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Deliverable 1.1.a

Mild Cognitive Impairment User Requirements

Responsible Unit: ANA Contributors: FSL, CNR, APOL, BART, IDE



Document Technical Details

Document Number	D1.1.a		
Document Title	Mild Cognitive Impairment Users Requirements		
Status	Final		
Work Package	WP1		
Deliverable Type	Report		
Contractual Date of delivery	28/02/2018		
Responsible Unit	ANA		
Contributors	All Partners		
Keywords List	MCI, Elderly, User Requirements		
Dissemination Level	Public		









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1 INTRODUCTION AND GOALS

Nowadays European society is increasingly facing many challenges connected with current significant social and demographic trends. Indeed, the ageing of populations, the change of lifestyles towards growing individualization, a strive for lifelong personal independence and the growth of single households are trends currently occurring together with a progressive and increasing digitalization of both private and professional lives. In this context, it is not by chance that the PETAL consortium decided targeting the elderly population, a group of people which is expected to highly increase in the next future. In particular, while the original plan of the project was to target elderly people affected by mild dementia, the PETAL consortium in the initial phases of the project has decided moving the focus to elderly affected by Mild Cognitive Impairment (MCI).

MCI is a quite frequent condition in the elderly population. It is generally characterized by an initial deterioration in a single or multiple cognitive domains such as memory, executive functioning, attention, or visuospatial abilities while generally global cognition and basic activities of daily living are mostly fine. However, many studies have suggested that persons with mild cognitive impairment are at increased risk of progressing to dementia. Preventive interventions and appropriate treatments should be able to improve cognitive performance and retard or prevent progressive deficits, thus it is crucial to intervene as soon as possible with those persons. In older adults with MCI, even subtle declines in cognitive abilities or everyday functioning are associated with e.g. decreased independence and safety, additional burden for caregivers, reduced chance of reverting to normal cognitive status, and, as said before, increased likelihood of developing dementia. The PETAL project takes on with these challenges and developments: based on an innovative technological solution, it aims to assist elderly people with MCI in order to satisfy their unique requirements for managing an active and independent life at home, while increasing awareness and control of their current lifestyle. This will be achieved through an intelligent platform able to monitor users' behaviour (movements, interactions) and support personalized control of lights and appliances in their environment, as well as providing them with relevant and tailored information in an intuitive and natural manner.

Thus, the reasons why the PETAL consortium decided addressing people with MCI instead of those affected by mild dementia (as originally planned) are rooted in a more in-depth consideration of the type of solution that PETAL aims to provide to its target users. Giving the technological connotation of the proposed solution and the intended active involvement of end users (caregivers and even elderly having some familiarity with technology) in using the developed platform for personalization purposes, we preferred considering a class of elderly with reduced impairments in judgments/reasoning, less difficulties with everyday activities, with a more autonomous lifestyle, and with less needs in terms of care management, also considering that patients in greatest need of chronic care management are those least likely to engage with technology. Indeed, elderly with MCI have a stronger potential to learn to use new technologies than those with dementia (even at a mild stage), and introducing systems for people with MCI when they are more capable to adapt and interact with the technology may have more potential.

As such, in order to ensure that the PETAL platform will properly support the needs of elderly with MCI, the specific lifestyles, capabilities, living environments and ambitions of elderly with





MCI must be taken into account in order to find adequate concepts and solutions for the purpose of promoting their independence. Accordingly, the present deliverable sheds light on the requirements of MCI older adults in their role of beneficiaries from care services and consumers, with their own specific, age-related interests, needs and requirements.

These initial requirements should be read in conjunction with the social, technical and regulatory environments as well as the needs and requirements of informal and formal caregivers (as described in the PETAL Deliverable D1.2 (PETAL, 2018)) and be taken as a basis for the upcoming development process and system design. In view of that, the present analysis pursues the objective to identify relevant issues allowing choices between potential features, modes of interaction and designs the PETAL system will adopt.

In particular, this deliverable is structured into the following parts: after the Introduction, we characterise the target population (elderly with MCI) in Section 2. Then, in Section 3 we describe the current situation in terms of i) practices, services, policies and interventions currently used for supporting the elderly; ii) use of digital services and devices by elderly; iii) technological solutions currently available to support the elderly. In Section 4 we describe the method we followed to gather user requirements (mainly guestionnaires), then we describe and analyse the collected data (Section 5). In Section 6 we summarise the main initial requirements and results identified, also providing some concluding remarks for the following of the project.













2 TARGET GROUP CHARACTERIZATION (ELDERLY WITH MCI)

Mild cognitive impairment (MCI) is a preliminary phase for different types of dementia. It causes cognitive changes that are serious enough to be noticed but the changes are not severe enough to interfere with daily life or independent function. MCI represents a mild decline in either single or multiple cognitive domains such as memory, executive functioning, attention or visual abilities while global cognition and basic activities of daily living (BADLs) remain intact (Albert et al. 2011; Gauthier et al., 2006).

MCI is considered to be a "symptomatic pre-dementia phase of Alzheimer's disease (AD)" according to the most recently developed diagnostic criteria (Albert et al. 2011). Persons with MCI often have more difficulty or may take longer than their normal counterparts in performing more cognitively demanding instrumental activities of daily living (IADLs) such as driving, telephone use, finding belongings, grocery shopping, medication management, food preparation, traveling alone, and handling finances (Aretouli & Brandt, 2009; Wadley, Okonkwo, Crowe, & RossMeadows, 2008).

There are four subtypes of MCI: *amnestic single-domain, amnestic multiple-domain, non-amnestic single-domain and non-amnestic multiple-domain.* The subtypes are based on the number of cognitive domains affected and whether memory is one of the domains affected (i.e., amnestic) (Winblad et al., 2004).

However, older adults with MCI generally live independently in their community. Although not to be neglected, the impairments these people report do not interfere with their ability to carry out important social, family and occupational roles alike (Aretouli & Brandt, 2009; Wadley, Okonkwo, Crowe, & Ross-Meadows, 2008). It is important to understand both the challenges these individuals face as well as how to assist them in meeting the challenges in order to assist older adults with MCI maintain their independence.

A vital role in both detection and care providing is played by the nurses as they aim to maintain maximum independence for persons with MCI. Supporting this statement, the most recent National Institute of Health statement has emphasized the importance of understanding and providing better care to individuals diagnosed with MCI (Daviglus et al., 2010). However, a recent review found that primary care providers have difficulty in identifying MCI in their patients and recording the diagnosis in the medical record (Mitchell, Meader, & Pentzek, 2011).

The prevalence of MCI varies depending on the population in which it has been studied. Using Windblad's (2004) diagnostic criteria, the prevalence of MCI was 42% in France (Artero et al., 2008), 28.3% in the United States (Manly et al., 2005), 24.3% in Austria (Fischer et al., 2007), 17.2% in Germany (Busse et al., 2006), and 12.7% in China (Nie et al., 2011). According to a recent review of population and community-based studies, the annual incidence rate of MCI ranged from 51 to 77 per 1,000 persons in those 60 years or older (Luck, Luppa, Briel, & Riedel-Heller, 2010). A review of forty-one cohort studies with a maximum follow-up of ten years suggests that, on average, **about 32% of people with MCI progress to dementia** (Mitchell & Shiri-Feshki, 2009). In addition, the risk of mortality increased by 50% to 150% in persons with MCI compared to those without MCI (Guehne, Luck, Busse, Angermeyer, & Riedel-Heller, 2007; Hunderfund et al., 2006; Wilson et al., 2009).

