Deliverable 1.1

UNDERSTANDING USERS AND CONTEXT

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1. INTRODUCTION

The work package 1 will deepen our understanding of the end users, the usage context in which the system will be used, and communicate both information to the designers and developers. Understanding the user and the usage context will be investigated by conducting a series of user studies, including surveys, expert interviews, focus groups, and field trials with potential end users. To communicate the insights within the projects we will (1) involve designers and developers directly in the studies and (2) conduct workshops were the results will be presented in interactive sessions. This will ensure that the designers and developers understand the end users, and will take their special needs into account when developing the prototype.

We will identify the usage context and the user requirements that are specific for users with MCI. Besides classical survey methods (interviews, focus groups) we will also do in-situ field observations to get a better understanding of the context of use. We will involve the primary target users but also other stakeholders, including care takers and family members. The abilities of the target users, usage frequency, and the context of use will be identified. The outcomes of the tasks are personas, use cases and scenarios that are grounded in a deep understanding of the users.

The current document summarizes the results of the initial user investigations made by the partners in the NavMem project. Chapter 2 reports literature studies, while the chapters 3 and onwards are devoted to the different studies performed by the partners involved in the WP1 work. The partners Roessingh Research and Development, Lund University and SIEMENS have performed initial user investigations for three different groups, persons with dementia, persons who have had a stroke and persons who are elderly. This is described is respectively Chapter 3, 4 and 5.

2. MILD COGNITIVE PROBLEMS

2.1. MCI AND ITS CONSEQUENCES

MCI (mild cognitive impairment) is a concept that has for many years been used in clinical research when memory tests and other tests results are not completely reliable or can be interpreted as an incipient dementia disease. A third of individuals diagnosed with MCI will over time (i.e. a few years), develop a dementia disease while a third will remain healthy and the rest still be classified as in a border zone (Interview with Peter Engfelt, Geriatrician in Sweden). Thus, MCI refer to a rather vague condition according to insufficient methods and uncertainties in determining cognitive function. In addition, an important element in determining dementia is time i.e. this is a progressive course with increasingly impaired memory functions and other problems. Because of the heterogeneity of people diagnosed with MCI there are ongoing debates whether MCI is a clinically useful concept or not (Rosenberg 2009).

Recent result from the Karolinska Institute in Sweden on assistive technology as cognitive support in everyday life for persons with dementia or stroke summarize the research result so far on the most common problems for those suffering from stroke or dementia (Lindqvist 2012). For stroke victims the most common signs are deficits in attention, short-time memory and language, orientation of time and executive functions and decreased awareness of the disease. Dementia diseases exhibit similar symptoms such as a gradual onset of memory impairment, aphasia, apraxia, decreased visuospatial and temporal ability, decreased executive functions. Both stroke and dementia seem to show signs of decreased awareness of the disease which in turn reduces the persons' ability to perform everyday activities and decreases their safety. Even if there are some differences between the symptoms, the way in which these symptoms affect everyday life is similar in the two groups.

Lindqvist refer to previous research that showed that due to difficulties derived from stroke or dementia they strive to hold on to tasks and performances that are of importance to them. They form new routines to be able to perform them or try to maintain already existing routines and patterns. They strive for autonomy, e.g. by trying to be in command of their lives and performing activities independently of others (Häggström & Larsson Lund, 2007; Öhman & Nygård, 2005).

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2.2. DEMENTIA

Currently one on every 93 Dutch citizens is diagnosed with dementia, comprising 180.000 people in total. It is estimated that another 70.000 people are not yet diagnosed, making an estimated total of 250.000 people with dementia in the Netherlands. This figure of diagnosed persons will rise drastically to 580.000 people in 2050 (website Dutch Alzheimer association, 2013; RVZ, 2002). This increase is primarily due to the aging population and increased life expectation. Consequently, the expectation is that the availability of professional caregivers will decrease. At the same time, the availability of professional caregivers will decrease. Thus, we can see a major socio-economic problem arising (RVZ, 2006; Stavros et al., 2010). Providing huge economic potential are assistive technologies for those affected by cognitive loss (COGKNOW project, 2009) (Healthcare costs for individuals with dementia are a substantial part (4.9%) of overall healthcare costs in the Netherlands (Dutch Alzheimer association, 2008-2011), In total, dementia-associated costs consisted of 3.9 billion Euros in the Netherlands in 2009.

Dementia is not a disease itself, but a syndrome caused by a specific disease e.g. Alzheimer. It is characterized by a progressive decline of cognitive functioning, which is in 60% to 70% of the cases

caused by the Alzheimer disease. Typically dementia occurs among elderly: 90% of the diagnosed persons in the Netherlands is older than 65.5
Dementia shows many different symptoms and these vary largely among each individual and the stage of the disease (RVZ, 2002). In early stages, typical syndromes associated with a cognitive decline are the loss of short-term memory, loss of the ability to produce and understand language (aphasia) and difficulties performing familiar tasks. These tasks might involve activities of daily living (ADL) as defined by Katz et al. (1976): walking, washing, sleeping, toileting, dressing, eating and transferring. When the disease progresses, symptoms may worsen and more might arise. People might be unable to perform ADL's without help, lose their sense of time and place, experience disrupted sleep or have the inability to learn new information.
Apart from the cognitive symptoms, one can distinguish behavioural and psychological symptoms (Lawlor, 2002) like wandering, agitation, sexually inappropriate behavior, depression, anxiety or delusion. Again, these symptoms might increase during any stage of the disease and differ largely among individuals.(RVZ, 2002)

In the Netherlands two third of all diagnosed demented persons (120.000) still live at home. It is estimated that nowadays 15% of them live solitary in home, a percentage that is expected to rise to 50% in 2030.(Dutch Alzheimer association, 2008-2011) The group of demented persons living in-home primarily has a mild to moderate form of dementia.2 As the diagnosis is in most cases done in the mid-stage of the disease, from that point people live on an average 4,5 years in their own home or in a rest home. The last 2,5 years are spend in a nursing home.(RVZ, 2002)
The need for care depends on the stage of the disease and the persons' functional abilities, as independence in doing these activities is promoted as long as possible.(Merkcken, 2005) For caregivers the key challenge is to provide the necessary medical and functional care and adapt this over time, as the need for care changes in accordance with the progression of dementia.(Vladeck, 1998)
In the beginning and mid-stage of dementia, persons are able to live in-home with the support of informal caregivers, who are in most cases the partner or children1, or professional caregivers. Indications for receiving professional home care are primarily personal care (57%, e.g. hygiene, bathing), supporting care in day programs (56%, e.g. social activities), domestic care (54%, e.g. doing the dishes) and nursing (39%, e.g. medication uptake). (Dutch Alzheimer association, 2008-2011)

In 60% of the cases, in-home demented persons depend on care at least once a day (Mercken, 2005). This home care is provided again in 60% of the cases by informal caregivers (RVZ, 2006), but is a strenuous and time demanding task to do. The most difficult problems for caregivers to handle are sleeping disturbances (65.2%), dangerous behavior (60.5%), mood disturbances (38.4%) and cognitive problems (24.7%)(Ferrario et al., 1999).
Informal caregivers have to provide home care and daily support over a long period of months or even years. This can become a large burden and lead to restrictions for their own (quality of) life (Mercken, 2005). The care for demented persons is a highly complex process that demands abilities to cope with patients' cognitive and behavioural problems, functional restraints and co-morbidities.(RVZ, 2002)On the other hand a trend is developing for staying in home as long as possible, despite having a functional or cognitive impairment.(Institute for Prospective Technological Studies, 2005) Therefore the demand on caregivers in-home, either on professionals or family, is increasing. And with a decrease in amount of children per elder, the availability of informal caregivers is on a slope as well (RVZ, 2002).
It can be difficult for both informal and professional caregivers to understand the day to day problems demented persons face, as they do not see them all the time. Moreover, the patients' memory can be insufficient or they have a certain shame to tell problems.(NIZW, 2004)

Studies (Institute for Prospective Technological Studies, 2005; Hensel et al., 2006; Wherton et al., 2008) shed their light on smart home technologies, stating that it does not meet user needs for reasons like a lacking usability by presenting unfeasible and complex information to caregivers, being obtrusive for the resident or an anxious attitude towards a new, unfamiliar device.
The latter factor is a specific issue for persons with dementia. Orpwood et al. (2005) opt that demented persons can become confused or anxious towards unfamiliar technology and therefore interaction with technology should be at a minimum. However this statement is debated by Davies et al. (2008) who designed an in-home cognitive prosthesis for mild-demented persons, where interaction with technology forms an important part. This discrepancy is explained due to the fact

that Davies et al. developed technology for mild-demented persons, whereas Orpwood et al. focused on more severe demented persons. This illustrates that minor differences in user needs can pose big differences in system requirements.

2.3. Stroke

Stroke can be caused either by a clot obstructing the flow of blood to the or by a blood vessel rupturing. Stroke is common – in Sweden about 30 000 persons get a stroke each year making stroke one of the most frequent causes of disability or death. Stroke is estimated to cost society around 18 billion SEK each year. Roughly equal numbers of men and women get a stroke. The average age for a stroke is 75 years, but approximately 20% of the persons who get a stroke are still working (aged under 65). Worldwide stroke is the second cause of death after ischaemic heart disease (http://ageing.oxfordjournals.org/content/38/1/4.full). According to the same source "In the elderly population of the 15-country Europe, estimates showed 2,700,000 prevalent cases, and 536,000 incident cases each year". According to a study for the UK published in 2009 (Saka O, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. Age Ageing 2009;38:27-31) the treatment of and productivity loss arising from stroke results in total societal costs of £8.9 billion a year, with treatment costs accounting for approximately 5% of total UK NHS costs. Direct care accounts for approximately 50% of the total, informal care costs 27% and the indirect costs 24%.

According to (Young J, Forster A. Review of stroke rehabilitation. BMJ 2007;334:86-90) motor impairments (typically upper limbs) affects most patients at the time of the stroke, and for 50-75% of this group the problems are persistent. Language problems affect around 25% of the patients immediately after a stroke, and the problems will persist in about half of the cases.

Neglect can also occur after a stroke. Neglect has been defined as "the failure to report, respond, or orient to novel or meaningful stimuli presented to the side opposite a brain lesion, when this failure cannot be attributed to either sensory or motor defects" (Unilateral Spatial Neglect, L.Swan, Physical Therapy September 2001 vol. 81 no. 9 1572-1580). According to the same source there are typically three types of neglect: memory and representational deficits (which affects the way space is remembered), action-intentional disorders (motor neglect – which is not a deficit of the motor pathway, but rather a failure or decreased ability to move), and inattention (sensory neglect – lack of, or decreased, awareness of sensory stimulation). The incidence of neglect is not clearly documented – figures ranging from 17-80% (after a right sided stroke) can be found in the literature according to L.Swan.

2.4. Elderly users

Elderly users were part of the user group in the EU project HaptiMap and the following text is an excerpt from the deliverable D1.1 Initial user Studies (2008) available at www.haptimap.org:

Studies looking specifically into the issues connected to elderly users are (Goodman, Gray et al, 2003), (Sjölinder, 2006). These studies imply that for older users working memory, motor ability and processing speed make size and simplicity but also security particularly important. (Goodman, Gray et al, 2003) also comments on negative attitudes towards technology, but other authors such as (Östlund, 1995) conclude:

"The results show that the function of technologies such as the telephone and the television becomes more specific and even more important to connect the home with the outside world. By this kind of technology the interviewees remain socially integrated but, which is one of their expressed preferences, with no demands on social participation. A growing need of privacy is succesfully combined with an increased need of security and help. Technology is not used to establish new contacts but relations to relatives and friends are maintained. The attitude and acceptance of new technology in general is positive due to their lifelong experiences of improvements. The difference is that they are not that interested anymore, referring to an increased pragmatic vue towards modernity, to a limited future-perspective and to their basic values."

