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PACT Analysis and Focus Group Reports

CAREGIVERSPRO-MMD PROJECT

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Executive summary

This is the first deliverable to be prepared in the WP2 regarding CAREGIVERSPRO-MMD platform enhancement and design adaptation. It presents the PACT Analysis methodology and results, as well as the reports of the focus group interviews. Basic requirements are identified to make the CAREGIVERSPRO-MMD platform a tool suitable for its end-users. Taking as input the report on the conditions of MCI and the abilities of people affected by cognitive decline to use the platform (D1.1 Accessibility Report), this deliverable will study and design a strategy for actions to maximize accessibility.

Mainly this report summarized work done in Task 2.1 (PACT Analysis and Requirement Elicitation), but also relates to the T2.2 (Gamification Service) in order to report believes and attitudes of end users about the plan to use gamification principles in the design of the new CAREGIVERSPRO-MMD platform. Focus will be given in User Centred Design (UCD) and thus the first part is dedicated to the outline of the general UCD approach.

The involvement of users in each stage of the design and development process is seen as a particular challenge due to the large scope of target end users that need to be involved. In this direction, all user group categories have been involved in the platform design and development process. User groups involved in the validation and actual testing of the final outcomes (later version of the CAREGIVERSPRO-MMD platform) are health professionals, caregivers, social workers and PLWD themselves. People Living With Dementia (PLWD) and caregivers appear as dyads as the minimal unit to consume services on offer by the CAREGIVERSPRO-MMD platform. A small sample of the very same user groups are involved in the interviews related to the PACT analysis.

After the introduction to the methods to be applied in the platform development to allow a UCD and User Sensitive Inclusive Design process, interview reports from pilot sites will be merged and summarized in the second part of the document. Those interviews were performed in order to identify design flows and new requirements. Initial results from processing of end user's responses will lead to functionality and content adaptation (T2.5).

In overall, D2.1 delivers requirements and guidelines needed to implement the CAREGIVERSPRO-MMD platform and help designers and developers to prepare demonstration material for usability study performed in T5.1.

List of Acronyms

Acronym	Title
AB	Advisory Board
CA	Consortium Agreement
UCD	User Centred Design
PLWD	People Living With Dementia
PIA	Privacy Impact Assessment
DMP	Data Management Plan
ICT	Information and Communication Technologies

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1 Introduction

A typical PACT analysis approach will be adopted to meet the objectives of the T2.1. This methodology will be used for analysing the needs and the preferences of the end users in projection with the existing platform design. The PACT analysis results regarding people and their activities into the platform will be interpreted into design guidelines to be included in D2.2 and D2.3. Key points in this approach are:

1) The current version of the CAREGIVERSPRO-MMD platform can be found on the Internet at: http://www.cuidadores.pro/?locale=en. This platform design was the outcome of previous work, but was used in this task as an example of existing technology in order to capture user's responses towards conceptual and usability issues.

2) Not all user groups share the same needs and preferences. Actually, one of the challenges of CAREGIVERSPRO-MMD is to provide a way to handle different priorities and serve different user needs, abilities and preferences. The PACT analysis will include focus groups and semi-structured interviews in 4 different sites (France, Spain, Italy and the UK).

3) The new platform will be redesigned in depth, will be adapted to new roles and so a PACT analysis is required to conclude on the most effective technologies.

Literature evidence and feedback collection from focus groups were used to generate conclusions on how to redesign the platform according to a top-down approach, how features should be prioritized and where to give emphasis on. An overview of the WP2 and basic data flows is presented in **Figure 1.** In the next sections, the followed methodology and the results of the PACT analysis are presented in section 1. The Focus Groups approach and the interview reports of the pilot sites are presented in the second part of the document.
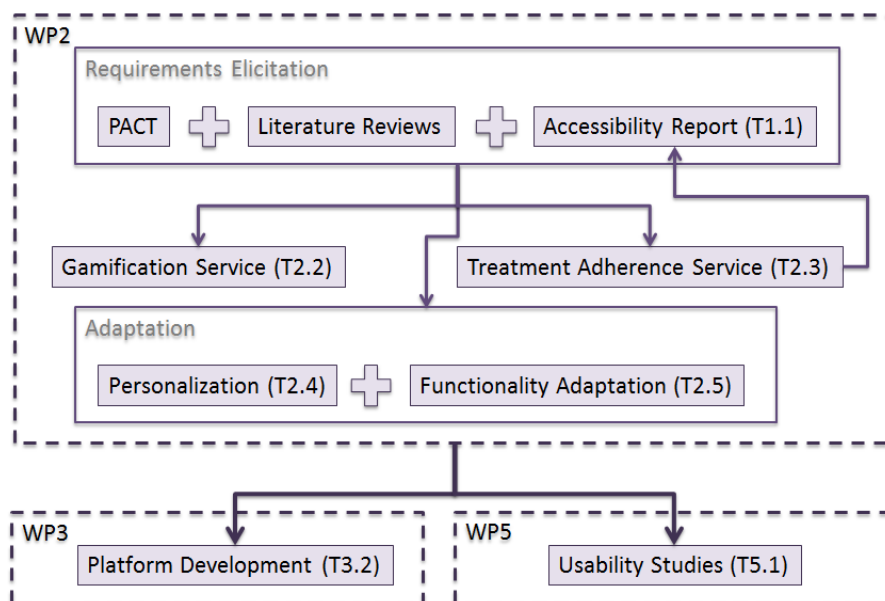
Figure 1. WP2 at a glance

1.1 Pact Analysis Methodology

What is PACT Analysis

An analysis based on People, Activities, Context and Technology, well-known by the acronym PACT is a generic framework used to analyse design situations in interactive systems. PACT analysis follows the principle that "*People* use *Technologies* to undertake *Activities* in *Contexts*" and covers the scope of Human-Computer Interaction (HCI) [Benyon et al., 2005]. By following this principle, designers understand how each element varies and how all elements affect one another.

Concepts related to working memory, perception, attention, reasoning, decision making and problem solving introduce cognitive psychology to describe relevant aspects of the **People** being involved in using technology in everyday life activities. People vary psychologically and physiologically, they differ in the different motivation, goals and in the mental models [Benyon, 2010] they use when interactive with ICT based systems. Designers must ensure that the interface designs provide sufficient information to help users to construct the right mental models on the platform concept and its elements before taking action and solve everyday problems with it.

Next the scope of human tasks and the need to model human **Activities** is introduced. User's requirements are expected to be inserted into the way activities are going to be performed. There are 5 aspects for activities: Temporal (frequency of the activities), Cooperation, Complexity, Safety-critical and the nature of the content [Benyon, 2010]. The type of activity, security issues and dependencies on other people and/or technological means are taken into account.

Talking about design solutions, there are influencing factors which give the **Context** of the activities. This includes people's expectations, physical, psychological, social and organizational context and anything else can describe human's perspective. In using a smartphone or a desktop computer to post a message in your social network, the context can vary from home use to hospital use for example.

Finally, the design solutions are applied on a **Technology** framework. The positive and possible negative aspects of this technology are described and the way an existing or new interactive system can be implemented. Designers should be aware of the latest technologies in order to choose the best option.

An extended version of this approach (IMPACT Analysis) includes two more elements: **Intention** used to determine why to evaluate and the **Metrics** to describe what to be measured and how [Ahonen, 2014].

When to Use a PACT Analysis

When to use a PACT analysis and what to expect from such a study is also important. In general, a PACT analysis can be proved particularly helpful when the concept is a design solution, especially when analysing a platform design that already exists and needs to be redesigned. With PACT methodology, designers become aware of the current situation and what end users think of the current design. In addition, it can help in determining which

parts of the current design are open for improvements. Actually, designers can visualize future designs and experiment with different people profiles, actions performed in the platform, context of use and various technologies on offer.

2 PACT Analysis in CAREGIVERSPRO-MMD

PACT and Focus Groups are two different methods used in CAREGIVERSPRO-MMD to identify requirements. This approach has been identified in literature having Focus Groups to be used in conjunction with other methods [Edwards & Holland, 2013]. Thus, those two approaches complement each other towards their common objective to provide design guidelines for the new platform designers. **Figure 2** presents the overall approach, in which the PACT analysis will propose the first version of requirements followed by the Focus Groups approach which will update the requirements based on the interview results.
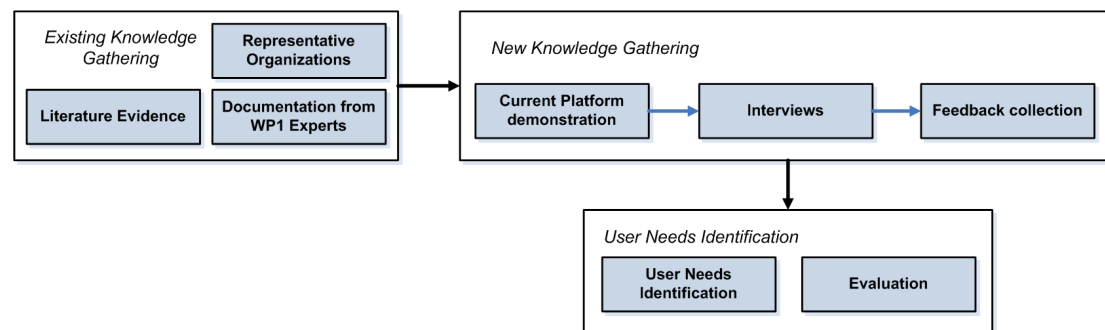
Figure 2. User needs identification through a typical PACT analysis approach

2.1 Innovation beyond the state of the art

Within CAREGIVERSPRO-MMD, existing PACT analysis approaches are applied (**Figure 3**), but some advances like the Focus Groups approach and the additional study on elderly motivation strategies are targeted in line with the provision of gamification and treatment adherence components. Thus, people will be described by WP1 documentation, but more details coming from the Focus Groups interviews will shed more light into the characteristics of the PLWD and their caregivers. Moreover, the Focus Groups approach will sense possible differences among populations which live in different countries and have possible cultural differences and will report other possible variations in healthcare systems, the context and the activities.

The CAREGIVERSPRO-MMD platform will be built on the characteristics of similar social networks (e.g. Stitch[1], Olderiswiser[2]) and healthcare platforms (like the iValueHealth.NET[3] and Seniornet.org[4]). Advances with respect to existing accessibility requirements are targeted like the requirements for people with Mild to Moderate Neurocognitive Disorders. Moreover, advanced features are aimed to be incorporated to platform components and

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[1] http://www.Stitch.com
[2] http://www.olderiswiser.com
[3] http://beta.iValueHealth.NET
[4] http://www.seniornet.org

new functional and interface features will be provided according to the current trends in healthcare technologies, gamification requirements as well as personalization requirements.
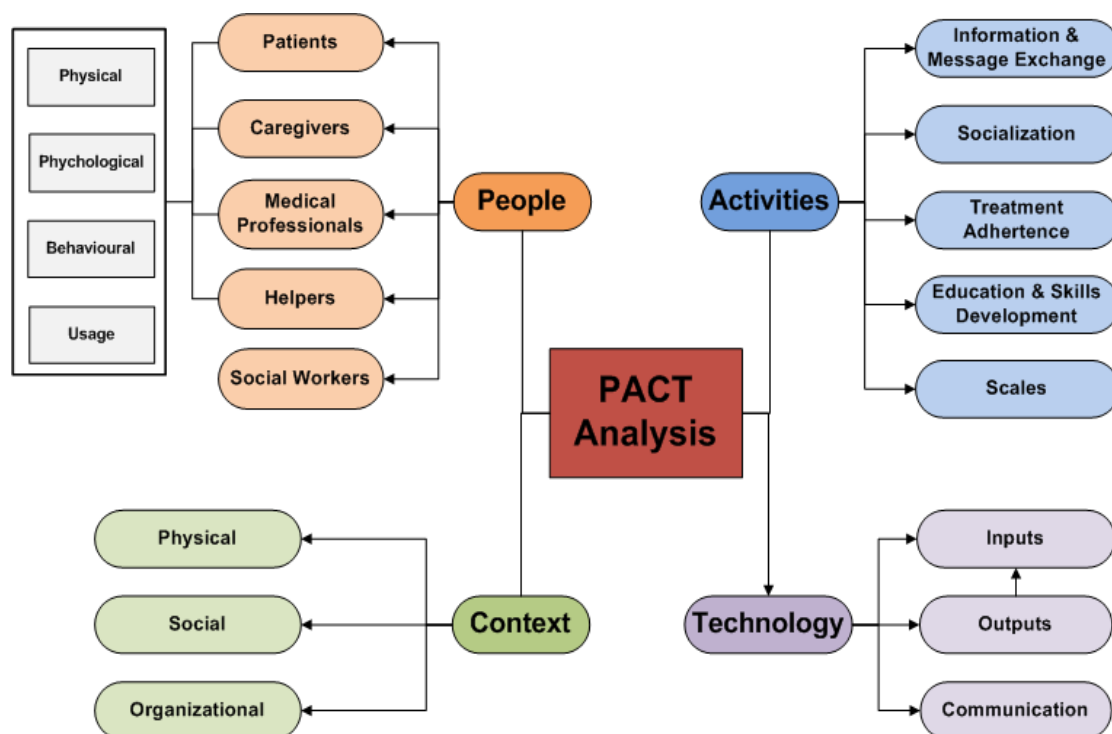
Figure 3. PACT analysis overview

2.2 People

For the needs of the CAREGIVERSPRO-MMD project, the PACT analysis was performed by taking into consideration all user categories, namely:

- PLWD people with Mild Neurocognitive Disorders or Mild to Moderate Neurocognitive Disorders. Participants who belong in this category are divided into two subgroups depending on the severity of their symptoms according to the diagnosis made by their doctor.
- Caregivers: Formal and informal caregivers (no matter if they are paid or not) are people who provide care to PLWD individuals with MND with his or her activities of daily living.
- Health Professionals: health care professionals (doctors, nurses, psychologists, geriatrics, specialists, etc.) who work as primary care giver of a PLWD in a hospital, skilled nursing facility or clinic. Those people are expected to make diagnoses and set treatment plans for PLWD and caregivers.
- Helpers: are unofficial caregivers who may provide help not in a systematic basis. The difference from caregivers is that helpers are not responsible for treatment adherence although they may talk to doctors and nurses on PLWD's behalf in case they are relatives or authorized in any other way.
- Social workers: are professionals who work with people with neurocognitive disorders and their families to provide support and help in order to improve outcomes in people's lives. They maintain professional relationships with people and

their families, may work for the state and are especially interested on the social status of PLWD.

