Abstract. Dementia is a progressive, chronic disease affecting 5% of all persons above 65 and over 40% of people over 90. The aim of the COGKNOW project is to achieve a breakthrough with research that addresses the needs of those with dementia, particularly those with mild dementia living in the community. This entails cognitive reinforcement in four main areas: helping people to remember, helping to maintain social contact, helping with performing daily life and recreational activities and finally enhance feelings of safety. Based on a sound foundation of needs reported in dementia literature, workshops and individual interviews have been carried out with dementia sufferers and their carers in three European countries. A ranked analysis of information from workshops and interviews, and the state of the art of successful ICT solutions will be the basis for formulating the functionalities of the technical solution and for the development of a cognitive prosthetic device with associated services for people with mild dementia. The research and evaluation will be conducted from human factors, technology, and business perspectives in three phases of one year each.
In this paper we discuss the design of the COGKNOW project, the first results of the user needs inquiry workshops and the ICT solutions the COGKNOW project will focus on in the first year.

**Keywords.** Dementia, ICT, Needs, User-centered, Business models

**Introduction**

Studies in which people with dementia themselves describe their needs indicate that the most frequently identified unmet needs are in the areas of information (on treatment, care and support, appointments), memory problems, communication, meaningful activities during daytime, and psychological distress [1-4].

The challenging aim of COGKNOW is to perform breakthrough research that addresses the needs of people with dementia, particularly those with mild dementia in Europe [5]. Our vision is to help people navigate through their day, by providing cognitive reinforcement. The social objectives of our research for the needs of people with mild dementia is, helping people to remember, maintain social contact, perform daily life activities and enhance their feelings of safety. The technical objective is to research and prototype a portable, remotely-configurable, user-validated cognitive prosthetic device, together with associated services for people with mild dementia.

The COGKNOW project started in September 2006 and will end in August 2009. It is supported by the European Commission and eleven participating organisations from eight countries.

1. **Persons with dementia and their needs**

Dementia is a progressive, disabling, chronic disease affecting 5% of all persons above 65 and over 40% of people over 90 years [6,7]. The term dementia refers to a combination of symptoms involving impairments of memory, speech, thought, perception and reasoning. Early impairments in performing complex tasks lead to an inability to perform even the most basic functional activities such as washing and eating. Often there are changes in personality, behaviour and psychological functioning, such as depressive symptoms, apathy and aggression. These neuropsychiatric symptoms appear to afflict the overwhelming majority of sufferers and are reported to be particularly potent precipitants of institutionalisation [8, 9].

The most prevalent type of dementia in the elderly is Alzheimer’s Disease (AD). Two thirds of older people and one-third of younger patients (50-65 years old) with dementia have AD. The clinical course is typically only slowly progressive.

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1. Participating organisations are: Telefónica (Spain), University of Ulster (Northern Ireland), Luleå University of Technology (Sweden), Telematica Institute (The Netherlands), VU University medical centre (The Netherlands), AcrossLimits Ltd (Malta), Groupe des Ecoles des Télécommunications – Institut National des Télécommunications (France), University Hospital of North Norway/Norwegian Centre for Telemedicine (Norway), Belfast City Hospital/Queen’s University of Belfast (Northern Ireland), Mobi Solutions OÜ (Estonia), Norrottens Läns Landsting (Sweden).
Demographic changes mean that the countries of Europe can expect a massive rise in the number of older people and a corresponding increase in the number of dementia sufferers. If one considers the associated costs of community-based caring strategies and the emotional and economic burdens associated with institutionalisation, it is clear that these unfortunate individuals must be considered in the context of both national and European healthcare strategies, as well as social and economic policies.

Until recently, these strategies and policies were based on what other persons considered important for persons with dementia. Relatively few studies exist in which persons with dementia were surveyed and allowed to describe their own specific unmet needs. Aside from physical problems such as loss of eyesight and hearing and incontinence, the most frequently identified unmet needs are in the areas of information (on condition, treatment, care and support possibilities, appointments with care services etc), memory problems, and communication and psychological distress (anxiety) [3,10-12]. A report examining quality of life issues of dementia sufferers has recently identified seven key domains [2]: physical and mental health, social contact with family and friends, being useful to others, enjoyment of activities, self-esteem (being respected by others), and self-determination and freedom.

