healthcare services to support chronic care in a patient-centred approach and with cooperation among professionals from different disciplines and different organizations.

The technical development is focused on supporting final users. Thus, their involvement is of great importance since the beginning of such process.

It is for this reason that end-users' organisations with expertise in Parkinson's and dementia have participated since the beginning in a co-creation process.

The co-creation process started with the analysis of requirements and functional design and then was followed by a process of early and iterative feedback to efficiently targeting the end-users' needs.

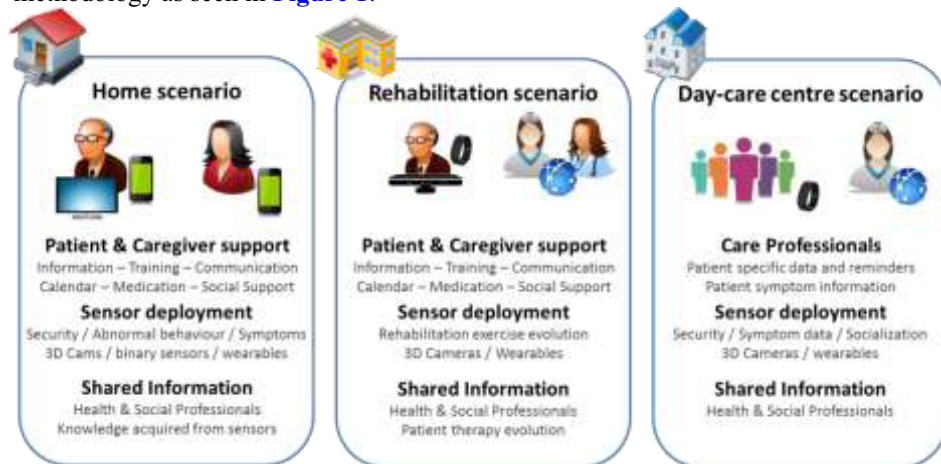
The project solution proposed relies on: new training models for the health and social care workforce as well as formal and informal care-givers; advanced multisensory-based analytics and integration with biomedical devices to patient activity and health status information to support security and risk detection at patient location; feedback-based decision-making engine to integrate patients' and care providers' data; improvement natural interaction mechanisms with patients using interfaces through SmartTV, smartphones and desktop applications. Web interfaces are responsive and use latest web technology (HTML5, Angular) to adapt to different devices and screens, additionally patient Android Apps have separated functionality from the interface with the objective of designing different interface layouts depending on patient disease stage to facilitate the use of technology to those patients with higher problems.

This paper focuses on one side, on the development of service technologies, which have been created with the cooperation of end-users. On the other side, it focuses on the process of iterative feedback started in 2017 that will end in July 2017 with concrete feedbacks for the project. It will enable service and platform improvement. The organization of ideas complies with the guidelines for papers provided by the AAATE2017[2], presenting the methods used in the first place, the results in the second place, followed by a discussion section before the concluding section.

## 2. Methods

The identification of end-users' requirements has followed a research methodology based on a multidisciplinary approach using recorded personal diaries of patients during their daily life and feedbacks of their care-givers, health professionals and social workers. This process has established set of requirements for the technology that has helped the technical team to adapt the functionality to end-users' needs and the interfaces to end-users' preferences.

Three main scenarios are considered and will be tested within the validation methodology as seen in [Figure 1](#):



**Figure 1** ICTPlatform testing scenarios

- **Home scenario** where personalized training, reminder, communication and rehabilitation services will support patient empowerment and independent living. The patient will be monitored through several sensors allowing to gather simultaneously real-time data and to detect abnormal behaviours. Thus, the patient and his/her health status will be constantly monitored while ensuring independent living. When a risky situation is detected, the platform will connect the patient with his/her family, care-givers and professionals through friendly tools. This approach contributes to increase the quality of life not only of the patients but also of carers who are often patients themselves. The platform is finally aimed to support the decision-making process of the professionals who will use the services to monitor the evolution of patient's disease symptoms.
- **Rehabilitation scenario** will support the analysis of patient evolution during the therapies and while performing exercises. The continuous monitoring will help professionals from the health and social sectors to assess the effectiveness of therapies and, eventually, to improve the integrated approach to care for people affected by these neurological diseases.
- **Day-care centre scenario** where several patients will be monitored simultaneously to support social carers and to obtain specific information on patient status. The project technologies will allow to collect patient specific data related to his/her specific symptoms and to establish an exchange of

information with professionals, in turn connected to the platform with specific tools.

Initially, with the first version of the technology, early feedback tests have been carried out on mockups and sensor-based tools in order to address the disease and the end-users' specific needs.

Additionally, a continuous process of iterative testing has been designed where functionality services will be experienced by end-users (patients, care-givers and professionals). The ratio consists in identifying usability improvements; clarifying service details and adapting the technology to user needs in a co-creation process of testing and development with a multi-disciplinary team of users, user experience designers and technical developers. This process is in place in three countries (Spain, Hungary and France) in order to address cultural differences, also including patients suffering different diseases (dementia and Parkinson's at different stages). Care-givers and professionals from the health and social sectors have been involved too.

