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Caregiver User Requirements

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1 INTRODUCTION AND GOALS

Nowadays, context-dependent behaviour is acquiring increasing importance in many applications and services covering a plethora of different domains. With the advent of the Internet of Things (IoT) its relevance is even more prominent given the increasing number of user environments characterised by the dynamic presence of sensors, objects and devices, according to which applications need to dynamically tailor their behaviour. In addition, applications that are targeted for a highly assorted population also need to be dynamically customized according to the needs of specific end users. All these aspects are especially relevant in the AAL domain, particularly for solutions targeting the elderly population, since they not only present a varied set of characteristics in terms of needs, abilities, knowledge (including technical know-how) and preferences, but also have specific, aging-related requirements that also evolve individually over time. In such environments it could be very difficult for developers to foresee all the possible context-dependent scenarios (and associated customizations to support in the software), because there could be some unanticipated (at design time) need that should be incorporated at runtime, when the application is actually used. Fortunately, the increasing affordability and availability of technology has also promoted new types of participation by end users in the creation process of software, such as EUD approaches (Lieberman et al., 2006), to improve the flexibility and acceptability of technological solutions by final users who at some point might want to incorporate new behaviour in their applications. This can be obtained through tools that do not assume specific technical background from their users.

Formal and informal caregivers are an important resource for MCI elderlies. Since sometimes only caregivers have an in-depth knowledge of the older adults' needs or preferences, it is important to offer them customizable environments through which they can appropriately tailor not only the support provided to the elderly but also the support (e.g., notifications, reminders, communication/coordination tasks with other caregivers) provided to themselves. To achieve these goals, the technological platform developed in the PETAL project will support controlling/monitoring daily elderly activities by exploiting a number of different sensors, devices, and modalities. Moreover, we also aim to provide caregivers with intuitive tools to easily customize interactive services to the various needs, requirements, tasks, and contexts of the elderly.

This deliverable reports the conducted requirements gathering activities focused on the formal and informal caretakers of MCI elderly. More specifically, it is structured into the following parts: in Section 2 we characterise the target population (formal and informal caregivers of elderly with MCI). Then, Section 3 describes the current situation in terms of i) practices, services, policies and interventions currently used for supporting caregivers; ii) use of digital services and devices by caregivers; iii) technological solutions currently available to support caregivers. Then, in the following sections (4-6) we describe the results we gathered by using different types of methods (questionnaires, interviews and focus groups). In particular, in Section 4 we describe the results gathered from questionnaires, in Section 5 those derived from interviews, and Section 6 the results derived from focus groups. Section 7 summarises the main requirements and results identified in this document, also providing some concluding remarks.

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2 TARGET GROUP CHARACTERIZATION (FORMAL AND INFORMAL CAREGIVERS)

Our consortium recognises the importance and the valuable role of caregivers in the elderly. The target group of our project is characterized by two main categories: formal and informal caregivers.

Formal caregivers are providers associated with a formal service system, who may work independently or be employed by various specialized institutions like nursing homes, institutions specialized in providing medico-social home care, non-profit organizations, charity service groups, seniors' centres and hospices. Although formal carers may have different professional backgrounds, knowledge and education levels they are all united by professional ethics in line with a person-centred care model (Broker et al., 2004), which represents a holistic alternative to conventional care practices.

Informal caregivers are any relative, partner or friend who has a significant relationship with, and provides a regular and ongoing assistance to another person without payment for the care given. Informal care far exceeds formal care in the number of hours of care provided, as well as in terms of monetary value (OECD, 2005). In fact, even in countries with a well-developed supply of formal long-term care, the number of informal carers is estimated to be at least twice as large as the formal care workforce (Ferrer, 2015).

In the last decade there has been a significant increase of attention on the effect physical and psychological and the burden that the management of a person with dementia may lead to those who provide care. In addition, recent studies have also reported an association between some specific components of behavioural and psychological symptoms of dementia and formal caregiver burden in some countries (Rosdinom et al., 2013; Zwijsen et al., 2014). Unfortunately, only few works explore the need and the consequence of MCI carers. This turns out to be not very comprehensible given the importance and role that this phase play as a precursor of a more advanced cognitive decline. Regarding formal caregivers, in spite of the fact that the burden may not be directly related to the severity of the clinical picture, different aspects can contribute to work distress. Lou and collaborators (2016) reported that, although formal caregivers perform a good practice in providing daily care in line with their professional ethics and principles, they also report some ambivalent feelings like disempowerment and infantilization when they encountered difficulties in daily practice, which were mainly attributed to limited resources. It is important to underline that this is only one aspect of formal caregivers and many others must be explored in order to guarantee an adequate and person-centred assistance for elderly with MCI. Thus, an effort by the scientific community should be done in this direction and our project may represent a starting point of this process.

Informal caregivers of people with MCI, in most case, are family members, especially spouse and adult child and they provide help and support with more complex instrumental activities of daily living, such as transportation, taking medication, or cooking, for 24 to 28 h/wk (McIlvane et al., 2008; Fisher et al., 2011). In this stage, they are at the beginning of experiencing caregiver burden and lower quality of the family relationship that could put them at risk of developing depression Garand et al., 2005, 2007; Lu et al., 2007). In fact, although negative outcomes, such as depression, stress, and burden, in the family members of people with MCI are not as pronounced as in dementia caregivers, they appear to be present and exceed symptomatology in the general population. There has been a marked increase in recent years in the number of studies assessing the effects of MCI on family caregivers. The pooled prevalence of depressive

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symptoms in MCI caregivers seems to be higher than that in the normative population (14%–19%) or in the community samples of older non-caregivers (9%–19%) and well within the range reported for dementia caregivers (19.7%–36%). Moreover, a recent review (Dean and Wilcock, 2012) indicated that the most commonly experienced emotions reported by caregivers of individuals with MCI were frustration, guilt, and anger. Other consequences associated with caring for a person with MCI are a strong sense of loss (Lu et al., 2011) and deprivation in the caregiver relationship with the patient (Lu et al., 2007), including less effective communication, a loss of intimacy (Dean and Wilcock, 2012; Davies et al., 2010), and decreased marital satisfaction (Garand et al., 2007) among spouses. Finally, the new responsibilities facing caregivers as a result of the need to compensate for the memory decline in those with MCI take a toll on the caregivers' own lifestyle, for example by reducing the amount of time they have for themselves (Garand et al., 2005) or for participating in their own recreational activities (Savla et al., 2011).
Information about the presence and the stability of an informal carer is often a key indicator of a person's ability to remain at home and provides an indicator of the potential in-home support and the extent to which the burden of care is absorbed by the informal caring system. The stability or otherwise of the informal carer's availability may be significant in the capacity of the patient continuing to remain at home. The increasing frailty of the caregiver has been shown to predict an early institutionalization of the patient over time (YAffe et al., 2002).
As the effects on and contributions of support by family caregivers are a large component of informal costs of dementia (Wimo and Prince, 2010; Alzheimer's Association, 2010), they are likely to be the drivers of the more modest costs of MCI. Understanding family caregivers lived experience with those persons who are at an increased risk of developing dementia is an important area in order to develop early and effective interventions.

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3 ANALYSIS OF THE CURRENT SITUATION

3.1 Practices, Services, Policies and Interventions Currently Used for Supporting Caregivers

Formal and informal caregiving has emerged as a prominent public-policy issue associated with aging and long-term care. A body of research has well documented that families provide the vast majority of support and direct care to frail elders and people with disabilities, yet they receive little support and assistance themselves, and they often face health risks, emotional strain, mental health problems, workplace issues, and financial insecurity Family caregivers of the elderly often experience high levels of stress, which can lead to depression, compromised physical health and even premature mortality. Although the caregivers support varies from one country to another and it's based on the socio-cultural context, the needs of families are practical, emotional and financial. The Alzheimer's Association works on a global, national and local level to provide care and support for all those affected by Alzheimer's and other dementias. They provide practical and emotional help, such as support groups and help lines. Family members of the elderly are mostly not rich and often contribute with their income and their savings to the cost of care.
The Alzheimer Europe's Report from November 2013 on "National policies covering the care and support of people with dementia and their carers" (Alzheimer Europe, 2013) provides very useful information about the situation in 33 countries regarding national policies focusing on the provision of care, the training of healthcare professionals and social care staff, and support at home, in the community and in nursing homes. As many countries do not yet have a national dementia strategy, certain qualified experts were asked to provide details of any other relevant policy provisions (e.g. guidelines, laws and regulations). Alongside national provisions, national Alzheimer associations provide a great deal of support to people with dementia and their caregivers. Wherever possible, the report has included details of the services and support they offer in comparative tables. The level and type of support provided in each country is dependent on the resources, structure and goals of national Alzheimer associations, combined with the kind of support already provided by the state and other organisations.

<u>The social and healthcare professionals that provide care and support</u>
Nursing staff, auxiliary staff, allied health professionals, specialists, general practitioners and other (in Austria - validation therapists if privately organised; also voluntary visiting services; in Italy - geriatricians and psychologists and in Romania only certified carers; no reports were available for Spain).

<u>Services and support offered by Alzheimer associations in different countries</u>
Helpline, Information activities (newsletters, publications), Website, Awareness campaigns, Legal advice, Care coordination/Case management, Home help (cleaning, cooking, shopping), Home care (personal hygiene, medication), Incontinence help, Assistive technologies / ICT solutions, Tele Alarm.

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Main types of support for carers

Although the types of support can be aggregated in several larger, similar categories, there is a significant variance between the level and content of support offered in each of the reporting European countries. Thus, the main categories analyzed were: 1) The type of training that social and healthcare professionals receive, 2) How the training of social and healthcare professionals is addressed, 3) Types of support for informal carers.

1) The training that social and healthcare professionals receive varies significantly

In Austria exists a clear structured and regulated approach, where for the nursing staff, knowledge about dementia is included in the special training of psychiatric nurses. This is covered in the Law on Health and Nursing Care (Law: "Gesundheits- und Krankenpflegegesetz). Auxiliary staff (who provide general assistance, usually with no medical or nursing training) are state recognised but there are different levels of training (i.e. varying from ten weeks to one year and provided by official or private schools). Social sector professionals, such as social workers, are educated to degree or Masters (BA or MA) level at state recognised "Fachhochschulen" (which are equivalent to universities). Allied health professionals (e.g. language therapists, physiotherapists, dieticians, podiatrists) have specific training, which leads to a state recognised qualification.

In Italy the Ministry of Health authorises training courses in all medical subjects including dementia (ECM, Educazione Continua in Medicina) for all of the professions above except the auxiliaries. Training for auxiliary staff is provided by the regions. The ECM courses are attended by health professionals on a voluntary basis and according to their needs. Attendance is not required by law and there is no central register of course attendance or completion.