A different personal perspective and lack of insight into their predicament causes patients to report fewer needs, and in some cases different needs, than their carers [1,3]. In one study the needs identified by the informal carers were associated with their own mental health [1] suggesting that the greater need of the carers could also be related with the mental health problems of the carers themselves. Unmet needs mentioned both by patients and carers include: information (on the disease, prognosis, care policy, possible care and support services, appointments), memory problems of the person with dementia; communication; (enough) meaningful activities during daytime; and feelings of safety.

If we analyse these needs as described above from various studies, we can see the importance of various strands of the person's life. This includes feeling of autonomy, that needs reinforcement of orientation in space and in time, of topographic memory and of (auto-) biographical memory. Also included is the ability for the person to maintain contact with their social environment and improve their relationship with it and their peers. This involves not only reinforcement of identity, episodic memory, and assisting the fight against apathy, but also facilitation of all aspects of communication and motivating people to express their opinions and thoughts, wishes and fears and reinforce their feelings of social belongingness.

In the COGKNOW project, field work and literature reviews will be performed to formulate functionalities of a multimodal technical solution that addresses those needs, and to develop a cognitive prosthetic device for people with dementia.

2. Method

The user needs will be further analysed by means of workshops and interviews with persons with dementia and their carers. Furthermore, a literature search will be performed on the state of the art of helpful ICT solutions for persons with dementia, healthcare models, technological infrastructures and existing standards in EU member states. This information will enable us to formulate functional requirements of a prototype that will be developed and tested in three iterations in the three countries (The Netherlands, Sweden, and Northern Ireland). The COGKNOW device will be
developed in a user-centered approach, each field trial will be performed with a maximum of 18 persons with dementia and their carers (6 dyads per test site).

The study has been approved by the relevant Ethical Commission of each test-site.

2.1. Workshops and interviews on user needs

The workshops and interviews will take place in Amsterdam (The Netherlands), Belfast (Northern Ireland) and Luleå (Sweden), with a maximum of 6 persons with dementia and their carers at each site.

The target group of patients involved in these workshops will be suffering from mild dementia of the Alzheimer type. They are recruited from memory clinics at the different test sites and meeting centres for people with dementia and their informal carers. To operationalise the stage of severity of dementia the Global Deterioration Scale of Reisberg [13] is used. Only patients with moderate cognitive decline (late confusional stage) and moderately severe cognitive decline (early dementia stage) are invited to participate in the workshops and the field studies. The (confirmation of the) diagnosis of Alzheimer's Dementia and the stage assessment is obtained from, or performed by, clinicians in the different sites (neurologist/psychiatrist/geriatrician from the memory clinic and programme coordinators of the meeting centres) based on the DSM-IV-TR criteria [14] and by using the Global Deterioration Scale (GDS). Besides information on the diagnosis and severity of dementia, data are obtained in individual interviews with patients and carers. Due to the deteriorative nature of the condition of the users, it is to be expected that only one or two persons will participate three years in the project, therefore new participants will be recruited for each test phase. In every test phase a maximum of 6 user dyads will be recruited on every test site (country). This means that a maximum of 54 patient-carer dyads will participate in the project. Informed consent will be obtained from all participants.

Separate workshops are carried out with persons with dementia, and with informal carers and professional carers who are involved in the care situation. At least two project members will be present. One leads the discussion, the other fills in when necessary and makes notes and observations. The workshops are organised following a set of guidelines. The workshop starts with an introduction of the project, the aims and structure of the workshop, and an introduction of all participants. Then, needs, wants and demands [15] are discussed in the four COGKNOW areas in relation to improvement of the Quality of Life (QOL) and experienced autonomy of the persons with dementia. This way data can be gathered on how people think that their QOL and experienced autonomy would improve for every COGKNOW area. The needs, wants and demands that are mentioned within each domain are outlined on a flip-over. The priority of needs, wants and demands is discussed with the participants in the context of the importance for their quality of life and experienced autonomy.

A list with explanations of the four COGKNOW areas is made beforehand to standardise the method in the workshop among the test sites, which will increase the comparability of the results. In the discussion we conceptualise and verbalise going through the day from awakening in the morning until going to sleep at night. To focus on different time frames during the day, time-specific pictures are shown in a slide show. Next, possible ICT solutions for the needs, wants and demands mentioned are discussed. Besides brainstorming with the participants, possible directions of solutions are brought forward to discuss about (what do they think about this idea, do they think
they can work with it). For each COGKNOW area some solutions are shown in a slide show. Also, the priority of preference for possible solutions in the different COGKNOW areas will be discussed.