The body of research in the area of technology and elderly persons has been rapidly growing lately. Partly for this reason, (Zajicek, 2004) states that it is often difficult for new designers of technology for elderly persons to directly use prior research results because they have to first filter a vast amount of details before arriving to useable guidelines. (Zaphiris, Kurniawan, & Ghiawadwala, 2007) adopted a systematic approach for the development of the SilverWeb Guidelines (a set of research based web design guidelines for older people). Some of these guidelines are valid for mobile location-based services. This is true also for guidelines such as the ones published by WAI-AGE (http://www.w3.org/WAI/WAI-AGE/). The WAI age project also has produced a literature review which (again) points to the fact that elderly users tend to do much the same things as younger.

Ageing-related functional impairments and their impact on the interaction with mobile location-based services

Vision is the most common physiological change associated with ageing. One third of the people aged over 65 have some kind of visual decline such as presbyopia (a loss in near vision), a reduced field of view, a reduced contrast and colour sensitivity (Stuart-Hamilton, 2000). This change is particularly important for the usable and accessible design of LBS, because such users may have difficulties in, for example, reading small characters or discriminating particular colours.

The use of sound to complement visual information can potentially resolve some problems generated by the age-related visual decline. However, according to some authors, 20% of the people between 45 and 54 years have some kind of form of hearing impairment. This figure goes up to 75% for the people between 75 and 79 (Hawthorn, 2000; Kline & Scialfa, 1996; Scheiber, 1992). Older people may have a reduced ability to detect high pitched sounds, to localize sounds and to follow a conversation in noisy surroundings. Thus, part of the benefits of audio interaction may be reduced, especially if users of mobile LBS are in noisy surroundings.

Age is also related with some decline in certain psychomotor activities (e.g. reaction time in complex motor tasks, target following, Hawthorn, op. cit.). Some cognitive functions such as focused attention, episodic memory, procedural and working memory may also be negatively affected by age (Howard & Howard, 1996). Also, a cumulative effect of various impairments may be observed.

However, research has shown cognitive adaptability in the great majority of elderly users when appropriate training had been provided (Zaphiris, Kurniawan, & Ghiawadwala, 2007). [end of the excerpt from D1.1]

The user studies in the HaptiMap project (which targeted navigation and thus are highly relevant also for NavMem) included a survey study and a focus group (in Belfast, Northern Ireland) with 23 participants aged over 60. To complement these results a similar study was also done in Bilbao, Spain. This study involved 12 persons, 6 living in a nursing home and 6 living independently. The most significant conclusion from the Belfast study was that current mobile technology is inconvenient for the older population, e.g. the keys and screen are too small, and mobile devices are mainly owned so that they can be used in an emergency. With regard to travelling, the most popular means of travelling is by car, followed by walking, however most participants did not appear to want to travel unknown routes. This was attributed to a fear of getting lost. Trust is important - any navigation device should be robust and relied upon to accurately convey the user's location.

The Bilbao study indicated that the (very) old users in the nursing home were not a suitable target group. They did not use computers or mobile devices and they never go out alone. The elderly persons living independently however find mobile phones useful. The main problem is the difficulty to use the user interface, the size of buttons and screen, the appearance of menus and geographical information. They would also like to access the device in easier way, such as voice commands, bigger buttons or simpler menu options.

To summarize:

- Keys and screen needs to be large enough
- Clear and easy to understand information

- Device should be easy to use
- Important not to get lost
- The device needs to be robust and reliable

Published guidelines
Zaphiris, Kurniawan, & Ghiawadwala (2007) gathered published studies related to web design and older people, obtaining individual guidelines, defining higher order categories of guidelines and verifyed the usefulness of those guidelines with target users. Some of these guidelines are applicable for interaction with the mobile location-based systems. Completed by the guidelines proposed by (Massimi, Baecker, & Wu, 2007), and (Muna, Hend et al 2012) we get the following list:

- Mobile devices should be compatible with hearing aids
- Mobile devices should have a wide range of volume levels
- Several input modalities should be included (audio hints can help for reduced vision)
- Slide-out keyboards should be avoided
- Program and command naming should be carefully considered and in accordance with the users' mental models
- Provide large, clear and bright screens
- Provide large buttons
- Eliminate buttons on the sides and rear of devices
- Provide the possibility to zoom in on small text
- Provide clear confirmation of target capture (i.e. button press, visited link). The user should not be expected to detect small changes
- Older users should not be expected to double click because of slower hand movements
- A single, consistently placed button for returning to the home state should be included
- Graphics should be relevant and not for decoration. No animation should be present.
- Images should have alt tags
- Icons should be simple and meaningful and also labeled (with a large enough font)
- Clear navigation should be provided
- Tapping often preferred to drag and drop
- Provide current location in the interface
- Clearly show which tasks are active
- Important features should be available directly via a labeled button and not via menu navigation
- Avoid pull down menus
- Do not have very deep hierarchy and group information into meaningful categories
- Important information should be highlighted
- Information should be concentrated mainly in the centre
- Provide ample time to read information
- Reduce the demand on working memory by supporting recognition rather than recall and provide fewer choice to the user
- Main navigation always the same and critical functions should not disappear
- Colours should be used conservatively
- Blue green tones should be avoided
- Background screens should not be pure white or change rapidly in brightness between screens. Also, a high contrast between the foreground should exist.
- Avoid moving text
- Avoid fancy font types
- An online help should be provided
- Error message should be simple and easy to follow

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3. Studies by Roessingh Research and Development – mild dementia

Roessingh Research and Development was focussed on understanding end users associated with mild dementia, i.e. patients with mild dementia and its (informal) care givers.

3.1. WORKSHOP CAREGIVERS

Methodology

A workshop with caregivers was conducted (as described in graduation thesis M.A. Brul, University of Twente), which can serve as input for the NavMem project. The workshop was based on a scenario description that mirrors the current situation.(Kensing & Madsen, 1991) This so called 'user story' is exposed to the participants (Beynon-Davies & Holmes, 2002) and describes how a professional and informal caregivers currently deliver home care to a representative by fictive demented Mrs. Geerdink (see Appendix 1). The user story pinpoints the difficulties of monitoring the demented person's functioning. The use of a user story aims at creating a common ground among the participants to discuss the problems they might face in having a proper insight in the demented persons' functioning.
The scenario was written by the student researcher, based on insights from two days of observations in home care delivery and conversations with different caregivers in the field. Preceded to the workshop the scenario was validated by an informal and a professional caregiver who would both participate in the workshop.

Five professional caregivers affiliated to a homecare organization and 4 informal caregivers participated in the workshop. All of them were involved in the care of solitary demented persons living in-home. Two of them were men and 7 were women, all middle aged. For all caregivers participation was voluntary and they were recruited via homecare organizations and health and welfare institutions operating in Twente. The inclusion criterion was that caregivers were not negatively towards technology as aid to support care delivery. The workshop was facilitated by a student researcher with the support of a senior researcher. The first one headed the workshop and the discussions and the second wrote down responses from participants on a flip-over. The entire workshop was recorded with cameras and a microphone. Throughout the workshop different assignments were given, followed by plenary discussions. Most of the assignments were performed in groups. Two groups were assigned, randomly mixing informal and professional caregivers equally. Table 1 shows the different elements of the workshop.

Elements of workshop	Goal
a. Introduction ○ Introduction participants ○ Presentation about background figures and aim of study	Inform participants about the background of study and create an open atmosphere for discussion.
b. Scenario analysis: current situation ○ Participants read and highlight activities and risks from a representative scenario description of the current homecare situation. ○ Plenary naming the activities and risks that are highlighted by all participants. Adding the list with own experiences.	Mirror the current care situation to participants and elicit the activities and risks that are badly recognized by the caregiver from the scenario.
c. Extending insight in activities and risks ○ Walk-through of one day of a demented person from morning to midnight, plenary denoting activities and risks one might perform and encounter. ○ Prioritizing activities and risks into a top 5, performed in 2 mixed groups of caregivers. ○ Plenary discussion about differences between the top 5 of both groups.	Understanding the activities and risks that are important for caregivers to take care of and in which insight might be insufficient.
d. Making mind-maps: create understanding activities and risks ○ Associate aspects around 3 activities or risks in a mind-map poster, focussing on: objects, individual deeds, place and time. Again performed group-wise. ○ Plenary discussing the mind-map posters. ○ Discussing statement: "as caregiver I sometimes have bad insight in the functioning of demented solitary persons".	Identify characteristics of activities and risks in order to understand how it could be monitored by means of sensors. Statement is given to finalize first part and to see if a common need has been recognized to think of technology.

Table 1: the structure of the workshop, showing the individual elements and each goal it pursued. Element b, c and d aimed at eliciting user needs, element e and f to define preliminary functional requirements.

After an introduction (element a), the user story was given. Individually participants had to recognize and distract common daily care problems of caregivers from this user story (element b). Subsequently participants were plenary asked to formulate problematic activities and risks a demented person might face according to their own experiences. The results were then prioritized by making a top 5 of 'activities' and 'risks' (element c).
The next step (element d) was making mind-maps of how these activities and risks are expressed (both done in groups). The mind-maps aim at getting a comprehensive understanding of how an activity or risk is characterized in terms of 1) objects involved, 2) individual deeds to perform an activity or being posed to a risk, 3) the place and 4) time an activity or risk mostly occurs.

Results

The workshop resulted in an overview of the caregivers' needs to obtain improved insight in the home situation of demented persons. This was in terms of important activities and risks that are demented persons undergo and are exposed to respectively. First the scenario about Mrs. Geerdink was read and participants were asked to read and highlight the risks and problematic activities the demented Mrs. Geerdink faced and were badly recognized by the caregivers. Then the participants mentioned their findings plenary, which ranged largely and were instantly added with experiences from their own practice. Table 2 shows the activities and risks as they were mentioned by the participants.

Activity		Risk
Monitoring course of dementia		
		(Disguising) forgetfulness
Social contacts (phoning (more often), agenda, supermarket, less visitors, less out of house, claiming certain persons by demented person)	↔	Loneliness
Less physical activity (but having the experience of having done a lot)	↔	Inactivity
Eating pattern	↔	Malnutrition
Cooking, making coffee		
Maintaining social contacts		
		Independence vs. need of help
Personal hygiene (e.g. washing, showering)		
Dressing		
Use of toilet		
		Not taking demented person seriously
Inactivity/remaining in bed	↔	Feeling sick, having pain, deteriorating health (and not being able to formulate this)

Table 2: activities and risks as mentioned on the basis of the scenario of Mrs Geerdink. Some activities are related to risks, as denoted with the arrows between them.

Then the list was extended during a 10 minutes plenary discussion headed by the workshop facilitator. This was done by walking through an entire day of the demented person (from morning to night) and asking for caregivers' own experiences and problems in recognizing the functioning of the demented person. These results are shown in table 3.