Risk and protective factors related to MCI are still debatable. Only a few factors have been associated with increased or decreased risk of cognitive decline. A diet rich in longer chain omega-3 fatty acids has been associated with a lower risk of developing MCI. On the other hand, increased risk has been associated with high blood pressure, depression, smoking and APOE-e4 allele genotype (Daviglus et al., 2010). Preliminary risk factors include cardiovascular risk factors





(e.g., diabetes, metabolic syndrome), alcohol intake, and being male. **Preliminary protective** factors include physical exercise, cognitive activities, and social engagement.

The diagnosis of MCI does not inform the patient in the same way a diagnosis of dementia does. For example, a diagnosis of MCI neither predicts whether the person will develop dementia, nor what type of dementia this might be. Because the cognitive and functional changes associated with MCI are subtler than those associated with dementia, the diagnosis is often missed, but patients and families may be left wondering what their "memory problems" might mean. Last but not least, there is less certainty in making a MCI diagnosis than in making a dementia diagnosis. Indeed, a relatively substantial proportion (31%) of individuals diagnosed with MCI revert to `normal' over 18 to 24 months (Manly, et al., 2008). Older adults and their families may be understandably confused about the implications of being diagnosed with MCI.

Another issue that has rarely been explored when referring to MCI diagnosis lays upon patient's reaction to the news - as mentioned before, people with MCI are able to express their own views and needs. There are a few descriptive and qualitative studies that have examined the patient's experience of MCI (Frank, et al., 2006; Joosten-Weyn Banningh, Vernooij-Dassen, Rikkert, & Teunisse, 2008; Lin, Gleason, & Heidrich, in press; Lin & Heidrich, 2012; Lingler et al., 2006; Lu, Haase, & Farran, 2007; McIlvane, Popa, Robinson, Houseweart, & Haley, 2008). Persons with MCI were able to accurately identify their own cognitive symptoms, described negative consequences of MCI (such as loss of self-confidence), had diverse emotional responses to their diagnosis (e.g., anxiety, relief that it was not Alzheimer's disease), and felt uncertain whether they would progress to AD. Few studies have examined the coping and self-care behaviors or strategies of persons with MCI (Joosten-Weyn Banningh et al., 2008; Lin & Heidrich, 2012; McIlvane et al., 2008). The studies showed that the persons with MCI engaged in self-care behaviors, such as use of supportive services (e.g., legal services, support groups) and strategies to prevent AD (e.g., mental exercise, physical exercise). They also used coping strategies to reduce stress and cope with memory loss.

MCI patients are often full of sorrows and worried about their gradual decay. They often tend to be depressed. Anything that brightens their mood, therefore, has great value. As is known, biodynamic light plays a central role in this task. In addition, it is important to recognize in good time that the patient's mood is deteriorating and countermeasures are initiated. Mental wellbeing is a motivator for coping with everyday life and other important activities, such as performing cognitive exercises.

In conclusion, although diagnosing and approaching an MCI patient and assessing all the relevant aspects are somewhat more challenging than addressing a patient with an already manifesting dementia, we considered that it makes solid sense to focus on MCI users within our current project.

This reasoning and decision are based on the following constellation of facts: on the one hand MCI users have an important risk of converting to dementia; on the other hand, they are less affected in their basic activities of daily living, are abler to engage in self-care behaviours (and implement coping strategies) and they are also abler to use technological solutions. Thus, this makes them a more suitable potential target for a preventive intervention including the use of technologies, also with the clear aim of reducing the incidence of dementia.





3 ANALYSIS OF THE CURRENT SITUATION

3.1 Practices, Services, Policies and Interventions Currently Used for Supporting Elderly with MCI

Interventions for MCI have been proposed in order to prevent, slow down and even reverse the progression to Alzheimer's disease. Proposed interventions can be grouped into the following categories: pharmacological (medication), physical training/exercise, cognitive intervention and psychotherapy. In general, recommendations focus on non-pharmacological interventions, such as physical or cognitive training, that rarely produce adverse events (Daviglus et al., 2010).

<u>Pharmacological</u>

At the moment no approved pharmacological treatment for MCI exists. Cerebral enhancing agents such as cholinesterase inhibitors and N-methyl-D-aspartate glutamate receptor antagonists are approved for use in patients with dementia aiming to slow down cognitive and functional decline. Cerebral protecting agents - antioxidants and omega 3 fatty acids - might increase neurotransmiters, hormones and cerebral bloodflow as well as slow or halt pathological processes. B vitamins, ginseng, ginko biloba and acetyl-L-carnitine may have benefits from both worlds, acting as both cerebral protecting and enhancing agents. Hormonal therapies including estrogen, testosterone and dehydroepiandrosterone have also been tested but with no conclusive results of the randomised control trials conducted upon these therapies related to an improvement of memory-related outcomes. Furthermore, statins, previously considered to be cerebral protective, were reported by the FDA to increase the risk of cognitive impairment (Rojas-Fernandez & Cameron 2012).

Physical training

Research on physical training/exercise programs targeting persons with MCI are rare. Moderate intensity physical training programs - walking for instance - may improve cognitive functions (e.g. executive function, memory) two topical reviews summarizing five clinical trials of physical training programs targeting persons with MCI have concluded (Lautenschlager, Cox, & Kurz, 2010; Teixeira et al., 2011). Women seemed to benefit more from physical exercise than men, especially due to higher attendance and adherence rates in the programs that predicted more improvement on cognitive outcomes (Lautenschlager et al., 2010; Teixeira et al., 2011). Nevertheless, without undermining its benefits, standardizing physical activity interventions for older adults would highly help clinicians translate the research findings to community settings (Elsawy & Higgins, 2010). Additionally, further research is needed to clarify which cognitive domain(s) benefit from physical exercise, the underlying neuronal- or vascular-protective mechanisms that occur due to physical exercise, the comparability of different types of physical exercise, and whether combining physical exercise with other types of non-pharmacological interventions is more effective than exercise alone in persons with MCI.

Cognitive interventions

These types of interventions are probably the ones in which researchers invest most of their time and resources. Cognitive interventions are based on the neuroplasticity theory and there are two





main approaches that have been applied: processing efficiency training (e.g., speed of processing training, dual tasks) aims to improve the broad capacity for fluid mental processing, whereas teaching cognitive strategies (e.g., teaching reasoning strategies, mnemonics) aims to compensate for the loss of specific higher order cognitive abilities. However, a truly successful cognitive intervention must also show transferrable (improvements from a particular training domain are generalizable to other untrained domains and daily functions) and sustainable (training effects last beyond the proximal post-training period) effects (Lovden et al. 2011). According to the most recent systematic review of 15 group- or individual-based cognitive interventions targeting patients with amnestic MCI (sample sizes ranged from 1 to 193), 44% of the objective measures of memory and 49% of the subjective measures of memory, quality of life, or mood significantly improved after interventions, while only 19% of objective measures of cognition other than memory improved (Jean, Bergeron, Thivierge, & Simard, 2010).