Thus, we decided to involve all user categories and people with such different abilities, needs, professional orientation and roles are going to be involved in the CAREGIVERSPRO-MMD PACT analysis process. The rest of the PACT schema, depicted in **Figure 3**, refer to the activities taken by those user groups, the context under which those activities are performed and finally the technologies involved in those processes.

The following sections discuss people characteristics and give emphasis on PLWD and caregivers when design and personalization issues are under concern.

2.2.1   Dyads (People with Neurocognitive Disorders and their Caregivers)

The number of people who suffer from neurocognitive disorders is increasing. It is expected that by the year 2040 the number of people with dementia will reach the 100 billion. Clinicians may be surprised by this phenomenon and they will find themselves unprepared to make accurate diagnosis and propose treatment. The mechanism behind the progress of Dementia and its prodromal conditions known as Mild Neurocognitive Disorder (MND) is still unknown. Apart from early diagnosis, the aim is to provide a platform to host social networks, to deliver education and skills training, to strengthen treatment adherence and create motivation for participation to all people involved, but especially for people with MND and their caregivers.

The most strained target group for CAREGIVERSPRO-MMD is described as people who either: a. are elderly, so they need all care derived from the age factor and practically delimits possible vision, acoustic and motor abilities of the end users or b. are people who live with Dementia (PLWD) and have some kind of cognitive decline. The diagnosis of MND is based on the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and goes beyond normal issues of aging.

Progress to major neurocognitive disorder (dementia) or other similar debilitating conditions is also described by DSM-5 and requires additional strategies to help maintain independence and perform activities of treatment adherence and daily living. Clinical symptoms in PLWD include cognitive symptoms, as well as behavioural and psychological symptoms as described in D1.2. (Dementia and psychiatric comorbidity symptoms assessment handbook). Moreover, effective treatments and platform design takes into account comorbidity issues described in the same document.

On the other hand, digital divide is the second major issue when working with people who are not young or they have -as for various reasons- limited knowledge or access to ICT technologies cause inequalities. A first research question is if this inequality is caused by age related impairment or it caused by what Prensky described as 'digital immigration' [Prensky, 2001]. According to this approach, people who have been born on the era of electromechanical interfaces face difficulties in using ICT and web based interfaces and also it is not easy for them to understand modern technological concepts. This digital divide is affecting people linearly with their year of birth and it is considered as a pessimistic approach.

On the other hand, there are studies which deliver literature evidence on the ability of the - otherwise excluded- populations to adopt ICT based technologies as long as the interface designs are accessible. Accessibility in our case is not linked only to the age-related conditions, but it is extended to cognitive decline conditions. Although there are standards for designers like the Web Content Accessibility Guidelines (WCAG 2.0 - W3C) and the usability guidelines for tablet applications for the elderly [Blendinger, 2015], there is lack of design guidelines for people with cognitive decline. Some sporadic design practices and guidelines are too generic and contribute very low in the actual interface design phase. The most important symptoms to take into consideration are attention disorders, executive dysfunction, reasoning and decision making disorders and memory loss. Also, people with MND face difficulties in orientation and navigation (information disorientation). As a result, the most popular approach, which is quite intuitive, is to follow a minimalistic interface design in order to minimize the memory load and to use simple navigation methods to restrict information disorientation.

Given the rising numbers of people who develop MND it becomes obvious that people need special care and need not to be excluded from the benefits of ICT. According to the 'active participation-better care' principle, there is a substantial clinical need not only to diagnose individuals who need care for cognitive issues, but to continuously support them in activities in and out of the platform. The User Analysis table of D1.1 (Accessibility Report) will help in determining those design characteristics which make the platform design accessible for elderly and the people with cognitive decline.

Physical Aspects

There are many diverse cultures at CAREGIVERSPRO-MMD pilot sites and also in EU societies. Hence the platform will support a lot of different types of people, with different physical aspects like body shape and sizes. Also variability in senses like sight, hearing, taste and smell can be considered. But those differences may not have too much significance in the platform design as standard input and output devices can absorb those differences. In general, people diagnosed with MND do not present different physical aspects than healthy elderly. The same is true for their caregivers. Perception may be the only exception to this rule because it involves both physical and behavioural aspects. Thus, vision, hearing, taste, smell and touch result from sensing organs and involves the nervous system. Finally, perception is an active receipt and response shaped by learning effect on stimuli, memory retrieval, awareness and attention.

Psychological Aspects

People diagnosed with Mild Neurocognitive Disorders preserve their general intellect and everyday activities, but minor changes in everyday activities may occur. However, they may exhibit significant behavioural and psychological signs and symptoms (BPS), also frequently observed in PLWD with Alzheimer's disease [Pocnet et al., 2015]. In the D1.1., an extensive list of psychological symptoms of PLWD is reported. Those vary from anosognosia to aggressiveness. Also, sleep and eating disorders have been reported [Pocnet et al., 2015].

Older adults may have negative attitudes towards the use of social networks due to privacy protection issues and the lack of code of social conduct [Xie et al., 2012]. We could say that

from a psychological point of view, social networks may create stress to seniors, especially when they are freshmen in social networking. What is needed to lower this stress is to find a way to: a) explain in advance the code of social conduct, b) create the feeling of privacy in conversations and social interactions, and c) secure the medical and other sensitive data transfer.

On the other hand, caregivers may be the most stressed population of CAREGIVERSPRO-MMD platform as they feel responsible for both their PLWD' health and their own. The stress related to the treatment adherence, the management of conditions, the meetings and the communication with the doctors and other medical professionals have a strong effect on their everyday life. Such a wide range of psychological aspects cannot be directly linked to design approaches, but designers can take additional actions in order not to burden those psychological conditions.

The platform, in its full activity will be pretty crowded which is expected to be perceived by users as stressful but pleasant at the same time. Users will speak different languages; will participate in circles and Café discussions. Thus, safer conclusions on psychological aspects may be drawn after the platform is ready and the community reach a critical mass.

Usage Aspects

Usage differences between users are expected to be high on account of the different computer knowledge and abilities. Performance when working on computerized means and perceived experience by using a platform may be quite different for a novice user compared to an expert. It comes natural that users with low confidence in using technology need guidance when they interact with a platform. The level of perceived difficulty is critical because under certain circumstances it may disappoint part of users or participants and this in turn may create discontinued user participation. Guidance can be offered by caregivers to their cared ones, but this guidance might be limited if caregivers are not computer literate.

Especially when designing services for heterogeneous groups, usage aspects should not be underestimated. In CAREGIVERSPRO-MMD we aim to design a platform for both professionals who may use computers and ICT products in a daily basis and dyads of PLWD and caregivers, which might not be technology experts. If the user categories were separated by isolated platforms this could be solved by simply designing one platform for each. But in this case designers are required to offer equal chances to all user categories dealing with all physical and behavioural aspects, plus usage differences.

As a set of additional questions to designers, do users make use of the platform frequently? Are all user categories usually frequent? The PACT analysis provided evidence to support that not all user groups are equally frequent users. However, the CAREGIVERSPRO-MMD platform is expected to be used in a daily basis by dyads, not only to report treatment adherence and other important aspects of the caregiving and health status, but also to socialize with others.

Behavioural Aspects

'Perception' is defined as the organization, identification, and interpretation of sensory information in order to represent and understand the environment [Schacter et al. 2011]. Attention is the behavioural and cognitive process of selectively concentrating on a discrete

aspect of information, whether deemed subjective or objective, while ignoring other perceivable information [Anderson, 2004]. Attention and perception are major areas of investigation within cognitive neuroscience and neuropsychology and there is literature evidence that people diagnosed with MND have different perception and attention abilities. Also, people from different cultural backgrounds may interpret things differently. Behavioural and psychological issues will be re-estimated at pilot studies and results will be reconsidered for final modifications on the platform.

In general, psychosocial and behavioural aspects may differ according to the type of Neurocognitive Disorder of the PLWD. For the PLWD, it is highly possible that they will have less contact with the social network than their caregivers. Also, it is expected that with time, and while the neurocognitive disorder progress, PLWD will be less active and less frequent users of the platform. To balance that, it is expected that caregivers will become more active in order to cover this missing participation.

2.2.2 Professionals

This section discusses briefly the characteristics of Social Workers and health professionals.

Physical Aspects

Nurses are among the most stressed teams of professionals who are burdened with the daily care of PLWD and this causes a lot of work related disorders by awkward postures, high loading requirements and psychological risk factors which results in neck, back and shoulder pain [Ellapen & Narsigan, 2014]. It would be beneficial for them to be able to educate and give examples to caregivers on how to take care of their PLWD on home environments in order to minimize the need for hospitalization, no matter if the medical causes are different than Neurocognitive Disorders or not. Physical aspects in relation to other professional teams are not reported.

Psychological Aspects

The potential of social media use for clinical practice and possible negative consequences has been investigated by [Anja, 2013]. One of the most important aspects is the low level of cooperation PLWD have with their caregivers and medical teams. A typical aspect of a stressful doctor-PLWD relationship is when PLWD start searching over the Internet for medical information and when different, it may lead them to lose confidence in their doctor or other medical professional they have come to consult. This negative effect is reported here because the management of the negative behaviour of PLWD is handled mostly by professionals. No to mention the raising malpractice suits against doctors; almost half of doctors according to a Medscape survey have been named in at least one malpractice suit [Peckham, 2015].

Medical professionals are also being involved with PLWD with terms of empathy and humanity. The demands of the job are such that doctors have to remain objective, handle PLWD's pain and proceed with careful diagnoses and design treatment plans. Self-criticism is related to high rates of depression and the overall physical and emotional distress may cause a burn out (Table 1).

Table 1. Emotional, cognitive, behavioral and physical symptoms of burn out in medical professionals [Peters, 2015].

Emotional	
Loss of humour	Irritability/resentment/bitterness
Feelings of failure/guilt/blame	Depressed mood, apathy
Cognitive	
Poor concentration	Rigidity/resistance to change
Stereotyping	Ruminations (of leaving, revenge, and so on)
Objectification/distancing	Suspicion/mistrust
Behavioural	
Work avoidance (absenteeism, clock-watching, and so on)	Diminished personal conduct with clients/colleagues
Inflexible behaviour	Habitual lateness
Acting out (alcohol/drugs/affairs/shopping, and so on)	
Physical	
Tiredness, lethargy	Sleep disorders
Increased minor illnesses (headache, backache, and so on)	

Usage Aspects

Although even in professional environments people may differ in their computer literacy and ways of taking advance of technology, those differences are not high and it is not expected to be have a serious impact on usage.

The standards expected of doctors do not change when moving from face-to-face communication to social networks-based communication [GMC, 2013]. McGowan et al [2012] studied how medical professionals are using social networks to share ideas and medical data with other colleagues and to identify the factors that influence the social networking for occupational training and professional development. On a weekly basis, those frequencies were raised to 61% and 46% respectively. Their attitudes against the overall usefulness was also very satisfying 57%.

Thus, health professionals, including psychologists and nurses) are expected to make use of the platform in a daily basis and not be only passive users who like following discussions and reading articles, but for be more interactive. Social workers might be less frequent users than doctors, but are expected to be weekly users to keep their records on social status of their clients updated.

Behavioural Aspects

It is expected that health professional profiles will be associated with valid scientific content, and this content will be easily promoted into the CAREGIVERSPRO-MMD community. Nonetheless, medical and healthcare professionals are also interested or advised to maintain a professional boundary between themselves and their clients. Thus, we may not

expect that this user category will generate plethora of content in the Café, or other discussion groups. As professionals, physicians will have limited time to stay long in the platform, so their login-logout sessions will be short but relatively more important than other user categories.

There will be differences in the quality of interaction and the types of actions undertaken by medical and healthcare professionals in the platform. For example, although they will be easily connected with their clients (and their caregivers), the social interaction with clinical populations will be relatively lower than between other community subgroups.

Overview of the People analysis

The main challenge is to handle such a diversity of mental models, motivation and intentions. Some might expect the platform to be used for skills training, while others see only social services on offer. Some users may use ICT products and services for treatment adherence and some others may have very limited experience in using healthcare platforms. In Table 2 the most important points of people analysis are summarized.

Table 2. People analysis overview and key-points for Dyads and professionals

Dyads
Physical
Size of the end device (tablets)
Size of visual elements and UI controls
Finger or hand disability
Vision/Hearing disability
Psychological
Language and cultural differences
Pressure on the end user for not having computer driving abilities
Usage
Users know how to use social networks from other platforms on the market
Not easy to use for first-time users
Behavioural
Psychosocial and behavioural aspects may differ according to the type of Neurocognitive Disorder of the PLWD.
The lower activity of the PLWD, the higher activity of the caregivers to balance the dyad's social presence and the overall activity
Professionals
Physical
Size of the end device (use of tablets and PC alternately)
Customization in UI layouts to meet priorities of their job description
Psychological
Language and cultural differences

Pressure on the end user for not having all the time or data needed
Usage
Users know how to use social networks from other platforms on the market
Easy connections to other existing means of communication like emails
Behavioural
Medical professionals will maintain a professional boundary between themselves and their PLWD.
Time constrains and the role of medical professionals will lead to shorter in-platform sessions

2.2.3   Motivation

Motivation can explain the reasons behind user's behaviour. This will answer the question " What causes an individual to want to participate in a healthcare platform, a treatment plan or a virtual community?". Increasing motivation in a workplace can help improve performance and boost productivity, but in a lifestyle club can help raise participation, socialization and morale. Thus, motivation and motivators (the ways to provide motivation) work for different types of user groups. For medical professionals, as well as for social workers, the CAREGIVERSPRO-MMD platform will be a place to work. On the other hand, for PLWD, caregivers and helpers, it is expected that the platform will be perceived as a place to make new contacts, to spend some time in discussions, to get information and advice. In overall, various user groups will get together in the CAREGIVERSPRO-MMD platform and for those user groups different motivators will be applied.