Additional activities and risks		
Less social activities (e.g. less often going out of the house)		Awareness of time
Phoning		Agitation/restlessness
Doing groceries		Repetition of activities/deeds: checking cupboards, drawers, keys, glasses, etc.
Eating: quantity, healthy vs. non-healthy or regularity/pattern		Maintaining proper day – night rhythm
Wandering (especially in the evening/night)		Use of equipment (e.g. television, radio)
Sleeping problems, often waking up		Use of central heating
Lacking daily structure for doing things		Lacking initiative for doing something
Getting up out of bed (in relation to co-morbidities: imbalance, risk of falling)		Waiting for something to come (e.g. the bus for day care)
Taking medication		Keeping a close eye on a clock, wanting to know what time it is
Drinking		Nocturnal fears
Inactivity		

Table 3: additional activities and risks mentioned in the plenary daily walk-through of a demented person. Note that the table is a list of all issues raised and no relation exists between both columns

Navigation and orientation (and mobility) is mentioned in three different aspects. First the risk of falling and not being found by anyone is a concern mentioned. Especially in the morning the risk of falling can be high. Second, also leaving the house, walking outside and consequently preventing inactivity are mobility issues for caregivers to take care of, to prevent deteriorating health. A proper insight into their degree of activity might lack. Patients stop doing their groceries for example. It was mentioned that "*a demented person can have a strong belief they went outside, but in reality this has never happened*". Consequently caregivers cannot always rely solely on the person's memory. Less social activities is also mentioned often, with the risk of loneliness. The third concern is wandering, which especially occurs in the evening or night. This can be either in home or outside, where in the latter case the risks of getting lost was stressed. Independence vs. the need of help, is a continuous balancing in the care of people with dementia. The person would really like to stay independent and active, but they will also need help in doing so.

References

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M.A. Brul. Designing a sensor-based monitoring system to support home care of demented persons - A user centered approach using scenarios. Master thesis Biomedical Engineering, University of Twente, 2009

Kensing, F., and Madsen, K.H. Generating visions: Future workshops and metaphorical design. In J. Greenbaum & M. Kyng (eds.), Design at work: Cooperative design of computer systems. Hillsdale NJ US: Erlbaum. 1991.

3.2. EXPERT INTERVIEW

An open interview was conducted with an expert in the field of technology and dementia, especially on eHealth for people with dementia in home-based and residential care. She was involved in several developments within Focus Cura (e.g. PAL4dementie, ADLifestylemonitoring), Vilans (GPS systems) and TU Delft (Klessebessers).

This expert will be actively involved in the design process. In this first open interview, the following points arose:

- The support for the use of ICT amongst elderly is small. This will change in the coming decades.
- The patient suffering from dementia can contact an informal caregiver in times of need. Two-way traffic might prove very useful: the caregiver can contact the patient for soothing, directions or just checking whether the patient is doing all right.
- A useful aspect of the system is to recognize a Disorientation Event. Since this requires a measurable parameter or event. One suggestion is to measure the amount of movement

(number of times leaving the house, amount of walking indoors, etc.) is a proper indication of mental well-being and confidence. A database can be build up in the background, from which statistical indications can be drawn.

- The (informal) caregiver is very capable of indicating the stage of the disease (such as progressive Alzheimer's Disease). A partner however, will often have the tendency to downplay or deny possible decline in well-being. A son/daughter usually maintains a greater (emotional) distance to the patient and can therefore assess the patients' well-being with higher accuracy.
- A mini questionnaire that is presented to the user in regular intervals, to assess the patients (mental) health, might be too obtrusive, annoying or confusing to be effective.
- When lost, the patient's heartbeat might go up, indicating the need for help. But heartbeat is also influenced by many other things (movement, stress levels) and is therefore deemed unsuitable for measuring a "Disorientation Event".
- In some cases, the user (patient with MCI) will not want to disclose their current location or destination. Implementing a function like "Temporarily do not track me." is probably unnecessary, due to the patient simply leaving the device at home.

3.3. ONLINE QUESTIONNAIRE

METHODOLOGY

An online questionnaire was developed to gain insight in the problems of people with mild dementia, their attitude towards technology, and their (future) use of technology. Also some applications for the navigation device are brought before, and some interfaces are shown, to see what kind is preferred. This questionnaire was administered to (informal) caregivers. Orpwood et al. designed technologies for people with dementia, taking the needs of users as starting point. Caregivers and family were included in the process of pinpointing problem areas (focus groups and formal questionnaires) and evaluating prototypes (cyclic process of evaluation and design), before including persons with dementia. Intimate caregivers and family were stated to be a better source of information to pinpoint problems than people with dementia; an approach which 'proved to be very effective'. Conducting the questionnaire, a two way method is used. In the first half of the interview, general questions were asked about the relation with technology, ICT, and navigation. In the second half, several interfaces and form factors are presented on which they can comment.

RESULTS

The questionnaire was started by 26 persons (4 male, 22 female) with a mean age of 51 years (min 24, max 74) of which 14 professional care givers and 12 informal caregivers. Seventeen questionnaires were fully completed (65.4%). The majority of the people had more than 5 years experience in caring for people with dementia (figure 1).

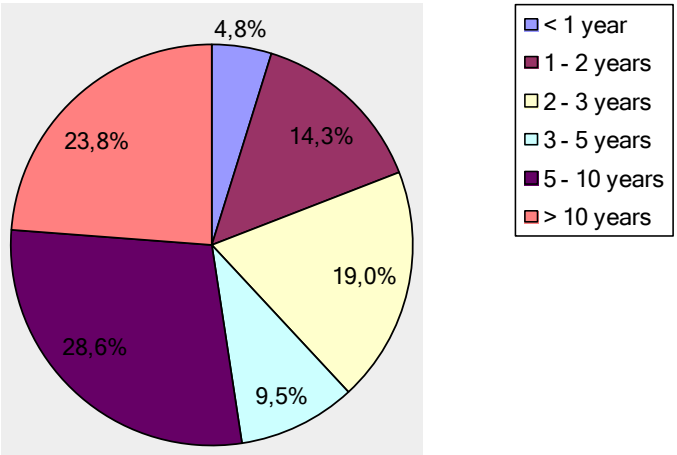


Figure 1; experience

Use of technology and daily problems

Does the person with mild dementia use a mobile Phone?
Yes (14%) / No, but able to (14%) / **No, and not able to (62%)** / Other (10%)

How does the person with mild dementia experience the use of a mobile phone? (n=7)
Not fun at all (0%) / not fun (29%) / **neutral (57%)** / fun (14%) / very fun (0%)
Very difficult (0%) / difficult (43%) / neutral (57%) / easy (0%) / very easy (0%)

What are the most important problems people with mild dementia experience?		
Options	Percentage responses	No. responses
Remember	100%	7
Concentrate	57%	4
Orient	43%	3
Time awareness	29%	2
Recognizing instructions (e.g. traffic signs)	43%	3
Have a conversation	43%	3
Emotional fluctuations	29%	2
Other	29%	2

The people are supported in remembering by using memory aids, i.e. a calendar on the wall (n=4), asking for help (n=3), the carer remembers things for the patient (n=4), (sticky) notes (n=2) or a memo board (n=1).

Use of navigation and attitude

Do persons with mild dementia use a navigation device, for example in the car?
Yes (17%) / No (83%)

Do persons with mild dementia use a paper map?
Yes (11%) / No (89%)

Do you believe people with mild dementia would benefit for navigation support?
Yes (56%) / No (44%)

Future navigation

What kind of device you think is the most suitable for people with mild dementia?
Wearable device without screen (44.4%) (figure 2)
Digital walking cane (11.1%)
Digital watch with screen (22.2%)
Smartphone (22.2%)

Figure 2: Wearable device without screen (TrekkerBreeze)

Which screenshot do you think is the most suitable for people with mild dementia to transfer the message: keep walking straight ahead?

Arrow (not moving) (44%) / Compass (0%) / Photo of surroundings with arrow (56%)

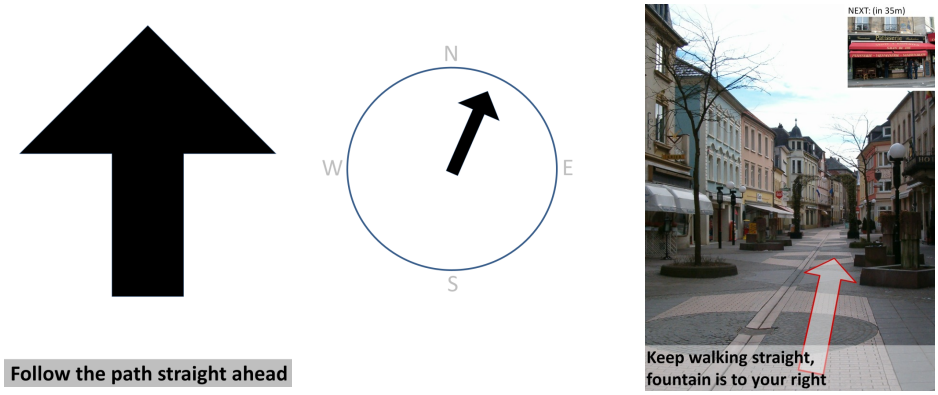


Figure 3; examples of screenshots for the message: keep walking straight ahead

Which screenshot do you think is the most suitable for people with mild dementia to transfer the message: take the second on your right?

Digital map (6%) / Instructions with traffic signs (0%) / **Picture of surroundings with arrow (78%)**

Figure 4; example screenshots for the message "take the second on your right"

Would 'tracking at a distance" be a valuable addition?

Yes (78%) / no (22%)

Would people with dementia have objections for this tracking?

Yes (56%) / no (44%)

How would you prefer a helpline? (multiple answers possible)

Helpline not necessary (0%)
Automatically: system recognizes when the user needs help (n=16, 89%)
Manually: user can push a help button (n=9, 50%)
Two-way communication: carer can also call user for giving help (n=9, 50%)
Video-calling (n=6, 33%)
Other (n=1, i.e. by voice recognition as person is calling for help)

Below are some requirements. Which 3 do you find most important for navigation support?		
Options	Percentage responses	No. responses
Low cost	6%	1
Solid	11%	2
Easy to use	**89%**	**16**
Safe to use in traffic	17%	3
Privacy is well protected	0%	0
Well tested	0%	0
Easy to learn	**56%**	**10**
Reliable	44%	8
To combine with existing reminders	28%	5
Able to give personal touch to device	0%	0
Easy to carry	22%	4
Unobtrusive	11%	2
Battery life	17%	3

Suggestions / additions

The persons could indicate whether they were missing some features. Two persons indicated that the device should also be used inside, for example in the caring facility. It is also mentioned that the user should receive an instruction, as the user has trouble learning something new, so he can read instructions next time.
Also for wheelchair use, compatible with other systems like wheelchair arm
The device should also be used by bystanders to call for help when necessary.
In the beginning phase of dementia, people are suspicious and believe nothing is wrong with them. They probably also believe they do not need navigation support. How do you 'sell' this to the user?

3.4. SCENARIOS MILD DEMENTIA

METHODOLOGY

Scenarios are "*narrative description of what people do and experience as they try to make use of computer systems and applications*", as defined by Carroll (2000).Scenarios are easy to understand, concrete descriptions of a system in a user environment. It is therefore a powerful tool to communicate and bridge the gap between users and design (Carrol, 2000). The main aspects of a scenario are the actors, their goals and objectives and the key episodes of the interaction between system and actors. In addition, scenarios may comprise e.g. storyboards, video mock-ups or scripted prototypes to visualize situations or systems.[65] Applications for scenarios are, among others, the requirements elicitation, user-designer communication, design rationale or evaluation.(Beynon-Davies & Holmes, 2002)
Scenarios can be used in any stage of the design process, from analysis to implementation. Beynon and Macaulay (2002) define four application areas for scenarios in the design process. First critiquing the current situation by analyzing what people do and want by means of *user stories*. Then envisioning how the situation should look like by generating ideas and understanding requirements from *conceptual scenarios*. From the requirements *concrete scenarios* can be defined for prototyping and evaluating design ideas and *use cases* are more formal and specific descriptions of design, both part of the last implementation phase. An overview is given in figure 5.