Other cognitive training studies might benefit from moving to a real-world context, such as managing finances and medication, driving, and grocery shopping. The Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study of 2,802 participants (Mage = 74) used this approach. One of the treatment arms in the ACTIVE, reasoning training, added content such as learning how to identify patterns related to real life situations, including identifying medication dosing patterns and filling a pill reminder case. The group that received reasoning training reported significantly less difficulty in overall IADLs than the control group, and the subgroup of MCI participants also benefited from this training (Unverzagt et al., 2009).

In the area of cognitive training, technology can provide valuable support. Exercises can be delivered on a technical platform, personalized and adapted to the patient's level and the software can provide automatic feedback. Techniques can of course also remind the patients that the exercises should be done now, or point out that they were not made at the scheduled time.

To do their exercises regularly, MCI patients need a strong stimulus and, above all, praise. Both must not be merely done automatically by software, but the human component is crucial and indispensable. Moreover, one should not leave everything to the informal caregivers – normally family members – but one should also have a supervision from external, professional forces, a kind of dementia care manager. It is very important to focus on positive reinforcement whereas interventions that could be interpreted as punishment have to be strictly avoided.

Psychotherapy

Psychotherapy interventions have been tested for their impact on coping with a diagnosis in MCI patients and caregivers which may prove in a real challenge. A comparison in terms of acceptance was made between patients with MCI that received information about their diagnosis without receiving any previous therapy and patients which benefited from therapy prior to their diagnosis announcement. One single-group study of cognitive-behavioral therapy of 22 participants with MCI and their caregivers found a significant effect on the patients' levels of acceptance of their diagnosis (Joosten-Weyn Banningh, Kessels, Olde Rikkert, Geleijns-Lanting, & Kraaimaat, 2008). In another study of 93 persons with MCI that included a waitlist control group, MCI patients that received therapy had significantly greater acceptance of their diagnosis and better management of memory problems, but overall levels of psychological distress and well-being did not differ between the groups (Joosten-Weyn Banningh, et al., 2010). Around 35% to 85% of persons with MCI have neuropsychiatric symptoms, and the most common ones are depression, anxiety, and irritability (Monastero et al., 2009). There are relatively few psychotherapies trials targeting persons with MCI. The role of psychotherapy for MCI symptoms and adaptation should be studied because it has potential to help improve awareness of and confidence in using cognitive strategies





and also possibly improve social connections and overall well-being in persons with MCI. This approach also holds the potential to help persons with cognitive decline effectively manage their non-cognitive symptoms, such as depression or anxiety, and improve the communication between patients and their caregivers. Moreover, as found in a previous study of older cancer survivors (Campbell et al., 2009), psychotherapy may also improve motivation in older adults with MCI to engage in healthy lifestyles which may also have a positive effect on the underlying neurobiology of cognition.

perspective described One example of national is for Spain at https://mundoasistencial.com/documentacion/guias-estimulacion-cognitiva/estimulacioncognitiva-personas-sufren-deteriodo-cognitivo.pdf. In this document it is highlighted that the activities that are being carried out for elderly people with MCI are centred mainly on cognitive stimulation, but also encompass combined types of intellectual, physical, social and psychological activities. In particular, the resources that are currently used for the elderly with MCI are: home help service, telecare, family integration, accommodation with young people, daily centers for the elderly, either temporary or permanent. A guide that contains exhaustive recommendations in terms of physical, mental, social and psychological activities used to improve, or if necessary maintain, the conditions of the elderly with cognitive impairment is available at http://www.sancyd.es/luis/tablas/99041.pdf

3.2 Use of Digital Devices and Internet Services by Elderly

Technology provides the opportunity for older people to renew or develop social contacts and engage actively in their own community. It can prevent social isolation of the elderly and the feeling of loneliness arising from changes in life such as retirement, health damage, etc. and can help those who are socially isolated to escape their situation. We live in an era where technology offers fast and relatively inexpensive contacts with colleagues and friends, thus promoting the participation of elderly people in society, with the effect of reducing their social isolation in the community.

However, elderly people have a difficult relationship with technology, especially because hardware and software have not been designed to fit for them. For a large part of the elderly, the technology is unfamiliar and "foreign" and even if the elderly realise the potential of technology, it considers the investment of personal resources necessary to use this new "artefact". The language of technology is unfamiliar to older people because it depends on a number of elements that are outside of their own culture.

In 2001 the Organisation for Economic Co-operation and Development (OECD) defined the term 'Digital Divide' as 'the gap between individuals, households, businesses and geographic areas at different socio-economic levels with regard both to their opportunities to access information and communication technologies (ICT) and to their use of the internet for a wide variety of activities'. Accordingly, there are two aspects to the Digital Divide (Negreiro, 2015): the first gap considers mainly the division between those who have access to ICT such as computers and the internet and those who do not. This type of scope often refers to the urban-rural divide, the latter having slower internet speeds, prices, and technological choice. The second gap refers to different types and levels of internet use, motivation and skills: looking at what uses and benefits people enjoy, once they have access to the internet. This also includes looking at the type of content and services accessed online (i.e. eHealth, eGovernment), as well as





whether these comply with international web accessibility standards to make their content accessible to all, including people with disabilities (according to the European Commission only about one third of public services websites were accessible to these groups).

The concept of the digital divide keeps evolving and broadening with new technological developments: some studies have looked into further digital divides emerging among internet users who use multiple mobile devices like tablets and smartphones to access the internet. Increasingly mobile devices complement the way we access and use the internet: the number of EU citizens using mobile devices such as tablets and mobile phones to access the internet has increased from 36% in 2012 to 51% in 2014. Therefore, as digital technologies continue developing, some users embrace them and enhance their online experiences, while others have a limited internet use or do not use the technology at all. Given its dynamic nature, the digital divide will not disappear, and some argue that it will never close as long as other inequalities exist in society (Negreiro, 2015). According to statistics, 30% of EU homes still do not have a subscription to fixed broadband, in spite of its availability ('Broadband for all by 2013' project aimed that every household in the EU can access basic broadband speeds of at least 144kbps). According to Eurostat, the most significant reasons for households not having internet access are: that it is unnecessary (45%); lack of skills (41%); and because equipment (27%), and access (24%), is too expensive. When considering broadband take-up progress by country, it is clear that wide disparities remain in the EU mainly along a North-South divide: the Netherlands, Luxembourg, Finland, the United Kingdom, Sweden and Germany registered the highest broadband penetration figures in 2014, while Bulgaria, Romania, Portugal and Greece have the lowest take-up rates in both rural and urban areas. When it comes to fast and ultra-fast broadband the numbers are even lower - fast speed broadband is available to 68% of the EU population, but mainly in urban areas (only 25% in rural areas). In terms of take-up, only 31% of all broadband subscriptions are at least 30 Mbps and only 9% of EU households subscribe to 'ultra-fast broadband' (>100 Mbps) (Negreiro, 2015).