Just like in motivational models for physical exercise [Phillips et al., 2004], mental exercise initiation and maintenance requires motivation models to be defined and used. Clinicians need to actively promote mental and physical activity, along with medication and diagnostics. Special interest is paid on gamification services for the elderly having in mind that gamification requires some adaptation to improve the elderly experience.

In general, the way technology is used is influenced by a technology generation, education, socioeconomic status, cognitive abilities and attitudes [Oppenauer, 2009; Hoof et al., 2013]. Specifically for lifestyle applications, digital gaming experiences can diagnose and treat neuropsychological diseases [Lopez-Martinez et al., 2011], encourage elderly people to physically and mentally exercise, delay the occurrence of mental diseases and thus improve their quality of life [Cota & Ishitani, 2015]. Studies on the motivations for playing digital games by the elderly do not show clear and specific results [Brown, 2012]. Thus the study regarding preferences, motivations and needs of elderly people on digital games is ongoing [Gerling et al., 2011; Cota & Ishitani, 2015].

Most studies agree that simple casual games and games transferred to computers like card and board games, puzzles and quizzes are standard preferences of older people [Vasconcelos et al., 2012]. Also, elderly prefer gamified experiences which support scenarios conferred health benefits like brain training and reflex tests [Gerling & Masuch, 2011; Nap et al., 2009]. The taxonomy of games and gamified environments for the elderly made by

McCallum [2012] propose five categories of applications: Preventative, Therapeutic, Assessment, Educational and Informatics. McCallum also provides evidence of motivation provided by market-ready solutions like the Lumosity platform[5] which hosts numerous brain training games for the elderly.

Based on all of the above, **Table 3** presents some techniques for providing motivation to users, per user category. Priorities are on goals setting, recognize effort and provide feedback.

Table 3. Proposed Techniques for increasing motivation per user category

Major Motivators	Description
All User Groups	
Mutual assistance	Combine social aspects with technology to build a community of mutual care. Among other things, communities whose members may request assistance and at the same time get motivated to play the role of caregivers, can serve as a platform to effectively organize the social resources, promote social connection, and introduce intergenerational activities [Gui et al., 2007].
Incentives	Create individual incentives for each user category and team incentives for clubs and members of the PLWD' circles to motivate users as a group. Symbolic incentives can include badges, points earned, various other prizes and certificates. This motivation approach should have strong connections to the gamification platform and incentives be directly linked with the award system of the gamified platform.
Recognize Achievements	Celebrate user's achievements through media and text notifications which will disseminate achievements in the user's circle. This may include celebrations at medical staff meetings (physical, virtual, or both), printed certificates for PLWD (apart from digital), short animations for reaching important milestones, etc. Recognize group accomplishments, as well as individual ones. Group accomplishments will be computed by summing up personal achievements.
Solicit User's Feedback	Survey end-users about their levels of satisfaction in a regular basis (just like the repetitive assessment made monthly in T2.1). Conduct anonymous polls and ask user's opinions to continually improve platform features and conditions of its use in the real homes, clinics, Cafes and working environments. This Feedback may also be forwarded to policy makers and this will be advertised in user groups and communities.
Provide Enrichment	Encourage users to continue their education and skills training through the platform and not only. Provide professional enrichment for medical professionals and social workers and education on neurocognitive disorders. On the other hand provide

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[5] http://www.lumosity.com

	general health education and best practices to caregivers and helpers.
Dyads	
Set personal goals	Make sure personal goals are reasonable and achievable for all user groups, especially for people with Mild to Moderate Neurocognitive Disorders
Set community goals	Make sure team goals are representative and that a shared identity can be created for sub-groups in the community
Medical Professionals and Social Workers	
Create a positive working environment	Motivate employees by giving them a positive work environment. Make proactive platform behaviour in order to cause changes by its actions and not only to react to changes when they happen. For professionals the platform will be an extension to their career-based environment, so take action to eliminate conflicts as they may arise and give them the freedom to work independently when appropriate.
Set Goals	Help employees become self-motivated by helping them establish professional goals and objectives
Profits	Profits cannot be shared by the platform and through the platform. Earnings will not be connected with platform profile activity and teamwork. This may be a matter of the business model for future market uses of the platform.

2.3 Activities

Activities include intentional and conscious actions made by the users in real life and in platforms. Activities are subjectively meaningful for the performing users and are made on purpose. A distinction can be made in online activities and real life activities. Online activities include all activities made in the platform and by the platform and most frequently those have been designed to help real world healthcare problems. Apart from activities which have been transferred from real life to the platform, like giving such as completing a depression test survey for example, there are other activities made to serve needs related to the platform itself. The online activity guided by the users can be described by its category, resources required or nature of the content (type text, show video, etc.), goal and intention, frequency and complexity. There are also security and safety issues related to the activities that need special care.

According to the PRC research [Pew Research Center, 2010] the Internet activity of elderly users (65+ years old) is increasing at the largest growth in a demographic group. Elderly users, which are expected to be the dominant user group in our PLWD and caregivers' user categories, use these tools to bridge geographic gaps. They are especially interested in bridging gaps between them and their loved who live far away or to re-connect with old

friends. Other important uses of the Internet include informational and educational activities and they are related to internal motivation of seniors.

Table 4. Popularity of Internet activities among Internet users in each generation and percentages of those generation groups in the total population [Pew Internet Surveys - pewinternet.org]

Millennials	GenX	Young Boomers	Older Boomers	Silent Generation	G.I. Generation
Ages 18-33 (30% popul.)	Ages 34-45 (19% popul.)	Ages 46-55 (20% popul.)	Ages 56-64 (14% popul.)	Ages 65-73 (7% popul.)	Ages 74+ (9% popul.)
Email	Email	Email	Email	Email	Email
Search	Search	Search	Search	Search	Search
Health Info	Health Info	Health Info	Health Info	Health Info	Health Info
Social Network sites	Get news	Get news	Get news	Get news	Buy a product
Watch video	Govt website	Govt website	Govt website	Travel reservations	Get news
Get news	Travel reservations	Travel reservations	Buy a product	Buy a product	Travel reservations
Buy a product	Watch Video	Buy a product	Travel reservations	Govt website	Govt website
IM	Buy a product	Watch Video	Bank online	Watch video	Bank online
Listen to music	Social network sites	Bank online	Watch video	Financial info	Financial info
Travel reservations	Bank online	Social network sites	Social network sotes	Bank online	Religious info
Online classifieds	Online classifieds	Online classifieds	Online classifieds	Rate things	Watch video
Bank online	Listen to music	Listen to music	Financial info	Social network sites	Play games
Govt website	IM	Financial info	Rate things	Online classifieds	Online classifieds
Play games	Play games	IM	Listen to music	IM	Social network sites
Read blogs	Financial info	Religious info	Religious info	Religious info	Rate things
Financial info	Religious info	Rate things	IM	Play games	Read blogs
Rate things	Read blogs	Read blogs	Play games	Listen to music	Donate to charity
Religious info	Rare things	Play games	Read blogs	Read blogs	Listen to music
Online auction	Online auction	Online auction	Online auctions	Donate to charity	Podcasts
Podcasts	Donate to clarity	Donate to charity	Donate to charity	Online auction	Online auction
Donate to charity	Podcasts	Podcasts	Podcasts	Podcasts	Blog
Blog	Blog	Blog	Blog	Blog	IM
Virtual worlds	Virtual worlds	Virtual worlds	Virtual worlds	Virtual worlds	Virtual worlds
Over 50%	90-100	80-89	70-79	60-69	50-59
Below 50%	40-49%	30-39%	20-29%	10-19%	0-9%
Percentage (%) of Internet users in each generation who engage in this online activity					

This part of the study introduces questions like: Which of the Internet uses can be satisfied from the new platform design? How frequent each certain activity is performed and by which user categories? Do these activities come as a result of an individual or co-operative work? Are frequent activities easy to do? Are they continuous or interrupted? Current practices, data input requirements and expected duration of the activities must be discussed too. It is important for designers to make the healthcare platform design as clear and simple as possible so that many people can use the healthcare platform in highest readability and without the need of help [Benyon, 2005].

The following sections discuss activities by categories. We distinguish activities related to information exchange, socialization and team belonging, personal skills and team development, clinical activities and treatment adherence.

2.3.1 Activities of Dyads

Unlike other social networking platforms like Stitch, which offer member-driven group activities, travel and one-on-one companionship, in this section we discuss Internet activities which can be introduced into the CAREGIVERSPRO-MMD platform. Activities that lies outside the platform may be referred by the notification system as interesting announcements.

Based on literature findings, activities for PLWD and their caregivers can be grouped into information and communication activities, socialization activities and personal development activities. Moreover, we introduce gamification and treatment adherence activities which are of particular importance in this project. Those two additional activity groups are advances to existing social network platforms.

Information and Communication Activities

People find information on printed and electronic media. Printed materials like leaflets found available on clinics and doctor's offices is an established method of communication for medical issues. People consider this source of information credible, but it is a costly mean to supply. On the other hand, electronic media like those found on the Internet provide an alternative source of information and communication. Official sites of clinics and known communities provide medical and lifestyle information for PLWD. In CAREGIVERSPRO-MMD, the platform itself will be an informative and communication space. Equipped with all tools required for searching, reading and posting messages and articles, this new platform will be the environment in which knowledge will be accumulated and shared among its users. Most people will make use of parallel information and communication channels, or they may continue to use printed media. Existing and new media used in the platform will not be mutually exclusive as in real life. Users may write original articles, post links to other articles, make references to external to the platform information channels, etc. In overall, it is expected that information and communication activities will be one of the most frequent kind of activity for all user categories.

Socialization Activities

All user categories need social experiences to learn their community, its cultures (including cyber-cultures) and to evolve their profile and avatar. Socialization activities can be divided

into two major categories: a. one related to the growth of the social network and includes making new contacts, send contact requests and explore the social space in subgroups (circles or clubs like in the Cafe) and b. another one related to the content of the social network which is the people participating in social activities, the knowledge accumulated in discussions and the cultures to be created within the platform. Actions of the second category usually include message posts, applying search criteria on user profiles and club discussions, editing favourites, etc.

No matter the result, trying to do something in a social environment might also be considered an action, even if it is unsuccessful. Thus, trying to convince other members of the community for an idea or make certain choices instead of others is socialization activity. In any case, from the designer's point of view, socialization activities require user's visibility, a critical mass of users (or simple participants in social events) and the tools to perform ideas sharing.

Indeed, there are some common aspects with communication activities, but socialization is closer to the social capital and the social interactions that are able to create culture. Posting a message to the circle or sharing a www link with others is not enough. Social norms in online societies may be similar and different than in real life. But for CAREGIVERPRO-MMD users' social activities types can be seen in relation to the known socialization types:

Online Primary Socialization: This is mainly influenced by the immediate caregiver(s), helpers (family and friends) and professionals (doctors and other clinicians). This activity can be required for moving to other socialization steps. A PLWD profile without sufficient personal information and without a minimum set of connections to Caregiver, Helpers and Doctors may not be considered mature enough to proceed with higher forms of socialization.

Simple Secondary Socialization: In a second stage, users learn how to be a member of a smaller group of the larger society. Learning the appropriate behaviour within a personal circle is the right example. Experimenting with PLWD's personal circle is the aim of this second stage of socialization. Activities include simple communication actions and control over the size and quality of the personal circle.

Advanced Secondary Socialization: It comes natural to most users to explore the whole community and see the bigger picture. Socialization activities in this category include extensive search over the social network and manage social groups and discussion rooms in the Café area. The differences between the simple and the advanced socialization may not be obvious or easily distinguished, but the chronology of the online socialization should follow this simple schema from the simple or initial socialization to the more advanced. Also, the socialization process should be stepped enough, just like in real life.

Re-socialization: As MND conditions progress by time and cause new states of cognitive decline, re-socialization will pay an important role in the CAREGIVERSPRO-MMD platform. Unfortunately, it is expected that PLWD will discard former behaviour patterns and will accept new ones as they move from mild to moderate neurocognitive disorder. This can be an intense experience as individuals will have to learn new norms after a break on their role playing.

Organizational socialization: In this process, users learn the platform itself and develop skills useful to drive their profile and activity towards their objectives and according to their role in the platform. It is expected that user's role in real life may have some (affordable) differences than their role in the social network and the platform. Thus, some actions naturally performed by users in real life (local healthcare system) may not be transferred to the healthcare platform, but this is not a problem as the platform is not meant to replicate the healthcare system. However, user's familiarization with the platform may influence user's overall activity.

As newcomers get familiarized with the platform and its communication tools, they will also learn about the social network organization and history, the gamification rules and treatment adherence procedures. They will go through stages of socialization like those proposed by Levine and Moreland [1982], and more specifically influenced by the relation of the communities to the social networks [Hansen, 2012].

It is expected that this acquired knowledge about the platform will affect the way they interact with the platform and others. Very low or no activity in a particular domain of the platform (e.g. posting new messages) may rise prompts to read the user manual or demonstrate how certain actions can be performed. The sensing of organizational socialization will ensure equal chances in participation.

