

# COLLECTING USER REQUIREMENTS FOR ELECTRONIC ASSISTANCE FOR PEOPLE WITH DEMENTIA: A CASE STUDY IN THREE COUNTRIES

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## **Abstract**

*Collecting user needs for a personal digital assistant for people with dementia and their personal environment is a demanding task. If these people are coming from more than one country with different cultural and socio-economic backgrounds, a tailored approach which can be customized has to be applied. Therefore in the Confidence project an adaptable iterative approach to collect user requirements for a system supporting people with dementia has been applied and validated within the user requirements engineering phase in three countries.*

**Keywords** – *user centred design, ambient assisted living, system supporting people with dementia, mobility safeguarding assistance service*

## **1. Introduction**

Changing mortality patterns in Europe lead to a growing number of older people. There is an increase in incident and prevalence of chronic conditions. One of the challenges in this context concerns the rising number of people with dementia. Dementia is a general umbrella term that subsumes diseases of cognitive impairment like Alzheimer's disease, vascular dementia or dementia with Lewy bodies [2]. Three stages of dementia can be distinguished: mild, moderate and severe [3]. In the first stages people suffer from moderate memory loss, difficulties with time-space relationships and disorientation even in places they are familiar with. Furthermore they have troubles in handling complex problems, are increasingly confused, lose the ability to do everyday tasks and related to this, show apathy and withdraw themselves from social life [3]. As a result of the increasing sense of disorientation people get fearful and consequently they gradually lose their independence and mobility. Common routes and tasks such as shopping, housekeeping or simply taking a walk become a daily challenge. They often feel unsure in their daily routine. In recent years people recognized that the possibilities of information and communication technologies (ICT) might support the elderly in dealing with their deficiencies caused by dementia [7]. Currently different systems on the market mainly address disorientation loss (e.g. GEOCARE, MethusaTrack,

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Vega<sup>1</sup>). With these systems it is possible to simply call for help in case of emergency by pressing a panic button. So called geo-fences (a predefined set of geographic boundaries) help to automatically raise an alert and forward it to a call centre if the elderly is leaving a safe area. As with many Ambient Assisted Living (AAL) products the functionality of these systems is often tailored to specific sales markets. Typically it is not possible to adapt these solutions to varying models of elderly care in different countries [8].

The Confidence project aims at providing mobility and safeguarding assistance services which are adaptable on the individual needs of people with mild to moderate dementia. A novel community-enabled service which combines “assistive technologies” with “personal help” is going to be developed. For this purpose a community consisting of family members, employees of home care agencies and trusted volunteers (neighbours, friends or social volunteers) will be built up. They will use information and communication technologies to collaborate in providing help for the elderly. The mobile Confidence service is planned as a “virtual companion” providing different levels of assistance which can be adapted depending on the situational needs of the patient and the degree of orientation loss. Conceptually five modules are planned (1) *assistance and training at home* (2) *virtual voice service* (3) *virtual video service* (4) *location tracking service* (5) *mobile community service*.

A challenge of AAL projects is that elderly often feel insecure and even frightened when testing technological solutions. In more and more projects elderly and their relatives are put in the centre of the system’s design and development phase. The way taken in the Confidence project is to follow the standard for user centred design for interactive systems [4].

## **2. Methodology**

Confidence services will be developed according to the user centred design approach [4]. Following this approach the two identified user groups for Confidence (people with mild to moderate dementia and formal and informal carers) will be actively involved in all phases of the project. The work is split in the four key activities “understand users and specify the context of use”, “specify user and socio-cultural requirements”, “produce design solutions” and “evaluate design against user requirements” [5]. The next section steps into the methodology which addresses the first key activity (“understand users and specify the context of use”) within the project.

### **2.1. User requirements engineering methodology using user centred design**

As the user requirements were collected by three end-user organizations (Hilfswerk Salzburg, Ana Aslan International Foundation/Academy of Ageing and terzStiftung) in three European countries (Austria, Romania and Switzerland) with different cultural and socio-economic background, a common approach was defined. According to the user centred design methodology an iterative process consisting of three stages and two iterations was defined (cf. *Figure 1*). For each stage several procedures/methods were proposed, so that for each country the appropriate procedure/methods could be used. In the following the stages of the process and the proposed methods will be explained. Thereafter the customized country-specific approaches will be presented.