In terms of internet regular users, their number in the EU increased substantially over the last decade from 43% in 2005 to 75% in 2014. Usage is also more frequent, with 43% of the population (i.e. 77% of regular users) now using the internet almost every day, compared to 29% in 2005. Likewise, the number of non-users (16-74 years old) has more than halved over the period, from 43% in 2005 to 18% in 2014 (close to the Digital Agenda target of 15% non-users by 2015). This means that about 58 million European citizens do not use the internet. According to the European Disability Forum (EDF), non-users are mainly the elderly and people with disabilities; as one in three persons with disabilities has never used the internet, representing 54% of those who have never been online. Furthermore, over 69% of people who lack basic digital skills are aged over 55 years (Negreiro, 2015).

When it comes to the Romanian population, the Romanian National Institute of Statistics (INSSE) stated that "Romania is already facing complex economic and social consequences of a population undergoing a slow but continuous demographic aging". In addition, a statistical portrait of the European Union 2012 showed that "Romania is one of the most affected country by the phenomenon of ageing. In 2010, the Romanian population median age was 38.3 years, close to the EU average estimated at 40.9 years.". Translated into numbers, according to INSSE report on 2013, PC is used by more than half (54.0%) of the individuals aged 45-54 years, by 38.2% of people aged 55-64 years and only by 16.8% of individuals aged 65-74 years (INSSE, 2013).

During 2006 – 2012 period, the percentage of households with Internet access increased in Romania from 14 to 54%. Furthermore, Eurostat Statistics in 2012 shows that in Romania, 73%





of users access the internet to read the news and newspapers online, 8% use internet banking services, 48% post messages on social networks, 24% use services related to travel and 9% need internet to create a website or a blog (Eurostat, 2017). In terms of devices, in 2013, the most commonly used devices for Internet accessing were mobile or smartphones - 61.8%, followed by notebooks with a 47.5%. The share of men who have accessed the Internet via mobile phone or smartphone was slightly higher than women (64.0% vs. 59.3%) and among those who have used the notebook, the most commonly type of network technology was Wireless (62.5%) (INSSE, 2013).

Regarding the situation in Spain, 74.6% of the people over 65 years of age have never used the Internet. One in four says that they have used it (25.4%) to carry out activities such as information search, purchase or management. The vast majority of the elderly prefer personal attention both to deal with the Administration (70%) and with banks (81.3%) (UDP, 2015). In 2015 the use of the Internet in men and women between 65 and 74 years of age was of 47.6% for men and 40.2% for women (INE, 2017).

	From 55 to 64		From 65 to 74	
	2011	2017	2011	2017
Participate in social networks	22.6 %	46.2 %	15.4 %	38 %
Search information on health issues	55.1 %	61.5 %	56.7 %	61.7 %
Electronic banking	44.2 %	49.9 %	36.1 %	43.8 %

Fig. 1 Percentages of people who have used the Internet in the last 3 months for the indicated services (Villarejo-Ramos et al., 2016)

3.3 Technological Solutions Currently Available for Supporting Elderly with MCI

As said before, while many elderly with MCI will progress to dementia, this is not inevitable. Thus, a crucial need is to develop novel systems that will help MCI older adults to improve their cognitive status, extend independent living at home and enhance their quality of life. Providing ICT supports to enable self-care/ self-management, as well as supporting cognitive stimulation also in MCI elderly's familiar environments, may allow elderly with MCI to draw upon varying levels of support tailored to their specific needs and provide stimulation and engagement to improve cognitive functions. Care at home is often preferable to patients and is usually less expensive for care providers than institutional alternatives. Various types of assistive technology can improve older people's safety, security and ability to cope at home, they include e.g. video monitoring, remote health monitoring, electronic sensors and equipment such as fall detectors, pill reminder, bed alerts, temperature and heat alarms. More in general assistive technology can:

- Promote independence and autonomy
- Improve confidence and quality of life for a person with MCI





- Help manage potential risks in and around the home
- Support elderly to live at home for longer
- Help with memory and recall
- Support a person with MCI to maintain some abilities
- Provide reassurance to caregivers and help them to feel less stressed.

There are various basic technologies that can be useful in supporting and assisting the elderly while they accomplish their daily life activities:

• Sensors. Smart sensors support the detection of various conditions of the elderly and her surrounding environment. Sensors require software to interpret their results and ensure that the correct response is executed.

• Audio/Video sensing devices. Audio data may be retrieved through the installation of microphones throughout the home, while smart cameras such as those described in (Williams et al., 2006) may be used in fall detection, location and object tracking.

• GPS. Global positioning system (GPS) can be used as a navigational aid in outdoor environments

• RFID. RFID tags may be used to track objects as well as monitoring daily patterns such as eating and taking medication.

• Phone/Video Communication Unit. Phones and video units are of major importance in keeping in contact with distant friends and relatives. Services such as Skype enable phone and video call communication at a low cost.

• Robotics. Robotic assistance in the form of robot suits used as mobility aids, as well as robots such as Twendy-One (Iwata and Sugano, 2009) for day-to-day support, help to maintain independence, ensuring that people are facilitated in their homes and carry out tasks which may otherwise be impossible without external assistance.

• Software-based Support. Apart from software used with previously mentioned devices, other software systems are very useful for elderly assistance. For instance, reminder systems bring a new lease of life for those with cognitive decline, ensuring that they remember vital tasks such as eating and taking medicine. Autominder (Pollack et al., 2003) acts as a plan management system ensuring that all critical tasks are carried out and that dependencies are maintained. By using AI techniques, it can be possible to model an individual's daily plans, observe and reason about the execution of such plans, and make decisions about whether and when it is most appropriate to issue reminders, so providing the elderly with adaptive and personalized reminders of activities.

A type of system that is receiving increasing attention in its capability of effectively supporting elderly in their daily activities is the one centred on light-based interventions. This technology has started to be investigated in a few research projects: "ALADIN" (2007-2009; FP6), "Guiding Light" (2012-2015, AAL), "Psylicht" (2015-2018, AAL) and "GREAT" (2017-2020, AAL). These projects aim to improve vision, health and emotional state of the end-users, who were elderly people (ALADIN, Guiding Light) and elderly people with dementia with or without psychiatric comorbidities (Psylicht, GREAT). "ALADIN" and "Guiding Light" aimed to improve vision, visual comfort and biorhythms of elderly people in their homes, while "Psylicht" and "GREAT" aim to address visual and biological light effects for demented persons in hospitals, care facilities or home-care settings. While the projects "ALADIN" and "Guiding Light" have already ended, "Psylicht" and "GREAT" are currently running.





During "ALADIN" new luminaires were implemented into private homes of elderly people. The installation of the luminaire was technically difficult and needed beside electricians, experts in lighting installation. The main problems at that time concerned the connectivity between sensors and control device of the lights. It took a lot of effort to run the system properly. After the field trials the system had to be removed from the private homes which was costly, time-consuming and again needed experts.

During "Guiding Light" field trials were carried out, where a new ceiling-mounted luminaire and various other light sources were implemented into the elderly's flats to improve vision and spatial orientation. While there were few technical difficulties during the field trials, some problems appeared after termination of the field trials. The luminaires and other devices were donated to the stakeholders, but not all participants wanted to keep the installed devices. Therefore, restoration of the former lighting solution had to be performed in few households, which was paid by the project partners in each area (Austria, Italy, Germany, Switzerland). The restoration process was difficult, because invasive installation (drilling holes, new electrical wiring, install suspended ceiling and new light switches) and inadequate lighting control (PIR-sensor did not work properly) was used. Furthermore, the restoration costs were significant (many end-users wanted to have simpler lighting solution with manual control after project end).