Development Activities

Seniors emphasize the informational and educational aspects of the Internet [Kamiel, 2016]. They are using it in an encyclopaedic fashion, thus activities related to education and skills development will pay an important role in CAREGIVERSPRO-MMD platform. Development activities include personal training and skills development (e.g. mental exercises) and also development activities targeted to treatment adherence (e.g. how to achieve better treatment adherence scores and maximize medical outcomes). Manually checking and recording the attendance of each PLWD can be a hard process and time consuming. It can also generate higher error rates and this will lead to inaccurate estimations. Thus, reliability in treatment adherence services is one of the most important aspects, but this will be a result of activities' development for dyads.

Gamification will pay an important role in activities' development. Gamification principles will make typical processes like education and training to be fun and the overall end-user satisfaction will be maximized. Development activities will be directly linked to the award system of the gamification component.

2.3.2 Activities for Health Professionals

Healthcare companies are entering social media and this causes changes in the way healthcare consumers and health organizations interact (HRI, 2015). Thus, the so called Medicine 2.0 is changing the digital healthcare environment. Medicine 2.0 can be defined as:

> *Medicine2.0 is the use of a specific set of Web tools (blogs, Podcasts, tagging, search, wikis, etc.) by actors in health care including doctors, PLWD, and scientists, using principles of open source and generation of content by users, and the power of networks in order to personalize*

health care, collaborate, and promote health education [Hughes et al., 2008].

To this end, participation in social platforms for medical professionals can range from relatively passive behaviour such as reading articles, posts and online discussions, up to more active participation like sending private messages, posting articles and web links in groups, or uploading multimedia content.

Social media have the potential to offer a number of advantages to healthcare professionals including professional development [Ventola, 2014], thus educational activities will be targeted to medical professionals too. According to a recent study, one out of four medical professionals use social networking sites daily or many times daily searching for medical information, while the 14% contributed to the contents by adding new information on a daily basis [McGowan et al., 2012]. Also there are evidence on how doctors follow social networks: three out of four use social networking sites, but only 30% use communication tools in the clinical praxis [Brown et al., 2014].

Based on the above, it is expected that doctors will contribute to the content development and they will keep live activities. Moreover, medical and healthcare professionals will create proposals for their clients and people connected to them. In this fashion, gamification activities initiated by medical and healthcare professionals will be presented to dyads as 'missions' to be undertaken in the gamified platform.

2.3.3   Temporal aspects

There is a difference between activities performed by individuals and those performed by teams of users. In addition, there is one more state, the dyad in which PLWD and caregivers constitute the smallest social unit in CAREGIVERPRO-MMD platform. Most activities are performed by 'social structures', but professionals may participate as individuals if they like.

In the first case (dyads) will pass through different phases of social inclusion as coupled individuals. Later they will have to shift their individual-level perspectives towards to a team level in order to participate in group activities like in the Café. This process introduces temporal aspects as it transpires over time at different rhythm for each group of users. Schroder et al. (1967) identified: a) the amount of information processing required (the team member familiarity will require a minimum amount of information processing) and b) the speed with which individuals can process information (team activity: team members may become more able, or more motivated) as the two main factors that will affect the speed at which integration can be completed.

Other important temporal aspects are related to the Neurocognitive Disorder symptoms. As the mental ability of the PLWD is getting lower, the dyad will become less active even with caregiver's efforts to preserve observed activity. Social activities, including gamified activities, will become an important mental health resource among older users (mainly PLWD and their caregivers) thanks to the sense of belonging to a social group. Moreover, the gamification component of the platform will offer the feelings of purpose with regard to everyday online activities.

Temporal aspects related to the rest of the user categories like social workers, doctors and other medical professionals are expected to be quite mild. Apart from the learning effect,

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that is a positive change to the platform experience, professionals can become advanced users as team players. The growing audience size (personal circles, Café, community sub-groups) will motivate professional excellence.

2.3.4   Safety and Security Issues

One of the objectives of the CAREGIVERSPRO-MMD project is to deliver a platform to help PLWD, caregivers to manage their health records, aware their medical and social states and maximize the treatment adherence of the medical treatment they follow. The social workers and medical professionals will access those data and will process according to the clinical praxis to make a picture of the PLWD's condition, propose an optimal treatment plan.

Health data is not the only sensitive information that needs to remain private. Other sensitive information include personal profile information, behavioral data (e.g. self-assessment, activity in the platform, etc.), statistics on feedback, performance and gamification status, and the personalized PLWD profile model, which is actually the combination of all the above used to model individuals. Moreover, the functionalities offered by the system needs to be secured also.

The following schema gives an overview of the data that is considered sensitive and requires protection:

- Demographic information
- Medical information
- Feedback
- Social network
- Awards & points
- Skills achieved
- Accessibility status
- Treatment adherence status

First we need to identify specific security requirements and threats associated to the activities in and out of the platform and according to various categories of users and data types. Threats and security critical issues related to the protection mechanism include the misuse of personal data, potentially harmful information via online communities [Leist, 2013]. Thus, the data input, storage, sharing and processing will require: a) the protection of the privacy of users, b) an optimal level of security for the data transactions, c) to safeguard data integration (from multiple sources), and c) the confidentiality between PLWD and medical professionals when using the CAREGIVERSPRO-MMD platform. Moreover, the related technology available has to be studied carefully.

All safety and security issues (like access and use of information, storage and backup of data, resourcing of data management, etc.) will be addressed according to the Data Management Plan (DMP) reported in D7.3, D7.7 & D7.8. The Personal, Screening, Treatment, Intervention and Dissemination Datasets ownership and access will be described in detail in the DMP. In here some common practices are reported which could be taken into account (Table 5). In any case, those requirements should be addressed according to the ethical board, the EU Commission Guidelines for data management and the Data Management Plan.

Table 5. Methods to address safety and security critical aspects (Data Management Plan in D7.3, D7.7 &D7.8)

Thread	Solution	Description
Data exchange between members of the consortium	**Data encryption**	Contemporary encryption methods are required to protect the privacy of data. According to the encryption algorithm, data are encrypted using a public key and then can decrypted only by the owner or the respective private key.
Unauthorized access to part of the data	**Data (Pseudo-) Anonymization**	To make data anonymized means that identification information is removed from sensitive data. Name and ID numbers like social security number are examples of such identification data. The identification data is replaced with new ID numbers and the records are linked to the identification information which is stored in a different place. This approach can minimize any risk of sensitive data publication.
Make use or access unused or outdated data	**Data Destruction**	Data can be destroyed to protect PLWD and other users. Some years after the pilot studies (for traceability and audits) both paper and digital documents can be destroyed (when the signed consent form is over). Electronic documents containing sensitive information (e.g. medical data) and measurements which they consider not significant (e.g. outdated) can be destroyed since they are not useful yet. The destruction protocol should foresee the possibility PLWD and their caregivers as owners of the data to be able to erase them.
Make use or access unused or outdated data	**Profile erasure**	If a PLWD and the caregiver -as a dyad- agree to erase, modify or block the access to their profiles, the system has to follow and perform those rules in all the collected data and all the information related to those accounts. However, the content created by this accounts can remain in the platform (e.g. discussion forums) anonymized. A message telling that this user has erased his/her account will replace the identity of the user.
Unintentionally jeopardising user's privacy	**Data Processing**	- Antivirus programs, junk mail and website avoidance - Credentials to CAREGIVERSPRO-MMD should not be shared with anyone not authorized - Contact administrator in strange behaviour detection - The consortium should minimize personal information of any user from communication messages within the consortium and encrypt when necessary - Delete personal information and faces from pilot photos from publications and oral presentations (Privacy Impact Assessment of the DMP)

2.3.5 Conclusion on Activities

This section described the activities performed by the CAREGIVERPRO-MMD users that constitute by: a) activities related to the healthcare system and b) activities transferred from real life to the platform. Key-points in Activities are summarized in **Table 6** per user category.

Table 6. Activities per user category

Activities	Description specification of Activities
All user categories	
Communication and Socialization	Communication and socialization activities are the most frequent activities for all user categories. This includes at least the following actions: invite a person in personal circle, accept invitation, post messages and send personalized messages to individuals
Group Identity	The 'personal circle' concept, as well as the social network around each user can contribute to the group or collective identity that is the shared sense of belonging to a group and sharing common ideas, problems and visions. Collective activities can form behaviours and individuals find motivation for permanent (and wished) behaviour changes.
Search	A search engine is mandatory to help people navigate in a big information space. The underlying search mechanism will help people to apply search criteria in user's profiles (name, country, spoken languages, short CV if available, personal preferences) and on the text contents of the platform. Media content can be represented on the search engine by using metadata provided by the initial uploader or the administrators of the platform.
PLWD	
Information	Access articles about physical and mental exercise, lifestyle and creative actions, self-expression activities
Personalization and proactiveness	Interface design adaptation (accessible interfaces), proactive risk detection activities
Training	Brain training, diagnostic and therapeutic activities like games and exercises for skills development, memory and attention preservation.
Caregivers and Helpers	
Information	Access articles about cognitive decline and dementia conditions, physical exercise and lifestyle, treatment organizing ideas and best practices, creative actions, self-expression activities
Self-control and management	Activities which promote and guide self-management on stress, burn-out and guilt in order to equip a caregiver with effective coping mechanisms for dealing with psychological stress ((Self-understanding, conflict resolution, positive attitude adoption, taking more regular and effective rest)

Personalization and proactiveness	Access to personalized information on individual's conditions and treatment, medical information on treatment side effects and ways to minimize those effects
Experience	Activities for sharing experiences with medical professionals, other caregivers and helpers, Café and discussion forums, sharing the public part of a personal diary
Medical Professionals	
Development	Activities related to the professional development of medical professionals (doctors, psychiatrics, physiatrists, neurologists, psychologists, nurses, etc.) like webinars, notifications for community organized happenings, participation in group actions and any other form of informal learning opportunities situated in practice. Possibly, professional development credits would be attributed to participants according to local ethics and practices (differently from state to state) when possible. It should be noted that the online activities in the CAREGIVERSPRO-MMD platform to support vocational education may not lead to qualification or credential required to obtain or retain employment. Thus, professional development opportunities may offer limited approaches like communities of Practice and eCoaching/eMentoring of young professionals from more experienced senior professionals.
System	
Notifications	Risk conditions detection, proactive security actions,
Matchmaking	Similarities in conditions, user's current state, performance, circle connections
Security	Data protection, secure personal profile and circle privacy, recovery from error, setting up priorities, conflicts resolution
Content	The status of each user profile, status and component in UI should be updated at almost real-time An error prevention management should be taken into consideration Language issues mostly in user-generated content Learning effect: The more users perform an activity, the more they learn and the easier it gets. So, by time the most frequent activities will become a commonality, especially for frequent users.
Safety	Notifications related to risk detection in closed or not connected devices

2.4 Context

We identify three types of contexts in which activities take place: a) the physical context, b) the social context and c) the organizational context. The context is the surroundings of an activity and there is no activity outside of a context [Benyon et al., 2005]. The study of context and technologies include:

1. Study of organized care situation

2. Study of social context

3. Study of physical context

4. Existing and potential technology

2.4.1 Physical Context

This type of context specifies the place and time platform activities take place and also specifies the physical circumstances, e.g. in home, mobile on the move, inside and outside, internet access and quality, noisy, cold, wet or dirty environments.

For CAREGIVERSPRO-MMD, the physical context is the place and time users are connected into the platform. The platform activity requires that a critical mass of users, from different user categories should be present or recently active. For dyads, common places to access the platform are home environments and day care clinics. Alternatively, PLWD and caregivers can access the platform while on the move, but this should not be considered as a often case. There are no time constraints apart from the fact that elderly people might not use the platform overnight as they tend to have early nights.

On the other hand, doctors and other professionals may have time and place constraints. They use their offices and the hardware available on their working environments to access the platform. They are expected to use the platform during their working hours and shifts and thus, the platform's usage and frequency of use is expected to be less for this user group than in other groups due to professionals increased workload.

In overall, the physical environment will be indoors in the majority of cases. Moreover, there is no one-to-one link between the physical and activities. Thus, activities may occur in various physical circumstances at the same time for different users. Personalization and interface adaptation will eliminate those differences.

2.4.2 Social Context

The social context describes how the surroundings of the activity are like. Social circumstances describe the supportive environment that offers plenty of help, tuition experts at hand to support, privacy issues, social norms that dictate conditions (e.g. sound, identity). This includes the presence of other people around, the visibility of other people accessing the same platform or those who participate in totally different activities and the existing social norms related to the place or the way the place is used.

Having in mind that Social capital in elderly is very important, Forsman [2012] proved that low frequency of social contacts with friends and neighbours and experienced mistrust in friends were all significantly related to depression [Forsman, 2012]. Thus, asking PwD or MCI and their caregivers to participate in a healthcare platform without transferring the existing social structures would not benefit them. The existing social structures have first to be transferred into the platform in order to give a starting point for elderly people in participating into the CAREGIVERPRO-MMD activities and community and secondly to allow new social structures become part of elderly people's lives. These social structures include users' social contacts with family members and friends, as well as the frequency of these

contacts. New social structures could include users' reunion with relatives or friends who live abroad or another city, or new contacts which can be created through the platform.

2.4.3   Organizational Context

The organizational context describes how an organization, in our case a clinic, a medical office, or a PLWD's community interacts with its users and clients. The organizational circumstances are influencing power structures, given status to caregivers, patients and doctors expectations from authorities and roles to live up to.

In CAREGIVERSPRO-MMD this describes how technology changes the communication: a) between PLWD and caregivers (interactions internal to the dyad), b) between dyads and c) between dyads and other user groups. While talking about medical environments, the organizational context may affect the PLWD's behavior or may cause inappropriate behaviors [Legares-Lemos et al., 2011]. Thus, changes in the organizational context may affect the quality or quantity of the user's interaction in the platform. This context is more relevant for care professionals, especially in a multicultural project where we have different healthcare systems, with different settings and where we expect that the platform is prescribed by the care system. CAREGIVERSPRO-MMD deals with integrated care under different systems and contexts in healthcare systems. This includes the centralization or decentralization of the structural context, other types of roles present in the local healthcare system (apart from platform users) like external service providers, and business processes which follow organizational patterns. Thus, we expect that all user groups can be sensitive to organizational changes. Safer conclusions can be made after the first pilot studies with the new version of the platform. **Table 7** summarises some important points related to the platform's context of use.