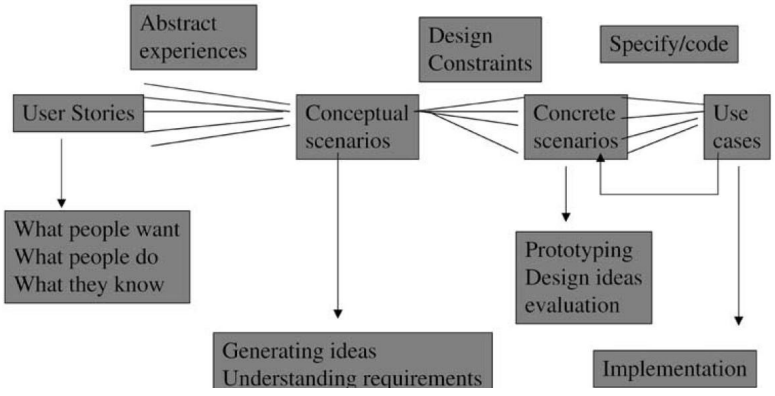


Figure 5: use of different types of scenarios in the design process, chronically ordered from left to right, adapted from Benyon and Macaulay.(Beynon & Macaulay, 2002)

In more detail user stories are narrative descriptions of what people do, e.g. in their daily work. It depicts the user's activities in full context, describing the social settings, resources, work practices and goals of users.(Minocha, 1999)Scandurra (2008)used user stories to describe the (mutual) "intra-care and inter-care" work activities of different types of health care workers during a "multidisciplinary thematic seminar". These user stories mapped the information needs of the individual health care workers and eventually formed the requirements for system design. In that sense, Scandurra used scenarios as user stories and conceptual scenarios for both understanding what users do normally and eliciting requirements respectively.

CONCEPTUAL SCENARIO

Mrs. Smith is a 76 years old woman and lives on her own. Since 3 months she was diagnosed having mild dementia. In spite of the diagnosis, knowing that it will become difficult to take care for herself independently, she wants to remain in-home as long as possible and stay independent. Her only daughter Jessica helps her mother once a week. They often go for a visit to the supermarket together, or go for a walk outside. She also receives help in home twice a week of Emily, a professional caregiver of a home care organization.

Jessica and Emily decided to download the Navmem application to the smartphone of Mrs. Smith. NavMem is a mobile navigation companion for that support Mrs. Smith in navigation, orientation and familiarization. An additional location sharing service allows Jessica and Emily to learn about the location of Mrs Smith to provide guidance on the phone.
Although Mrs Smith would really like to go outside as she enjoys walking, she doesn't go outside anymore by herself, because she is often disorientated. Mrs Smith now sometimes uses a taxi to bring her to places, where she used to go by herself. Jessica is worried that her mother will get too inactive, and will feel lonely.
Mrs Smith is a bit suspicious about this new technology, and thinks she doesn't need it. But Emily brings the Navmem device with them when they go for a short walk, and Mrs Smith sees that Navmem is easy to use and learn.

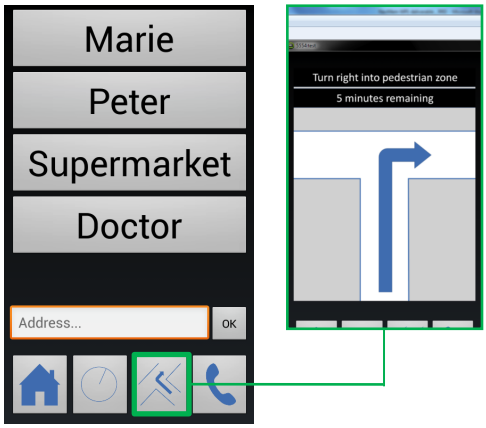
Situation 1: Navigation to the supermarket

Mrs Smith wants to go to the supermarket. Because she feels insecure in going, she takes the Navmem device with her. She chooses 'supermarket' from her favourites on the Navmem application, puts the smartphone in her hand bag and starts walking. She easily finds her way to the supermarket herself, and the Navmem application stayed in background mode. Mrs Smith feels proud she found her way, and no-one noticed she had a little help in the background, as the application is so unobtrusive.

Situation 2: disorientation

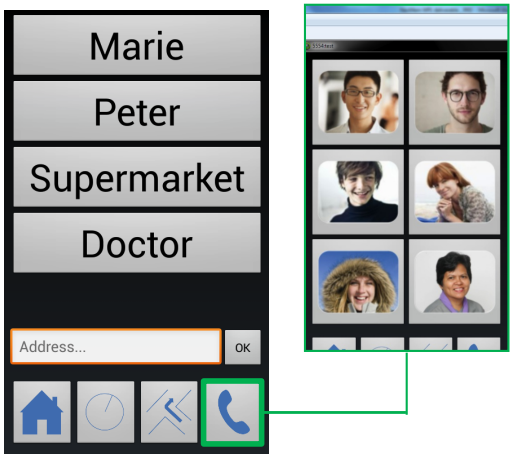
Mrs Smith would like to visit Peter, her son, who bought a new home this year. She chooses 'Peter' on the application, and starts walking. After 10 minutes walking, Mrs Smith doesn't recognize anymore where she is. She stands still, and keeps turning around, hoping she remembers. Navmem automatically recognizes the disorientation of Mrs Smith, and starts to help her way finding. On the screen of her phone she can see she has to walk in the direction of the church before her, there she

has to turn right. This is shown by an arrow. Mrs Smith starts walking and after a few minutes she recognizes the street Peter lives in.



Situation 3: calling

A week later, Mrs Smith visited an old friend. But on her way back, she gets really confused as she doesn't know where she is. Should she take a bus, or is she near her house? She calls Emily by choosing her picture on the Navmem application. Both Emily and Jessica are able to access the system with their computer and can inquire the processed monitoring data after a secured login. They also have the possibility to access the system with her smartphone or tablet, which Emily already uses for administrative purposes. Jessica sees that her mother is on the other side of town. She talks to her mother to give moral support and explains she has to take bus line nr 4 at the bus stop on her right. Mrs Smiths calms down, and gets in the bus. The Navmem application reminds her where she has to get out of the bus, and 20 minutes later she is back home. She really enjoyed her day, and did not feel alone.



3 months later

After a couple of months of using the Navmem application, Mrs. Smith's average levels of activity are increased, she gets out more often. Mrs Smith feels to be more independent and more self confident as she can go to places without help. She really likes the social contacts with friends she is now visiting.

Emily and Jessica really like the Navmem application as it saves a lot of time. They do not need to go with Mrs Smith all the time. Jessica really likes she can see where her mother is, and is not constantly worried anymore. Emily and Jessica are considering buying the extended version of Navmem, which is connected to an in-home reminder / agenda system.

References

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Beynon-Davies P., Holmes S., *Design breakdowns, scenarios and rapid application development*, Information and Software Technology, Volume 44, pages 579 – 592, 2002.

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Scandurra I et al., *From user needs to system specifications: Multi-disciplinary thematic seminars as a collaborative design method for development of health information systems*, Journal of Biomedical Informatics, Volume 41, pages 557 – 569, 2008.

3.5. USER NEEDS ELICITATION – MILD DEMENTIA

There is a clear need for navigation support. People with mild dementia would like to stay independent and need the support in daily and social activities, as they experience problems with orientation and navigation. Consequently, they avoid going outside and they can become inactive and lonely.
"Self-effacing navigation support in daily activities for an independent life"

From the user studies the following user needs / requirements arose:

User requirements	Why
- The system should support an active lifestyle - The system should support in doing daily activities outside - The system might provide navigation support inside	To prevent inactivity and thus deteriorating physical health
- The system should support in doing social activities (e.g. visit to friends/family)	To prevent loneliness and thus maintain quality of life
- The system should automatically recognize a disorientation event - The system should provide support in case of disorientation	To provide support in the navigation and orientation problems of the user
- The system should only provide navigation support when needed - The system should support the user in navigation and orientation in an unobtrusive manner	To provide feel of independence
- The system should facilitate help provided by (a informal) caregiver automatically when needed - The user can contact an informal caregiver in times of need - The (informal) carer could also contact the user (two-way communication) - The device should also be used by bystanders to call for help when necessary	To provide support by a (known) person in case of need
- The system must contain "tracking at a distance" - The system could monitor the activities performed by the user	To support the memory of the user in what activities the user performed, To provide the (informal) carer reliable information on the user's activities. To provide security of knowing where the user is (when this is needed).

- The system should be easy to use - The system should be easy to learn - The system should be reliable - The interface should be very simple - The interface could include information about the surroundings to support memory - The system should also be suitable for wheelchair use - The system could be compatible with other memory aid systems (e.g. digital calendar)	To make the system suitable for this target group

4. Studies by Lund University - stroke

Lund University focused on users who have had a stroke (the work was done together with the partner SSA).

4.1. INITIAL INTERVIEWS

To get an overview of what it can be like having had a stroke, we performed a round of initial interviews. In total 10 persons from SSA were interviewed (7 of these had had a stroke themselves). The interviews were made in the home of the person. On the whole the project was seen as relevant, and many of the persons interviewed wanted to be able to be “out and about”. The following problem areas relevant for the project were indentified:

1) fear of falling. This is a huge problem, and depending on your motor ability it may also be the case that even if you are not hurt by the fall, you are unable to get up again. It is really important to be able to call for help. Many of the persons already have security alarms, but these only work in the home.
2) half-sided motor problems are common – all technology developed needs to be able to use with only one hand. Buttons should not be small and “fiddly”.
3) memory problems may occur. There is a need for simple memory support. Text should be kept short – otherwise you may forget the initial sections before you get to the end.
4) it may be difficult to process information simultaneously. It is important not to disturb concentration but to support it. Neglect may occur – which is something that forces the person to concentrate a lot. Neglect is something different from not being able to see parts of the world, a person with severe neglect does not appear to be aware of the existence of half of the world. This can lead to the person walking into things, but also to the person only seeing the latter half of each word in a text. Severe neglect has become less common, and in less severe versions of the problem the result is more like a difficulty to attend to half of the world – unless the person concentrates, things and events in this space are easy to miss.
5) problems with navigation – if you have short term memory problems it is difficult to navigate in new environments. Known environments work – and a new environment can become known after much practice – but this takes a long time.
6) motor problems makes it important with accessible routing. You want to be able to avoid stairs, cobbled streets, loose gravel or sand, steep edges etc.
7) aphasia occurs. You may need help finding words, and images (or video) can be an important complement.
8) You may have hearing problems and/or visual impairments. It is important the technology takes this into account.

Some of the persons interviewed also reported being lonely. They may have no friends, or only one. There were mentions of feelings of shame – you may be ashamed of your lack of memory as one example. This is certainly not true for everyone, but there were persons who said this was the case. All persons interviewed had a mobile phone (although one said it was never used). Only one person had a smartphone.

4.2. INTERVIEW OCCUPATIONAL THERAPIST

To validate the initial user interviews we also did an interview with an experienced rehabilitation occupational therapist who has worked with persons with stroke for a long time. This interview showed that the initial interviews had covered the area quite well. There was no obvious "white spots" - but there were two more subtle problems that can be difficult to understand from just a short interview:

1) "Brain tiredness". Persons who have had a stroke can become very tired - this is not like ordinary tiredness where you can push yourself even though you are tired - it is more described like "pulling down a curtain" . You really need to stop & rest.
2) A more subtle problem which one may not be aware of oneself is difficulty "getting started", they seem to have lost “the start button”. Consequently they haveproblems with the initiative - execution - evaluation process.

