Intelligent Environments 2018
I. Chatzigiannakis et al. (Eds.)

doi:10.3233/978-1-61499-874-7-526

INLIFE - Independent Living Support Functions for the Elderly: Technology and Pilot Overview

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Abstract. In this paper, we present the European H2020 project INLIFE (INdependent LIving support Functions for the Elderly). The project brought together 20 partners from nine countries with the goal of integrating into a common ICT platform a range of technologies intended to assist community-dwelling older people with cognitive impairment. The majority of technologies existed prior to INLIFE and a key goal was to bring them together in one place along with a number of new applications to provide a comprehensive set of services. The range of INLIFE services fell into four broad areas: Independent Living Support, Travel Support, Socialization and Communication Support and Caregiver Support. These included security applications, services to facilitate interactions with formal and informal caregivers, multilingual conversation support, web-based physical exercises, teleconsultations, and support for transport navigation. In total, over 2900 people participated in the project; they included elderly adults with cognitive impairment, informal caregivers, healthcare

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professionals, and other stakeholders. The aim of the study was to assess whether there was improvement/stabilization of cognitive/emotional/physical functioning, as well as overall well-being and quality of life of those using the INLIFE services, and to assess user acceptance of the platform and individual services. The results confirm there is a huge interest and appetite for technological services to support older adults living with cognitive impairment in the community. Different services attracted different amounts of use and evaluation with some proving extremely popular while others less so. The findings provide useful information on the ways in which older adults and their families, health and social care services and other stakeholders wish to access technological services, what sort of services they are seeking, what sort of support they need to access services, and how these services might be funded.

Keywords. active aging; elderly support systems; cognitive impairments

1. Introduction

The numbers of older people with some form of cognitive impairment are rising and will continue to do so as life expectancy increases [1]. Across Europe there is also a growing number of mainly ICT-based solutions targeting this population that have until now been developing in parallel. Harnessing these solutions and making them available at scale could help to alleviate this growing problem, by supporting older adults with cognitive impairment to remain living independently for longer.

The majority of older people with cognitive impairment want to live independently for as long as possible. New technologies can support independent living and overcome many problems that occur in daily life [2]. This means supporting people to function within and outside the home, including travel. All of these domains require further evaluation along with greater understanding of the acceptance of technical systems by older adults, and their needs and desires as customers within the European and international market. The major challenge is in providing a holistic service that can address all aspects of a person's life and the challenges posed by cognitive impairment.

Loss of cognitive functions, abilities and capacities may be further exacerbated by other age-related conditions, such as limitations of mobility, visual and hearing impairments (e.g. macular degeneration), diabetes and stroke [3]. Additionally, many older people living alone feel lonely, which is strongly related to physical or mental health [4]. Reduced social contacts and social participation may be due in part to impaired communication, which is also common in many neurological conditions. Dementia and other progressive conditions (e.g., Parkinson's disease, Huntington's disease, motor neuron disease) may interfere with communication in a number of ways including the ability to produce and comprehend speech, or to initiate, maintain and end conversations [5]. People with neurological diseases may also experience restricted vision, hearing, mobility, and motor skills, which further complicate communication and reduce opportunities for social participation. There are also frail older people who have both cognitive and communication difficulties but no formal diagnosis and therefore receive limited support.

Additionally, many people in Europe live in countries other than where they were born and where they speak different languages to their mother tongue. When these people develop cognitive and communicative difficulties, the demands on interaction partners and carers can be compounded. The growing multilingual and multicultural

population of older people highlights the need for easily accessible communication tools, methods and strategies [6]. Adaptable responsive solutions are needed to tackle these cognitive, physical and social communication challenges to keep older adults participating in the social world.

Development outcomes of past projects (such as the German project insideDEM[2], the Canadian project Age Well[3], or the British project Sphere[4]) have shown the potential to deploy real ICT with pragmatic user groups (i.e. diversity in users with cognitive impairments either as the primary symptoms or as co-morbidities). ICT applications and services should be valuable for the needs of older people with cognitive problems while remaining affordable. Adopting technology is known to be very important for self-efficacy of people with cognitive impairment [7], but there currently exists a spectrum of reactions to IT from openness to adoption through to rejection or abandonment.