In the project "Psylicht" a new lighting system was implemented into a whole ward in a clinic in Hall (Austria). Light installation took place in the course of a renovation of the ward A3 (dementia station; 24 beds). Thus, not only a new lighting system but also a new entrance, a new door closing system to bedrooms and staff's rooms and a new recreation area for patients with moderate dementia was built/installed. Field trials were carried out for one and a half year, ending in March 2018. During this time, technical problems occurred some times. A good contact between Bartenbach and the hospital staff as well as appropriate and immediate technical service by Zumtobel (for lighting control) was needed to run this period of field trials successfully. After completion of the field trials, the implemented light system will remain in the ward, running properly at the moment. There are no problems expected after termination of the project.

For the project "GREAT" a new standing luminaire, reducing the implementation effort to a minimum, was developed to avoid problems during the implementation phase in the field trials. Only for one special location ceiling-mounted luminaires based on the same technical principle were developed. In combination with a scent and a sound module the system has been evaluated in functional tests in a clinic in Austria and in care facilities in Italy and Switzerland as well as in private settings. First results showed that this kind of modular solution seems to work well and is easy in use for the end-users. Nevertheless, few technical problems mostly concerning the controlling of the system occurred also. In the current status of the project, end-users using the GREAT system in their homes are acquired. Therefore, different communication channels were used, but it turned out to be difficult to find participants in private settings for the field trials. Especially in Austria, but also in Italy and Switzerland, elderly people with dementia, who were cared at home, are not very affine to new technologies. Furthermore, the fact that the planned field trials will run for more than one and a half year, hampers their will to participate. Finding target end-users is even more challenging, because selection criteria are very strict: medical diagnosis of dementia, living alone or with a caregiver, access to internet, problems in behaviour, sleep or in controlling emotional state, etc.

One of the lessons learned from such experiences is that implementing lighting solutions into private homes, care facilities or hospitals is quite challenging and time intensive. Respect for privacy and empathy for difficult daily situations of people dealing with a progressive cognitive disease is needed and it is a prerequisite to work in this kind of projects. One main point that has





to be solved in advance (before implementation and field trials) is the ownership status of and the responsibilities for functioning of the luminaires and implemented devices (e.g. sensors). In "ALADIN" luminaires were removed after the field trials, in "Guiding Light" and "GREAT" the devices were and will be donated after the field trials to stakeholders using the luminaires and other devices in private homes. In "Psylicht" the tirol kliniken bought the service and lighting system. For donations and provided service after the field trials a concrete contract is needed, signed by stakeholders and project partners. Another lesson learned is that solutions containing lights and other devices should not need too much installation effort. The usage of wireless technology and already installed power connections reduces the time- and labour-efforts significantly.

Another line of research that has recently emerged as having special relevance for people with MCI is *brain training*, where a person engages in serious gaming for cognitive stimulation. Indeed, digital games offer many potential benefits for improving cognitive and social function in a way that is motivating and enjoyable. In addition, they represent a huge opportunity for involving people with MCI in activities that may contribute to seniors' well-being through social interaction, cognitive stimulation, and physical activity that may motivate them to positively manage their well-known commercial example is Nintendo's lives. One the Brain Aae (https://www.nintendo.com/games/detail/Y9OLGBWxkmRRzsOEOtygGgZ63 CiS 9F), which promotes cognitive function, although not specifically developed for MCI people.

Other well-known commercial products, still in the area of cognitive stimulation include Smartbrain Pro (http://www.smartbrain.net/sb_new_en/), available as Web application, and for Android and Windows platforms; Fit Brains Trainer (http://www.fitbrains.com/) available for iOS, Android and Windows platforms; Lumosity (https://www.lumosity.com/) available as Web application, and for other operating systems (e.g. iOS, Android). Also one of the partners of PETAL, Ideable, has launched its own cognitive stimulation platform, Kwido Mementia (http://www.kwido.com/cognitive-stimulation/). Kwido Mementia is a multi-device platform which provides memory exercises in a multimedia environment to help reinforce therapies and improve adherence to treatment. So, whether via tablet, touch screen or digital whiteboard, elderly users can carry out individually designed training exercises, whilst professionals can monitor data to evaluate performance, keep users informed and notify relatives of their progress.

In the research area, a relevant work is the one from researchers at the University of Cambridge (Savulich et al., 2017), who recently developed 'Game Show', a memory game app whose effects on cognition were tested with amnestic MCI patients (those having day-to-day memory difficulties and motivational problems). Results show that gamified cognitive training can enhance visuospatial abilities in such MCI patients, and episodic memory robustly improved in the cognitive training group (compared to the control group).

For the goal of supporting elderly in navigation and orientation there is NavMem (a system connected with an AAL Project finished recently: <u>http://www.navmem.eu/</u>). It is targeted at elderly travellers, but includes a number of features targeted specifically at MCI users. The main scenario focuses on supporting people when visiting unfamiliar environments, such as travelling within unknown areas of a city. The navigation companion provides three different modes: (1) Background mode: the system provides coarse multimodal spatial cues, such as direction and distance to the next intermediate goal, such as a bus stop. Users try to find their own routes, which will stimulate their spatio-cognitive abilities. (2) Navigation mode: the system will provide





detailed navigation instructions that are tied to landmarks. (3) Safety line: In case the user is not able to overcome disorientation, the system can temporarily share the user's location on demand to (informal) care givers to get personal support.

Another system connected with a recently finished (January 2018) project is the one developed in the IN LIFE project (http://www.inlife-project.eu/). The project has aimed to prolong and support independent living of seniors with cognitive impairments, through interoperable, open and personalised ICT solutions that support home activities, communication, health maintenance, travel, mobility and socialisation tasks. The main targeted user groups are: 1. Older people with: Mild Cognitive Impairment (MCI): Early and later stages of Dementia: Cognitive impairment and co-morbid condition; 2. Caregivers (formal and informal). Over the duration of the project, more than 1.800 end users (older adults and carers) were involved in the project in different pilot sites in Greece, Slovenia, Spain, Sweden, The Netherlands, and the UK. Different solutions where developed and tested. These include the IN LIFE platform itself, which provides easy and personalized access to all the supported Ambient Assisted Living (AAL) services, as well as a telemonitoring platform incorporating personal area network sensors allowing for almost real-time monitoring of vital signs and alerts or warnings enriched with current user location, and a number of online applications, fall detection and other security services.

In order to better support elderly in their interaction with digital services and devices, various applications have been designed especially for people who are "not very experienced". Examples are Eldy (http://www.eldy.eu) a software that turns any standard PC into an easy-to-use computer for people that have never used a computer before, BIG Launcher (<u>http://biglauncher.com/en/</u>), a simple Android interface for seniors and people with vision problems, Wiser Simple Launcher (https://play.google.com/store/apps/details?id=com.wiser.home), a free app designed to make smartphone navigation simple for people having problems in interacting with small icons, by creating a custom home screen with large icons for the most important apps.