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<sup>1</sup> [www.geo-care.de](http://www.geo-care.de), <http://www.ctrixs.com/methusatrack>, <http://www.everon.fi/en/products/hardwares/vega/>

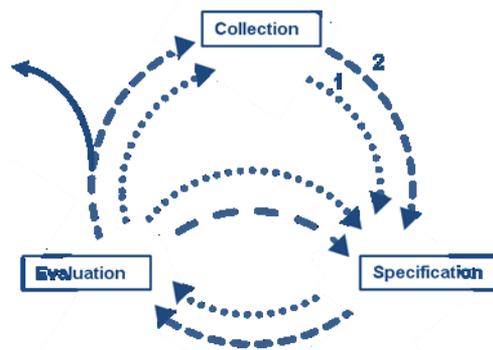


Figure 1: Iterative approach with three stages

In the first step of the *Collection* phase secondary end-users (e.g. nurses, physicians, psychologists, social workers and family members of people with dementia) were asked about useful functions of the Confidence system. As each of the involved end-user organisations has access to the secondary end-users in different ways (employees, relatives from customers, patients of the end-user organisations, members of a senior network) two popular methods of user centred design for requirements gathering were incorporated – focus groups and questionnaires [5]. The resulting user requirements were then directly integrated into the *Specification* phase. In this phase country-specific personas (fictional characters to represent potential system-users) which characterize a typical end-user and reflect its cultural and socio-economic background were defined. For each persona a corresponding user story consisting of at least five scenarios was written [9]. During the *Evaluation* phase both personas and user stories were examined and revised by dementia specialists of the end-user organisations. In the second iteration also primary end-users (people with mild to moderate dementia) had the opportunity to bring in their own ideas. Therefore in the second iteration of the *Collection* phase only focus groups with family members, care professionals and people with dementia were performed. These workshops were based on the scenarios created in the first iteration [6]. People with dementia were also able to grab the idea of Confidence and bring in themselves with new ideas. The additional requirements were then directly integrated into the second *Specification* phase and country-specific personas and user stories were adapted and extended. In the final *Evaluation* phase both country-specific personas and user stories were examined and revised by dementia specialists of the end-user organisations and also by external specialists in form of interviews and expert surveys.

## 2.2. National implementations

The above described general approach was adapted for Austria, Romania and Switzerland according to country-specific conditions. In *Austria* focus groups were done for both iterations. The first focus group consisted of eight people (2 social scientists, 1 nursing scientist, 5 nurses specialized in geriatrics). In the second iteration 20 people participated (3 people with dementia, 7 informal carers, 8 nurses specialized in geriatrics, 2 social scientists). In *Romania*, three workshops were held. The focus group of the first iteration consisted of 13 people (3 doctors specialized in geriatrics and psychogeriatrics, 2 psychologists, 3 medical assistants with competence in long term care at home for seniors with dementia, 5 informal carers). In the second iteration two focus groups were done. One focus group including people with dementia (3 doctors specialized in geriatrics and psychogeriatrics, 1 psychologist, 2 medical assistants, 9 people with dementia) and another focus group with people involved in the dementia topic from different non-profit organisations and public entities such as the national organization of handicapped persons, the national association for

patients protection or the national council of old people. The *Swiss* project partners decided to prepare a questionnaire for their senior network for the first iteration. The questionnaire was sent out per e-mail to 300 senior network members resulting in 67 completed and evaluated feedbacks. For the second iteration they did not directly involve end-users but they had a meeting at a day care centre for people with dementia where they tried to validate the requirements. Furthermore expert surveys with nine experts (2 nurses specialized in geriatrics, 2 call centre employees responsible for a dementia hotline, 1 doctor specialized in gerontology, 3 doctors specialized in psychogeriatrics, 1 social scientist) have been conducted.

### **2.3. Classification, negotiation and prioritization of the requirements**

After the collection phase in each country the user requirements were brought together and classified in order to be able to assign them to the five Confidence modules (assistance and training at home, virtual voice service, virtual video service, location tracking service and mobile community service). Thereafter the requirements were negotiated by stakeholders of the end user organisations during a user requirements workshop [1]. In a final step they were prioritised by the whole project consortium.