Table 7. Analysis of Context and overview of key-points for Dyads and professionals

Dyads
Physical Environment
Most people will access through their homes in no hurry
Wireless access to the Internet may provide limitations in bandwidth
Outdoors wireless access may be limited or charged
Social Context
Most PLWD will access the platform with their caregivers (dyads)
High level of support will be needed for first time or infrequent use
When in public, avoid too harsh error messages for not insulting the users
Warnings for risks and high priority advices should be displayed upfront
Assessment of the impact as to what level the new system will affect existing social dynamics
Structures and the social interactions within dyads
Organizational Context
Supervision by the caregiver will be needed to make sure PLWD are being honest with entering treatment adherence and profile information

Tablets are always charged and device charging is available when needed	
Internet connection is available at all times (for notifications)	
Professionals	
Physical Environment	
Most professionals will access through their workplaces that are clinics and offices raising some time and privacy factors	
Typical office Internet connections are fast enough for demanding processes and transactions	
Social Context	
It is expected that professionals will access the platform on their own	
Low level of support is expected	
Platform issues may be discussed outside of the platform (word of mouth)	
Organizational Context	
Most of the medical data will be inserted by data integrators	
Wireless Internet connections are expected to be present in all parts of the clinics, so notifications in mobile devices will work regularly during the day.	

2.5 Technology

Social Media technologies and applications allow people to exchange media rich content. This content may be created by users (user-generated content) or others outside of the platform. Social media include forums, the blogosphere (such as Twitter), content communities (such as YouTube and Flickr) and social networking sites (such as Facebook and LinkedIn). There are two major types of social networking sites available:

Professional: Intended explosively for medical staff. Doctors and other medical professionals identify their expertise or occupational status at sign-in. Examples of Healthcare networks of that type is the Doximity[6] and AthenaCollector[7].

Consumer: Those types of social networking applications are designed for the wider public. Anyone can create an account and participate in community activities without restrictions. The content and discussions are specialized more depending on the targeted community sub-groups. Popular examples of consumer networking sites are professional networks like LinkedIn[8] and the famous social networking service Facebook[9]. A complete picture of social networking penetration worldwide can be seen in Figure 4.

Table 8 presents some examples of apps and other types of social networks for healthcare. There are mainly three types of social networks: a) applications, b) websites and forums and c) Social media groups. The difference between the second and the last one is that the social media groups are hosted in an independent platform.

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[6] https://www.doximity.com
[7] http://www.athenahealth.com/practice/athenacollector/practice-management
[8] https://www.linkedin.com
[9] https://www.facebook.com

Facebook   Twitter
VKontakte   QZone
Odnoklassniki   Facenama
no data
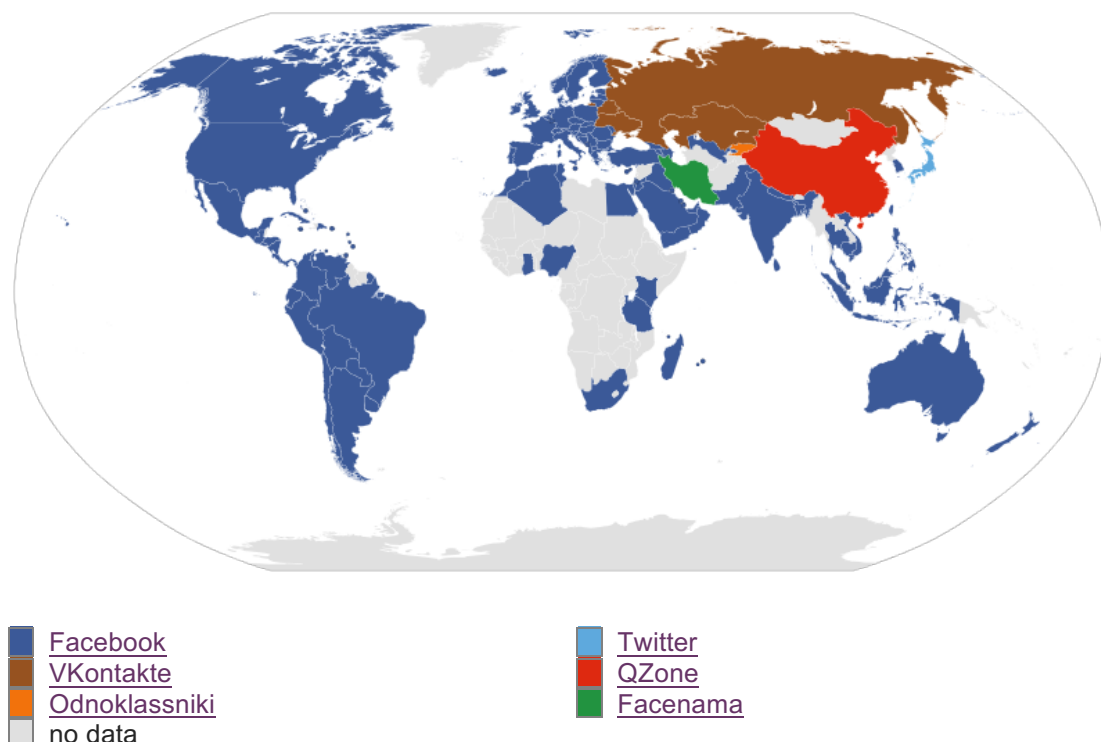
Figure 4. Most popular social networking sites by country [Source: Wikipedia Commons]

Others appear as a set of applications which share common objectives and resources, like the MindMate. This is an Alzheimer's and Dementia set of apps which appear like a guardian angel ready to help and to entertain. It consists of three different Apps: 1) One for the individual living with dementia, 2) one for family members and 3) one specifically designed for residential care.

Table 8. Examples of networks for healthcare [UpCity, 2014]

Type	Name	Description
App	Doximity	Designed for physicians, Doximity[10] is a social network for doctors. Currently it appears to be the largest social community in the USA.
App	Figure1	Figure 1[11] is a mobile application to access a networking site which allow medical professionals to share and access images of PLWD ailments to trigger discussions and exchange expertise
Forum and Website	Doctors Hangout	Doctors Hangout[12] is a worldwide social networking website which aims to connect doctors (medical students are

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[10] https://www.doximity.com
[11] https://figure1.com
[12] http://www.doctorshangout.com

		welcomed) and create Interaction with various medical groups
Forum and Website	AllNurses	This is forum for nursing practitioners to provide scientific information (mostly articles). Users of AllNurses[13] can host questions and collect responses
Social Media Group	American Medical Association	The American Medical Association[14] is a social network to access a union of physicians hosted in LinkedIn
App	Sermo	Sermo[15] is another very popular application for physicians with over 600.00 members. Users can discuss clinical cases and share resources.
Social Media Group	Medical Group Management Association	The Medical Group Management Association[16] website is a social media group
App	MindMate	The MindMate Apps[17] is a set of applications for Alzheimer's and Dementia

Technologies used in social networks development are similar to modern web development. Contemporary Web technologies include standard social networking services, scientific data visualization, content management system and user authentication. Moreover, CAREGIVERSPRO-MMD will add personalization, accessibility, and gamification technologies in the platform.

Social networking technologies implement social networking services which are typical Web 2.0 internet-based applications, while other commonalities unique to current social networking services have been identified are [Obar & Wildman 2015]: the user-generated content (UGC), the service-specific profiles created by users and the social networks development by connecting a user's profile with other individuals or groups of people.

Other technology-related commonalities refer to the communication, input and output components. Common visual controls are used in interface designs, but user-friendly sand accessible touch screen interfaces seem to be an important aspect for the elderly.hot areas used in touch screens is getting very popular in accessible interfaces, especially for elderly people. For tablets and other mobile devices, virtual keyboards help in text input. Other sources of input, apart from User Generated Content (UGC), come from data integrators, which are medical and clinical personnel dedicated with the responsibility to insertwere responsible for inserting existing medical data into the system. For person-to-person communication, text and media-based messages are exchanged between user profiles and groups of users.

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[13] http://allnurses.com
[14] https://www.linkedin.com/company/american-medical-association
[15] http://www.sermo.com
[16] http://www.mgma.com
[17] http://www.mindmate-app.com

What makes output more interesting is the use of visualization technologies to present big data (e.g. diagnostics, summary of PLWD monitoring data, overall social networking status, etc.) in efficient ways. Visualization software is used to create visually appealing graphical displays and interface layouts. The underlying technologies include libraries of graphical components (e.g. interactive charts, Gantt charts, diagrams, etc.) and software editors for deploying data displays for desktop and web-based healthcare and social networking applications. In Table 9 the most important technology cues are presented.

Table 9. Major Technology issues

Technology
Inputs
Pictorial, hot area and buttons selection in touch screen
Text input in both physical and virtual keyboard (in touch screen)
User credentials in cookies to speed up logon activities
Automatic input of scale results into user history and profile
Manual input of medical data by integrators (medical professionals)
Outputs
Beep, vibration and flashing components on the interface for notifications
Instructions in human voice in priorized notifications
Avatars to represent users in social environments (personal circle, contacts, Cafe)
Short animations to indicate milestones and gained awards
Visual proofs of achievements for performance visibility
Visual animated instructions for stepped procedures (video-tutorials)
Highlighting selected components, current actions and tasks
Printout of achievements, data completion tasks, treatment adherence assessment results
Communication
Instant responses for user's selection and achievements
Data Visualization engine for media-enriched charts and infographics
Reporting engine for personal data management, treatment adherence and scales results

3   Focus Groups

3.1   Introduction

Following the results from PACT analysis, focus groups and semi-structured interviews were conducted to collect users' (PLWD or MCI, caregivers, and medical and healthcare professionals) opinions on the current version of CAREGIVERSPRO platform. In this section

we present the protocol of these focus groups and we present the findings from the pilot sites which performed the interviews (Spain, Italy, United Kingdom and France).

3.2 The Focus Group Approach

The focus group approach is a method in which a group of people take part in interviews to discuss a topic previously defined by the researchers [Edwards & Holland, 2013]. While the number of participants depends on the nature of the study, previous studies suggest that six to ten people is enough. Individual interviews were conducted where focus groups were not suitable. In T2.1 interview managers run the discussion with a series of questions to guide the course having the first platform prototype and the demonstration material (starting point) as stimulus to present the platform to users.

Participants in focus groups were defined mostly by the end-user categories as they were described in section 2 (PACT analysis). Additional groups, like experts, were used to offer additional knowledge and experience in this approach. All focus groups are presented in **Figure 5**.
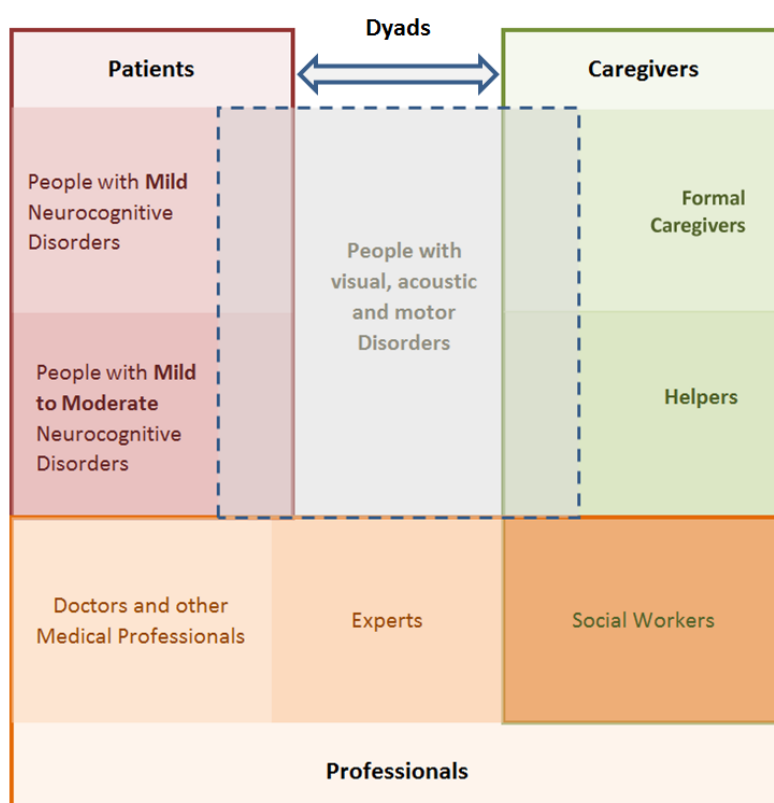
Figure 5. The Focus Group participants

We can see that there are some overlapping areas:

* While PLWD are people with Neurocognitive Disorders, other kinds of disorders, such as sensory and motor disorders may be present in other end-user categories as well. The most characteristic example is caregivers, either formal or informal, who may face such kinds of disorders and thus designers should take this into account. It

was expected (and finally proved) that accessibility issues could be sensed by the dyads, either by PLWD or formal caregivers.

- Social workers are caregivers but they are healthcare system professionals also, meaning that they offer their services during working hours and they have to prepare documentation for their clients like social status reports.

The Focus Groups can be used for generating ideas about the participants under research and this is especially useful at the start of a project [Edwards & Holland, 2013]. On the other hand, the Focus Groups can be used during the development of a project or at the end to provide feedback on results or for assessment in an evaluation design. Actually, both were used in CAREGIVERSPRO-MMD: a) at the beginning of the project to shed more light into the targeted user categories, b) at the development stages to evaluate the new platform designs and c) at the end of the project to provide feedback on results and to validate the new platform.