In Romania formal care service is provided only by certified carers. There are two types of certified carers (as they appear in the Romanian Occupational Code): home carers for people who are ill and home carers for elderly people. They are certified on the basis of Government Ordinance. 129/200 and they are legally certified by the Ministry of Employment. Their training should be organized by providers who have been accredited by the National Council for the Professional Training of Adults. A person can become a certified carer after attending a training course. The course is open to anyone interested in obtaining such qualifications in order to find a job or those for whom this type of activity is a part of everyday life such as having an older family member in need of care. In order to be certified, home carers of elderly dependent people should follow 11 training modules over 360 hours of training (120 hours for theory and 240 for practice). More information, in Romanian, can be found at: http://developeyourself.wordpress.com/2011/11/24/curs-de-ingrijitor-batrani-la-domiciliu/.,
Any NGO that is accredited by the State can organize courses for carers. The State only sets the number of hours and curricula for these courses. The qualified people can then be hired by different organisations (state social departments, NGOs, private sector) or become authorised personnel in the field (i.e. they can be self-employed). Private companies avoid having certified carers because the training period is too long and expensive. Most of the private companies work with untrained personnel; they only recommend "carers" and require a fee from the carer and from the beneficiary. Then the patient or the family illegally pays the carer. Taxes on wages are so high that only rich people can afford to hire a carer legally.

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2) How the training of social and healthcare professionals is addressed - in Austria it is covered by national guidelines and policies, whilst in Italy there is no policy in place; in Romania the formal carers are trained and certified following the procedures mentioned in the previous paragraph.

3) Types of support for informal carers - whereas for the informal carers, although there exist several types of support, they are also less consistent across Europe and more country specific.

In Austria national policies even cover certain types of support.
Respite: Carers who are caring for a person with care level 3 needs are entitled to three weeks per year respite from caring, which is financially covered by the Federal Social Office (the "Bundessozialamt").
Training: There is no national policy covering the training of informal carers.
Consultation/involvement in care decisions: Carers who are the legal representatives of a person with dementia are consulted and involved in care decisions in accordance with guardianship legislation.
Counselling/support: There is no national policy covering counselling/support for informal carers.
Other: As of 1 January 2014, people caring for a person with needs defined as care level 3 will be entitled to three months' break from work ("Pflegekarenz") or three months' part-time work ("Pflegeteilzeit"). For the three-month break, carers will receive a payment based on their last wage but up to maximum of EUR 1,400 per month. For the part-time work, carers will be able to reduce their working time by a minimum of ten hours per week and the payment they receive will be calculated on the basis of their reduced income. These two measures are designed to make it easier for carers to combine work and care responsibilities during difficult periods without fearing losing their jobs. However, the request for a caregiver's break must be approved by each person's employer. Support for carers is also provided by private organisations such as the carers organisations ("Interessensvertretung pflegender Angehöriger), Alzheimer Austria; MAS-Alzheimerhilfe, Bad Ischl, the Red Cross and Caritas. The communities and regions also provide support through projects.

In Italy there is no official support for informal carers. However, the "top-quality" centres provide support, usually in cooperation with local Alzheimer associations (e.g. Respite care at home, Training for carers, Support groups for carers, Counselling, Helpline, Information activities - newsletters, publications, Website, etc.)
Also in Italy, among the rights of the elderly, there is the "accompanying allowance", provided by law to economically support those who take care of a person with a serious chronic illness and unable to perform normal daily actions. According to the Framework Law on the assistance, social integration and rights of people with disabilities (L. *104/1992 art. 33– Dlgs 151/2001 art. 42)* three days a month of work permission are covered by contributions to those who must assist a family member with disability.

In Romania, services are as follows:
Respite: There are no organised services covering respite care at home. However, in rural areas, there have been isolated cases of carers asking their relatives to come and look after the person with dementia for a couple of weeks so that they can have a break or go on holiday. Sometimes, when carers are no longer able to cope, they try to arrange for the person with dementia to be admitted into a psychiatric ward for several days. This is possible if they know a doctor who is

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understanding and willing to admit the person with dementia for a short time. Private homes exist which accept people with dementia for short periods of time. This usually costs between EUR 600 and EUR 1,400 per month.
Training: Training is available for carers. This is partly funded by the State and partly by the carers themselves.
Consultation/involvement in care decisions: The Romanian Alzheimer Society is not aware of any specific obligation to obtain service users' views about such services. It has found such specifications only in a guide issued by the Romanian Government in collaboration with the Ministry of Health and Social Protection and the National Institute for Preventing and Combating Social Exclusion of Persons with Handicap. Moreover, the Romanian Alzheimer Society is not aware of any initiatives by service providers to obtain and assess the opinions of people with dementia and carers about the quality of home care services.
Work/tax related support for carers and carer allowances: Carers are not entitled to paid or unpaid time off work or flexibility in their working hours in order to care for a person with dementia. The State does not provide free or subsidized pension contributions to people who give up paid employment as a result of care giving. Carers do not benefit from tax benefits or incentives for the care they provide. However, carers of people with dementia with the severe disability degree receive payments from the State towards the cost of caring. The National Authority for Handicapped People grants an allowance of EUR 177 per month.

3.2 Use of Digital Devices and Internet Services by Caregivers

Approximately, 72% of caregivers gather health information online, and 52% participate in online social activity related to health (Roupa et al., 2010). Just under half go online to learn a diagnosis. In addition to searching for information on medical problems, treatments and drugs, many go online to read about the personal experiences others have had with certain health conditions — as a way to understand more about their loved one's health or even a condition they're dealing with themselves.
A study dated 2016 (Catalyst Project, 2016) and mainly investigating the US situation, highlighted that caregivers are technologically literate, comfortable using a variety of devices, and already use technology in their caregiving. Nearly all caregivers (97%) are comfortable with computers. Four out of five are comfortable with tablets (80%) and smartphones (80%), and three in five with other personal devices. While comfort with computers was high across all groups, the 65+ population of caregivers reported the lowest levels of technology comfort for smartphones, tablets and devices. A majority (57%) of caregivers already use technology in at least one way to assist with their caregiving duties, once a week or more frequently.

Focusing on the European situation although at a more general level (i.e. not considering just the caregivers, but having a broader scope on the whole European population) the 2016 'Survey on ICT (information and communication technology) usage in households and by individuals' (Eurostat, 2016), highlights that a large majority of Europeans used Internet in 2016, although internet habits of different countries and age groups vary significantly and 14 % of the EU population have never used the Internet. A report of the European Commission dated back to 2014 showed that six out of ten Europeans have searched for health information on the Internet (European Commission, 2014).

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As for professional caregivers, their technological literacy is expected to be higher than the informal ones. This is also confirmed by the fact that a 2013 survey (JRC, 2013) shows that 75% of European hospitals have some type of electronic health records (EHR) system in place, thus formal caregivers use digital services at their workplaces.

3.3 Technological Solutions for Supporting Caregivers

The use of new technologies by caregivers of older people is becoming more common. Indeed, one important aspect in AAL is the monitoring of elderly's daily living activities, which is widely used in health care, and refers to daily routines on which the ability of a person to live independently is assessed (e.g. bathing/showering, dressing, food preparation, eating, personal hygiene, taking
medicines, telephoning). One of the systems that is well known for remote monitoring of elderly is video surveillance, however it is not easily accepted due to its intrusiveness. Thus, new systems are developed to collect data from subjects without bothering them on a day-to-day basis, which do not cause a loss of privacy, that are easy to install in a home, and which can be easily adapted to the different needs of the subjects and which can be configured, monitored and supervise remotely.

Ideable for example proposes Kwido, a multi-device solution for caring for elderly people. It is aimed for caregivers to connect with patients' health monitoring http://www.kwido.com/health-monitoring/ with a specific app available for caregivers inside an eldercare company https://play.google.com/store/apps/details?id=com.eldersarea.manager. Kwido includes a wide range of features: telecare & teleconsultation (videoconferencing), social apps, chronic disease monitoring, medicine taking, cognitive impairment detection, etc. More info at https://www.youtube.com/watch?v=nJTkx73Qnhg&feature=youtu.be
It provides mobile or tablet application for patient monitoring, where professionals at patients' homes or nursing homes can quickly include daily health data of all their elderly patients, even connecting with wireless devices. In addition, through Kwido caregivers can allocate health variables to be measured for each patient, with customised alerts and full schedule of tasks for each centre and each professional.

Another solution, MedMinder (https://www.medminder.com/), offers caregivers support for monitoring medicine intaking by chronically ill patients, who are on complicated drug regimens (e.g. they typically take more than ten pills a day). MedMiner consists of a digital tablet dispenser that has the same appearance of a common model for seven days. A part of the pillbox remains blocked until the time when the medication is taken, while the other part is unlocked. It works in the following manner: The caregiver fills the medication tray that is put into the device. The caregiver enters the web, programs the ingestion sequence remotely and can know if the user complies. The dispenser emits flashes (if it is blocked, unlocks) when it is time to take a pill, then sounds if the medication has not been ingested. Refill trays make refilling the pill dispenser more convenient and reduces the possibility of medication errors. Refill trays can be filled ahead of time by family members, a pharmacist or caregiver and placed directly into the MedMinder medication dispenser.

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Among the commercial products, Philips offers Lifeline (https://www.lifeline.philips.com/), a medical alert service (especially used in the US) which is delivered as a personal assistance button for home use that is worn hanging from the neck or attached to the wrist, and that can detect if the person has suffered a fall. It works in the following manner: the base station is plugged into the wall, whereas the button sensors are connected wirelessly to the base station and distinguish between a fall and another movement. If a fall is detected, the connection to the response center / caregivers is established.

Another commercial system is GrandCare (https://www.grandcare.com/). It monitors daily activities, has medical monitoring options (glucose, oxygen, blood pressure, weight) and can present any type of information: diets, plans for hospital discharge, exercises. An interactive touch screen (TV) allows the patient to watch videos, listen to music, play games, read the news or hold video conferences with the family. By using an internet connection that communicates with wireless sensors installed throughout the house, caregivers can access a website to observe patients' activities, write messages or leave them directives. Optional wireless activity sensors, environmental sensors, and digital health devices can be added to the system as needed. They can be used to notify designated caregivers by phone, email, or text if anything seems amiss or if wellness readings fall out of range.

The use of lights to support elderly life has been considered in some previous work. The Guiding Light project has considered how to enhance the activity and mobility by supporting a circadian rhythm with specific lighting parameters (Guiding Light, 2011). However, the solution proposed in that project once deployed in the elderly home was difficult to change in terms of the rules driving the automatic modification of the lights parameters, and such changes required the intervention of specialized technicians. Using the solution proposed in our project such rules can be specified even by people without programming experience. (Morris et al., 2017) have proposed a solution to allow individuals to configure the lights in one another's homes as well as their own. They explored possible scenarios to use them for supporting remote communication without considering the specific aspects of the elderly support. Similar topics were explored by Clark and Dutta (2015) who investigated how Internet of Things can be exploited to support subtle ambient and incidental exchanges between people who live in different home, for example using synchronized lights across houses.

One further relevant aspect concerns tools helping elders reach their goals with IT products by working with their caregivers. One example of the latter is the work of (Zhao et al., 2015) who present the CoFaçade approach helping elderly people to reach their goals using digital artefacts by working collaboratively with helpers. In this approach, the elder uses a simple interface having a small number of customizable triggers, which are mapped to procedures that accomplish high-level goals with any IT product. The caregiver uses a customization interface to link triggers to procedures that accomplish frequently-recurring high-level goals with IT products. To demonstrate the effectiveness of their approach, the authors implemented a prototype using a handheld physical trigger interface and a desktop customization interface for defining procedures for both computer applications and consumer electronics. Then, they performed an evaluation in which they compared the CoFaçade approach with a baseline approach where 18 helpers either taught elders to perform a computer task or customized the trigger interface to perform that task. Their results indicate that the CoFaçade approach reduces helpers' workload and elders' frustration, and improves elders' task completion rates. While this approach goes in the direction

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of supporting the elderly in their everyday tasks, differently from our solution they do not consider context-dependent aspects that can modify the execution of procedures.