The INLIFE project[5], an EU H2020 project that ran from 2015 to 2018, aimed to prolong and support older adults with cognitive impairment to maintain independence through interoperable, open, personalized and seamless ICT services that support home activities, communication, health maintenance, travel, mobility and socialization, and with novel, scalable and viable business models, guided by feedback from large-scale and multi-country pilots. In this paper, we first present an overview of the project, including the system architecture, and then present the initial results of the pilots carried out within the framework of project. At the end, we discuss the findings and their implications.

2. Method

A. Participants

First, a baseline assessment was conducted with 953 users. Next, six pilot sites were established in Greece, the Netherlands, Slovenia, Spain, Sweden, and the UK. Four groups of participants were identified for INLIFE: older adults living with cognitive impairment, informal caregivers, health and social care staff, and representatives of stakeholder organizations. Each site recruited representatives of each of the four participant groups, totaling 1958.

B. Measures

All pilot sites used the EQ5D [8] and the Quality of Life in Alzheimer's Disease [9] questionnaires. Several sites also used a measure of cognitive function concordant with the measures used in local memory services, either Mini Mental State Examination [10] or Addenbrooke's Cognitive Examination III [11]. Informal caregivers also completed the Zarit Caregiver Burden Interview [12] to provide an assessment of their subjective experience of distress related to caregiving for a family member with cognitive impairment. Participants also completed a demographic and socioeconomic status questionnaire. This included questions relating to current living arrangements,

[2] http://insidedem.de/
[3] http://agewell-nce.ca/
[4] http://www.irc-sphere.ac.uk/
[5] http://www.inlife-project.eu/

education, employment status, access to healthcare, and total annual family income. At the end of the pilot phase participants completed questionnaires relating to their experience of using INLIFE during the study and their intention to use it in the future.

C. INLIFE platform

The INLIFE architecture comprises an open cloud-based platform integrating 17 services across four themes: Independent Living Support (7 services), Travel Support (3 services), Socialization and Communication Support (3 services) and Caregiver Support (4 services; see Fig. 1). The INLIFE technical infrastructure was designed to support older people with cognitive impairments in a variety of indoor and outdoor activities. This was to be achieved through monitoring user activities and preferences in an unobtrusive way. INLIFE was also designed to provide help and support to caregivers. The intention was to provide easy, transparent, personalized and contextualized access to INLIFE services and applications through a single application center.

Different tools used in the project are spread among many different devices and technologies. For example, fall detection and user activity level are recorded and recognized on a smart watch on the user's wrist. When the user is driving a car, he or she uses the dedicated application that works on an Android tablet, while socialization and cognitive assessment is facilitated by carers using a web browser on a computer. A common platform was designed in order to gather data sent across different devices, to allow user authorized access to all of the services and to allow carers different levels of access to user's data depending on their role. Furthermore, the platform analyses user's behavior and usage of the system, and through a matchmaking procedure recommends new tools for the user that might prove useful (Fig. 2). For example, active users of the travel support module might also be interested in the activity monitoring service