On the overall level (this is very crudely put) right sided injuries may result in spatial problems - neglect/spatial inattention, while left sided injuries may result in aphasia (language difficulties). All the persons I interviewed said maps are ok, but the occupational therapist said maps can be a problem. You sometimes see problems with right-left or even spatial rotation (like when you turn a jumper to get it put on the right way). The most common problem after a stroke is motor problems. Aphasia- and neglect-like problems are also quite common.

To sum up the occupational therapist confirmed that the problems/situations caught in the interviews had "good coverage":

1) falling/fear of falling. Falling can cause severe injury and it may also be difficult getting up again. Important to be able to contact someone!
2) half-sided motor problems are common - technology should always be possible to use with only one hand (and buttons etc should be easy - not tiny & difficult to manipulate). This type of motor problems are common after a stroke.
3) memory problems occur - simple ways of recording & getting reminders useful. Text should be kept short (hard to remember if it is too long). Learning new things can be affected (takes much longer to learn).
4) it can be difficult to process a lot simultaneously. Shared attention becomes problematic. It is important to support people in a way that does not interfere with the concentration needed for the task at hand. Avoid information overload. Neglect (although not the severe version sometimes mentioned in older literature, this is more a case of "inattention" to half of the world) can cause people to miss things in the environment. This can make moving in traffic difficult and dangerous.
5) orientation problems - with short term memory problems it becomes difficult to navigate in new environments. Known environments tend to work, but it takes a long time to make an environment known.
6) motor problems/wheelchair makes it important to be able to find accessible routes avoiding stairs, difficult ground (eg sand or loose gravel for wheelchairs) etc etc .
7) aphasia occurs - it can be difficult both to find words or to recognize - images may be a good complement.
8) you may also have vision and hearing problems. A reduced field of vision sometimes appears after a stroke

4.3. SCENARIOS - STROKE

The information from the initial interviews was condensed into a set of preliminary scenarios. These scenarios were discussed in two separate focus groups (4 and 5 participants respectively). The preliminary scenarios were refined after the group discussion which also added a new scenario on public transportation. The following section describes these scenarios and also reports comments from the discussion.

Simple memory aid

A common theme in the interviews was the need for a simple memory aid – to remember items for shopping, to remember people you met, to remember after a phone call etc. Some users also had problems finding their way back to places. A slightly more targeted situation was that several users talked about the way they knew they got tired from longer walks and had to time their walks in order not to get too tired. The images in figure 1 illustrate the first type of scenario – you want to remember a few items or a person.

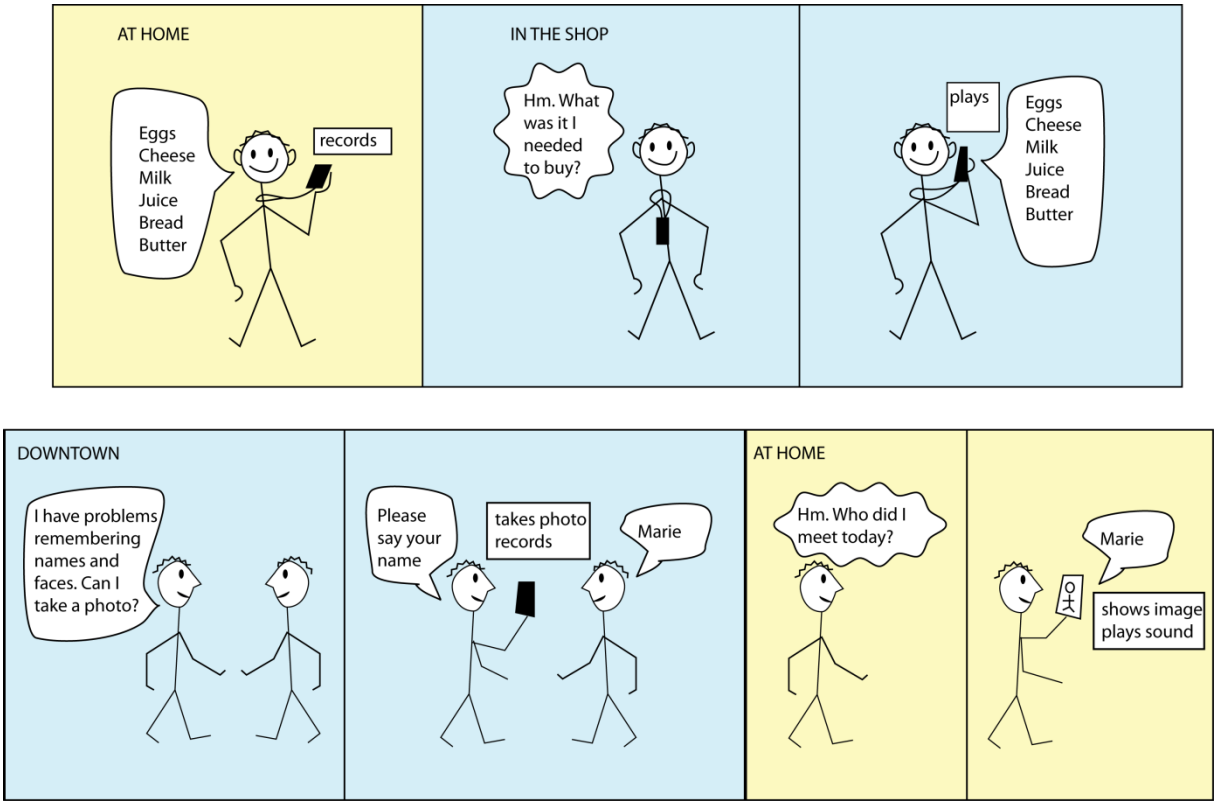

Figure 1. Top: simple audio memory aid. Bottom: simple image and audio memory aid.

These scenarios were generally felt to be very relevant (although one person said "you don't just walk up to someone and asks their name" – this is of course correct, the scenario assumes conversation before the image/name is recorded). There is a need for a very simple aid (only one message that gets deleted when you record a new one), but possibly also for more complex ones with more items in a list. For sound recordings it is important that the message allowed is long enough. We tested an existing memory button which had 10s message time and this was WAY too short.

In addition to the situations in the scenarios, it was mentioned that this could also be useful when someone phones – or if you plan things for the day in the morning and want to remember what you thought. It was mentioned that if you could get speech recognition it would be very useful – several users find it difficult to write due to motor problems, and would like to be able to generate written lists by talking.

It should be noted that the device should be easy to bring, have big and clear buttons, be possible to manipulate with one hand only – and it is also important to think about the fact that series of steps (instructions, items in a list etc) are difficult if you have memory problems. When you have progressed down the list, you have forgotten what was at the beginning.

A final comment here was that sometimes you need to remember what you shouldn't do (eating unhealthy things, buying too much etc).

Image 2 shows the "remember a location" scenarios.

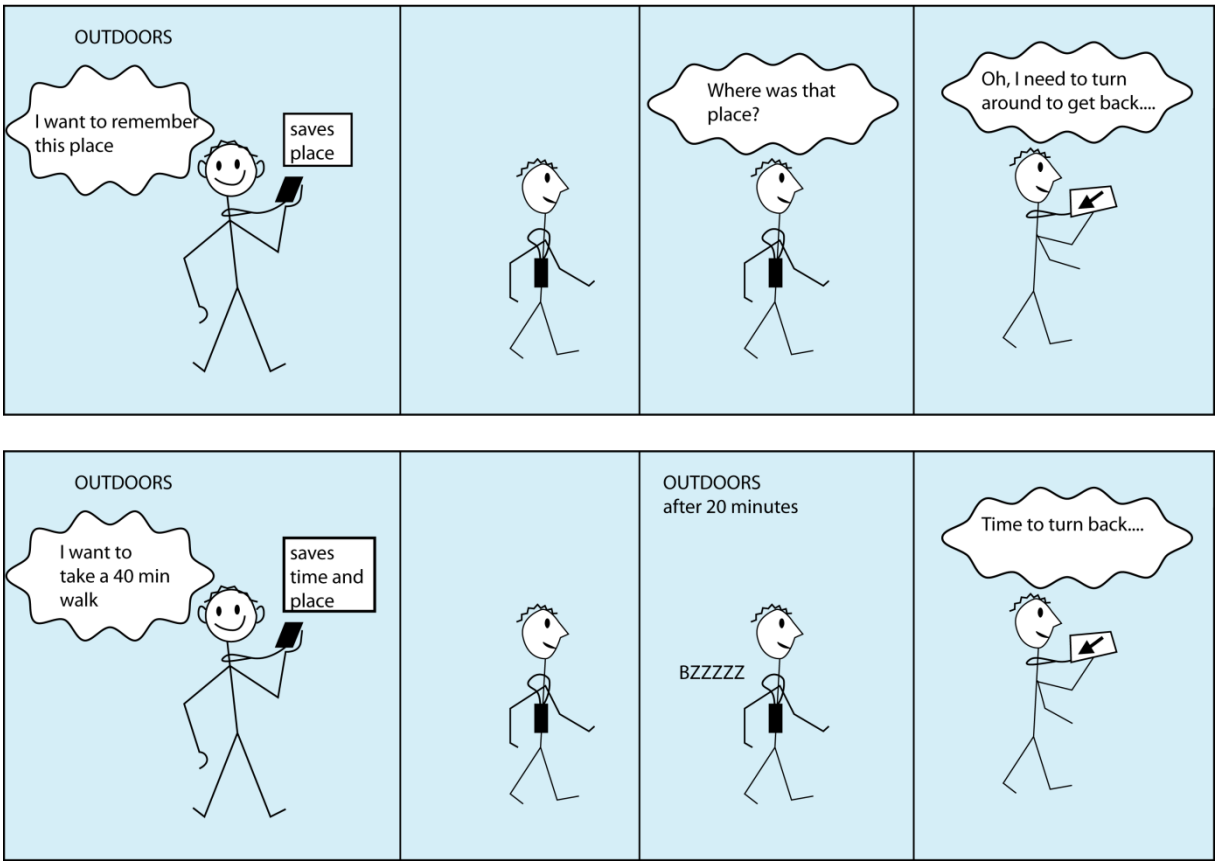

Image 2. Top: record a location in order to get back to it. Bottom: turn around after a specified time (to avoid getting too tired).

Also these scenarios were felt to be relevant. It is important to exercise, and something that helps you get back before you get too tired. As for information there is a need for very simple instructions – and these need to be adjustable as well as available in multiple modalities. A simple application with only one location (that gets erased when a new one is recorded) was thought to be useful, but as in the previous scenarios a list with several locations was also thought to be useful.

As in the previous scenario it is important to allow one handed manipulation. It was stated that you wanted very clear verbal (or other) instructions – "you are now at XXX", not just a buzz or pling. You want information, but you don't want the device to "nag" you, this is something that can quickly get annoying. An image when you arrive as a complement to speech/text/sound/vibration information is useful.

It is a MUST for both these applications that there is a warning if the battery is about to be drained. The warning should be given sufficiently in advance so that you can turn around and get back.

The persons familiar with GPS were worried about location precision. It is important the user somehow gets information about how reliable the information is.

Lifeline

Being able to call for help was seen as maybe the most important thing. The current security alarms work only indoors, and since many of the persons in the group wanted to go out they wanted to be able to call for help also outdoors. Image 3 and 4 shows three scenarios of increasing seriousness/urgency.