When participants cannot or do not want to join the workshop, interviews are conducted following the same structure as in the workshops. In separate interviews with persons with dementia and their carers, background characteristics are inventoried (age, education, relation patient-carer, etc.), as well as cognitive disabilities (cognitive section of the CAMDEX [16]), difficulties performing activities of daily living [17], needs, experienced autonomy, coping, informal network, and quality of life. This will generate relevant information to specify technical requirements of the device that will be developed, and will make the characterization of the user group on which the prototype in the COGKNOW project is tested possible as well as comparisons of the user groups in the different test sites in the three countries. The aim is to contribute to the development of really user-friendly applications, as this is a strong and currently often unmet requirement for persons with dementia.

2.2. Development and evaluation of prototype in three field tests

The prototype will be developed in collaboration among the COGKNOW partners, and it will then be evaluated in three field tests at the same test sites as were the workshops are conducted, that is Amsterdam, Belfast and Luleå. During these field tests (one each project year), people with dementia and/or their carers are provided with the COGKNOW device in their daily life for a period of several days up to several weeks. The evaluation will be performed from three perspectives, identifying critical human, technology and business success factors.

2.2.1. Human Factors

The human factors analysis intends to define the functionality, performance, intended results and other user requirements which the system to be developed must fulfill in order for services to be adequate for testing. The testing will be performed by sufferers of mild dementia and their carers, both informal and professional. There are four evaluation objectives:

1. Obtain better insight into the needs, wishes and demands of the users in the COGKNOW-selected domains of daily life with reference to the key areas of remembering, maintaining social contact, performing daily life activities and enhancement of feelings of safety.
2. Evaluate the user-friendliness and usability (performance, reliability etc) of the device for the users;
3. Evaluate the usefulness (helpfulness in their individual daily life, safety factors, suitability or desirability) of the device for the users;
4. Evaluate the impact of the developed system on functioning of the users in the selected COGKNOW domains, on actual and perceived autonomy and quality of life.
Users collaborate in the development and evaluation process (using a method of “users as designers”) and will be asked to make comments on the user friendliness, usefulness and impact of the developed service on their daily life throughout the project. The prototype will be developed and tested in three phases in three countries in order to investigate the significance of different social contexts on the usability. During each test of the prototype service and device, the data are collected by means of standardized scales and questionnaires, semi-structured interviews and possibly a software platform SeniorXensor which is an extension of SocioXensor [18] (SocioXensor is an extensible toolkit that captures data about human behaviour, their context information and user experience). Based on the outcomes of these tests a further Human Factors Analysis will be performed. This analysis aims to determine the supportiveness of the prototype in enhancing (actual and perceived) autonomy and quality of life of the persons with dementia, as it relates to the four main COGKNOW areas remembering, maintaining social contacts, performing daily life activities and feeling safe.

At the end of the first year a prototype test will be carried out at the three test sites with a maximum of six participants per site. In this first field test, information will be collected on user friendliness and usefulness of the device by means of semi-structured interviews and diaries to inventory user problems. On the basis of that test and the collected data, a Human Factors Impact Analysis will be carried out, in order to feed back information to the developers. At the end of the second year an updated prototype will be tested. Again the focus will be on user friendliness and usefulness of the device by means of semi-structured interviews and diaries to inventory user problems. On the basis of that test and the collected data the second Human Factors Impact Analysis will be carried out to help the developers to fine-tune the prototype service and device.

At the end of the final test in year three, a deep analysis of the results will be carried out and the results from the previous tests will be added. This will deliver the final Human Factors Analysis on the impact of the developed system on functioning in the selected domains of daily life of the person with dementia and on actual and perceived autonomy and quality of life. In this last phase the main focus will be on the usefulness and efficacy of the system.

Concrete questions will be for example:

- Does the device support the memory problems of the persons with dementia?
- Does it help them to communicate and stay in contact with their family and friends?
- Does it help them to execute, or participate in, activities that they enjoy?
- Does it influence their mood and self-esteem positively and does it decrease their feelings of being isolated and unsafe?