The PETAL platform for personalization of elderly support is based on trigger-action rules, which are intuitive to specify also for non-technical people. This type of approach is considered by some commercial tools, such as IFTTT (https://ifttt.com/), which allows people without programming experience to create simple applications such as 'If I arrive home then turn lights on'. IFTTT is a popular trigger-action programming environment that allows users to easily connect existing applications in such a way that if something happens in one, then some effect can be generated (for example, a functionality is activated). One of its distinguishing features is that, besides being able to express recipes that concern the hosting device, it communicates with widely used Web services, thus allowing the automatic execution of functions related to the internal state of applications such as Facebook, Instagram, eBay, YouTube, and others. A recent study (Ur et al. 2014) found that trigger-action programming can express the most desired behaviours in order to customize smart home devices. They also found that inexperienced users can quickly learn to create programs containing multiple triggers or actions obtained by extending the IFTTT language, which has limited possibilities, since it only supports applications with one trigger and one action. This shows that this approach seems suitable to support EUD of context-dependent applications, but needs to be improved in order to allow users to express various desired combinations of events and corresponding actions. However, one of its main disadvantages of this solution is that it is rather limited in terms of expressiveness since it does not allow users to create more structured rules, i.e., those combining multiple events and actions (Ur et al., 2014). In this project, we consider the TARE platform (Ghiani et al., 2017), which overcomes such limitations and is mature for deployment in real contexts since it has already been used in the PersonAAL project (http://www.personaal-project.eu/).

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4 GATHERING REQUIREMENTS THROUGH QUESTIONNAIRES

4.1 Description of the Questionnaire Used

According to the project plan we have carried out a survey of elderly people with MCI and of formal and informal caregivers to assess the specific needs of both target groups. We aim to better understand what a personalisable assistance system should provide, so that it meets the elderly needs, and what kind of devices, interfaces, control mechanisms are already familiar or accepted by the target groups.
The methodology chosen was a survey using a questionnaire, which had to be filled in by the target persons themselves. The caregivers received a brief introduction to the planned assistance system.
Mainly similar to the questions submitted to MCI elderly (see PETAL Deliverable D1.1a) the questionnaire targeted to caregivers dealt with the following topics:

- Technological literacy
- Communication tools and habits
- Lighting situation in the house
- Requests and expectations with regard to lighting
- Acceptance of various forms of light and visual signals
- Hazard to fall and sleeping quality
- Caregivers and assistants
- Socio-demography

With regard to the target group the questionnaire had to 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 already tested 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 by PETAL Partners

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.

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Altogether we collected the answers of 75 formal and informal caregivers working with MCI patients.

4.2.1 ANA

The questionnaires for the caregivers 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:

1) 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 carers (usually life partners or children) and
2) The Clinic of Geriatrics-Gerontology and Old Age Psychiatry from the Elias Universitary Hospital, where the head of clinic 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; here they are being taken care mainly by professional carers, trained in dealing with these categories of 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:

1. In the Memory Center mainly informal carers who came to the center with the MCI patients 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
2. In the Geriatric Clinic mainly by the formal carers working in the Clinic who agreed to contribute to this action and 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.

4.2.2 Fondazione Santa Lucia

The Fondazione Santa Lucia (FSL) selected only caregivers of elderly diagnosed with MCI from the Memory Clinic database. From the initial sample of 30 caregivers contacted, 5 refused to fulfill the questionnaire and 3 was not traceable. The final sample collected in Rome was composed by 22 informal caregivers. The first contact was made by phone call explaining the purpose of the project and the need of their collaboration in this phase. For those who accepted to participate an appointment was fixed in FSL in order to fill out the questionnaire. The two psychologists that handle these phase were informed and trained on the purpose of the project questionnaire and assumed the responsibility to monitor the accomplishment of the data collection. Before performing the questionnaire all caregivers were informed of the anonymous use of the data in full respect of privacy. The fulfilled questionnaires were collected and the data obtained were entered in the online data management.

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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.

4.2.3 CNR

In the end, for the questionnaires, CNR was able to involve 10 caregivers (formal and informal): 7 informal caregivers and 3 formal caregivers. In particular: 7 were the relatives of 7 MCI elderly attending the "Train the Brain" (TtB) program (who correspondingly filled in the PETAL questionnaire for collecting requirements by the elderly). The remaining 3 persons were the three female psychologists of the TtB program. The questionnaires were collected in the period End of January – Mid of February. Informal caregivers filled in their questionnaire at home, without receiving any specific support: each elderly gave to his/her informal caregiver a questionnaire to fill in, then the elderly brought back the filled questionnaire at the TtB structure when coming for attending the cognitive lessons of the TtB program. Regarding the experience of the 3 formal caregivers (all females) involved, they had about 10-year experience in applied psychology.

4.2.4 Apollis

For the recruitment of caregivers familiar with MCI target persons 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 caregivers of seniors 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 cases of 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 assistant, Verena Amort, at the Griesfeld Foundation..
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 questionnaires.
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.

4.2.5 Bartenbach

The questionnaire distribution for elderly people and caregivers in Austria was organized by Bartenbach. Lisa-Marie Neier (BART) informed Josef Marksteiner (Tirol Kliniken), an associated partner in the project PETAL, about the goals and target groups of the developed questionnaires. Dr. 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. Dr. 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 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

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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. After about 7 days Lisa-Marie Neier (BART) picked up the collected questionnaires at the outpatient clinics and entered the data to the online database. This first 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 caregivers were available. The staff was instructed to go further with the distribution but the second collection brought no more questionnaires. The responsible nurse told Lisa-Marie Neier, that it was too much effort and doctors told her to stop because her other tasks were neglected. To find out the problems that have been occurred, the staff was asked for specific occasions and they reported that the questions were too complex for most of their patients. Patients wanted to ask the staff about the meaning of single questions or how to answer specific questions, but due to their work tasks the staff was not able to bring up a lot of time to support the patients in filling out the questionnaires. Furthermore, most patients told the nurse that they only use TV and landline-phones and therefore are not able or willing to fill out the questionnaire. Tough the staff was very helpful and solicitous this extra-effort was not planned and not feasible to go further with the questionnaire distribution.

4.3 Results Gathered from Questionnaires

4.3.1 User Demographics

The sample includes altogether 75 caregivers of persons with MCI.

Three quarter of the caregiver are female; one quarter is male.

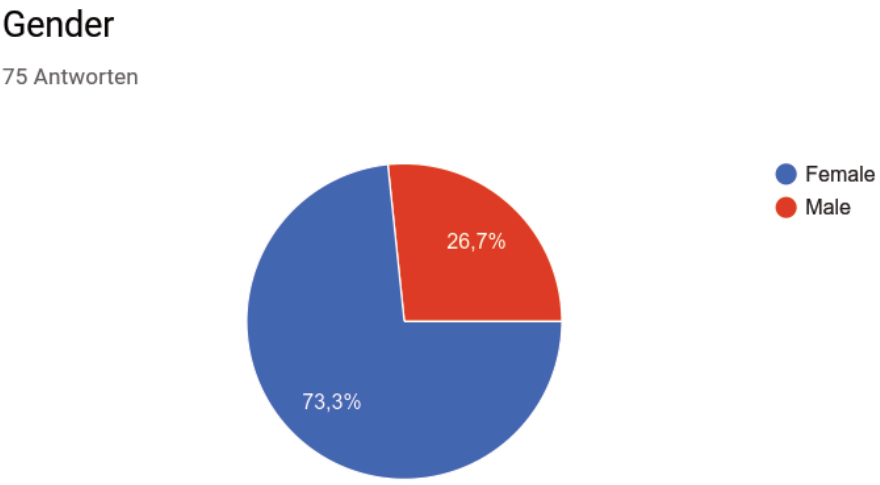

Fig. 1 Pie chart showing the ratio of the sample between female and male

More than a third of the interviewed caregivers are partners, a quarter sons/daughters and other

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family members. Professional caregivers (including 2 psychologists and one private paid person) amount to another third of the sample. The remaining 5 percent without answer to this question seem to be partners or relatives.

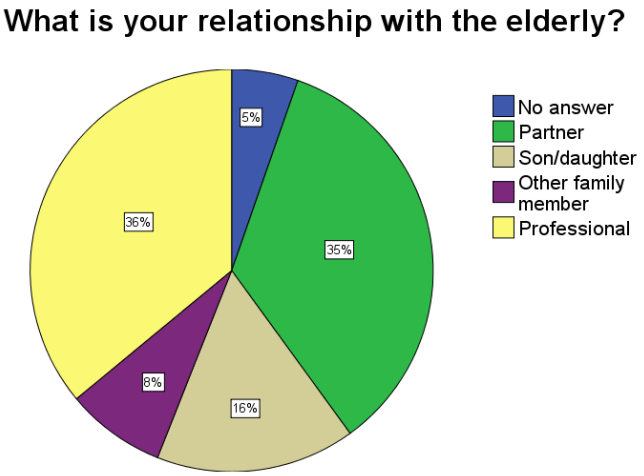

Fig. 2 Pie chart showing the relationship with the elderly

Partners are almost equally wives and husbands, sons/daughters and other family member mainly women. Professional caregivers – with one exception are all female.

Gender * What is your relationship with the elderly? Crosstabulation

Count

		What is your relationship with the elderly?					
		No answer	Partner	Son/daughter	Other family member	Professional	Total
Gender	Female	3	12	10	4	26	55
	Male	1	14	2	2	1	20
Total		4	26	12	6	27	75

Fig. 3 Table showing the relationship with the elderly by gender

The age distribution has an interesting form with a maximum around the age of 50 years but another peak around 75 years. Actually partners of MCI patients have a mean age of 73 years, other family members and professional caregivers a mean age of 50 years.

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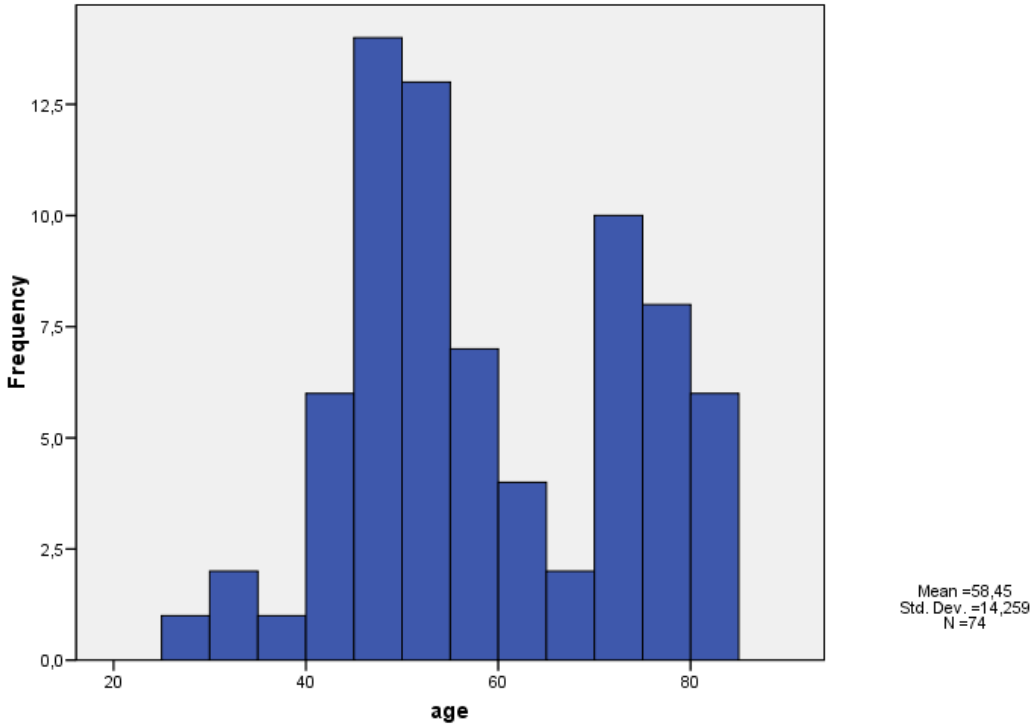

Fig. 4 Histogram showing the composition of the sample by age

Half of the interviewed caregivers come from Italy (37), one quarter (17) from Romania, one fifth from Spain (15) and the remaining 8 percent (6) from Austria.