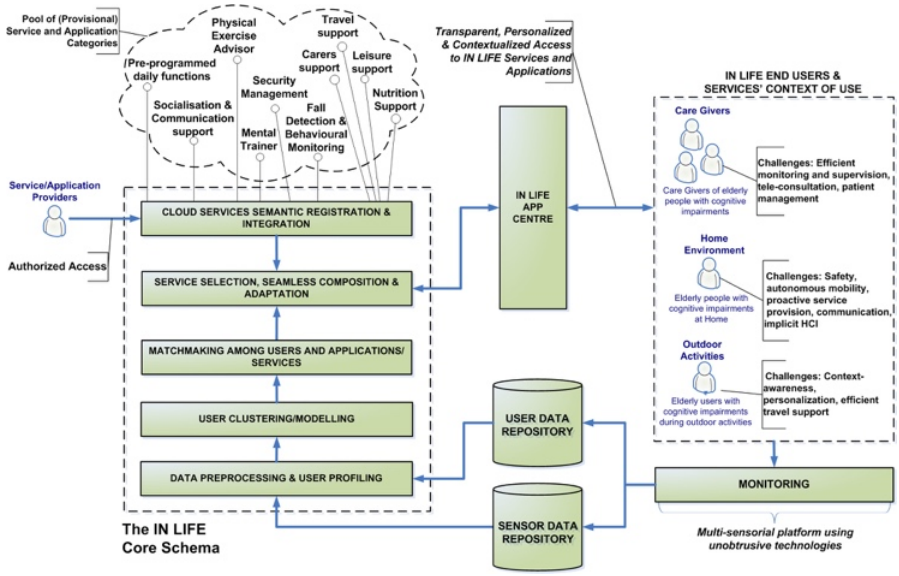

Figure 1: INLIFE conceptual architecture.

provided on a smartwatch in the fall detection module.

Most of the tools have an intermediate server for facilitating the tool at the country of use as opposed to one central server for all of the tools and services. This architecture allows better response times, lower costs for data transmission, and is more robust to a single point of failure. Furthermore, due to different legislation in each country, it is not always allowed to share or store certain data about the users outside their country of residence or where the data were collected. Servers use the REST protocol over HTTPS for communication. Depending on the type of the data, the data are anonymized, encrypted and/or only stored locally. RFC 4880 standard is used for encryption services.

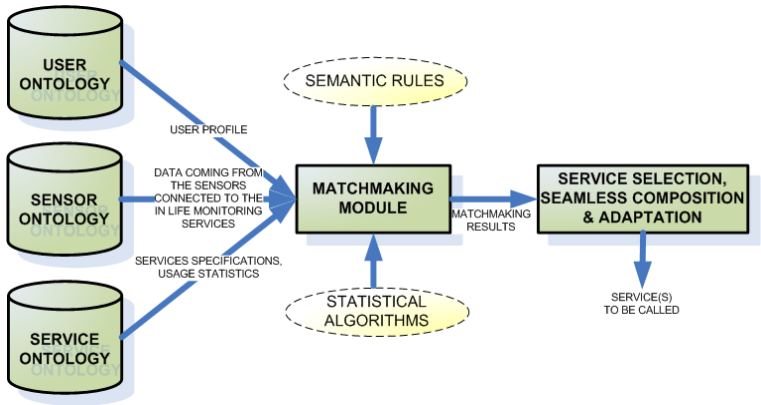

Figure 2: INLIFE service matchmaking.

D. Procedure

Participants were recruited at the six pilot sites between January 2016 and September 2017. Recruitment was conducted across a range of services including outpatient clinics, assisted or supported living facilities, and long-term care and nursing homes. Assessment was undertaken at baseline before the introduction of any INLIFE services. This comprised the formal measures and demographic questionnaires to characterize the participant groups prior to offering the INLIFE services.

The pilot phase immediately followed the baseline. Each pilot site offered a different combination of services to their participants to maximize the feedback for the wide range of services (Table 1 & Table 2) – some services, such as leisure support, were offered at several sites, while others, such as the fall detection wristwatch, were offered only at a single site. The same formal measures were repeated and after using the INLIFE services participants completed the questionnaires relating to the experience and future intentions to use.

Table 1. Services offered to people with cognitive impairment at each pilot site

Pilot site					
Greece	Driving assessment	Trip planning	Physical activity monitoring	Guardian angel	Mental training tools
NL	Web-based exercises	Health monitoring	Teleconsultation	Leisure support	
Slovenia	Fall detection wristwatch	Home security functions			
Spain	Daily functions assistant	Public transport support	Web-based exercises	Leisure support	Virtual training
Sweden	Socialization and communication support	Multilingual support	Leisure support		
UK	Leisure support	Daily functions assistant			

Table 2. Services offered to informal caregivers, healthcare professionals and stakeholders