In overall the benefits the Focus Group approach has to offer in CAREGIVERSPRO-MMD can be summarized in the following:

- Participant's interaction can give insight into their beliefs, attitudes and special language they use.
- Despite the efforts in organizing focus groups, the immediacy of the feedback collected and the speed data can be generated are both valuable for the designers
- The eSurvey engine[18], as part of the new version of the platform was given priority in order to support the Focus Groups and provide a uniform and automated way to collect and report feedback. The eSurvey engine can also support pilot studies in WP5 by allowing site managers to undertake Focus Groups online if wished [Stewart & Williams, 2005].
- Focus Groups will serve social support and will prove the strength of the method used in stigmatized or vulnerable participants [Peek & Fothergill, 2009] like people with Neurocognitive Disorders and their family members.
- A very particular type of social interaction between couples (e.g. Dyads) is accessed and this has been indicated as very valuable [Bjørnholt & Regland, 2012; Edwards & Holland, 2013]. According to this, one researcher interviews two participants who know each other very well (PLWD and caregiver).

3.3 Interview Protocol

Interviews with Focus Groups were performed with respect to a common interview protocol. This protocol ensures that results are comparable and overall conclusions can be made for all sites, despite local differences. A list of requirements and common approaches was applied on the recruitment of participants, the context of the interview, the materials and the feedback collection tools:

Recruitment: The recruitment process made use of common communication media like phone, social media, within clinic, direct mail, etc. Minor differences in recruitment process

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[18] eSurvey engine is a software platform that provides standard tools (questionnaires development, responders access and interview sessions management) for performing empirical research

may have been occurred between pilot sites. More information on local processes may be sought in the interview reports at sections 3.4 to 3.7.

Physical Settings: Regarding Interview settings, it was required that interview spaces should be accessible, have good lighting conditions, avoid interruption and have privacy. Interview organizers took into consideration that the physical context of the interview may also affect the social context (home, clinic, café).

Time Constraints: It was paid effort to keep the whole interview process within 100 minutes when possible. In any case, the protocol was flexible enough to allow a second meeting if needed.

User Hardware: Demonstration material and hands-on experience with the old version of the platform should be presented in desktop computers, laptops or tablets. There is no need to define specific technical requirements as long as the used devices respond well (fast enough) to user's actions.

Internet Connectivity: Cable or wireless (WiFi) Internet connection is required. Common office bandwidths should be enough to ensure a uniform user experiences free of interruptions and network delays.

Used Demonstration Materials: The old version of the platform (available at http://www.cuidadores.pro/?locale=en) and 17 videotutorials (video demonstrations) were prepared in order to be used as demonstration material during the Focus Group process. The full list of those videos are presented in **Table 10.**

Table 10. List of videos used as demonstration material during the interviews with Focus Groups

Video Demonstrations (mp4 video files) with captures in English (also translated into Spanish, Italian and French)			
Title	**Reference link**	**Description and User Groups**	**Duration**
Login	https://goo.gl/JZyF6T	Login process for all user categories	55 sec
Profile	https://goo.gl/1m6vEE	Profile overview for dyads (PLWD and caregivers) as well as for doctors (for accessing information).	7 min, 54 sec
Posting	https://goo.gl/Hj6mfT	Posting for PLWD and caregivers	5 min, 32 sec
Questionnaire	https://goo.gl/swCMbq	Filling up a questionnaire embedded into the platform for PLWD and caregivers) (and medical professionals (for information)	5 min, 51 sec
Support	https://goo.gl/wvWCbc	Support for dyads (PLWD and their caregivers)	4 min, 14 sec
Doctor	https://goo.gl/27qka7	All actions related to the medical professionals	5 min, 17 sec
Connecting with Other	https://goo.gl/MNosxp	Demonstration of the social connectivity features for PLWD and caregivers	5 min, 21 sec

<u>Feedback Collection Instruments:</u> Interviews were performed as interviews with respect to common questionnaires used by all interview sites. The list of questions which need to be covered during the interview in a particular order and way (semi-structured) is presented in the Annex A. It should be noted that those questionnaires refer to the minimum set of questions used uniformly be all interview sites. Additional questions were inserted by interview managers in order to capture important aspects and according to the local needs. It was hypothesized that interview managers knew their targeted participants better than anyone else, so they were also free to repeat questions by rephrasing them in order to make things clearer to the interviewees.

<u>Demo User Accounts:</u> In order to be able to perform certain actions in the platform, it was required that user accounts were present at the time of the interview. Those accounts served all user categories and all local languages of the sites during the interviews (**Table 11**). Those platform accounts were considered mandatory to save time from creating user profiles and because participants needed some kind of material to be present in their demo accounts. Otherwise, new user accounts would be empty and some actions could not be performed at the time of the interview under the time constraints of the interview process.

Table 11. List of demo user accounts used for demonstration purposes during the interviews with Focus Groups

Language	Role	Email
FR	Doctor	doctor_fr@email.com
IT	Doctor	doctor_it@email.com
ES	Doctor	doctor_es@email.com
UK	Doctor	doctor_en@email.com
UK	Caregiver	R.J.Dunn@hull.ac.uk
UK	Caregiver	P.Zafeiridi@hull.ac.uk
UK	Helper	E.Wolverson@hull.ac.uk
UK	PLWD	K.Paulson@hull.ac.uk
FR	Caregiver	Isabelle.Landrin@chu-rouen.fr
FR	Caregiver	Marie.Berard@chu-rouen.fr
FR	Helper	Laetitia.Malherbe@chu-rouen.fr
FR	PLWD	Nadir.Kadri@chu-rouen.fr
IT	Caregiver	m.antomarini@cooss.marche.it
IT	Caregiver	f.cesaroni@cooss.marche.it
IT	PLWD	f.scocchera@cooss.marche.it
ES	Caregiver	ftetard@cuidadores.pro
ES	Caregiver	rafa@mobilesdynamics.com
ES	Caregiver	elara@mobilesdynamics.com
ES	Caregiver	XGirones@umanresa.cat
ES	PLWD	PLWD1@email.com

<u>The interview process:</u> After a short introduction to the scope and the objectives of the project (~5 min), participants were given the consent form tread and sign before taking part in the interview (~5 min). During the demonstration (~20 min) participants were given series of videos depending of the user category they belong to. During actual use of the platform (~30 min), participants made use of the current version of the platform and they were asked

to perform the similar processes to those they saw in the videos. For elderly users' convenience this process could be performed step-by-step, meaning that after a short video demonstration they were asked to perform in the platform before proceeding with the rest of the process. During the questionnaires phase participants had to complete a demographics and a usability questionnaire with closed questions (~ 10 min). Last but not least, the interview phase (~10 min) gave participants the opportunity to express themselves more freely and give advice to platform designers. The interview questionnaire consisted of open-ended questions to capture participant's opinion on current technological trends, their attitudes towards the use of technology in healthcare, their preferences against games and gamification, etc.

Figure 6. A screenshoot of the English version of the Profile video demonstration

3.4 Description of Focus Groups Participants

The Focus Group participants consisted mostly of people who belong to the CAREGIVERSPRO-MMD user categories. Additional groups were used in the T2.1 interviews in order to help in designing the new version of the platform. The aging professionals for example (used by COOSS) extend the medical professionals by giving valuable information on aging conditions. In overall, participant groups are described in the following list:

PLWD. Persons with Mild Neurocognitive Disorder or with Mild to Moderate Neurocognitive Disorder (scaled conditions). Those two subgroups were separated when possible, but they used the same demonstration material, they performed the very same tasks in the platform and also they gave their feedback using the same questionnaire. The differences between PLWD's subgroups were highlighted when giving requirements.

Caregivers. Formal or professional who provides caregiving services to one or more PLWD. Caregivers could also be considered as 'PLWD' in the platform under certain circumstances that have to do with caregiver's health, especially psychological conditions.

Helpers. Family member, neighbour or any person able to help to decrease the burden of care. They can participate in various social circles related to PLWD.

Doctors and other Medical Professionals. Health professionals (doctors, psychologists, physiatrists and allied professionals) serve/manage PLWD and may operate within various branches of healthcare like medicine, pharmacy, psychology and nursing. Other professionals who work for the common good of the aging society may be included in this group, like the aging professionals.

Social workers. Those professionals are a separate group of platform users. They should receive alerts and notifications related to the social status of the PLWD and connect to the social cockpit to manage people they are in charge of. Typically, those persons will visit PLWD at their homes and use the platform to update social information.

Initially, the objective was to recruit 20 participants for focus groups according to the T2.1 description, but after the Barcelona Consortium meeting the team was advised to have at least the 10% of the pilot studies participants and be prepared for a 20% loss during the task. Therefore, 74 people were recruited and successfully participated in the interviews. This number is considered to be sufficient for the first cycle of the Focus Groups study. A more detailed distribution of participants per user category and per site can be seen in **Table 12**.

Table 12. Interview participants and user categories

Focus group	UHULL	COOSS	FUB	CHU-ROUEN	Total
PLWD	4	2	6	4	16
Caregivers	5	2	6	-	13
Doctors & other Medical Professionals	9	4	6	5	24
Social Workers	-	-	8	5	13
Others (additional)	-	2 Helpers 6 ageing researchers	1 Foundation Manager	-	9
Sum	18	16	27	14	74

Interviews were hosted in site's facilities or at users' homes, and were performed by researchers using the demonstration material created for the Focus Groups. The interview protocol explained previously in section 3.3 was respected by all pilots, while there were

cases in which sites added more participants and additional questions to sense local attributes, as well as people's characteristics and attitudes.

3.5 Performed Scenarios and User's Activities

Interviews were performed after video-demonstration and a live demonstration of the existing platform (current version). Although the new platform will offer new features and innovative functionality which is missing from the old version, it was very important to take feedback from participants on existing functionality. This included common social networking activities like communication, profile management, search of people and other information within the platform, etc. A complete list of supported activities (organized as 'scenarios of use') that were evaluated as typical to socialized healthcare platforms are presented in Table 13.

Table 13. CaregiversPRO-MMD Scenarios for Focus Group Reports

#	Title	Description
PLWD		
P1	User Authentication	Users log in to the platform using their username and password
P2	Access and update personal information (user profile or account)	Users are asked to locate their profile first and then to update some of their personal information (appear as interests). A first photo upload or update is strongly recommended in this scenario. The session ends after 'Save Changes' button has been pressed.
P3	Manage Disorders	Search for a specific disorder and add it to profile. Also search and add a drug as treatment to this disorder. Although it can be considered as a part of S2, disorder management is tested separately as a new scenario.
P4	People Search	Find people to follow and/or friends. Includes examine common interests and view profile details. The session ends with 'Add as friend' or 'follow' actions.
P5	Wall message	Publish a message or a web link on the wall and choose the level of publicity (public or friends). This can be implemented as a reply to existing post. Also can be implemented in public or private cycle (only Family and Doctors).
P6	Adherence evaluation	Fill up an online questionnaire and read adherence evaluation report
P7	Communication	Make a contact with your doctor and other PLWD (send personalized message, friendship request or

		invitation)
P8	Support	Create a new ticket and upload a file
Caregivers		
C1-C8	P1-P8	Same as PLWD
C9	Contact other caregiver	Locate and exchange messages with other caregivers in the (digital) café area (experience sharing, asking for advice, warning)
Healthcare Professionals (Doctors)		
D1	Manage doctor's profile	Same as P2 but Add/manage information and connections to PLWD as additional tasks
D2-D4	P3-P5, C2-C4	Same as PLWD and Caregivers
D5	Overview of PLWD's evaluation interface (cockpit)	Select a PLWD and see his/her Hospital Anxiety and Depression Scale, the treatment adherence and other evaluation diagrams
D6	Manage Evaluations	Add a new scale for a specific PLWD, enable/disable scales
D7	Contact caregivers, PLWD and/or other doctors	Like C9, but extended to all end-users (PLWD, caregivers, doctors)
D8	Add a new case	Add a new case as a doctor
D9	Scientific contribution	Add a new paper or review on the platform
Helpers		
H1-H7	P1, P2, P4-P8	Same as Caregivers, except from P3
Social Workers		
SW1-SW6	P1, P2, P4, P5, P7, P8	A selection of typical user's tasks
SW7-SW10	D5-D9	A combination of caregiver's and medical professionals' tasks

The scenarios described earlier were executed by Focus Group participants on sites (France, Italy, Spain and UK) during the first T2.1 task period (June-July, 2016) and the related interview reports are presented in the following sections. Those will bring updated knowledge on local healthcare and people's characteristics, level of technology penetration and ways ICT can be used in serving health and social needs.

3.6 CHU-ROUEN Report

3.6.1 Introduction

The University Rouen hospital recruited participants from three user categories, namely PLWD (PLWD), Doctors and other Medical Professionals (Geriatricians) and Social Workers. As a university hospital, in addition to delivering medical care to PLWD, CHU-ROUEN provides clinical education and training to future and current physicians, nurses, and other health professionals. They performed interviews during June 2016, by recruiting personnel from more than one hospital as platform users.

3.6.2 Methodology

The actual version of the CAREGIVERSPRO-MMD platform was presented to end-users. Doctors and psychologists involved in the project met on 8th June to select a panel of potential end-users who could accept to test and give their opinion on the platform. Finally, we interviewed 4 PLWD, 5 doctors and 5 social workers.

These interviews were made during week 3 and 4 of June. Depending on the selected groups, interviews were done by doctor and/or psychologist.

For PLWD: We selected PLWD with diagnosed MCI (3) and Mild dementia (1). All the PLWD were treated in a day centre for Alzheimer's disease (CHU de Rouen- Hôpital de Oissel). The trial was described to the PLWD. Interviews were done on volunteers who accepted to test the platform and responded to the questions. All were able to give informed consent. All PLWD had already used IT tool or wanted to use it. A doctor (Dr M. BERARD) and a psychologist (L. MALHERBE) were present to help PLWD to use computer. Face-to-face interviews were done.