The composition of the sample regarding the relationship between caregivers and patients is different in each country according to the recruiting procedure adopted. In Spain only professional caregivers were asked to fill in the questionnaire, in Austria and Italy nearly all interviewed persons are family members, in Romania the distribution is equilibrated between relatives and professional caregivers.

Where do you come from? (current residence) * What is your relationship with the elderly? Crosstabulation

Count

		What is your relationship with the elderly?			
		No answer	Partner/family member	Professional caregiver	Total
Where do you come from? (current residence)	Austria	3	2	1	6
	Italy	0	35	2	37
	Romania	0	7	10	17
	Spain	1	0	14	15
Total		4	44	27	75

Fig. 5 Table with the composition of the sample by current residence and elderly relationship

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The educational degree of the sample is rather high: more than one third has a senior high school diploma or even a university degree, another third professional training, the rest a compulsory school degree (elementary or junior high school).

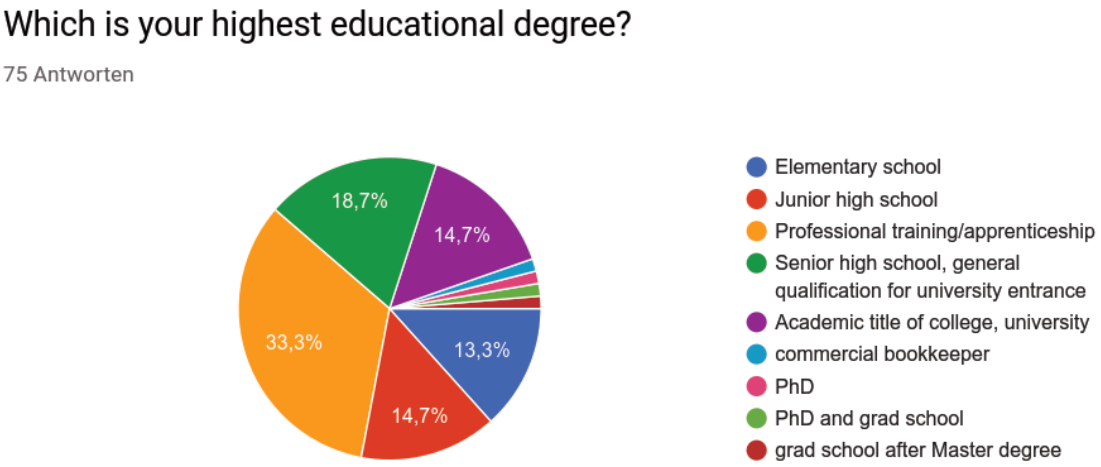

Fig. 6 Pie chart showing the composition of the sample by education

There are large differences between formal and informal caregivers: formal caregivers apparently access to their job through a professional training (except for the two psychologists). Informal caregivers are surprisingly highly educated – a fact the was remarked also for the sample of elderly with MCI – more than half of them have a senior high school diploma or even a university degree.

4.3.2 Familiarity with Technology

4.3.2.1 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 are not unexpected: roughly four in five use TV and smartphone, about one half uses each kind of PC (tablet, laptop and desktop), only 7 percent rely still on a traditional mobile phone.

The most frequent purpose of using these devices is calling, for three quarters also sending messages and getting information, one half uses the devices for entertainment and managing something.

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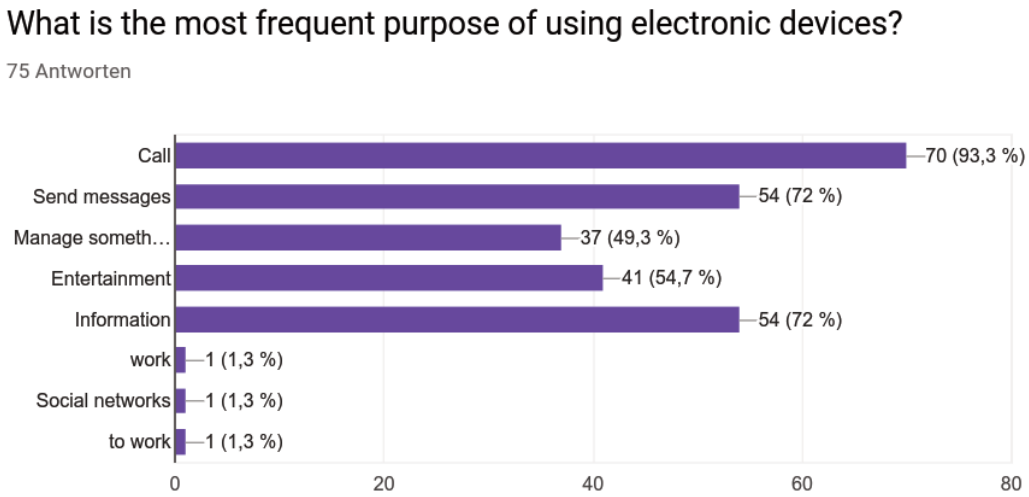

Fig. 7 Bar chart showing the most frequent purpose of using electronic devices

Most of the caregivers have internet access at home (85%) and/or at the workplace (32%), a minority of the interviewed persons has no access at all (14%). The percentage of caregivers without internet is slightly higher for family members but even in this group more than 80 percent have access to the world wide web. The main difference is that a majority of caregivers uses internet also at the workplace.

4.3.2.2 Communication with assisted elderly

The by far most preferred communication tool with the elderly is making a phone call (96%). Only one in six caregivers likes also text messages, 7 percent e-mails.

The image gets more complex if the question is about the preferred form of receiving reminders or alarms concerning the elderly: phone calls are appreciated by everyone, text messages by one third, audio messages, sound signals, e-mails and PC/mobile applications each by one tenth.

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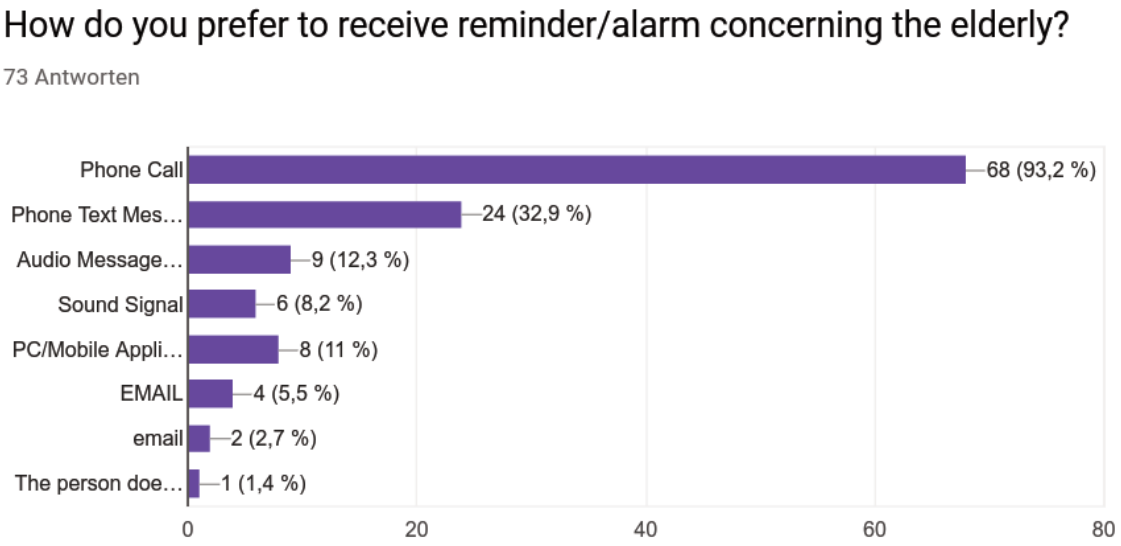

Fig. 8 Bar chart showing the preference on how to receive reminders/alarms concerning the elderly

The answers are similar when asking on the actually used devices to communicate with caregivers:

- everyone calling
- 1/10 instant messages
- 1/10 e-mails
- 1/4 health measurements
- 1/5 games for cognitive stimulation (tablet, paper)

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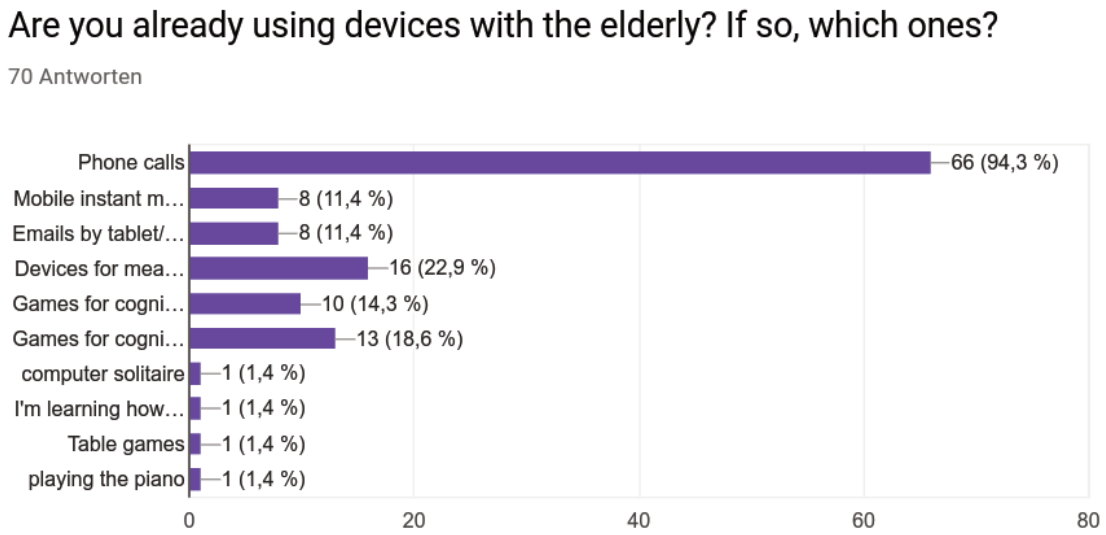

Fig. 9 Bar chart showing the usage of devices with the elderly

Caregivers think that TV is the device which is most familiar to the elderly. Beside that tablet and smartphone are judged to be appropriate by a quarter of the caregivers, followed by mobile phone, laptop and desktop.