To determine the usefulness and efficacy of the device in the user groups at the three test sites a 'pretest-posttest one group' design will be used in this final test. Semistructured interviews and diaries will be used to assess the user friendliness, usefulness and efficacy of the device in the daily life of users. With regard to the efficacy of the device, before and after the third field test data are also collected. This is done by standardized measuring instruments on the person with dementia’s severity of dementia, cognitive (dis)abilities, deterioration in daily activities, ways of coping, quality of life, experienced autonomy, contextual information, information on received care and (unmet) needs. The results from this analysis provide crucial insight in user requirements on future products for future exploitation.
2.2.2. Technology Factors

The technical evaluations will focus on technology itself as opposed to the impact it may have on the user. The aim is to advance the state-of-the-art in the following areas:

- Capability of predicting context
- Mobile based delivery of reminding services
- Pervasive and ubiquitous computing, balancing transparency vs proactivity
- Deployment of we-centric services
- Use of multi-modal services

It is necessary that each individual component be evaluated in terms of integration performance with all other system components in addition to evaluation in isolated terms. Figure 1 provides a general overview of the four proposed main technical components of the system.

Within each technical component, an evaluation of technical performance aspects will be assessed based on the COGKNOW functional requirements. For the Cogknow Cognitive assistant these are amongst other things, impact of software upgrades, application system crashes, device recall, and battery life; for the Cogknow Server: down time, reliability, response time and delay; for the Cogknow Home Hub: average processing time, aborted connects, uptime and cost-effectiveness; for the Cogknow Sensorised Home: technician call outs, aborted connects, device sensitivity; and for all aspects: interoperability issues, system stability, and ease of integration.

![Figure 1: Overview of the four main technical components within the system](image-url)
2.2.3. Business Factors

Getting innovations from the pilot state to actual innovations in the market is notoriously difficult, especially in health care; as it requires cooperation by multiple parties to provide valuable service offerings. Therefore the evaluation of the COGKNOW device also considers the Organisation and Financial Domains of the developed business models in order to make the business opportunities emanating from COGKNOW innovations sustainable on the market considering potential competition. The main COGKNOW innovation will be a user-validated cognitive prosthetic device with associated services for people with dementia. The aim of the evaluation is therefore: to check the viability of COGKNOW business opportunities, and to identify critical business success factors that feed back into the development of COGKNOW services.

This leads to the following research questions:

- What constitutes a viable business model for the service bundle (four services) that we develop in COGKNOW?
- What are or could be the mentioned services which together form the COGKNOW services? What is the core service or value of the COGKNOW bundle?
- What can we learn from business models for provision/dissemination of other comparable ICT services, or service bundles, for ageing people (with dementia) already on the market?
- What roles are needed to deliver the COGKNOW services?
- Which actors could fulfil these roles?
- What are potentially viable business configurations for providing the COGKNOW services?
- What are the critical design factors?
- What differentiates COGKNOW services from other alternatives? How can the COGKNOW services be introduced to the market?

The critical success factors will be analysed in the financial and organization domains. Those factors are distinguished in: market factors (clear target group, compelling value proposition, non-obtrusive customer retention), business modelling factors (complexity of business model - single-actor vs networked business; profitability potential), and actor viability factors (sustainability of business model, acceptable quality of service delivery - the resources provided by the selected commercial actors, customer reach of the selected actors).

3. First results of the workshops on user needs and possible ICT solutions

The data on user needs and ICT solutions were collected in Amsterdam by means of workshops and one individual interview, in Belfast by means of individual interviews and in Luleå by means of individual interviews and group interviews. In Amsterdam, all participants were willing to participate in the workshop, one couple was on holidays and was therefore interviewed later (separate interview for person with dementia and carer). In Belfast and Luleå, persons with dementia and their carers seemed not familiar with talking about their illness and needs in workshops, and they therefore participated in (small group) interviews. Characteristics of the participants are shown in Table 1.
Table 1. Characteristics of participants at the three test-sites.