Pilot site	Informal	Healthcare	Stakeholders
Greece	Guardian Angel Physical activity monitoring	Guardian Angel Physical activity monitoring Mental training tools	Whole INLIFE platform
NL	Patient management and monitoring	Web-based exercises Patient management and monitoring Leisure support	Web-based exercises Patient management and monitoring Teleconsultation
Slovenia	Caregiver monitoring Fall detection wristwatch	Caregiver monitoring Caregiver scheduling Fall detection wristwatch	Fall detection wristwatch Security functions Whole INLIFE platform
Spain	Daily function assistant Web-based exercising Public transport assistant Leisure support	Daily function assistant Web-based exercising Leisure support	Daily function assistant Whole INLIFE platform
Sweden	Socialization and communication support Multilingual support	Socialization and communication support Multilingual support	Socialization and communication support Multilingual support
UK	Leisure support Daily function assistant Whole INLIFE platform	Leisure support Daily function assistant Whole INLIFE platform	Leisure support Daily function assistant Whole INLIFE platform

3. Results

A. Participants with cognitive impairment

Across the six pilot sites 803 older adults living with cognitive impairment took part in the baseline assessment. They were aged 39-104 and 60% were female. One third lived with a spouse or other family member(s), with 27.5% having only primary education, 17.5% secondary education and 13% higher education. Fifty-one percent had access to government-funded health care with only 1.25% having private insurance or self-paying for healthcare.

In the pilot phase of INLIFE, data was collected from 1163 older adults with cognitive impairment. They ranged in age from 39-104 years, 60% were female and

37% lived with spouse or family. Thirty-one percent had primary, 16.6% secondary, and 16.8% higher education. A little over 1% stated they had no formal education. Fifty-one percent had access to government-funded healthcare and 7% either self-pay or private insurance. In both the baseline assessment and the pilot study, a substantial number of people provided no answer or chose not to answer, including almost one half when asking about the healthcare insurance.

B. Informal caregivers

In the baseline phase of the project, there were 140 informal caregivers. Eighty-seven percent were family members of people living with cognitive impairment and 6% were friends. Half were under 60 years of age, with a further 40% aged between 60 and 75 years of age. Sixty-five percent were female.

In the pilot phase, data were recorded from 362 informal caregivers. Eighty-two percent were family members and 2.7% were friends. Two-thirds were female, with 53% aged under 60 years of age and a further 36% aged between 60-75 years of age. Again, in both cases, some people provided no answers.

C. Healthcare professionals

Ten healthcare professionals were recruited in the baseline phase of the project. They were all nurses, aged under 60 years of age and 70% were female. In the pilot phase, data were collected from 407 healthcare professionals.

D. Stakeholders

In the pilot phase data were collected from representatives from 26 stakeholders including health and social care providers, housing, charitable sector, community services and long-term care. Fifty-eight percent were female, 46% were under 60 years of age, and 35% between 60-75 years of age.

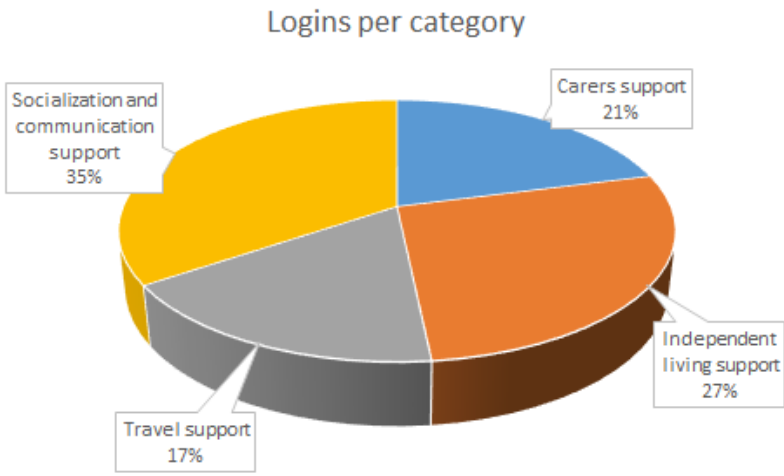

Figure 3: INLIFE application center – logins per category

E. Accessing the INLIFE platform

All 17 INLIFE services were accessed through the INLIFE application center and the percentage distribution of logins from a service belonging to a particular category are shown Fig. 3. As can be seen, the distribution across the four categories varies with Socialization and Communication Support accounting for about a third of all logins.