Interviews were done on 22th and 24th of June

For doctors: All doctors are geriatricians, 2 of them were or had been working in a memory clinic. They were voluntary for testing the platform and a doctor (Dr I. LANDRIN, Dr Th SIMON) made the interviews. The doctors are working in rehabilitation centre in CHU (4) and in CHI Elbeuf-Louviers (1). Doctors, PLWD and caregivers account was presented.

Interviews were done on 15th and 17th of June

For social workers: Social workers are working in hospital (CHU:2; CHI Elbeuf-Louviers:1) or in social services in community (CLIC:2). They were volunteers and gave informed consent. Whereas no social account was created, account of doctors, PLWD and caregivers was presented.

Interviews were done on 20th and 24th of June

All trials were done following the protocol below. All materials had been translated in French.

1. Introduction and presentation of the project
2. Informed consent
3. Videos of the platform: each group viewed a personalized video
4. Test of the platform and discussion

5. Fill questionnaires (personal information and platform questionnaire. All questionnaires were filled in real-time.

3.6.3 Description of participants

In total 14 people participated in CHU-ROUEN interviews. A more detailed description of the participant's characteristics can be found on the following table. The scenarios supported in this local interview implementation were described in Table 13.

Type	Characteristics
PLWD	4 PLWD had MCI. All had mild to high socio cultural level and mostly had knowledge on ICT. They had 77 to 86 years old 1 PLWD with moderate dementia aged 81 with high socio cultural level
Doctor	5 geriatricians; all worked in rehabilitation or memory clinic. They are not involved in the project. They have a good knowledge on dementia and problematics of caregivers. They have willingness in using ICT for working. Age ranged from 32 years to 52 years.
Social worker	5 social workers: 3 working in 2 different hospitals, and 2 social workers working in community for elderly people. All are aware of dementia and caregivers problems. Age ranged from 31 to 57 years.

3.6.4 Results

The interview results are presented below organized per user category.

PLWD

Part A - About you	User1	User2	User3	User4
Sex (* at the time of birth)				
Male	*x*	*x*	*x*	
Female				*x*
Other (please indicate): {Textbox}				
Age				
{Textbox, block off any keystroke that is not a number}	77	77	86	84
Type of memory problem, if known (Multiple choice)				
Mild Neurocognitive Disorder	x	x	x	
Moderate Neurocognitive Disorder				x
Year of first diagnosis of memory problem (If memory problem known)				
{Combobox control with first choice 'I do not know' and then years from 1980 to 2016}	2012	2014	2013	unknown
Mother Language (Multiple choice)				
French	x	x	x	x
Work Status (Multiple choice)				
Wholly retired from work	x	x	x	x
If not Retired, main Type of Employment Status (Multiple choice)				
Worker				

Employee	x	x		x
Self-employed and contractor			x	
Director				
Office Holder				
Level of Education (according to ISCED 2011, Multiple choice)				
0-Early Childhood Education				x
1-Primary Education				
2-Lower Secondary Education				
3-Upper Secondary Education			x	
4-Postsecondary, non tertiary education		x		
5-First Stage of Tertiary Education	x			
6-Second Stage of Tertiary Education				
Number of people in your household including yourself (Multiple choice)				
1				x
2	x	x	x	
Living status (Multiple choice)				
Living at home independently				
Living at home with health care provided by family member	x	x		x
Living at home with health care provided by professional carer			x	
Living in care home				
Visual, acoustic, or motor Impairments (Multiple response)				
No specific impairment	x	x	x	x
Part B - Use of Technology/Communication means				
What do you use the Internet for? (Multiple response)				
Communication (email, video chat, etc.)	x			
Online Shopping/Selling				
Online Entertainment (video/movies, games, music, etc.)				
News Reading				
Work				
Social Networks				
Sharing information (blogging, photo sharing, etc.)				
Education/Training				
Looking for medical advice				
I do not use the Internet		x	x	x
Other (please indicate): {Textbox}				
Which kind of devices you prefer/feel more confident to use? (Multiple response)				
Personal Computer (PC)	x			
Tablet/iPad				
Laptop				
Smartphone (Android/iPhone)				
Other (please indicate): {Textbox}	phone	phone		
What other means of communication do you use for socialization with other people living with dementia? (Multiple response)				

Club (reading, games, craft, sport…)		x		
Memory workshop (in an institution) or day hospital	x	x	x	x
Forum discussion or social network				
Others (Please specify): ……………………………..				
What means do you use for communication with your doctor and your caregiver? (Multiple response)				
Visit at home/ doctor's office	x	x	x	x
Telephone conversation				x
Mail conversation				
Other (please indicate): {Textbox}				
What means do you use for self-managing your treatment? (Multiple choice)				
I take my treatment day after day, without preparation			x	x
I prepare my treatment to the day with boxes (morning; afternoon; evening)	x			
I prepare my treatment to the week with a weekbox		x		
I do not prepare myself my treatment				
Other (to specify): ………………………………….				
Part C - Gamification and Games				
How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)				
I play no games	x	x	x	x
I believe that a game-like experience from an application or a webpage would motivate me to participate.				
1- Strongly disagree				
2- Disagree				x
3- Neutral	x			
4- Agree		x	x	
5- Strongly agree				
I believe that a game-like experience from an application or a webpage would benefit more.				
1- Strongly disagree				
2- Disagree		x		x
3- Neutral	x			
4- Agree			x	
5- Strongly agree				

Document Repository- Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)	User1	User2	User3	User4
I encounter no problems logging into the system	NA	1	1	5
I found logging into the system intuitive	7	2	7	2
I prefer a different design for login	8	8	6	4
I encountered no problems in locating and updating my profile (my account)	NA	NA	NA	2
I found locating and updating my profile (my account) intuitive	5	2	4	1

I prefer a different design for profile management	5	8	8	4
I encounter no problems managing disorders and treatments	NA	NA	4	1
I found managing disorders and treatments intuitive	NA	6	8	1
I prefer a different design for the management of disorders and treatments	NA	8	3	4
I encounter no problems in searching and connecting with other user profiles	NA	NA	8	2
I found managing connections with other users intuitive	NA	3	8	2
I prefer a different design for searching and connecting with other users	NA	8	8	8
I encounter no problems managing posts and wall messages	NA	NA	NA	3
I found managing posts and wall messages intuitive	NA	2	6	4
I prefer a different design for managing posts and wall messages	NA	8	6	3
I encounter no problems participating in an online questionnaire about adherence evaluation and reading the report	NA	NA	6	4
I found participating in an online questionnaire and reading the report intuitive	NA	3	6	3
I prefer a different design for online questionnaires and reports	NA	9	6	4
I encounter no problems communicating privately with users like doctors, other people living with dementia, caregivers, helpers and social workers (send personalized message, friendship request or invitation)	NA	NA	NA	1
I found private communication with other users intuitive	NA	NA	NA	1
I prefer a different design for private communication with others	NA	NA	NA	5
I encounter no problems in creating a new ticket and uploading a file	NA	NA	NA	3
I found creating a new ticket and uploading a file intuitive	NA	NA	NA	2
I prefer a different design for creating a new ticket and uploading a file	NA	NA	NA	3
I encounter no problems in actively participating in the café.	NA	NA	NA	6
I found actions related to the Cafe intuitive	NA	NA	NA	4
I prefer a different design for the Café.	NA	NA	NA	3
I completed all tasks related to my role in the platform	NA	NA	NA	3
I can use this platform on my own	NA	1	1	1
This application was user-friendly	NA	1	1	1
Did the platform respond at your expectations?	NA	1	NA	2
Do you understand the notion of circle in the platform?	NA	3	NA	2
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	NA	8		2

NA: Not answered. Questions were not answered because questions were either too difficult to understand or they had forgotten how to use the platform or they didn't want to answer

Despite some functions of the platform were not working in local language; the platform has been integrally tested.

Even with a mild disease, PLWD had difficulties to use the platform and it was necessary to help all of them during the whole evaluation. They had never used a computer or tablet for 3

of them but had a mobile phone. One had a computer and used it for basic research and for communication (email).

The way to share with other PLWD with cognitive disorders was in day hospital or club.

They were sceptic and confused during the test and found the design not incentivising. They were lost with the number of items (too many), didn't understand how to navigate from one task to another. They were stressed by the device and need reassurance along the interview. They had great difficulties to interact (ex: café)

Because of ICT low-knowledge, they were unable to provide inputs. They couldn't provide the contribution about what ICT could help them to deal with their disease.

They asked question about protection of private life and find the platform too intrusive in their life. They didn't find advantages of this kind of support for their disease.

They said they'd like having games and could play games (stimulation games, crosswords, Sudoku….).

For Semi-structured questionnaires:

They were disrupted by open questions and couldn't answer some questions or refused to answer these questions

None of the PLWD had already used an app or internet to learn about cognitive diseases. They manage their medical follow-up with agenda or with professionals (i.e.: pharmacist)

They do not know how an ICT tool can help them to manage their medications

They said they'd like having games and could play games (stimulation games, crosswords, Sudoku, etc.).

Open questions:

PLWD were tired after demonstration of the platform and mostly didn't want to answer to questionnaires. Some of them had forgotten how to use the platform and couldn't answer to open questions. One wanted a different vocabulary, more understandable. One thought it was too intrusive, he fells platform put himself bare.

Doctors

Part A - About you	User1	User2	User3	User4	User5
Sex (* at the time of birth)					
Male	x				
Female		x	x	x	x
Other (please indicate): {Textbox}					
Age					
{Textbox, block off any keystroke that is not a number}	32	49	39	52	52

Mother Language (Multiple choice)					
French	x	x	x	x	x
Place of work					
{Textbox}	CHI Elbeuf	CHU	CHU	CHU	CHU
Number of people living with dementia you are responsible? (Multiple choice)					
less or equal to 25					
26-50					
51-100			x	x	x
More than 100	x	x			
Context/Place of healthcare professional services (Multiple choice)					
Day care institute					
Home of people living with dementia					
Hospital/Clinic	x	x	x	x	x
Community mental health team					
Years of Professional Experience (Multiple choice)					
Less than 5 years of experience	x				
6-10 years of experience					
11-15 years of experience					
16-20 years of experience				x	x
More than 20 years of experience		x			
Part B - Use of Technology/Communication means					
For which of the following clinical activities do you use the Internet for? (Multiple choice)					
Ordonnance		x	x	x	x
Diagnostic purposes	x				
Contact other professionals	x	x	x		x
Contact people living with dementia					
Contact caregivers			x	x	
Professional reading	x	x	x	x	x
Medical forum	x				
What other means of communication do you use for socialization with other doctors and healthcare professionals? (Multiple response)					
Phone call	x	x	x	x	x
Regular post	x	x	x	x	x
E-mail	x	x	x	x	x
Professional forum					x
Seminar			x		x
Other (please indicate): {Textbox}		SMS	direct contact		
What means do you use for communication with your people living with dementia and their caregivers? (Multiple response)					
Phone call	x	x	x	x	

Regular post	x	x		x	
E-mail			x		
Professional forum					
Seminar					
Other (please indicate): {Textbox}				Direct contact	
Part C - Gamification and Games					
How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)					
I play no games	x	x	x		x
Once a week					
Once a month				x	
Everyday					
If you play digital games, can you tell us about your experiences? (Multiple choice)					
Positive experiences				x	
Negative experiences					
Barriers to using games					
Nonchalance experiences					
Other (please indicate): {Textbox}					
I believe that a game-like experience from an application or a webpage would motivate my people living with dementia and their caregivers to participate.					
1- Strongly disagree					
2- Disagree					
3- Neutral					
4- Agree	x	x	x		x
5- Strongly agree				x	
I believe that a game-like experience from an application or a webpage would benefit more.					
1- Strongly disagree					
2- Disagree					
3- Neutral	x	x			
4- Agree			x		
5- Strongly agree				x	x

Document Repository- Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)	User1	User2	User3	User4	User 5
I encountered no problems in locating and updating my profile (my account)	8	8	9	10	4
I found locating and updating my profile (my account) intuitive	6	8	9	7	3
I prefer a different design for profile management	4	5	10	10	10
I encounter no problems managing disorders and treatments	5	5	NA	NA	5
I found managing disorders and treatments intuitive	4	5	NA	NA	2
I prefer a different design for the management of disorders and	6	5	NA	10	10

treatments					
I encounter no problems in searching and connecting with other user profiles	4	5	5	NA	NA
I found managing connections with other users intuitive	3	5	NA	1	10
I prefer a different design for searching and connecting with other users	7	5	NA	10	10
I encountered no problems during the overview of the cockpit of people living with dementia?	2	7	9	1	1
I found overviewing cockpit of the people living with dementia intuitive.	3	7	9	1	4
I prefer a different design for overviewing of the cockpit of people living with dementia.	8	5	5	10	10
I encounter no problems managing evaluations	3	8	5	5	NA
I found managing evaluations intuitive	3	7	5	10	NA
I prefer a different design for managing evaluations	7	7	5	10	NA
I encounter no problems communicating privately with users like people living with dementia, other doctors, caregivers, helpers and social workers (send personalized message, friendship request or invitation)	5	NA	2	NA	NA
I found private communication with other users intuitive	6	NA	NA	NA	NA
I prefer a different design for private communication with others	4	NA	NA	10	NA
I encounter no problems in creating a new case	6	8	NA	NA	NA
I found creating a new case intuitive	5	5	NA	NA	NA
I prefer a different design for creating a new case	7	5	NA	NA	NA
I encounter no problems in posting my new scientific contribution	9	5	NA	NA	NA
I found posting a new scientific contribution intuitive	9	5	NA	1	3
I prefer a different design for creating a new scientific contribution	1	5	NA	NA	10
I completed all tasks related to my role in the platform	3	2	3	NA	NA
This application was user-friendly	2	5	4	3	5
How useful you consider the platform to follow up people living with dementia?	8	8	8	10	10
How useful do you consider the platform to delay institutionalization for people living with dementia?	9				
Did the platform respond at your expectations?	2	6	3	1	5
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	1	2	10	1	5

*NA: not answered

All doctors who accepted to test the platform were geriatricians with experience in dementia and knowledge on caregiver's burden.