<table>
<thead>
<tr>
<th>Persons with dementia</th>
<th>Amsterdam (n=6)</th>
<th>Belfast (n=6)</th>
<th>Luleå (n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean 64.0 (range 56-78)</td>
<td>Mean 72.7 (range 65-86)</td>
<td>Mean 67.8 (range 60-77)</td>
</tr>
<tr>
<td>Gender</td>
<td>3 female 3 male</td>
<td>5 female 1 male</td>
<td>3 female 2 male</td>
</tr>
<tr>
<td>Civil status</td>
<td>5 married 1 widow</td>
<td>3 married 2 widowed 1 single</td>
<td>5 married</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carers</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean 58.5 (range 49-78)</td>
<td>Mean 53.0 (range 40-72)</td>
<td>Mean 61.4 (range 23 – 78)</td>
</tr>
<tr>
<td>Gender</td>
<td>4 female 2 male</td>
<td>3 female 3 male</td>
<td>2 female 3 male</td>
</tr>
<tr>
<td>Relation to patient</td>
<td>5 spouses 1 daughter</td>
<td>3 spouses 2 children 1 cousin</td>
<td>4 spouses 1 son</td>
</tr>
</tbody>
</table>

In each country reports were made of the workshops and interviews. The most important needs (according to the participants) and the most preferred ICT solutions (according to the participants) were summarized for each COGKNOW area. Based on this overview and on the state of the art of ICT solutions that have proven to be helpful for persons with dementia, a Top 4 list of preferred ICT solutions was made for each test site. This top 4 list is presented in Table 2.

This top 4 list was discussed between the test site leaders and technological partners who assessed the feasibility to implement these ICT-solutions or functionalities in the first field trial. The main functionalities that are proposed to be studied and developed further are: reminding, picture dialling, support for activities for pleasure and safety warnings. The aim is to provide these functionalities as an integrated system. Next, functional requirements will be formulated, based on remarks of persons with dementia and their carers during workshops and interviews, results of questionnaires and scales on (dis)abilities of users, and literature review.
3.1. Examples of the four functionalities of the COGKNOW device in the first field trial

- **[reminding functionality]** At 10 o’clock the COGKNOW navigator reminds Martin to take his medicine using a specific sound that is backed up by a written message on the display. Martin reads that it is time to take his medicine.

- **[picture dialling]** To call his son or daughter, Martin has to touch the phone symbol under their photographs. He presses the phone symbol and a connection is made to his daughter, with whom he talks for a while.

- **[support for activities for pleasure]** During the evening Martin frequently uses the COGKNOW navigator to turn on the television because he has trouble finding the right TV channel and programme on his television.

- **[safety warning]** When Martin goes out for a walk and he forgets to take his mobile and/or his keys with him, the front door sensor will always provide a gentle reminder as he passes through it. If he doesn’t know where he left his mobile, he can touch a pictogramme of a mobile at the COGKNOW stationary device and a buzzer sound leads him to the place were he left it.

### Table 2. Top 4 list of preferred ICT-solutions at the three test-sites.

<table>
<thead>
<tr>
<th>Amsterdam</th>
<th>Belfast</th>
<th>Luleå</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>COGKNOW area: Support for memory</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reminding and remembering</strong></td>
<td>Item locator, misplacement of items is a key early, and almost universal, symptom of a dementing illness – reflected in BCH workshops and literature review (see SMART home, BIME (Bath Institute of Medical Engineering))</td>
<td>Activity reminder/electronic calendar, stationary device with touch screen</td>
</tr>
<tr>
<td>Reminder for not forgetting activities/appointments/take medicine/to take things outdoors, like key and mobile phone/mobile device. The solution should preferably be stationary with touch screen as well as mobile: f.i. Neuropage [19-21]</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| **COGKNOW area: Support for social contacts** | | |
| **Enable communication with family and friends** | | |
| Picture dialling function on touch screen integrated within the screen of the stationary device of the reminding system (thus not as a separate pictophone) | Electronic calendar with emphasis on appointments and social activities pending. Usefulness emphasized in workshops and within research community; see Forget-me-not http://www.ihagen.no/english.htm | Picture dialling function on touch screen integrated within the screen of the stationary device of the reminding system (thus not as a separate pictophone) |
4. Conclusion

The COGKNOW approach is anticipated to result in a cognitive prosthetic device and associated services for elderly people with mild dementia, with a focus on the real needs and wants of users. This solution will help this group of people to navigate through their day; improve independence and quality of life; and also improve infrastructure and processes for professionals in dementia care.

The identified services, requirements and technical vision will be further developed within the COGKNOW project, and the results will be published in reports and articles in scientific and professional journals, and presented at national and international symposia and congresses.

For more information, visit the project website, http://www.cogknow.eu.

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