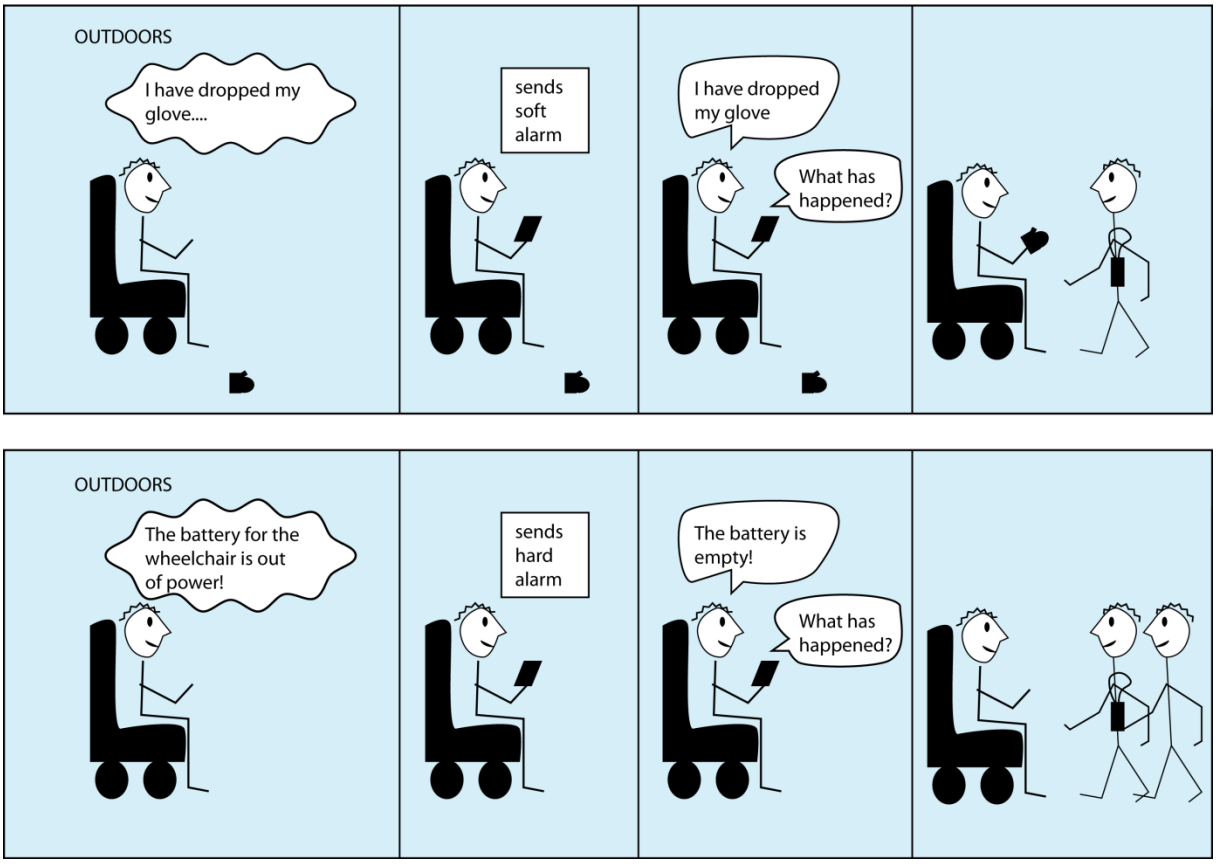

Image 3. Top: a less serious problem. Bottom: a more serious problem.

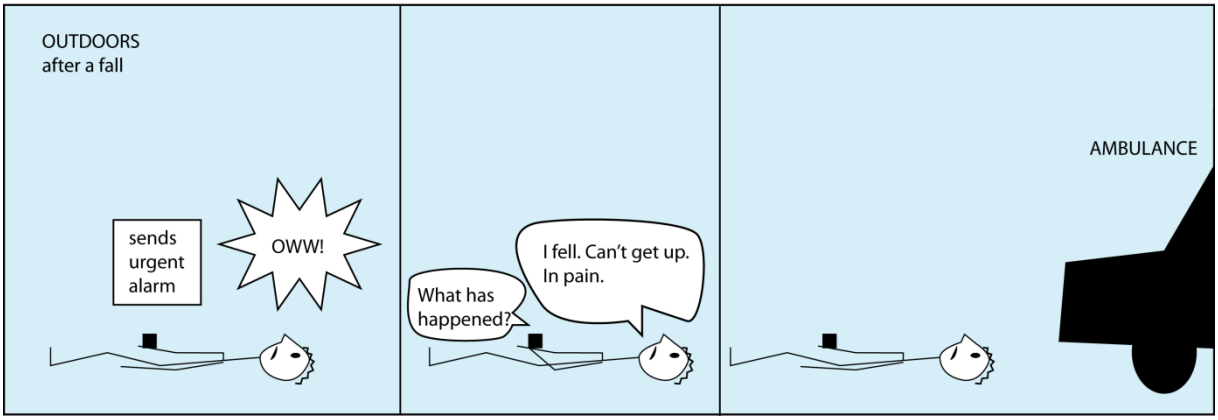

Image 4. A very serious alarm The person has fallen and needs an ambulance.

Although the scenarios show three degrees of urgency, our users thought all alarms should go to the same place: the home help service. This is the organization that gets current security alarms, and friends or family were not thought to be good for this (they may be at work or not available). There was still a need for different levels urgency of the alarm – one person had in fact been told by the home help services to press repeatedly on their security alarm when it was urgent. It is an open question if three levels are needed – our user groups thought two levels would be enough.
Since this to some extent may depend on the social setting and social services available, we have kept three levels in the scenarios for now.
Finally, there was also a suggestion that it would be good if falls could be automatically detected.

Navigation

Under the theme navigation, the problem of getting to one location appears again (very similar to the navigation scenario under memory support), but here we focus more on the navigational details. There is a need for simple navigation support, but (given that the system should also be useful for more main stream users) in addition for more complex map and navigation applications.
The first scenario (top in figure 5) illustrates the idea of the simple navigation.

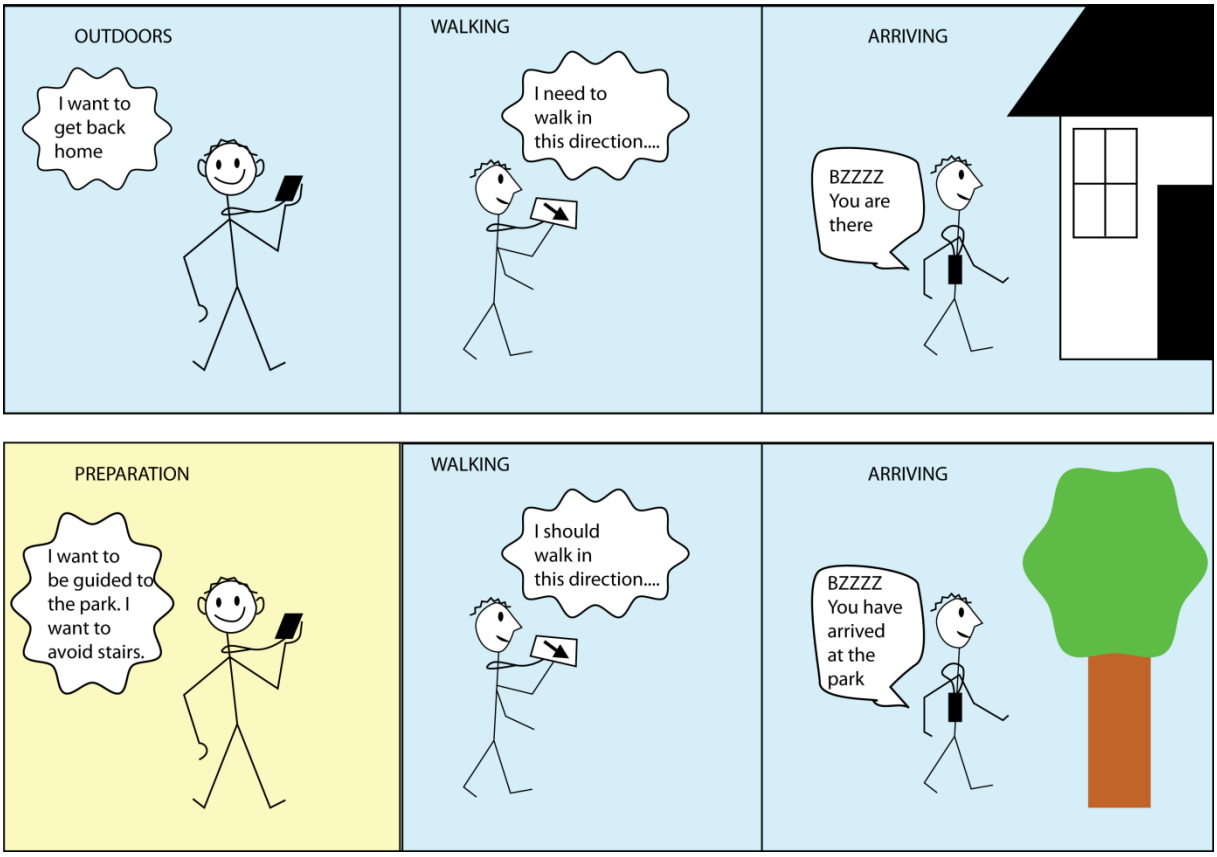

Image 5. Top: simple navigation support. Bottom: Navigation support with accessible routes.

The participants wanted to know both direction and distance. Street names were also mentioned as being of interest. Once you get there you may want more – an image of the place, phone number to a person living there, etc etc. It was suggested that it could be nice to be able to add locations from the mobile phone phone-book. You need to get arrival information – not just a buzz (or a pling).
As before a single location is useful, but a collection of several favourites may also be of interest.
The ability to create accessible routes (Image 5, bottom) was seen as very useful. Many persons have mobility problems, or are in the company of persons with such problems and being able to get good routes would be very useful. It should be noted that the same person may have different preferences – preferences should be saved, but it is good if one can have more than one profile. Stairs, edges, cobbles, steep slopes, loose gravel or sand was mentioned as problematic.
During the discussion we touched on public transport. Although these have many services the information isn't always available or accessible (hearsay reports on bus drivers who turn off the speech because it is annoying). At bus stops you may find electronically updated signs, but these are not accessible for persons with visual impairments. Image 6 provides an overview of this type of situation.

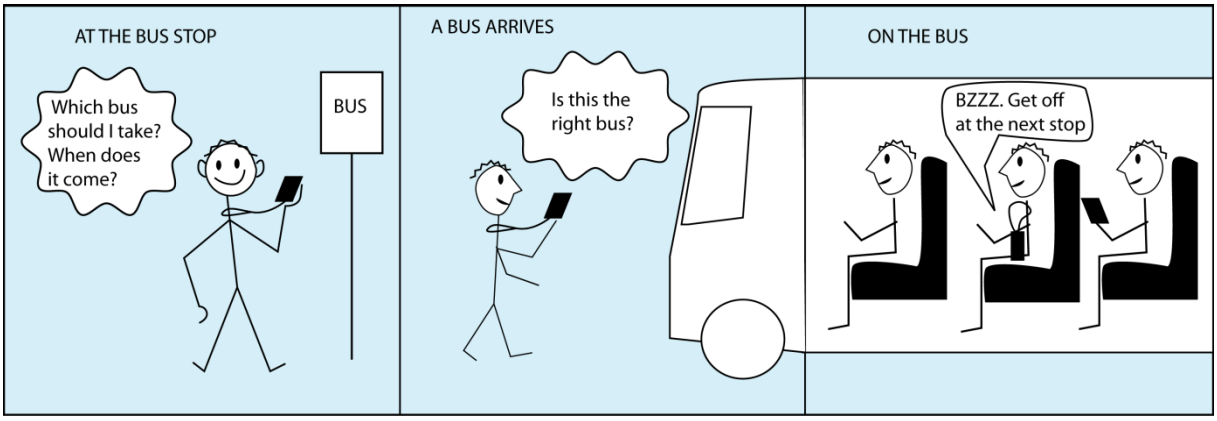

Image 6. Public transport (this can be part of a route or separate). Although this scenario provides feedback at the stop you intend to get off, we expect the usual reporting of names of bus stops to be included (although as the scenario was written this was thought to be part of the existing infrastructure).