The views differ between formal and informal caregivers: whereas half of the professionals retain tablets to be easy to use for the elderly only one in six informal caregivers is of the same opinion. On the other hand, family members are more confident about smartphones and mobile phones.

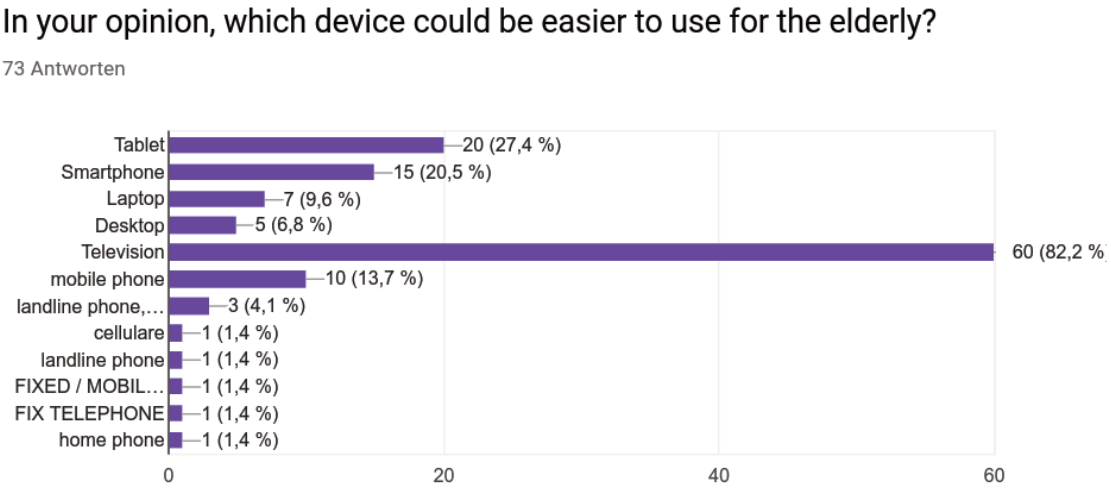

Fig. 10 Bar chart showing the devices that could be easier to use for the elderly

Half of the caregivers are convinced that the elderly would be able to learn how to use devices for technical support by specific training, another quarter does not exclude it.

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4.3.3 Use of Sensors, Devices and Lights

4.3.3.1 Need for specific aid

We also wanted to understand which situations the elderly judge to be particularly difficult for them, so that there is need for specific aid. Caregivers, especially the professional ones, listed many different situations, such as:

- going to bath at night
- taking medicine
- daily structure
- remember appointments
- Eating
- emergency call
- … and several others.

4.3.3.2 Lighting devices

According to the caregivers all of the elderly use normal white light, more than one third night light, one out of five dimmable light and a few automatic light, coloured light and signal or alerting light.

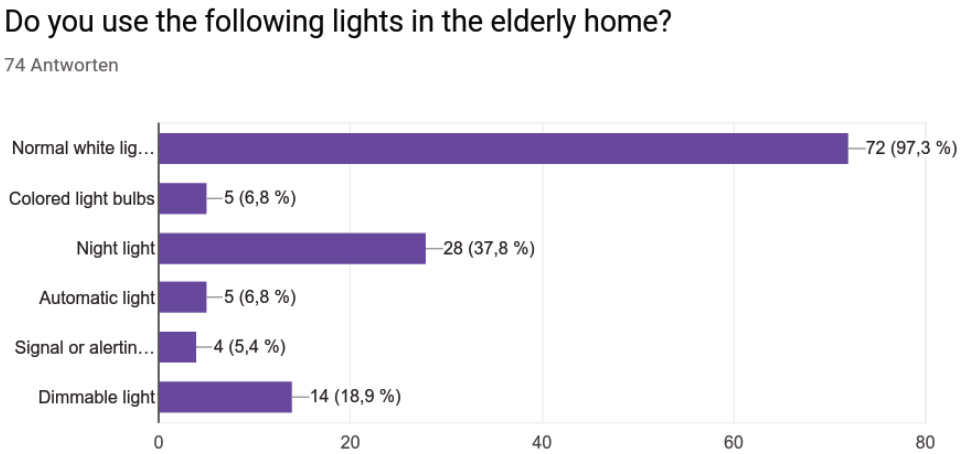

Fig. 11 Bar chart showing the usage of lights in the elderly home

The majority of caregivers thinks that normal white light is also very useful for the elderly. But especially night light, automatic light and signal and alerting light should play a more important role in the houses of the elderly than it actually is the case.

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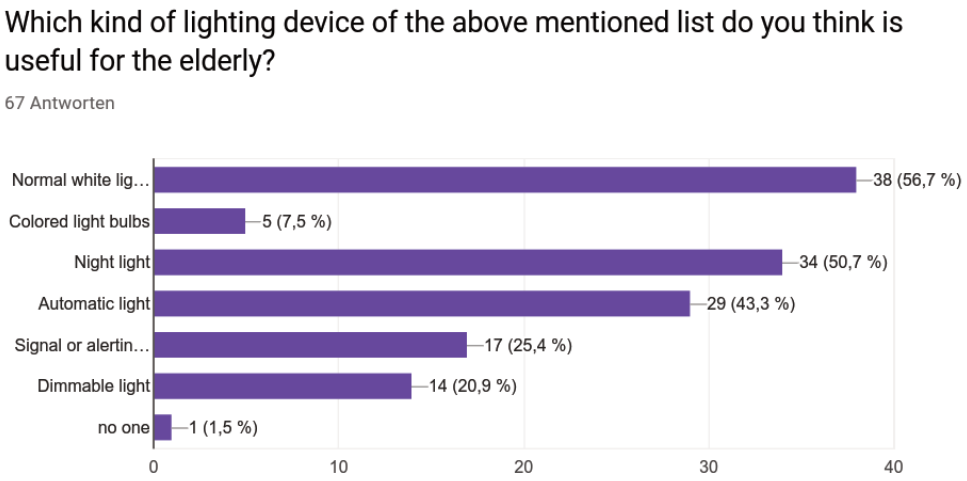

Fig. 12 Bar chart showing the favorite lighting devices useful for the elderly

The caregiver confirm that the only form of lighting control currently used by seniors are switchers.

4.3.3.3 Use cases for monitoring through sensors

The suggestions of caregivers with regard to monitoring technology were stimulated by the following question:

"In your opinion, what aspects of the elderly life and environment could be useful to be monitored through sensors connected to a support platform?"

The answers cover a large variety of use cases, such as (see also graph with word cloud and complete list):

- automatic light (trigged by movements)
- automatic curtains or blinds
- control of doors: cam, digital peep-hole, opener
- remind of taking medicines, appointments
- remind of drinking and eating
- monitoring movements inside the house
- money management
- sleep monitoring
- going to the toilet
- control of the stove

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Fig. 13 Word cloud generated on the answers on the aspects of the elderly life and environment that could be useful to be monitored through sensors connected to a support platform

Aspects of the elderly life and environment to be monitored through sensors	
A cam to see who's calling in building entrance or ringing door bell	Main door
activities of daily living	maybe at night an automatic light when she needs to go to the bathroom
alcohol consumption	meals
AMBIENT TEMPERATURE, CITIZEN ACTIVITIES	MEDICATION, BALANCED FOOD PROGRAM
Automatic blinds	MOBILIZATION, FOOD, DRUGS ADMINISTRATION
automatic curtains / blinds	money management
Automatic curtains / stores	monitor blood pressure and remember to take medicines
Automatic curtains / stores and automatic doors for entering home	monitoring his position inside home
Automatic lights at night	monitoring memory loss
Automatic open / close of window blinds	monitor trips outside the home

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Aspects of the elderly life and environment to be monitored through sensors	
Automatic window blinds and main door	MOVEMENT
Blinds control	open/close blinds
Cam for doorbell	Peep-hole at door
control better when alone and to communicate more often	PERSON IMMOBILIZED AT THE BED, PERSON NEEDED TO REMOVE (FRAME, BAG WITH BOLTS)
Control to home by caregivers using webcam	PRESENT
cooking	remember appointments
DAILY ACTIVITIES, AMBIENT TEMPERATURE, THE HOURS OF TIMES, THE MEDICAL TIME	remember to eat and do not leave things on the stove on
daily activity	remember to take medicines
Daily living - What they do during the free time? What they eat? Do they do physical activity? Do they take medicines?	remember to turn off the gas when making coffee
DAILY ROUTINE, STATE OF THE PATIENT, DRUGS ADMINISTRATION	reminder signals for regular drinking
Digital door peep-hole	Reminder signals for taking medicine
Digital peep-hole at door	reporting falls
Door open	Sensors at bed
emergency call	sensors for ambient temperature sensing
Fire, water and night lights	Sensors for lighting when moving
gas sensor	Sensors in sofas and in windows blinds
going home	sleep monitoring
going to the toilet	TABLE, TOILET, BATHROOM
going to the toilet	taking meals
leaving the house	taking medicines
Light by movements	to go out without leaving nothing turned on
Light on by movements	to stimulate the elderly in releasing daily activities
LIGHTING	Turning on / off with movements
Lights on with movements	walking to wash

4.3.3.4 Use cases for reminders, alarms and warning

A similar question was on possible support by reminders, alarms and warning:

"How a support platform able to generate reminders, alarms and warning, could help you?"

The answers to this question are less explicit and often very general, like "to keep relatives informed", "easy care" or "to solve the problem from a distance". Quite often the repeat

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suggestions mentioned already as answer to the preceding question.

Some of the ideas are quite precise and stimulating:

- It could be useful to create efficient association "alert/light -> activity" to memory recall something to do.
- Make the elderly less apathetic.
- It would limit phone calls to remind her to do things and check that she did them.
- Possibly a programmable memory for certain things that have continuity (time for a walk, time for the coffee in the afternoon, garden) -> like the new digital watches for sports activities.

Fig. 14 Word cloud generated from the answers on how a support platform able to generate reminders, alarms and warning, could help the caregivers

Reminders, alarms and warning
Alerts to relatives / caregivers
avoid negative consequences
by communicating events on your phone or TV
by telephone, audio or SMS communication
could help keep a fixed timetable for drugs administration
Could help my work and relatives care by improving elderly's quality of life
Could help them when being alone

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Reminders, alarms and warning
could help to better monitor the elderly
Could send alerts when being alone at home
EASTERN MONITORING OF GERIATRICS
EASY CARE
FOR A FIXED PROGRAM, TIME TREATMENT, FIXED MEAT
FOR BETTER SURVEILLANCE
FOR RESTORING EVENTS
For the family
For warnings to caregivers
Giving us and relatives information and even remote control
HELP IN CARRYING ACTIVITIES OF GERIATRIC
if I forget it, the device will take care of it
IMPROVEMENT OF MEDICAL SERVICES OFFERED TO THE GERIATRIC
It could be useful
It could be useful to create efficient association "alert/light -> activity" to memory recall something to do
it would give her more autonomy and I would be less apprehensive
it would limit phone calls to remind her to do things and check that she did them
make the elderly less apathetic
MORE EFFICIENT CARE TIME SHOULD STILL GO TO THE PATIENT
NONE
possibly a programmable memory for certain things that have continuity (time for a walk, time for the coffee in the afternoon, garden) -> like the new digital watches for sports activities
possibly via mobile phone, receiving warning
remember to have lunch and dinner
reminder for medication hours
Reminder for taking medicines - day and time info
reminders for my own work
Sending warnings to caregivers in potentially dangerous situations
SMS ALARM NOTIFICATIONS, VISUAL AND ACOUSTICAL ALARMS
the device will take care of it
through light or sound
To inform not only caregivers but relatives too
To keep relatives informed
To keep relatives informed
to remember the dates of appointments, visits and expirations bills
to solve the problem from a distance
to train attention
Useful to track activity

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Reminders, alarms and warning
Warning if does not go out from bathroom
Would help sending warnings to caregivers when elderly patient may be in trouble

More than one half of the caregivers thinks that light could (eventually) be useful for the elderly to remember things.