## **3. Results**

In this Section we point out some country-specific results. Finally, embedded into the five conceptual Confidence modules, the ten user requirements selected for implementation (10 out of 81) during afore mentioned user requirements workshop will be briefly described.

### **3.1. Country-specific user requirements**

In case of emergency accurate localisation is an essential requirement. Due to rough terrain this can be challenging in *Austria*. Furthermore environmental information like current weather conditions in combination with proper clothing recommendations or information about sunset and sunrise should be provided by the system for the end-user. In *Romania* many relatives of the participating end-users live and work abroad due to the current economic situation. Therefore different functions for communicating with relatives (video or voice) are of increased importance. Furthermore, in Romania public transport services are interrupted often due to strikes. A possible functionality for Confidence in this case would be a news headline to avoid stress situations for helpers. In *Switzerland* due to the well-developed public transport services, topics like “route information in public transport” or “how to operate a ticket machine” play a major role.

### **3.2. Core user requirements**

#### **3.2.1. Virtual voice or video service**

*Need assistance:* A person suffering from dementia could easily get in a situation where she/he needs help and therefore wants to talk to someone. She/he must have the possibility to press a button on her/his Confidence device and be immediately connected via voice call to a person she/he is familiar with. If supported by the device, the helper can activate the video service helping to give trust to the person in need.

*Calling the person in need:* A helper must have the possibility to call the person in need via voice call and talk to her/him at any time. If supported by the device the video service can be activated too.

### 3.2. 2. Assistance and training at home

*Send emergency alerts:* In case the Confidence system detects an emergency an alert has to be raised. A helper needs to confirm the alert to tell the system that it was received and the according actions are initiated.

*Receiving reminders:* A person suffering from dementia must be reminded on her/his Confidence device via pre-configured reminders to not forget important activities. Some very important reminders like medication reminders need to be confirmed to be sure she/he has read them.

*Viewing daily schedule and tasks:* People with dementia must have a simple view of their daily schedule including all appointments and tasks they may have to do today.

*Get environment information:* A person suffering from dementia must be able to easily access environmental information on demand (e.g. weather conditions, sunset and sunrise).

### 3.2. 3. Location tracking service

*Localise a person in need:* In case a person in need either *needs assistance* or actively raised an *emergency alert* the helper must have the possibility to localise the person and get information on her/his current position via a mobile device.

*Find way back home:* If the person in need loses her/his way she/he must be able to call a familiar person who has all information to guide her/him home.

*Find next step in public transport:* The person in need must get on-demand information on her/his route part in the public transport system to get to her/his destination easily. The information must at least consist of a bus or train line to take next and the location of the nearest station.

### 3.2. 4. Mobile Community Service

*Stay in contact with loved ones:* People with dementia as well as their family members and friends must have the possibility to stay in contact via the Confidence community service using their mobile devices. Voice and video communication must be supported.

## 4. Discussion and conclusion

The idea of combining assistive technologies and personal help involving the social environment of people with dementia was well received by workshop participants and interviewed persons. The three stages of our approach (Collection, Evaluation and Specification) have been successfully applied within two iterations and three countries. Each time additional requirements have been created which have not been considered by the consortium when thinking about possible functionalities for Confidence. One of these ideas has been a reminder component which was classified as very important by primary and secondary end-users. Furthermore it could be shown that the involvement of the primary end-users even in the second iteration of the process has been the right decision. At this time first user stories were available so that the project was not as abstract

as it has been in the first iteration. The end-users now had an idea what Confidence might be and they were able to give feedback and additional input. The requirement *viewing daily schedule and tasks* has been created within the second iteration by the primary end-users. Also the openness of the presented approach regarding the use of different procedures/methods (e.g. focus group, interview and questionnaire) has been beneficial. So each end-user partner had the possibility to choose a suitable procedure/method for its country-specific conditions. In all workshops and interviews in each participating country *three general findings regarding the system acceptance emerged*: Country-specific requirements must be considered in order to achieve a system acceptance in each country. Disease acceptance (by patients as well as relatives) and privacy protection of patients are the most crucial requirements for successful adoption of the system.

## 5. Acknowledgment

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