The final scenarios are more complex and involve the user being able to see what can be found in the vicinity, be it locations of interest or friends. Image 7 shows this type of more complex application where you can see where you are, you find out what is around you, you can get guided, you get information as you pass locations of interest and you get arrival information.

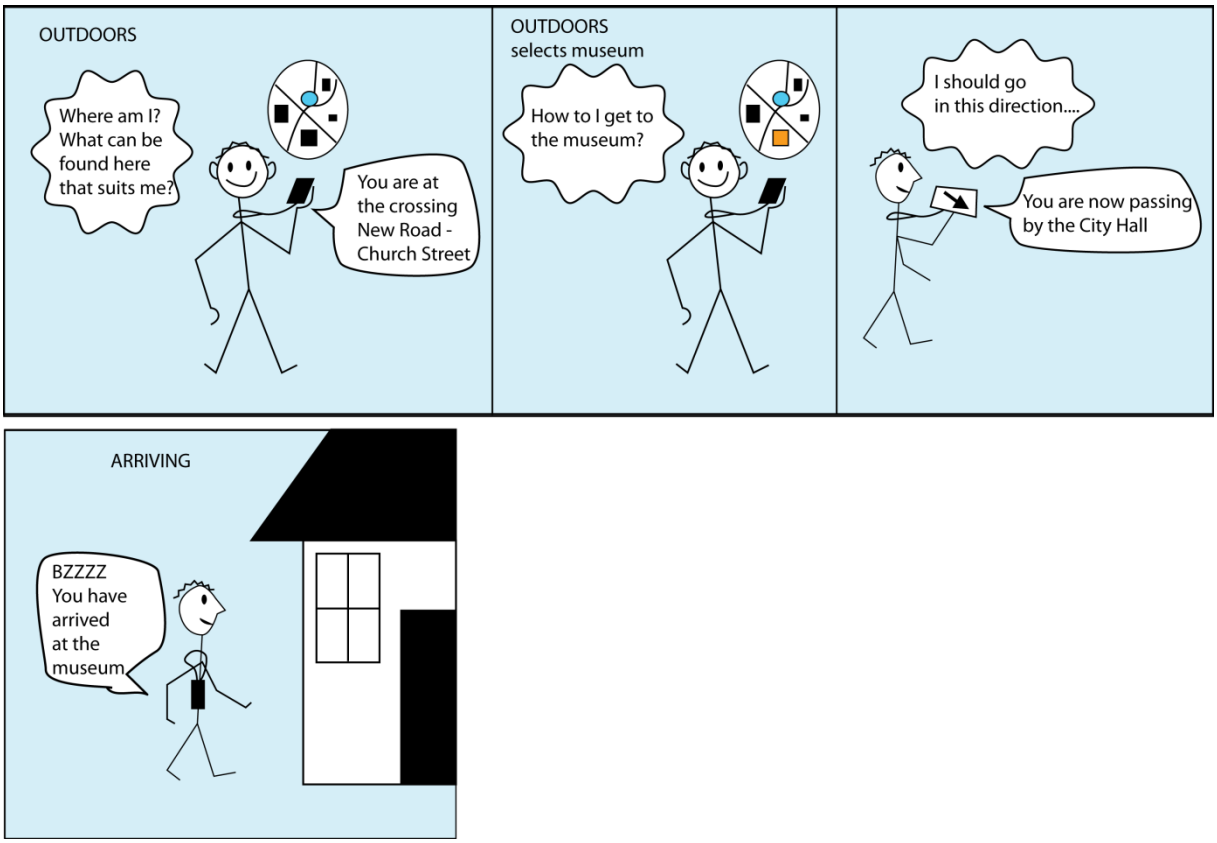

Image 7. A more complex navigation application

A specific comment here was that some of our participants liked to plan in detail while some did not. The ones who preferred to explore liked the idea that you would be notified as you passed something – you could then just go out and explore and find out about interesting things as you pass them.

You may want images, street names but it could also be useful to be able to record something (that is played as you reach the location). Both having locations on a map and having them in a list was discussed – but for this kind of complex application a map provides good overview. You could also

point the phone in different directions although this could potentially create problems for persons with memory difficulties since they would forget the earlier places as they reach the later in the scanning gesture.
A similar application focusing on friends is shown in image 8.

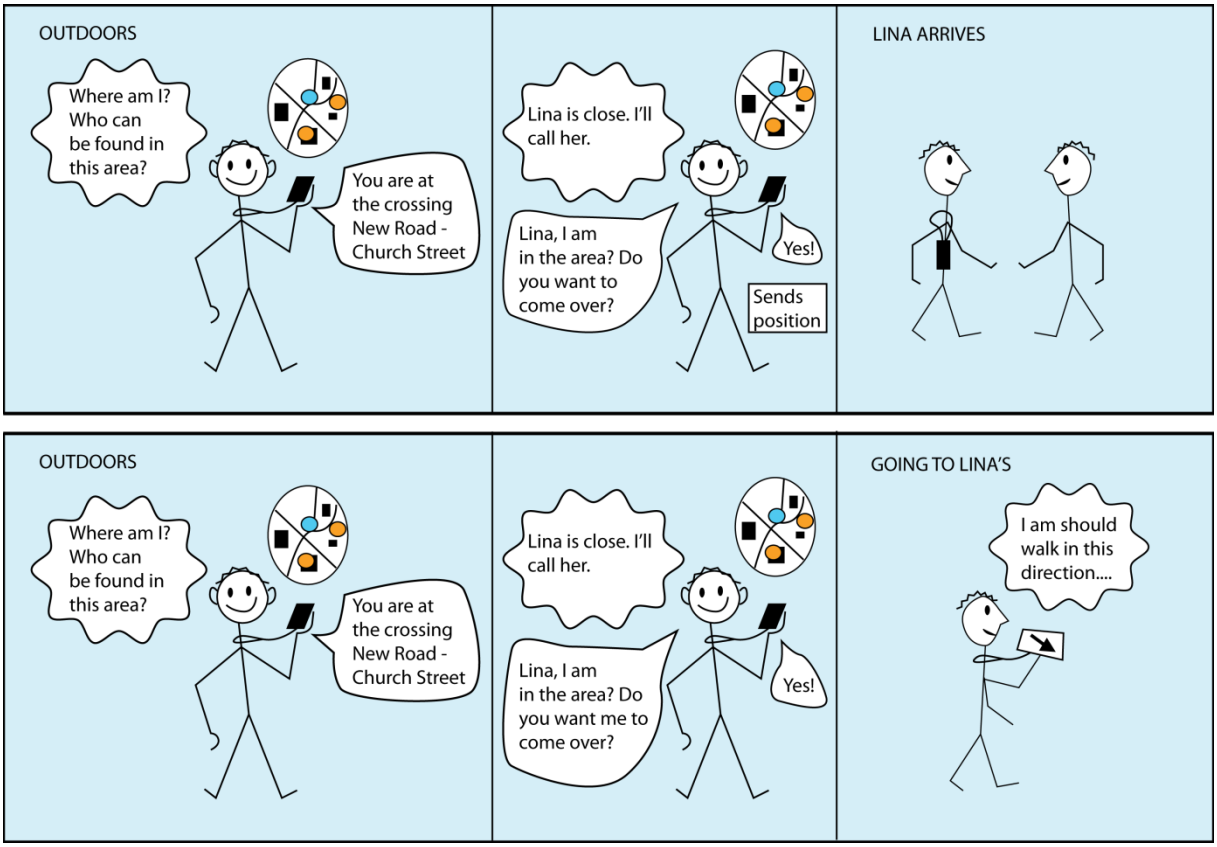

Image 8. Finding friends. Top: in this case the person you contact will come to you. Bottom: here you go to the person you contacted.

For the contact it was thought SMS or phone call would be best. A comment was that sometimes it was the person at home (relative, friend etc) who worried and might want to keep track of where the person out moving was. The friend list was thought to be about 10 persons (acquaintances can be more) – you want image, name, address and number (but it needs to be voluntary to fill fields in, you may not want to tell everyone everything).

4.4. Resulting requirements

4.5. General requirements

Security & safety – many persons have motor problems, and are afraid they will get injured if they fall, but also they may not be able to get up again after a fall. This requirement is also relevant for the operation of the device – the user should not be left stranded (with no battery left), or guided to unsuitable or dangerous areas (eg. guiding a person who has difficulty wlaking to steep stairs, leading a person to walk in a lane reserved for heavy traffic etc).

Flexible & adaptable – the user group we target contains persons with a wide range of abilities and preferences. The system needs to take this into account and be flexible and adaptable.

Possible to manipulate by one hand only – many persons will have half-sided motor problems after a stroke, and any design/device targeted to this group should be possible to manipulate with one hand only.

Easy to manipulate – persons with motor problems also need an interface that is easy to manipulate. The interface should not require a high degree of fine motor skill – no “small and fiddly” buttons should be used. A possible alternative is speech input.

Easy to bring – if you have memory problems it is important that the device is easy to bring – possibly by allowing the user to hang the device around the neck, or carry it strapped to the arm.

Easy to remember – for persons with memory problems one cannot rely on the user remembering what should be done. The design should be self-explanatory (designed for first time use).

Keep texts short – a person with memory problems may not be able to remember a long text, the beginning may already be forgotten as the person comet to the end. Thus texts should be kept short, and if possible complemented by images. The same goes for lists – they should be kept short to avoid users forgetting the initial topics in the list.

Minimize the number of steps – with memory problems it is hard to remember which steps you already did, and if there is a sequence to go through each step needs to be self explanatory.

Limit the amount of information – many persons who have had a stroke have problems processing things simultaneously, and care needs to be taken not to cause cognitive overload. Avoid distracting the user from attending to traffic or other important things in the environment.

Provide appropriate reminders – a user with memory problems may need reminders for charging the device, for remembering to bring the device etc.

Images are useful – form many users (for example aphasia) images can provide a useful complement.

Make information available multimodally – the user may have problems hearing or seeing the information. Make sure information is available in more than one modality.

Keep orientation information, directions etc concrete, clear and grounded in the environment – a person with orientation problems may have problems interpreting a map and performing the mental rotations needed to translate a general map position into a navigation plan. Avoid coded messages – don’t just give the user a buzz (which requires the user to know what the buzz means) – provide concrete information if possible instead.

4.6. Desired functions

Simple memory aid – with memory difficulties a simple memory aid becomes useful.

Lifeline – the ability to call for help when you are in trouble, when things go wrong or stop working is important.

Accessible routing – many users who have had a stroke would appreciate routes that avoid stairs, cobbled stones and other difficult surfaces.

Simple and advanced navigation support – our user studies so far indicate the need of both simple navigation and more advanced navigation support.