4.3.3.5 The utility of light with respect to prevent falling and improve sleeping quality

Falling in the house is known to be a major hazard for all seniors. Nearly one half of the caregivers reports that an accident of the elderly falling at home due to poor lighting actually happened.

And a large majority of the caregivers is convinced that a guiding light system could contribute to prevent such incidents of falling in the house.

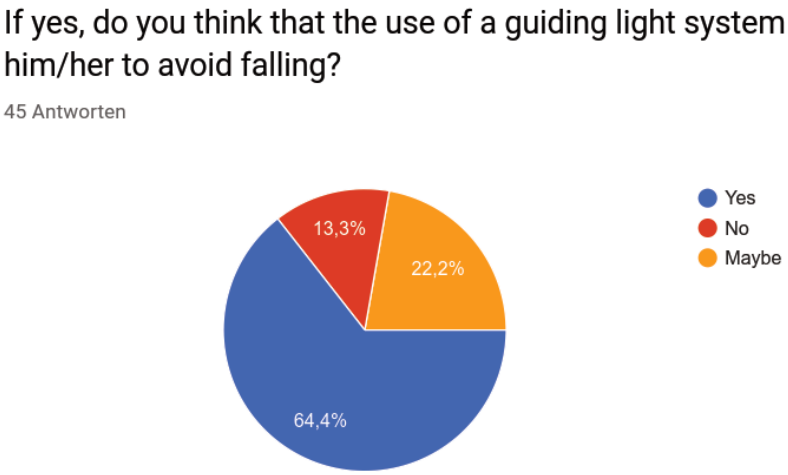

Fig. 15 Pie chart showing the ratio on the usage of a guiding light system to help the elderly to avoid falling

The reported sleep quality is good for more of one half of the elderly. A quarter of the caregivers think that the elderly they assist have sometimes problems to fall asleep, for the remaining quarter it seems to be quite often problematic.

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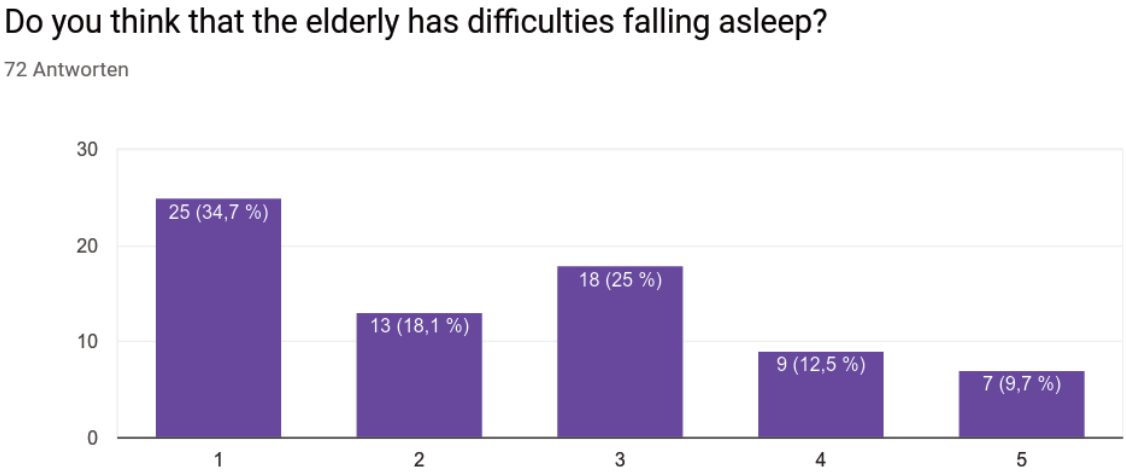

Fig. 16 Bar chart showing the percentages of the sample who think that the elderly has difficulty falling asleep

Three quarter of the caregivers think that gradual reduction in light intensity could be helpful for those elderly having (sometimes) problems to fall asleep.

Four in ten caregivers think that it happens to the senior to wake up during the night and not to know where he/she is. That coloured night lights could eventually be helpful in such a situation is likely for half of the caregivers.

4.3.4 Information about assistance

Most of the caregivers provide assistance directly at the house of seniors with MCI in form of home care, only a few (6%) in form of telecare.
Half of the interviewed caregivers are convinced that technological support will reduce the need of the care for the elderly, another fifth thinks that it is at least likely.

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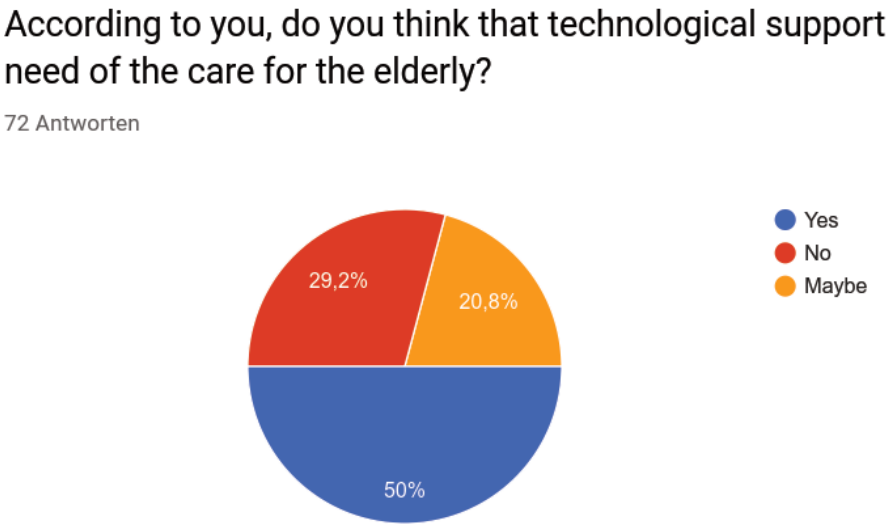

Fig. 17 Pie chart showing the ratio on the usage of a technological support to reduce the need of the care for the elderly

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5 GATHERING REQUIREMENTS THROUGH INTERVIEWS

5.1 Description of the Interview Structure

We used a presentation (prepared by CNR and then refined/improved by the Consortium) to introduce the main goals of the project to interviewed people. Then the interview followed. The following questions (agreed upon beforehand by the PETAL consortium) were used for the interview:

- What aspects of MCI care pose the most problems for informal and formal caregivers? In which situation the support provided by caregivers could be improved?
- What are the elderly's activities, events or situations (even anomalous) in the elderly life that caregivers would like to detect, track, monitor?
- How technology could provide it?
- Lights: how they can be used to support spatio-temporal orientation? where they should be positioned? How to exploit different colours? How to exploit light blinking? How to exploit fade and intensity?
- In which type of device, they prefer to receive notifications (PC, tablet, smartphone)? How should they be rendered (sms, textual, voice, graphics, vibrotactile feedback, …)? When they should be sent?

5.2 CNR

5.2.1 Interviews with 2 Neuropsychologists (in Leghorn)

5.2.1.1 Procedure

The CNR researchers interviewed one male and one female neuropsychologists working at a private cognitive rehabilitation clinic (named "Studio Cortex") in Leghorn. The two neuropsychologists currently work with MCI patients and their informal caregivers and are specialized in cognitive rehabilitation.). The duration was about 1h and it took place on 19 February 2018 in Leghorn.
CNR staff used a laptop for PETAL project presentation (video, slides) and an audio-recorder for saving the interview for later recall and verification purposes.
The procedure started with a warm up-presentation, then CNR researchers displayed an introductory video showing some potentialities of the PETAL platform and additional slides regarding the project highlighting the main features of the PETAL platform. Then the actual interview was carried out, driven by a set of open-ended questions. All the material was firstly agreed in the project. The interview to the two neuropsychologists have been carried out simultaneously by two CNR members, and it was also audio-recorded.

5.2.1.2 Results

The key findings that emerged from the semi-structured interview conducted by the CNR researchers concern the already used IT systems with MCI patients and caregivers and explore

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future possibilities in this field. Regarding their work, they refer that generally both paper-based and computerized tools for cognitive stimulation are used (e.g., memory training exercises). The tablet seems to be the most used device for cognitive stimulation. In addition, they also said that they generally applied *individual* interventions with MCI patients to better cope with the various needs of MCI elderly, who significantly differ each other.
From their point of view, the main cognitive areas on which support for MCI patients is needed are: attention (sustained, divided, selective), memory, language, executive function, and problem-solving. They also suggest system requirements for the elderly:(a) the system should help the elderly in the specific area(s) compromised, as they could differ even significantly, (b)the system should support safety requirements (e.g., detecting gas leaks), (c)the system should provide elderly with reminders associated with specific actions (e.g., medication adherence).

Asking them about the possibility of using light-based interventions for better supporting the elderly, they said that this kind of intervention is more suitable for treating severe conditions (e.g., dementia). In addition, the neuropsychologists said that MCI elderly could have spatial disorientation episodes but mostly in unfamiliar environments (e.g., outside home). In any case, they emphasized the importance of having system interventions properly calibrated to the patient's specific situation (also emotional): the platform should always respect the elderly and avoid being too intrusive.

They also identified a number of requirements for caregivers. In particular, (a) the system should support monitoring MCI elderly medication adherence. In addition, (b) it should encourage adherence also to (e.g. cognitive) exercises assigned by formal caregivers.
The two psychologists also emphasized the fact that the system should provide MCI elderly with an active support rather than a "passive" one: it should not just do things on behalf of the elderly, rather, elderly should be stimulated to commit and work hard to improve their conditions since the progression of the disease can improve and even revert

5.2.2 Interview with one Psychologist (in Pisa)

5.2.2.1 Procedure

One CNR researcher carried out an interview (on March 2 2018) with the female psychologist and psychotherapist responsible for the design and management of the cognitive team for the Train the Brain project. The interview was carried out in the Train the Brain laboratory and was recorded with a smartphone. Before starting the interview, the PETAL goals were introduced and a video showing possible examples of light-based support was chosen. The interview lasted about 45 minutes.

5.2.2.2 Results

The psychologist said that the elderly with MCI may be aware of the own deficit. A difficulty that can be faced by formal and informal caregivers is managing an elderly with MCI that does not have awareness of the own deficit. In elderlies with MCI, and more generally in people in the third age, the cognitive processes change, especially those related to metacognition. Therefore, the ability to reason about the reasoning process itself (meta-reasoning) and eventually

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compensate or otherwise make a correct use of compensatory strategies that allow them to overcome and face certain attentional and social problems is something that is more difficult to access for these people. Thus, structuring a strategy but above all the spontaneous use of a strategy for the MCI person can be difficult.