4 METHOD FOLLOWED FOR GATHERING REQUIREMENTS

4.1 Description of the Questionnaire Used

In order to receive information useful for gathering relevant requirements we have carried out a survey of elderly people with MCI and of caregivers to assess the specific needs of both target groups. The requirements identified for caregivers are described in Deliverable D1.2.a (PETAL, 2018). Instead, in this deliverable we aim to improve our understanding of the most suitable assistance systems so that it meets elderly's needs, and what kind of devices, interfaces, control mechanisms are already familiar or accepted by the target group.

The methodology was a survey using a questionnaire, which had to be filled in by the target persons themselves. The target persons received a brief introduction to the planned personalisable assistance system. To answer the questions relatives or researchers provided information or assistance upon request.

The questionnaire dealt with the following topics:

- *Technological literacy*: it aimed at gathering information about the familiarity of the elderly with technology and digital devices in general terms.
- *Communication tools and habits*: the tools and habits the elderly has with respect to communication with relatives (e.g. favourite devices)
- *Lighting situation at home*: for gathering information about the current status of the elderly's house in terms of light-based systems
- *Requests and expectations with regard to lighting*: for collecting information about the hopes and prospects of elderly towards lighting
- Acceptance of various forms of light and visual signals: for gathering information about the level of acceptance of light-based systems as perceived by the elderly
- *Hazard to fall and sleeping quality*: to understand the perceived risk of falling and the current quality of sleeping, as perceived by the elderly
- *Caregivers and assistants:* to gather more information about the type of relationships between the elderly and their primary caregivers
- *Socio-demography*: to collect demographic information on the involved elderly.

With regard to the target group the questionnaire had to be very simple and rather short. This is the main reason why it was decided not to use validated instruments but develop the questions ad hoc. There were several bases:

- a set of questions on light and related issues provided by Bartenbach;
- a long questionnaire on housing, light and technology of elderly persons developed and used by Apollis in a former AAL project (ALADIN), see (Gavat et al., 2009);
- a series of questions contributed by CNR.

The first draft of the questionnaire was elaborated by CNR, the further development and completion is the result of a rather intensive interaction process among the partners including a couple of Skype conferences.

After that the questionnaire was translated by the research team itself from English in the national languages of all partners: Italian, German, Romanian, Spanish.





The English version of the questionnaire was implemented in #Google Forms in order to allow transferring the data from the original paper version in digital format. This was done by each partner for its own data requiring the translation of answers to some open questions from the original language into English.

The statistical analysis was done on the base of the tables and graphs delivered directly by Google Forms integrated by other statistical tools (OpenOffice Calc, SPSS).

4.2 Procedure Followed

The field work was done by all partners between the end of January and the middle of February 2018 as described in more detail below. Altogether we collected the answers of 72 elderly persons with MCI. In the following subsections we detail the specific procedures followed by the various partners (e.g. recruiting, logistics).

<u>ANA</u>

The questionnaires for the MCI patients were translated in Romanian, together with the one page short presentation of the project.

They were printed and distributed to the two sites that administered it, namely:

- The Memory Center of ANA the outpatient center which is diagnosing and treating patients with neurodegenerative diseases (from MCI to mild and moderate stages of AD and other dementias) and where most of the patients come accompanied by their informal caregivers (usually life partenrs or children) and
- 2) The Clinic of Geriatrics-Geronotlogy and Old Age Psychiatry from the Elias Universitary Hospital, where the head of clinc is Prof. Dr. Luiza Spiru (also the President of ANA) - where patients with neurodegenerative diseases in all stages (from MCI to severe cases of AD and other dementias) are hospitalized for short and long term care; professional caregivers, trained in dealing with these categories of patients, take care of the patients.

The administrative coordinators from both sites received training on the content and scope of PETAL project and regarding the purpose and the structure of the questionnaire; they then assumed the responsibility of selecting the adequate caregivers, in accordance with the description of the target group.

The questionnaires were administered to the selected caregivers as follows:

- In the Memory Center to the MCI patients who came for their regular check-ups within the period of the research and who agreed to fill in the questionnaire; most of them filled the questionnaire on-site, very few took it for completion at home and brought it back after 4-5 days
- In the Geriatric Clinic mainly by the MCI patients who were admitted in the Clinic for short-term hospitalization and who agreed to contribute to this action - they filled in the questionnaire on-site





All questionnaires were collected by the administrative coordinators of the sites and sent to ANA's office, where they were collected and the data were introduced in the online database. They were also scanned and archived in digital form.

Fondazione Santa Lucia

There were 48 elderlies with a diagnosis of MCI selected from the Memory Clinic general database. We excluded patients aged under 65 years old and those converted in Alzheimer's disease at the last follow-up visit. MCI diagnoses were made by a neurologist and specialized psychologist after a neuropsychological and neurobiological evaluation (up to six months before).

The first contact was made through a phone call explaining the purpose of the project and the willingness to come to FSL in order to fill out the questionnaire was requested. The administration of the questionnaires was performed in specific appointment one to one or during the follow up visit. Before performing the questionnaire, all participants were informed of the anonymous use of the data in full respect of privacy.

The head of the FSL Laboratory of Neuropsychiatry (Dr. Spalletta) and the Dementia area coordinator (Dr. Banaj) managed the implementation of this stage of the project.

<u>CNR</u>

For recruiting elderly with MCI for the questionnaires, CNR has contacts with the "Train the Brain" (TtB) program, which is a controlled study -currently ongoing in the CNR Research Area of Pisathat investigates the effects of a combined (cognitive stimulation and physical activity) rehabilitation program on mild cognitive impairments subjects. The enrolment of the patients took place at the neurology clinic of the University of Pisa while the actual intervention of the program is carried out in the TtB structure within the Research Area of CNR in Pisa, and is managed by the CNR Neuroscience Institute (see figures below).



Fig. 2 Picture of the "Train the Brain" lab for cognitive stimulation





Mild Cognitive Impairment User Requirements



Fig. 3 Picture of the "Train the Brain" lab for physical activity

The "Train the Brain" program is divided into the following phases: i) patient enrolment and baseline cognitive assessment; ii) evaluation of instrumental baseline; iii) intervention; iv) evaluation of the effect at the end of the intervention; v) evaluation after seven months after the end of the intervention.

The cognitive stimulation program provides eight cycles each of them composed of 18 stimulation sessions, with exercises and target activities to stimulate multiple cognitive functions. Each cycle lasts three weeks, after that the sessions restart with a complexity based on the results of the previous cycle. Each cycle corresponds to a specific cognitive stimulation: auditory attention, visual attention, visual memory, imagination, orientation, spatial memory, temporal and personal orientation, verbal memory, lexical abilities, memory of terms and means, affective memory, texts memorization, face and name memorization, logic. Each of them starts with a theorystrategic lesson managed by the expert and focalized on specific cognitive processes as memory, learning, attention and metacognition. During the different session, there is and alternation of pencil and paper tests, social games and computer-based exercises. The cognitive training is based on the alternation of sessions related to one single cognitive modality and sessions with multimodal activities. The multimodal sessions are thought to stimulate specific cognitive domains, as memory, attentional and executive functions. The multimodal activities are structured to rebuild the ecological environment with the aim of stimulating socialization and interpersonal changes in a stimulating context. There is an overlap of pencil and paper test and neuropsychological tasks used for the cognitive evaluation. Physical Training is made in groups of 10 people and provides aerobic exercises on a cycle ergometer. The time dedicated to the activity increases with the improvements of the subjects (from 10 to 20 minutes). The multicomponent training aims to have an impact in terms of motivation providing a comprehensive set of activities, including music therapy.