5. Initial user study by SIEMENS AG - Elderly

Within the NavMem project the partner Siemens AG interviewed 11 elderly people in face to face interviews. The participants were selected randomly and nearly equally distributed in terms of gender: 6 male and 5 female. The youngest participant was 71 and the oldest 87 with an average age of 81.

Only one of the users does not own a mobile phone since the user is not interested in modern technologies. Of the ten other users four use it for making or receiving calls and the rest only for emergency / security reasons to be able to call for help. One of the users had a special senior mobile phone where the others possess regular mobile phones.

In terms of navigation devices 4 users own a navigation system and use it for driving in a car when undertaking longer drives. One of them had a PND where the others use in-built systems. Only two of the users consult maps when navigating since they offer a better overview of the region and one can see more than just the next turn ahead.

With respect to physical limitations three users were severely and one minor motor impaired and rely upon a walker where one uses an electric one. This user expressed interest in a mobile navigation solution if it would calculate routes depending on the actual battery load. Of the other users 2 are willing to pay for such a device (150 and 700 Euro) and the others could not make any statements since they are not buying electronic devices themselves but would most certainly do so if they would need it, could use it and it would offer them additional security in case of a medical emergency.

The question if they would prefer a single, special device or an application on their mobile resulted in no clear statement. Four of the users wanted a special device, with two opting for a bigger one and two for a smaller one, four users prefer a smartphone application, two were indecisive and one not interested at all. However, all of them agree that it has to be easy to use!

Ten of the users do not mind at all that their position, when being outside, is broadcast to someone if they can determine to whom. Seven would like this someone to be a close relative and three a service provider since they determined that a professional service provider could more easily help them in an emergency and the problem nowadays is that most relatives do not live close to their parents.

With regard to activities outside their home all of them more or less are interested in very usual things like shopping, walking visiting friends and family, participating in social events e.g. theatre, concerts, talks, etc. While still being able to do most of those things the participants try to avoid too steep inclines, prefer to use lifts or escalators and avoid in general all those things that require a lot of strength. Most of them emphasized that they are a bit more careful than in their younger years and carry less heavy things. All of them agreed that they do not yet need a geo-fence and did not show an interest in thinking about ever needing one since it basically relies to a mental decline.

With respect to modern technology only two of them are only using a TV set and a phone. All others showed a much higher usage of modern technological devices e.g. flat screen TV, DVD player, household appliances, computer / tablets and power tools for garden work.

The two users who do not use more than a TV set and phone find modern devices just too complicated and thus do not own them. The others agree that most of the devices are rather

complicated and not usable without reading too long manuals which contain too many features they do not need and use. They find it rather complicated to find suitable devices that are easy to use and sometimes reading displays causes problems because they are to small, the lighting is bad since the displays are too dark and it is too easy to make a mistake and mess up some settings and then one needs help to fix it again or read the too long manuals to find out how to repair it.

In conclusion one can summaries that there is a tendency to use a NavMem system when it offers the following features:

- Easy to use
- Big buttons
- If a special device, small, light and long power supply
- Display has to be readable under all lighting conditions
- The system should contain a GSM unit in order to call for help in an emergency
- One can decide who should be called and who should be able to determine the whereabouts

All users expressed their interest in a further participation in the project and would like to test a prototype.

6. Conclusion

These initial user investigations provide background information for the development to be done in NavMem. Although the user investigations have targeted different groups (dementia, stroke, elderly) a common theme of simplicity emerges. Current day smartphones and GPS devices are seen as too complicated, and there is seen to be a real need for simple and easy to use navigation applications. The device/application to be developed should be easy to use – but also safe to use (it is important the user does not get suddenly stranded or led into areas not suited for walking). The designs need to take different sensory abilities into account – the user may have limited eyesight or have hearing problems. A specific requirement from the stroke investigations is that the device should be possible to manipulate with one hand only.

Although "Simple and easy to use" comes out as an overall requirement, what an individual user finds simple/ easy varies greatly, and the continued development within the project needs to iteratively test designs with target users. Another consideration that needs to be taken into account is that it is useful if both simple and more complex alternatives exists - although the more advanced functionality should be designed in such a way as not to clutter the interface & confuse users who want the simple alternative (one possibility is to have "simple mode" and "advanced mode" with simple mode as the default).

User requirements, dementia

- The system should support an active lifestyle
- The system should support in doing daily activities outside
- The system might provide navigation support inside
- The system should support in doing social activities (e.g. visit to friends/family)

- The system should automatically recognize a disorientation event
- The system should provide support in case of disorientation
- The system should only provide navigation support when needed
- The system should support the user in navigation and orientation in an unobtrusive manner

- The system should facilitate help provided by (a informal) caregiver automatically when needed
- The user can contact an informal caregiver in times of need
- The (informal) carer could also contact the user (two-way communication)
- The device should also be used by bystanders to call for help when necessary

- The system must contain "tracking at a distance"
- The system could monitor the activities performed by the user
- The system should be easy to use
- The system should be easy to learn
- The system should be reliable
- The interface should be very simple
- The interface could include information about the surroundings to support memory
- The system should also be suitable for wheelchair use
- The system could be compatible with other memory aid systems (e.g. digital calendar)

User requirements, stroke

- The system should provide simple memory aid
- The system should provide a lifeline
- The system should provide accessible routing
- The system should allow both for simple and more advanced information

- Safe and secure
- Flexible and adaptable
- Possible to manipulate with one hand only
- Easy to manipulate
- Easy to bring
- Easy to remember
- Keep texts short

- Minimize numbers of steps
- Limit the amount of information
- Provide appropriate reminders
- Consider using images
- Information available multimodally
- Clear information on directions and avoid coded information or mental rotations

User requirements, elderly users (navigation devices)

- Easy to use
- Keys and screen needs to be large enough
- Clear and easy to understand information
- Important not to get lost
- The device needs to be robust and reliable
- If a special device, small, light and long power supply
- Display has to be readable under all lighting conditions
- The system should contain a GSM unit in order to call for help in an emergency
- One can decide who should be called and who should be able to determine the whereabouts

User requirements, elderly users (mobile devices)

- Mobile devices should be compatible with hearing aids
- Mobile devices should have a wide range of volume levels
- Several input modalities should be included (audio hints can help for reduced vision)
- Slide-out keyboards should be avoided
- Program and command naming should be carefully considered and in accordance with the users' mental models
- Provide large, clear and bright screens
- Provide large buttons
- Eliminate buttons on the sides and rear of devices
- Provide the possibility to zoom in on small text
- Provide clear confirmation of target capture (i.e. button press, visited link). The user should not be expected to detect small changes
- Older users should not be expected to double click because of slower hand movements
- A single, consistently placed button for returning to the home state should be included
- Graphics should be relevant and not for decoration.
- Images should have alt tags
- Icons should be simple and meaningful and also labeled (with a large enough font)
- Clear navigation should be provided
- Tapping often preferred to drag and drop
- Provide current location in the interface
- Clearly show which tasks are active
- Important features should be available directly via a labeled button and not via menu navigation
- Avoid pull down menus
- Do not have very deep hierarchy and group information into meaningful categories
- Important information should be highlighted
- Information should be concentrated mainly in the centre
- Provide ample time to read information
- Reduce the demand on working memory by supporting recognition rather than recall and provide fewer choice to the user
- Main navigation always the same and critical functions should not disappear
- Colours should be used conservatively
- Blue green tones should be avoided

- Background screens should not be pure white or change rapidly in brightness between screens. Also, a high contrast between the foreground should exist.
- Avoid moving text
- Avoid fancy font types
- An online help should be provided
- Error message should be simple and easy to follow

In general the requirements for the different groups are well aligned – easy to use (big buttons, multimodal presentation, no menus etc), simple, reliable and secure appear in all the lists. Specific for dementia is the larger focus on tracking and monitoring while the stroke group has the one handed use as a specific requirement. Differences, in the lists is in some part due to method differences and we suggest the overall requirements for elderly users are taken as a starting point, but that the development focuses on the specific needs of the users with dementia and stroke.

APPENDICES

APPENDIX 1 - USER STORY DEMENTIA (in Dutch)

Mevrouw Geerdink is 76 jaar en woont op zichzelf in een rijtjeshuis in Hengelo. Haar man is 3 jaar geleden overleden. Sinds 3 maanden is bij haar de diagnose Alzheimer gesteld. Ondanks deze diagnose wil zij zo lang mogelijk thuis blijven wonen. Mevrouw Geerdink krijgt 1 keer per week 3 uur huishoudelijke hulp (schoonmaken, opruimen) en 2 keer per week persoonlijke hulp (douchen) van de thuiszorg. Haar enige dochter Margreet gaat 1 keer in de week bij haar moeder langs om haar te helpen met de administratie en het doen van zware boodschappen.
Er is ongeveer 1 keer per maand contact tussen Margreet en de thuiszorg. Margreet leest sowieso altijd de notities van de thuiszorg in de map om te zien wat er gedaan en gezien is de afgelopen week. Ze leest dat de thuiszorg het vermoeden heeft dat mevrouw Geerdink minder actief is de laatste tijd en nauwelijks nog buiten komt. Margreet denkt dat dit wel meevalt, maar vraagt dit toch na bij haar moeder. Mevrouw Geerdink ontkent dit: ze was gisteren nog naar het park gelopen, het was zo'n lekker weertje!
Twee maanden later is het gasfornuis afgesloten. Verschillende keren had de keuken blauw gestaan, omdat mevrouw Geerdink vergeten was dat de aardappels op het vuur stonden. De buurvrouw wist telkens tijdig aan te bellen om mevrouw Geerdink hierop te wijzen. Het gas was definitief afgesloten toen mevrouw Geerdink zich ernstig had verbrand aan een hete pan. Nu ze gebruik maakt van "Tafeltje Dek Je", die aan huis avondmaaltijden langsbrengen voor de hele week en opgewarmd worden in de magnetron, komt ze ook weer een beetje aan. Margreet heeft de buurvrouw gevraagd zo af en toe een extra oogje in het zeil te houden.
Op een vrijdagochtend dat Karin van de thuiszorg langskwam, lag mevrouw Geerdink nog in bed. Normaal is ze altijd al in de kleren. Vier dagen daarvoor op maandagochtend was Karin als hoofd verpleegkundige nog bij mevrouw Geerdink. Karin had voorafgaand aan het bezoek nog even met de tweede verantwoordelijke wijkverpleegkundige gesproken in het wijkcentrum. Zij was 2 dagen daarvoor (woensdag) nog langs geweest en had toen niets bijzonders opgemerkt. Karin vermoedt dat mevrouw Geerdink sinds het laatste bezoek van de thuiszorg ziek op bed ligt met hoge koorts. Naar eigen zeggen had ze geen kracht om uit bed te komen om te eten, te drinken of het toiletbezoek. Haar bed lag vol met ontlasting.
Na enkele dagen in het ziekenhuis gelegen te hebben, is ze weer thuis. Ze bleek een virusinfectie te hebben gehad. Omdat ze nog verzwakt is en in de war van het ziekenhuisbezoek, krijgt ze tijdelijk extra hulp van de thuiszorg en gaat Margreet nu 3 keer in de week langs haar moeder. Margreet is erg bezorgd om haar moeder en is bang dat er weer iets mis zal gaan, zonder dat zij het zal opmerken. Na 2 weken geeft mevrouw Geerdink aan dat haar dochter niet meer de extra hulp hoeft te geven. Ze voelt zich namelijk alweer een stuk beter. Margreet geeft hier gehoor aan, maar ze is nog steeds bezorgd dat haar moeder weer wat zal overkomen.