As for the strategies for organizing the focus of attention or remember something, she said that, for example, the use of an agenda or alarms or shopping lists to remember doing things or to take notes are all things that all people (even without MCI) use every day because they know that memory has limited capacity, especially the working memory. Thus, all the information that is reworked with various strategies is supported through external media (for example, post-it, cellular note, wake up, reminders). These are metacognitive strategies that require the awareness of having a certain limit and desire to address it through an external support. In a person with MCI this is less automatic than in a young adult without cognitive problems, thus a platform that supports this can be a useful aid. While making the shopping list for a young and adult person is immediate, (e.g. "I do not go to the grocery store without a list because I know I will forget objects"), something that reminds a person with MCI of doing the shopping list" can be helpful. A problem for elderly with MCI is that they experience frustration, anger, they think that they are not sufficiently taken into consideration, listened to, they do not hold the trust of people. Then they can experience anger, annoyance, intolerance.
Main aspects to consider are the safety (the kitchen, the stove), take the medicine, pay the bills, give money only to trusted people.
Lights can be useful for spatial orientation (e.g. path lighting), for temporal orientation, if they are modulated, helps the elderly in understanding the current moment of the day. For instance, if at 22 the light is very bright, this could be confusing. The psychologist said that she would put lights in positions that do not bother but illuminate, if it is a matter of guiding a path; she would set the lights near to switches or calendars to illuminate the objects directly. To attract attention, the psychologist said that she would use cold and bright colours, warm or soft colours to stimulate relaxation or sense of well-being.
She said that is problematic for the elderly to remember the meaning of a certain symbol, e.g. when a lamp colour is coding specific information. It could help something less symbolic and more tangible, for example, to beam the image of a medicine on a white wall.
In addition, she said that elderly, in general, use technological devices very little. To communicate with them it would be easier an SMS, or just labels on a table. The information more useful to communicate is to remember to take medicine, to make an appointment, to make a phone call, to water the plants or the garden, to advise on what day the cleaning lady is coming, a sort of calendar (metacognitive strategy).

5.3 APOLLIS

5.3.1 Procedure

Interviewer: Hermann Atz (APOLLIS)
Interviewed Person: Barbara Plagg
Date of interview: 16th February 2018

Profession:

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Biologist (molecular and clinical neurobiology), doctoral thesis on Alzheimer disease
Actual position:
Postdoctoral researcher, Free University of Bozen-Bolzano (I), Transdisciplinary Research Network Health and Environment (Faculty of Science and Technology)
Member of the steering committee of the South Tyrolean Alzheimer Society ASAA

The interview was based on the questions specified above following a semi-structured interview technique, which was conducted in German.

5.3.2 Results

The answers can be summarized as follows:

Characteristics of MCI
Mild cognitive impairment 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. Recent research indicates that only 50-60 percent of persons with MCI later develop Alzheimer's or similar diseases.

Cognitive training
The main challenge with regard to MCI patients is the prevention or slowing down of cognitive decline. Therefore, it is particularly important for this group of people to do regular cognitive training. Here, 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. Technique 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.

Risk prevention
MCI patients are exposed to a number of hazards that should be avoided or mitigated if possible. First and foremost, fall prevention has to be mentioned, because if injuries resulting from a fall lead to a longer hospital stay, this often also negatively affects cognitive abilities. MCI patients are often poly-morbid, I.e. affected by various (chronic) diseases. Technology can reduce the risk of falling in various ways, but a central role is played by light, which allows a better orientation in the apartment and makes possible obstacles visible.
Other typical hazards are leaving windows or the front door open or that the stove is not turned off after use. Here automatic alarm signals are very valuable.
Another problem or hazard with MCI patients is that they can lose the ability to handle money responsibly. On the one hand, they easily forget the wallet if they want to make purchases. On the other hand, they may lose the understanding of what something can cost or how much money

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is available to them at all. As a consequence, they sometimes make absurd purchases. An appropriate technical support system could perhaps alleviate this problem.

Mental Well-being
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 well-being is a motivator for coping with everyday life and other important activities, such as performing cognitive exercises.

Supporting daily activities
Technical support and automatic reminders can be very valuable with regard to health issues. This concerns e.g. the measurement of blood pressure, the transmission of other health data, the correct and timely intake of medication as well as reminding the elderly to take sufficient liquid. Remembering a doctor's appointment or other important dates is another important task where technology can be very helpful.

Record for caregivers
Caregivers usually are dependent on the information they get from the elderly. If they are not constantly present, but only occasionally come to visit the patient or make a phone call, then they would like to know reliably what has happened in the meantime. It would reassure them to understand exactly if the patient has had the normal daily routine: whether he has eaten, taken his medication, done his exercises, etc. and whether there had not been emergencies or problems. A software that could deliver records on these activities or events would be extremely helpful.

Alarming system
A great concern of the caregivers is to be informed immediately if an emergency would occur to the elderly. They want to be sure that the patient is either able to do it himself or that an automatic system triggers the alarm. Both can be ensured by suitable technology.

Doing things together
Digital communication and applications are a way for caregivers and the assisted elderly person to spend time together in meaningful ways. Especially volunteers do not always know what to do with the elderly. Cognitive applications or serious games have proven to be helpful with regard to this situation.

Privacy
Especially with MCI patients, it is important to respect the personal autonomy. Monitoring and warning systems can be very helpful, but they must never be used without the consent of the elderly person. Privacy is a very delicate issue in the context of home care.

Acceptance of technology by caregivers
The acceptance of technical assistance systems is still rather low for most caregivers. The potential of these systems is often not recognized yet. It therefore needs pioneers and pilot

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applications. If someone gets enthusiastic about such a system, then it has a good chance to spread according to the snowball principle.

5.4 Bartenbach

5.4.1 Procedure

Fig. 18 Josef Marksteiner

Interviewer: Lisa-Marie Neier (Bartenbach)
Interviewed Person: Josef Marksteiner, physician and head of the department for psychiatry and psychotherapy with wards for geriatric patients at Tirol Kliniken in Hall (Austria)
Bartenbach already collaborated with Josef Marksteiner in different projects to provide good light for higher visual requirements of elderly people with dementia in the hospital setting and therefore is aware of different possibilities of lighting designs and biological light effects. The provided PETAL presentation from CNR was used to introduce into the theme, followed by the interview. The interview was based on the questions above mentioned, translated into German.

5.4.2 Results

The collected answers (translated with the best knowledge by Lisa-Marie Neier (BART)) were collected by Bartenbach.
Most important situations to support the elderlies with MCI and their caregivers appear in terms of impaired spatial orientation, safety aspects (falls, candles, …) and wellbeing (agitation, sleep, emotions). Notifications would be very helpful for caregivers in case of falls, medical emergencies, patients showing "risky" behaviour and, also in case everything is fine to calm the caregiver. The PETAL system should provide a support that fits very individually to the needs of a patient and his caregiver and it needs to be easy in use and stay in the background (no extra effort).
Concerning lighting, the suggestions are to improve vision (to avoid falls, hurts and discomfort through glare) during the day and during the night (orientation light at night, signing things with light). The use of daylight is a very important fact and in case of missing daylight the use of a high quality artificial light should be provided. Light should also be dimmable and provide changes in colour temperature. This helps to positively affect the emotional state of a patient, because warmer and dimmed light is cosier. In addition, it provides positive effects on sleep also. Coloured light should be used with caution because it can irritate a MCI patient. Blinking light seems to be inappropriate for MCI patients (frightens and irritates). Beside lighting rooms, transition zones and corridors should not be neglected, because falls mainly happen there.
Concerning technological devices best usable to receive notification seems to be a smartphone. Simple symbolic icons about the status of a person (for caregivers) or symbolic icons to remember a patient about medication seem to be an ideal way. Too much text is inappropriate.

Detailed answers of the interview:

	Question	Answer

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Elderly & Caregivers	What aspects of MCI care pose the most problems for informal and formal caregivers?	• Impaired spatial orientation • Safety aspects (mainly falls, but also electricity (oven left on, heating pads, …), water, candles, too less light for visual requirements) • Wellbeing: agitation, sleep, emotions
	In which situation the support provided by caregivers could be improved?	Support needs to fit individually and personalized according to patient-caregiver's needs
	What are the elderly's activities, events or situations (even anomalous) in the elderly life that caregivers would like to detect, track, monitor?	• Falls • Medical emergencies • Information, that everything is fine (for calming the caregiver)
Technology	How technology could provide it?	• Needs to be easy in use and in the background (no extra effort) • Improve surrounding: make obstacles better visible • No glaring of lights (old people are very sensitive to glare) • Orientation light at night when getting up, but without frightening patients (maybe light near the floor) • Alarming system for caregivers e.g. signalling that the patient left the bed or flat • Signing things more clear
Lights	How they can be used to support spatio-temporal orientation?	• Lights should provide natural reference (no discrepancy between artificial and natural daylight) • High quality light for visual requirements (to see good supports orientation) • Light for wellbeing: warm-white light makes cosier • Not clear if coloured light would irritate patients too strong, maybe it supports orientation (Josef Marksteiner is not sure if coloured light is good – patients are too heterogeneous)
	Where they should be positioned?	• Whole flat should fulfil standards for good visual requirements • Main room (centre of life) is most important • Transition zones (corridors) should not be neglected, very important for orientation and falls

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	How to exploit different colours?	If coloured light will be used, then bright yellow, no dark colours, only one colour (to avoid irritation)
	How to exploit light blinking?	No blinking for patients with cognitive impairments – great risk for irritation. "Turn on light and leave on light for a while" is the only option.
	How to exploit fade and intensity?	High intensities during day, low intensities during night. Dimming is welcomed to make the ambience cosier and to calm down patients, but there should be an automatic dim back mechanism otherwise lights will stay dimmed the whole time
Notification system	In which type of device, they prefer to receive notifications (PC, tablet, smartphone)?	Smartphone
	How should they be rendered (sms, textual, voice, graphics, vibrotactile feedback, …)?	Personalized, simple symbolic icons of the state of the patient or speech messages, but not too much text. Especially the older the caregiver the less text should be used and the clearer the symbols should be. For patients, most important is to not frighten the patient e.g. vibrating tablets, …
	When they should be sent?	Whenever the state of the patient changes: • Events: falls, medical emergencies • Prophylactic whenever patient shows "risky" behaviour e.g. climb on chair, leaves flat, cooks, … And for calming down the caregiver: • Information, that everything is fine

5.5 Ideable

5.5.1 Procedure

For recruiting caregivers working with MCI elderly patients we worked with 3 organizations.
- Televida. Spanish telecare company.
- Cognitiva. Spanish memory units for combating cognitive impairment.
- SSI Group. Home care agency from Biscay region (Spain).

In all cases, we shared by email a presentation with the goals of the psychologists of all organizations. In one of the cases (SSI) we had an interview with her and the others, we carried it out by phone.

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Before that interviews, all organizations had a day in their headquarters with caregivers, in order to complete the questionnaires. And after that, we offered specific more general questions to psychologists in those interviews.

5.5.2 Results

General opinions:

- The tablet is the only device they recommend if there must be interaction:
  - TV needs the remote control which is really hard to use apart from changing channels or volume.
  - Smartphones are too small.
  - Computers are too complex.
  - Tablets are quite more intuitive and usable. They are affordable, wearables and easy to integrate with other devices.
- Lights should help in avoiding falls and helping reaching rooms.
- Apart from lights, other elements may be helpful:
  - Cameras for door entrance
  - Sensors in bed, for fire, water, etc.
  - Lights should warn of problems and help to move into the house, especially at night.