In respect of the end of pilot questionnaires regarding the use of the INLIFE platform, over 67% of older adults living with cognitive impairment said the system was easy to start using. Fifty six percent said they felt the INLIFE platform would increase their confidence in day-to-day activities and 53% agreed it might increase their independence. When asked about future use of INLIFE, the majority of each of the four participants groups said they would be prepared to pay for the service: older adults 57%, informal caregivers 61%, healthcare professionals 73%, and other stakeholders 50%. On the other hand, if the service were free, then 70% older adults with cognitive impairment, 100% of informal caregivers, 99% of healthcare professionals and 100% of other stakeholders would use it again.

4. Discussion

The project has recruited participants from a wide range of settings to test the integrated INLIFE platform. The analysis to date suggests firstly that older adults with cognitive impairment are interested in using technology in all aspects of their daily lives. The results show that the majority of elderly users found it rather easy to start using the INLIFE system, even though most of them did not have much technology knowledge at the start of the study. The majority of the users who indicated that they found it “difficult” or “very difficult” to use were very elderly with no technology knowledge, and/or no education, vision issues, or hand tremor. Some users did not know how to use it, had various degree of memory/cognitive decline or had experienced some kind of malfunction.

Regarding the services available, those in the support for independent living category and socialization and communication support were accessed the most. This may in part reflect the distribution of services that were tested across the pilot sites. The feedback on all four categories was generally positive with older adults feeling that the services could support their independence. All types of users appreciated the potential of the INLIFE services for supporting them in their daily lives whether this was living with cognitive impairment or caregiving. The possibilities for continuous monitoring and communication between the older adults and caregiver through INLIFE were noted. Additionally, a majority of participants in each of the four participant groups said that they would use INLIFE in the future, especially if it was freely available to them.

In respect of lessons learnt the example of the Slovenian pilot illustrates some of the practical issues of implementing the INLIFE services. The Slovenian pilot focused on testing the smartwatch-based technology for fall detection, a service offered in the Support for Independent Living category. User reaction to the technology varied. Generally, the users found wearing the smartwatch convenient as they were already used to wearing wristwatches. Users who were living independently at home - the younger and more active part of the group involved in the pilots, who can be viewed as

the target demographics for the technology - embraced the watch and actively used it [13]. Some users became more active and started going out for walks or doing chores around the house, because of the renewed sense of security. On the other hand, the users in nursing homes were less interested in using the watch as they already felt secure. Furthermore, users with advanced stages of dementia were unable to remember even basic instructions for the watch and were therefore not able to use it for the intended purpose.

The main complaints about the watch were related to the size and ergonomics, as the device used was rather large. The watch was not waterproof which meant it had to be removed before taking a shower. A major issue turned out to be the battery life, as the watch required charging on a daily basis. When analyzing the number of false alarms, the users did not seem to mind having about one false alarm per day (one they could also cancel manually and did not necessarily result in a call to the call center). They stated that false alarms reminded them that the system is still functioning properly and that there was someone (the call center operator) actively taking care of them.

Based on the findings in the pilot, the Slovenian team decided to work on developing dedicated hardware instead of the commercial hardware with dedicated software used in the pilots, to allow better ergonomics and waterproofness, and significantly longer battery life by keeping only the sensors and interfaces that are relevant for the fall detection system to work. The lessons learnt from other pilot sites will be described in detail in future publications.

INLIFE was an ambitious project with the intention to provide a range of services for older adults living with cognitive impairment in the community. This was approached by bringing together a range of services, some of which were mature and others that were emergent, to offer support for all aspects of life of older adults living with cognitive impairment. The six pilot sites provided access to different demographic and socioeconomic groups of participants and different models of health and social care provision. The project also provided the opportunity to examine real-world implementation of not just one, but multiple services accessed through a single portal. Additionally, the INLIFE services were offered on a range of devices including wearables, tablets, and smartphones. As the data analysis continues the lessons learnt are only beginning to emerge but we anticipate the findings of INLIFE having an impact for developers, researchers, service providers and, of course, older adults living with cognitive impairment.

Acknowledgment

This project was funded by the EU H2020 project INLIFE, Grant number 643442.

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