Using this contact, for the questionnaires, CNR was able to involve 8 MCI elderly all diagnosed with MCI and currently following the TtB program. CNR researchers went to the TtB structure for the questionnaires: they first provided the subjects with general information about the PETAL Project and then they submitted the questionnaires to the elderly, who autonomously filled in questionnaires while being at the TtB center (CNR researchers were available all the time while they filled in the questionnaires for any help). The questionnaire-filling lasted on average between 20-35 minutes (taking into account also the time needed by the elderly to make some questions during filling in).

Bartenbach

The questionnaire distribution for elderly people and caregivers in Austria was organized by Bartenbach. Lisa-Marie Neier (Bartenbach) informed Josef Marksteiner (Tirol Kliniken), an associated partner in the project PETAL, about the goals and target groups of the developed questionnaires. Josef Marksteiner is the head of the department psychiatry and psychotherapy A at the Tirol Kliniken in Hall, Austria. Beside the stationary part there is a specific part for gerontopsychiatric outpatients with memory complains. Josef Marksteiner arranged the distribution in this gerontopsychiatric outpatient clinic. The big advantage of this location is that patients are officially diagnosed and therefore, patients with mild cognitive impairment (MCI) and their formal or informal caregivers were selected precisely according to our project goals. In the outpatient clinic, the patients and their caregivers were shortly introduced by the ambulant nurse at the registration desk about the goals of the questionnaire and how to fill it in. Patients and caregivers were instructed to fill in the questionnaire alone and to fill in every question they can answer and to leave questions that cannot be answered. All questions should be at least tried to answer. While patients and caregivers were waiting to see their doctor, they filled in the questionnaires in the waiting room and brought them back to the staff.

The staff collected the filled-in questionnaires. The collection brought 12 filled-in questionnaires (6 MCI patients, 6 caregiver). Mostly the caregivers were represented through the partner of the patient and therefore were nearly in the same age range. Only few younger or professional



Figure 4: Tirol kliniken. The red circle shows the location of the outpatients' clinic for memory consultancy



caregivers were available. The staff was instructed to go further with the distribution, but because of the staff's extra effort the distribution was stopped.

APOLLIS

For the recruitment of elderly with MCI Apollis has mainly relied on its local cooperation partner "Griesfeld Foundation" of Egna/Neumarkt which is very active in the care of patients with dementia but mainly within the two nursing homes the foundation is managing.

In order to be able to contact people with MCI, the director of Griesfeld asked the general practitioners who work both at the Griesfeld Foundation and in the doctors' offices of Egna, to identify some patients with MCI and to hand them out the PETAL questionnaires. The physician asked for collaboration indicated several elderly persons and their family caregivers willing to complete the questionnaires, which were then delivered to the director's assistant, Verena Amort, at the Griesfeld Foundation ...

Concerning the completion of the questionnaire, it was noted that older people had difficulties filling out the questionnaire for reasons of understanding and that people often had no idea what they were referring to when referring to "digital / electronic devices".

The research team of Apollis acted similarly and asked several people known to have relatives with MCI symptoms to collaborate. Eventually two more elderly and the respective caregivers answered the questionnaire.

Overall, 12 questionnaires (6 seniors and 6 caregivers) were completed this way. Five of them used the German version of the questionnaire, one used the Italian version. Two questionnaires (1 senior and 1 caregiver) unfortunately could not be included in this analysis because they arrived too late.









5 ANALYSIS OF GATHERED DATA

5.1 Demographics of the Sample

The sample includes altogether 72 elderly persons with MCI. 61.1 percent of the elderly are female, 38.9 percent male.

Most of them are between 70 and 80 years old with a mean age of 76. On average, women are slightly older the men, but there is no significant difference between the two genders. Below there is a graph showing the composition of the sample divided by age and gender (e.g. 100% females= 14% under 70 + 20% in the age range of 70-74 + 43% in the age range of 75-79 + 23% in the age range of 80 and older).



Fig. 5 Bar chart showing the composition of the sample by age and gender

Two thirds (49) of the interviewed persons come from Italy, one quarter (17) from Romania, one tenth (6) from Austria. The composition by sex is nearly the same in each country.

The educational degree of the sample is rather high: 46 percent have a senior high school diploma or even a university degree. There are large differences between countries: the persons originating from Romania have the highest formal education, those from Austria the lowest.



Fig. 6 Bar chart showing the composition of the sample by current residence and education

Three quarters of the interviewed elderly with MCI live with a relative, one quarter lives alone (including one person which lives with a professional caregiver). This is slightly less than the mean percentage in the EU of persons living alone among the population of age 65 and older (32%).¹

Moreover, there is a big difference in the living situation between gender: man use to live with a partner or share house with another family member, while women use to live alone more commonly.

5.2 Familiarity with Technology

Technological Literacy

As a first aspect of familiarity with technology there was a question about which devices were used by the target group. The results indicate: everyone uses TV, one half smartphone, about one quarter uses each kind of PC (tablet, laptop and desktop) and one out of six a traditional mobile phone.

Three quarters of the elderly paid themselves for these devices, for one quarter the costs were sustained by relatives.

One out of five interviewed persons are planning to buy a digital device, mainly smartphones and tablets. The majority of seniors (56%) think that training could help them learning how to

1 http://ec.europa.eu/eurostat/cache/infographs/elderly/index.html (28/02/2018)





use such devices.

The most frequent purpose of using these devices is calling, for one half also sending messages and entertainment, for one third information and for one fifth managing something.

What is the most frequent purpose of using them?



Fig. 7 Bar chart showing the most frequent purpose for buying a digital device

More than one half of all elderly (more men than women) have internet access at home (see Fig.8). More important is the difference between the countries of residence in the sample: in Austria no one has internet at home, in Italy and Romania the incidence is almost the same, that is: a good half of the respondents. Due to the lower educational level of the target group in Austria and the fact that usage of internet is correlated with educational degree, this result is not surprising.





Fig. 8 Bar chart showing the internet access availability by gender

Communication with Caregivers

Elderly with MCI prefer to communicate with their relatives/caregivers via phone calls. One third of the seniors also use text messages, one out of six uses e-mails.

Results show similarities if the preferred way of receiving reminders or alarms from caregivers or relatives is asked: phone calls are appreciated by everyone, text messages by four out of ten, audio messages and PC/mobile applications by one tenth.





How do you prefer to receive reminder/alarm from relatives or caregivers?



Fig. 9 Bar chart showing the preference on how to receive reminders from relatives or caregivers

Asking for current use of devices to communicate with caregivers, the following results were noted:

- everyone calling
- 4/10 instant messages
- 1/6 e-mails
- 1/10 health measurements
- 1/10 games for cognitive stimulation (tablet, paper)





Are you already using devices with relatives or caregivers? If so, which ones?