The iterative testing is based on a cyclical procedure with testing and development periods in order to gather feedback from all end-users (patients, caregivers and professionals), identify improvements and develop new functionalities based on the feedback before initiating another testing period. The process runs in parallel in three countries in order to gather feedback simultaneously. Feedback is incorporated in a unified template to identify improvements to be made and also needed adjustments due to cultural or regional context. Additionally the process also supports bug identification improving system stability with every testing phase.

A common research methodology has been developed in order to collect data around the whole project and thus to provide comparable final evidences. The key information has been included in a unified research book for all country teams. It is an important part of the iterative testing process to better assess the results and feedback provided by the end-users and to do health and social research with additional information. Also as a unified research book will enable the comparison of results among different countries to taking into account the cultural differences and to observing how the platform is deployed in different contexts. The implementation process is flexible and will be adapted to the feature of the context.

The research will also contribute to create knowledge on the impact produced by the same eHealth technology when applied in different real scenarios. More in particular, the analysis of scenarios will be supported through the implementation of a method developed by a further EU initiative [3], aimed at discovering the strengths and weaknesses of a given geographical region. The objective is to ensure the successful and effective scaling up of the developed platform.

### 3. Results

The platform integrates a set of technologies tailoring end-users' specific requirements acquired during the first year of the project.

More in particular, the project integrates several levels of support for end-users: first, friendly tools with services for patients and caregivers based on empowerment, personalised training, information sharing and communication with their care professionals; second, sensor-based tracking platform to support patient independence at home detecting the patient health status and supporting data acquisition and improving home security by warning carers of risky situations. Finally, artificial

intelligence modules embedded in the platform, are aimed to support service personalisation based on the concrete needs of each patient and the professionals' decisions based on a deeper understanding of the patient situation by fusion of sensor data and patient's health and social electronic records.

All service functionalities will support integrated care processes involving directly patients and care-givers but also the cooperation among professionals as regards the patient treatment and care decisions.

Iterative testing process and data research are providing results in the fields of service efficiency and usability, technical recommendations to support elderly patients and caregivers and information needs for different professionals from the health and social sectors.

The testing feedback help us in the continuous improvement of the services, functionality and interfaces offered to all end-users (patients, care-givers and professionals) in order to better address their needs, and additionally will help in the development and improvement of the internal functionality that supports the services, like data fusion and analysis, decision support functionality and sensor-based functionality.

Current results from iterative testing process target mainly interface improvement, by selecting proper devices, feedback directs us to use also tablet layout for patients with higher difficulties in hand movement and those not used to Smartphones, screens are bigger and elements on the screen are easier to see. Additionally content structure changes have been proposed in order to facilitate user access to it and new functionalities to support easier interface navigation, such as voice commands to directly access concrete modules by voice in different languages. On functionalities based on professional content it has been useful to identify adequate content structure in order to facilitate the understanding by elderly users.

The testing feedback process is put in place periodically during the project lifetime. The first prototype of the technology was presented to relevant European organisations representing end-users. The event was the occasion of testing reactions and gathering information on how to improve the technologies and make them more coherent with the end-users' needs. Participants had the possibility of playing with them, especially when it came to interfaces.

The contact with end-users' organisations as well as policy makers and stakeholders started at the beginning of the project. Every partner was asked to provide information in this regards and to constantly update the so-called stakeholders list. This step allowed to build the basis for creating synergies and establishing an exchange of information on a periodic basis, through the project's dissemination channels. The communication approach is targeted and adapted to the audience.

#### **4. Discussion**

Validation will be done in real use case scenarios in three European countries. This will be aimed to support end-users in integrated care processes, to measure the effects of treatment and to evaluate project developments. We want to analyse how ICT platform could contribute to support in integrated care processes by facilitating coordination and cooperation among professionals, care-givers and patients and to overcome organizational, economic or cultural barriers to scale up innovations.

Integrated Care deployment has important barriers like organizational barriers and new care roles, cultural barriers among end-users and the need of economic models that support organization cooperation. An analysis on how to overcome these barriers and how ICT can support in the deployment and efficiency of integrated care processes is needed and the research feedback will support it.

The iterative feedback compiled until now has been very useful to adjust interfaces and some functionality modules. Process must continue in order to test all developed functionalities and gather additional feedback from new functionalities implemented. Nevertheless some difficulties have arisen due to different functionality preferences mainly due to cultural differences but also different technological backgrounds of the users. New functionalities or content changes need to be implemented in a way that facilitates the adaptation due to concrete preferences, therefore modules and system should be able to work also without them.

## 5. Conclusions

The process of iterative testing started in 2017 provides us feedback from end-users. The iterative testing is based on cyclical testing and development phases in order to incorporate new functionalities and test them with different users in a continuous process of improvement.

The feedback obtained already has enabled us to adapt the hardware preferences including layout adaptations for Tablets and incorporate new functionalities for interface navigation and user access. It has been important for the technical team in order to better understand the limitations and requirements of end-users especially those that are elder and that have low technological experience.

As testing has been running in several countries an important aspect of the testing has been the use of common feedback templates and a common Research Book for additional research objectives of the project. This enables us the comparison between countries and have homologated data from different testing scenarios for further analysis. Nevertheless it has to be taken into account that although using common feedback resources the cultural and background differences among countries needs to be taken into consideration to make functionalities that can be adapted and personalized to specific contexts at country or personal level.

## References

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- [3] See Scirocco project (2017), at <http://www.scirocco-project.eu/>