What aspects of MCI care pose the most problems for informal and formal caregivers? In which situations the support provided by caregivers could be improved?

- Elderly MCI users usually don't go outside without help. If we may detect that this user has gone out from home without the help of any or the caregivers, it would be really helpful to warn the caregivers about it.
- Most of the situation should be reactive: detection of problems at home (water, fire, kitchen, etc.) and giving caregivers and elderlies help in answering calls to home doorbells.
- THE PROBLEM: Getting up from bed at nights. How to monitor it?

What are the elderly's activities, events or situations (even anomalous) in the elderly life that caregivers would like to detect, track, monitor?

- Curtains/blinds open at night or closed during daylight.
- Bathroom light turned on for a long time, especially at night.
- Going out from home without help.
- Every call at the home door. Beacons?
- Going to the bathroom at night.

Lights: how they can be used to support spatiotemporal orientation? where should they be positioned? How to exploit different colors? How to exploit light blinking? How to exploit fade and intensity?

- Light-activated by movement would be really helpful. Especially at night. But better if after using they are turned off manually to check better their activity and to trigger possible reactions. This is the key point... when and why to trigger??
- Blinking will make them nervous. Lights must help, not alter.

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6 GATHERING REQUIREMENTS THROUGH FOCUS GROUPS

6.1 Description of the Focus Group Structure

The PETAL Consortium agreed beforehand to pose a number of questions to the participants to the focus group, mainly addressing two aspects (and along the same line of the questions posed in the interviews).
First, the role of technology for supporting needs of elderly MCI people aging in place and for supporting needs of caregivers themselves was explored by the following questions:

- "What aspects of MCI care pose the most problems for informal and formal caregivers?",
- "In which situations the support provided by caregivers could be improved?" and
- "What are the elderly's activities, events or situations (even anomalous) in the elderly life that caregivers would like to detect, track, monitor?"

Secondly, how technology could provide support to the needs of MCI people was supported by the following questions:

- "Lights: how they can be used to support spatio-temporal orientation?"
- "Where they should be positioned?"
- "How to exploit different colours?"
- "How to exploit light blinking?"
- "How to exploit fade and intensity?"
- "In which type of device they prefer to receive notifications (PC, tablet, smartphone)?"
- "How should they be rendered (sms, textual, voice, graphics, vibrotactile feedback, …)?"
- "When they should be sent?"

6.2 Focus Group ANA

In Romania a focus group was organized at the Clinic of Geriatrics-Gerontology and Old Age Psychiatry from the Elias University Hospital on 15th of February 2018, from 13:00. The participants were 5 resident physicians, 3 nurses, 4 formal caregivers and an orderly. The meeting started with an introductory speech of the moderator, who explained briefly the purpose of the focus group, followed by the presentation of the project and the declared desire to engage them from its early development, contributing with their already acquired experience in caregiving regarding the challenges faced and the possible ways a solution like the one proposed by the PETAL projects could ease their work and also benefit directly the MCI patients. As a consequence, the questions described in Section 6.1 were asked to stimulate the discussion. In order to obtain good quality information, a 30-minute presentation was held to both accustom and engage the caregivers in this developmental phase. In the last slides the previously listed questions were added, whose results are described in the next section.
The invitation to attend the focus group was addressed by the head of the clinic, Prof Dr. Luiza Spiru and all the caregivers able to attend did participate. Also the young residents expressed their desire to participate in the focus group, to better understand the proposed solution and also to contribute with practical suggestions from the perspective of younger persons, more accustomed with new technologies and thus more creative in indicating innovative outcomes.

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As the focus group was gathered at the clinic and the presentation held in the same location, the logistic requirements were as low as they could be, only needing a laptop, a projector as well as a presentation panel.

The whole meeting was both audio and video recorded in order to build up a transcript immediately afterwards. In this way, every second of this meeting was used to facilitate the interaction with the caregivers, constantly engaging them in the process.

When it comes to the aspects that pose the most problems as well as require a more in-depth look we mention *falls*, *nutrition*, *drug administration and treatment adherence*, *hygiene*, *night lighting* or *systematically and habitually transmitting information*. Moreover, these activities are amongst those that caregivers wish the monitor closely too.

Spatial-temporal orientation was suggested to be maintained by both putting up a light pattern that can orient and guide the user to a specific place and the use of a specific color for each room/item (e.g. the place where the drugs are stored).

In terms of light position, the ceiling- as a chandelier or light spots, on the floor (mainly the stairs) and the location where drugs are stored were presumably the key points of interest that may highly benefit from light signaling.

Light blinking was proposed to be used for raising awareness, reminders, orientation, assistance and guidance through the night or as stimuli, while fade and intensity were unanimously accepted as useful when it comes to turning on and off the light during night time.

It came to no surprise that the chosen device on which caregivers would like to receive notifications was the smartphone. Furthermore, in our caregivers' opinion, notifications should be rendered as text messages or push notifications and they should be sent immediately when it comes to the imminent need of providing help (e.g. falls, injuries) or after a period of time, allowing the platform to inform or warn the user regarding the matter and allowing an interval for the matter to be solved.

6.3 Focus Groups FSL

In Italy, a semi-structured focus group was organized at the Fondazione Santa Lucia on 16th of February 2018. The focus group was composed by four participants: a self-employed psychotherapist specialized in caregivers counseling, a psychologist from the Tor Vergata Polyclinic of Rome and two psychologists from FSL specialized in geriatric patients. The meeting lasted 45 minutes and was performed in a reserve adequate meeting space where privacy and sociability was guaranteed.

First of all, each participant introduced himself and his professional experiences (5 minutes). Then, the Petal project and its goal were exposed within 15 minutes. Followed 20 minutes of discussion according to two main areas established previously by the partners (see questions specified in Section 6.1). Finally, they highlighted the principal aspects, which are reported in the next section.

From the Focus group carried out by FSL emerged that the main aspects that represent a problem in caregiving of an MCI are: monitoring on pharmacological therapy, control of personal care, the acknowledge of the elderly movements when he/she is away from home and to know when he/she uses the car, feeding behaviour and carrying out recreational activities at home.

In particular, support to caregiver should be increased in monitoring drug therapy, reminding the elderly to take drugs at the correct times and in the right dosages. Also, taking the elderly to

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medical examinations is an important aspect, because of a memory deficit might not understand or forget some fundamental information given by the doctor. Moreover, with regard to nutrition, a caregiver may not be able to keep the elderly under control. It would be more helpful to monitor food expenditure and if the elderlies are likely to eat foods that are harmful to their condition (e.g. elderly people with diabetes).

About unawareness of memory deficits, it is a less widespread phenomenon among MCIs than ADs. But in cases where the elderly is not aware, he refuses to receive help from informal or formal caregivers. Therefore, in these cases it would be useful to count on other systems that in some way do not make the elderly too suspicious and uncooperative. Finally, many MCI are still autonomous and drive their own car. This becomes a problem for the caregiver when the elderly's memory deficit becomes a danger to his safety on the road. Hence, the caregiver has to accompany the elderly anywhere, or if he can't, he should ask someone else to do it.

Moreover, support of lights in spatio-temporal orientation is given by the possibility of helping the elderly to distinguish rooms by colours. If necessary, they should be placed on the entrance door of the room in order to recognize them even before accessing them. Different colours could be useful for mood regulation through colour therapy, by stimulating the performance of certain activities through colours in the rooms where usually the elder stays longer or even help him finding lost objects, for example using portable coloured lights to place it next to an object that could serve him later. Gradual illumination instead, can be useful if it increases intensity as it gets dark to help the elder to recognize the passage of time.

Finally, the most suitable devices to receive notifications are a computer or a tablet, since they can be easier to use by an elderly person with both MCI and caregiver. It's important that it features simple and intuitive user interface. Use of notification sounds is preferable to messages that may also be inconvenient for reading. In addition, many seniors barely text with devices they regularly use, but prefer voice communications. Such notifications can be sent to remind them to take their medications, to eat their meals at regular times, to remember doing their cognitive stimulation exercises.

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7 Summary of Results

7.1 Main Requirements Identified & Recommendations for Future Work

The sample of caregivers of seniors with mild cognitive impairment contacted in four different countries (Austria, Italy, Romania, Spain) is composed of two distinct groups: almost two thirds are family members caring for their relative, one third is trained professional caregivers working with MCI patients. Most of them provide home care, only a few are also involved in telecare services. Despite of the predominance of informal caregivers a majority of the sample is familiar with modern digital devices and open to advanced applications. For instance, most of the caregivers have internet access at home (85%) and/or at the workplace (32%).

On the other hand, for communication between caregiver and assisted person the technology is normally used in a very traditional way, mainly making phone calls. Also for reminder/alarm concerning the elderly calling and sending text messages are the most preferred forms.

Caregivers identify a series of situations where the seniors with MCI need specific aid, such as going to the bath at night, taking medicine, drinking enough or remembering appointments. And they are quite optimistic that monitoring through sensors and a platform able to generate reminders, alarms and warning, could be helpful. Moreover, half of the interviewed caregivers are convinced that technological support will reduce the need of the care for the elderly, another fifth thinks that it is at least likely.

The interviewed sample of caregivers confirms the actual lighting situation in the houses of seniors is mainly limited to normal white light and eventually night light. The majority thinks that night light, automatic light and signal and alerting light should play a more important role in the houses of the elderly than it actually is the case. The same is true for the positive effects that light could have on sleeping quality and on the prevention of falling. They also provided some indications of aspects that need to be carefully considered in order to better design the introduction of lights in the remote support, such as the potential irritation that can be stimulated by blinking lights or the possible difficulties to interpret the light colours if they have specific meanings.

Compared to the view of seniors with MCI, interviewed in a parallel survey, caregivers are more aware of problematic situations, hazards and the need of support. The potential help that digital devices and communication technology can provide to ease the burden of care and the quality of life of the assisted persons is also estimated higher.

Caregivers will therefore assume a crucial role if it gets to implement our supporting system as well in the pilot households of the field tests, as in the market itself afterwards.

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8 Conclusions

This document describes the results of the activities that have been done in the PETAL Project for gathering requirements of formal and informal caregivers of MCI elderly. This activity has been carried out by involving all the PETAL partners, and it has exploited several techniques ranging from questionnaires, to focus groups, to interviews.

The findings so far have identified a series of aspects that need to be supported by the project to ensure its later adoption. First, a number of situations have been identified by caregivers when the seniors with MCI need specific aid (e.g. getting up from bed at night especially for going to restroom). The planned PETAL platform, thanks to its monitoring features and its capability of generating proper and personalised reminders, alarms and warnings taking into account the specific needs of the elderly, is expected to be very helpful in this respect, not only for elderly but also for caregivers.

In addition, TV, smartphones and tablets are seen like among the most interesting devices to communicate with end users.

Finally, caregivers have confirmed that the current lighting situation in the houses of seniors is limited to basic usage of lights, which gives many opportunities for the PETAL project to investigate ways for improving various aspects of elderly life through personalised light-based interventions. Furthermore, the gathered results have highlighted the crucial role that caregivers will assume in providing relevant input during the development of the PETAL platform, in that they are fully aware of elderly's problematic situations, potential hazards and the specific support they need.

The next version of this deliverable, which will be updated according to the first development and evaluation results, is planned for M15.

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