71 Antworten



Fig. 10 Bar chart showing the usage of devices with relatives or caregivers

5.3 Use of Sensors, Devices and Lights

Need for specific aid

To understand the specific needs of elderly in daily living, we asked for critical situations. This question revealed to be very difficult for our target group. Actually, two thirds of the persons could or did not indicate any situation where help is needed. The remaining third identified a series of situations suited for support, such as:

- household
- daily care
- taking medicine
- remember appointments
- eating
- light (at night)

... and some other ones.

Lighting devices

Only one out of eight interviewed seniors would like to have other or better lights in his/her home, the rest seems to be satisfied with the actual situation. The improvement of the lighting situation particularly concerns kitchen and corridors as well as the bathroom, bedroom or living room.

Actually everyone uses normal white light, one third night light, one out of seven dimmable light and one out of ten automatic switch on/switch off of lights.





Do you use the following lights?





Fig. 11 Bar chart showing the usage of lights

The imagination of which kind of lighting device of the above mentioned could be useful for them does not lead very far. One fifth did not give any answer the answers of the other reflect more or less the current situation. The only remarkable difference between status quo and perceived need is automatic switch on/switch off of lights mentioned three times.



Which kind of lighting device of the above mentioned list do you think is useful for you?

Fig. 12 Bar chart showing the favorite lighting devices

The survey shows that lighting is currently controlled via switchers in all cases. Only two persons use touch panels for lighting control.

Only 4 percent of the sample think that the current lighting situations at home is not appropriate for their visual requirements. One third uses during the day artificial light together with daylight, the other two thirds only daylight. There seems to be enough daylight in most houses and in all





71 Antworten

types of rooms, except for corridors and in part for bathrooms.

These are the perceptions on different light functions:

- 4/10 light signal could help to remind things (i.e. leaving on the oven, taking pills
- 1/2 automatic light could help in daily activities
- 1/3 coloured light could help to remember things
- 1/3 spotlighting could help to remind on daily living tasks.

The Utility of Light with Respect to Prevent Falling and Improve Sleeping Quality

Falling in the house is a major hazard for many seniors. But in our target group only one in seven persons reports on having fallen at home due to poor lighting.

The reported sleep quality is rather good: One third reports on having sometimes difficulties falling asleep.



Do you have difficulties falling asleep?

Fig. 13 Bar chart showing the percentages of the sample with difficulty falling asleep

Of those having sometimes problems to fall asleep one third thinks that gradual reduction in light intensity could be helpful.

One out of ten wakes up during the night and does not know where he/she is. 40 percent of them think coloured night lights could eventually be helpful to improve orientation at night.

5.4 Information about Caregivers and Assistants

Most of the interviewed elderly persons with MCI are more or less regularly assisted by other persons, in most of the cases by their partner (one half) or a son or a daughter (19%). One of five relies on professional, mainly private paid help. One in ten seems to manage the daily activities still without personal assistance.



Who does help you regularly?

Fig. 14 Bar chart showing the ratio of caregivers and assistants by kind

Persons living with relatives are in 80 percent of the cases assisted by their partner or a son/daughter, only in 15 percent by persons not being family members. One quarter of the persons living alone does not have any assistance. The rest of this group rely on a son/daughter or a professional caregiver assisting them in daily routines.

Three quarters of the seniors with MCI are assisted at home, 7 percent use telecare, the remaining cases receive other types of assistance or do not need assistance at all.

The project PETAL is cofunded by the Active and Assisted Living Programme (AAL-2016) and the following National Authorities and R&D programs in Italy, Portugal, Austria and Romania.

PROGRAMME

🕼 Ministere della Salute





Fig. 15 Bar chart showing the kind of care received from relatives/caregivers

One fifth of the sample needs daily home care, one fifth several times a week and another fifth about once a week. The remaining 40 percent need only rarely help in their daily living.

How often does somebody come to your place to help you?

67 Antworten



Fig. 16 Pie chart showing the percentages on frequency of external help

A joint analysis of the frequency of external help and the main caregiver reveals that the two types of assistance are somehow complementary: if the principal caregiver is the partner or a private paid help the need for external help is lower compared to elderly cared be their children or by professional institutions.





How often does somebody come to your place to help you? Percentage of "more than weekly"

Fig. 17 Bar chart showing the frequency of caregivers/relatives in place more than weekly





6 Summary of Results

6.1 Main Requirements Identified & Recommendations for Future Work

The sample of seniors with mild cognitive impairment contacted in three different countries (Italy, Romania, Austria) seems to be representative with regard to the composition by age, sex and type of household. However, there is an obvious bias towards persons with higher school education, arisen from the high-educated group of elderly in Romania. Most of them have some assistance for their daily activities, mainly by partners and children but also by professional caregivers. But altogether, the majority seem to be still rather autonomous. Support from outside the household refers mainly to home care and less to personal assistance. The situation gets more problematic when the senior lives alone, a situation concerning almost exclusively women.

The familiarity with modern digital devices and the openness towards them is higher than expected. Roughly one half, for instance, has internet access, almost one half uses text messages and e-mails. Apps to manage things, audio messages or digital games for cognitive training are known to a significant minority. On the other hand, the technology is normally used in a very traditional way, like making phone calls or watching TV. Despite of the widespread access to internet the preferred communication tool (also for reminder/alarm) with caregivers is calling. This means that a good part of the target group fulfils the basic requirements for an advanced use of modern communication technology but they have to be convinced and trained to use it. The seniors themselves are only scarcely conscious of the situations and the tasks where support is needed and possible.

In particular, the interviewed elderly with MCI are – like seniors in general – completely unaware of the potential benefits of appropriate lights and correlated functions. In their homes, they use mainly normal white light with standard control devices (switchers). And they think that the lighting is sufficient, a perception that many studies have revealed to be overoptimistic. The same is true for the possible effects that light could have on sleep quality and on the prevention of falls.

It is therefore very important to rely not only on the subjective judgements of the elderly about the possibilities opened up by new technologies to support their needs, but to collect expert views and the perceptions of professional and informal caregivers.





Conclusions 7

To sum up, this document describes the results that have been gathered by surveying a number of elderly with MCI about some aspects that are relevant for the development of the PETAL system. In particular, we identified some areas where support is required and where technical support can be effective. The upcoming platform that will be developed during the PETAL Project can provide the needed support easy in use.

In conclusion, the diverse characteristics of the target users and their living situations confirms the need for personalisable and personalised system features. The current familiarity of elderly with MCI with modern digital devices and the openness towards them seems highly promising also in terms of the expected use of the platform that will be developed by the PETAL consortium. The commitment of elderly with MCI (having a good familiarity with technology) to specify rules for tailoring the assistive support. In addition, the lack of elderly's awareness of the benefits that appropriate lights and correlated functions can bring to their lives is an area on which the PETAL project is committed to work also for boosting elderly motivation and their active role in improving their current conditions.

The next version of this deliverable, which will take into account to the results of the first cycle of development and evaluation foreseen in the project, is planned for M15.











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