For semi-structured interviews:

What means do you use for managing of your people living with dementia medical data and treatment suggestions?

All are current users of ICT for personal or professional use. They use traditional means such as papers but more often informatics technology to manage medical data and treatment.

What other computerized means do you use for risk detection, diagnosis and prevention?

They do not use ICT to detect, prevent or diagnose disease.

What means do you use for scientific contribution and accessing scientific material?

For them, Internet is a resource for scientific contents (via pubmed mainly as with national websites for recommendations), as well as seminars, workshops scientific publications, books.

Do you recommend an application or a website about memory disorders? Which ones and why?

Geriatricians recommend to PLWD or PLWD sites like of France Alzheimer or forum.

What kind of resources or services do you think people with MND or caregivers may find useful or beneficial when using online websites?

They think that resources and sites that could be useful for PLWD or caregivers are:

- Forum or exchange of experience
- Sites on Alzheimer's disease like "France Alzheimer"
- Sites of social organisation (i.e.: CLIC, CCAS….)
- Sites in order to find a list of contacts (doctors, nurses, etc.)
- Online health record
- Information on therapeutics
- Information on the disease and caregiving
- Information on psycho-compartmental disorders
- Geriatric sites
- Information on Respite care

What design guidelines or ideas would you recommend to interface designers to make the platform PLWD-friendly and to enhance usability? Any 'must haves' and/or 'must not'?

For design guidelines and improve platform, doctors recommend:

- taking into account that PLWD and caregivers have a low knowledge on ICT.

- Have a design that can help PLWD and caregivers to browse

- The presentation is not intuitive for PLWD and caregivers

- improve functionality, colours, recreational, attractiveness…. Even for doctor's account

- improve the design with a friendlier design for all end-users

- Change the colours for brighter colours

- Font size may be increased (eye impairment)

- Have large icons. The left banner is not optimal and difficult to understand.

- On icons: have message to help PLWD, caregivers….

- Have large emoticons. Choice of emoticons colours is not optimal.

- Have an agenda for PLWD (date, hour, season and why not weather)

- Not too much information in one page

- Have a function "return"

- Issue with pulldown menu: too difficult for PLWD and some caregivers

- Having an icon for social information

 - use words that are easy to understand

- Professionals are not friends but create a section: professionals

- Be careful with colours codes (risk of confusion…). A colour code for each user.

- View on alerts

- For medications: photo of pills, indication of treatment (what the treatment's for?)
They have doubts that side-effects may be stressful and provoke a risk of stopping
medications? (be careful with the message conveyed), Reminders for treatment taking-> can
help adherence

- the initial box with the text "how do you feel" should be removed in another place

- the possibility to see the password when logging

In what way could an online website help professionals to improve the care they provide to
people with dementia and their carers? (information, socialization, support and advice,
assessment of outcomes, follow therapy, etc.).

A website can help professionals by giving information on treatment adherence, permits to
have a look on burn-out of caregivers, follow behavioural disorders

Another interest would be to have professional information on the disease (news,
recommendations, links with interesting professional sites, etc.)

For open Questions:

Enumerate parameters and information that you would like to see when you realize a medical control with your people living with dementia every 6 month

Doctors would like to have on the platform

- Questionnaire on nutritional intake, Body Mass Index, a follow-up of weight,
- a questionnaire on treatment adherence
- a questionnaire to follow evolution of psycho-behavioural disorders,
- activity daily living questionnaires

Please say how we could improve the design (if different for each please, indicate separately).

Design could be improved:

- Design is too sad. It needs more colours
- It is not intuitive
- It is not use-friendly and not fun
- Use icons

Please indicate which tasks/steps were more difficult to complete.

- One doctor said she had difficulties to select scales. No comments for others

What were your expectations regarding the platform?

Doctors said that there are different expectations about the platform:

- considering the platform itself: design
- considering the role of the platform for PLWD in daily care (treatment adherence, socialization, etc.
- Considering the role of the platform for professionals: Improving communication between PLWD, caregivers and professionals
- Having a support for caregivers: sharing difficulties with others
- Having a role of socialization

What features would you like to add in or remove from this platform?
No feature was listed but a comment on confidentiality (take into account confidentiality of information)

Do you consider the platform can improve treatment adherence focus on symptoms related to the disease? How?
Platform can play a role and can alert caregivers and family on treatment adherence if a PLWD forgets his medication.
By highlighting symptoms, it may be helpful for family and caregivers.
By giving contents, it may help treatment adherence

Do you consider the platform can improve control of the people living with dementia and prevent other diseases with PLWD and caregivers?

Only for caregivers. Not for PLWD

The platform is a tool to follow not for control

The platform may have a role on caregiver burn-out detection

What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
- Survey on food intake
- Cognitive games for stimulation (-add new services like "games")

Is treatment adherence important to your people living with dementia? How a web platform could help?

A platform may help by sending different alerts: reminder for taking medications, reminder for the name of medications

A platform may help to explain the symptoms and the disease in order to cope with these symptoms

They consider that the platform could improve the quality of medical work by collecting data on PLWD and caregivers. Having this information before consultation in memory clinic may be helpful for medical team and also for general practitioner and may facilitate their work.

Social Workers

Part A - About you	User1	User2	User3	User4	User5
Sex (* at the time of birth)					
Male					
Female	x	x	x	x	x
Age					
{Textbox, block off any keystroke that is not a number}	50	42	57	45	31
Mother Language (Multiple choice)					
French	x	x	x	x	x
Years of experience as a social worker (Multiple choice)					
Less than 5 years of experience		x			x
6-10 years of experience					
11-15 years of experience					
16-20 years of experience					
More than 20 years of experience	x		x	x	
Number of people living with dementia you follow (Multiple choice)					
less or equal to 25	x			x	x
26-50					
51-100					
More than 100		x	x		
Context/Place of profesional services offering (Multiple response)					
Day care institute					

Home of people living with dementia		x			
Hospital/Clinic	x			x	x
Other (please indicate): {Textbox}		clic	clic		
Part B - Use of Technology/Communication means					
What means do you use for communication with people living with dementia, their families, doctors and their caregivers? (Multiple response)					
Visit at home/ doctor's office		x	x		
Telephone conversation	x	x	x	x	x
Mail conversation		x	x	x	x
Other (please indicate): {Textbox}	x interviews			Appointment in hospital ; at the bedside ; multidisciplinary meeting	Appointment in hospital ; at the bedside
What means do you use for communication with other social workers? (Multiple response)					
Forums/Workshops			x		x
Telephone conversation	x	x	x	x	x
Mail conversation	x	x	x	x	x
Blogs				x	
Socal networks					
Other (please indicate): {Textbox}				Regular mail ; work meeting	
Part C - Gamification and Games					
How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)					
I play no games		x			
Once a week					x
Once a month				x	
Everyday	x		x		
If you play digital games, can you tell us about your experiences? (Multiple choice)					
Positive experiences	x				
Negative experiences					
Barriers to using games					
Nonchalance experiences			x	x	x
Other (please indicate): {Textbox}					
I believe that a game-like experience from an application or a webpage would motivate my people living with dementia and their caregivers to participate.					
1- Strongly disagree					
2- Disagree					

3- Neutral			x		
4- Agree	x	x		x	x
5- Strongly agree					
I believe that a game-like experience from an application or a webpage would benefit more.					
1- Strongly disagree					
2- Disagree					
3- Neutral			x	x	x
4- Agree	x	x			
5- Strongly agree					

Document Repository- Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)	User1	User2	User3	User4	User 5
I encountered no problems in locating and updating my profile (my account)	6	4	4	8	3
I found locating and updating my profile (my account) intuitive	5	4	4	7	3
I prefer a different design for profile management	2	4	2	6	6
I encountered no problems during the overview of the cockpit of people living with dementia.	9	8	9	9	6
I found overviewing the cockpit of the people living with dementia intuitive.	9	8	9	7	6
I prefer a different design for overviewing of the cockpit of people living with dementia.	2	2	2	3	2
I encounter no problems managing posts and wall messages	1	7	4	9	4
I found managing posts and wall messages intuitive	1	4	3	7	6
I prefer a different design for managing posts and wall messages	9	7	8	4	3
I encounter no problems communicating privately with users like people living with dementia, doctors, other caregivers, helpers and social workers (send personalized message, friendship request or invitation)	1	3	1	1	1
I found private communication with other users intuitive	1	3	1	3	2
I prefer a different design for private communication with others	10	8	10	8	7
I encounter no problems in updating social information of people living with dementia.	ND	ND	ND	ND	ND
I found updating social information of people living with dementia intuitive.	ND	ND	ND	ND	ND
I prefer a different design for updating social information of people living with dementia.	ND	ND	ND	ND	ND
I completed all tasks related to my role in the platform	1	1	1	4	2
This application was user-friendly	3	6	3	3	1
How useful you consider the platform to follow the social status of people living with dementia?	7	7	7	6	5
Did the platform respond at your expectations?	6	6	7	5	3
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	6	7	8	4	2

*ND: this functionality was not available

No social account was created when we interviewed social workers. A large panel of different types of social workers were represented (hospital working, social service in community) which is representation of social working in France. All had a work focussed on elderly people.

Have you ever used an application or a webpage about memory disorders? What was your experience?
Three of the 5 social workers interviewed have used webpage to have information on dementia diseases. The objective was to get informed on the disease

What means do you use for updating social information of the people living with dementia you follow?

Traditional means like papers, are the principal tools. Every social worker use more frequently ICT for personal and professional work.

Their professional activity conducts them to use professional sites for social processes (ex: Alzheimer's association, Trajectoire, Alzheimer's care plan, sites specialised site on cognitive problems….) and frequently emails.
For social working, oral communication is important.

How the internet and ICT technologies might support you or meet your needs on social management?

They think that an ICT device for the caregiver is important and useful and could be a support for the caregiver. A goal of the device is to break down the social isolation and share experiences and have a better understanding of the disease. They think that providing social information for caregivers is essential.

An ICT can be useful to update information by caregivers and by professionals and follow social needs.

It may facilitate communication between partners (caregivers and professionals)

Some information is private and confidentiality and security of information must be protected

What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
A gamified app could give information on the disease and social assistance by e-learning. It may reduce feeling of isolation

What other computerized means do you use for risk detection and conditions prevention?
None. No ICT available in France

What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).
Games like memory games, test on knowledge for PLWD
Games that deliver information by e-learning for Caregivers and perhaps also by videos

How could we improve the design? (Colours, fonts, layouts, etc.).
The main comments are

- Design is not friendly
- The page is "cold" not user-friendly. Change for bright colours
- Not incentive and complex. Too much information and it is difficult to browse
- It is necessary to have icons
- Some icons are too small

Please indicate which tasks/steps were more difficult to complete.

- Send a publication is not easy for people with a low-level on ICT
- Login is not incentive for PLWD

What were your expectations regarding the platform?

They think that an ICT device for the caregiver is important and useful and could be a support for the caregiver. A goal of the device is to break down the social isolation and share experiences and have a better understanding of the disease. They think that providing social information for caregivers is essential.

What features would you like to add in or remove from this platform?

Social workers think that some questionnaires may provoke anxiety such as: side effects of medications, cardio-vascular risks

Questionnaires on activity daily living and autonomy are necessary.

What kind of questionnaires and data-collection tools for screening of social status you might like to be included in the platform?
Create questionnaires about: needs for help at home, knowledge of social support and respite care; on what caregivers is expecting …
Questionnaire about satisfaction on social assistance

Other "open" comments were made on this platform

The main positive comments were:

- Sharing publications is interesting for professionals
- Discussion between professionals is important
- Create alerts
- Create a space where people could join and ask for friends
- Share videos
- "Demystify" medical information
- Have a social "space" in Caregivers account (not in other account): helping caregivers to find information on social resources
- Helping PLWD in treatment adherence
- Have a moderator for the forum
- Define the limits of professional responsibility

- Be careful in terms of data protection and data sharing (medical data cannot be share with social workers)
- Lack of data-> there is a need to create contents
- Professionals are not friends but create a section: professionals (doctors, social workers…)

3.7 FUB Report

3.7.1 Introduction

This section described the followed methodology and the results of the Focus Groups interviews performed in FUB. Emphasis was given on the social dynamics and more specifically on the Social Psychology principles in order to describe the behaviour of user groups that results from the interactions of individual group members. This may contribute to seeing a wider landscape of social interactions in and out of the social platform.

3.7.2 Methodology

Open questions asked in the focus groups:

Focus Group "**Ageing Professional**" (**clinical team**). 6 persons + 1 foundation manager

- Doctors, gerontologists, nurses, neurologists and neuropsychologist

Focus Group "**Social workers**". 8 persons

- Social professionals

Focus Group "**Dyad**" (people living with dementia and their caregivers)". 6 dyads (12 persons)

- Caregiver, professional or not, family or not, of people living with dementia.
- People living with dementia (mild to moderate).

For the three Focus Groups:

Focus group dynamics

1) Information session explaining the project and the platform

- Information about the project
- Informed consent for the focus groups

2) Focus Group Session

- Person Actions Context and Technology (PACT) discussion
- Interaction with the platform and PACT project surveys:

People

[Talking about impact of dementias in their lives and/or professional]

First stage. Initial analysis: open questions related to: disease social problems, health and economics

- From your point of view What is most important?
- How do you deal with these issues?
- What resources are you using? (public, private)

Second stage. Proposals: (open questions proposals)

- Would you like to improve?
- Do you think that technology could help you?

Activities

[Talking about activities associated with the impact of dementia in their daily lives and / or professional]

First stage. Initial analysis: open questions: describing your activities/needs

- How do you do them? Prioritize these activities / needs
- Which are the most / less important?
- How often do you perform these activities? Do you have time enough?
- Can you do these activities / needs alone?
- If not, who is helping you?
- In what way social/sanitary services cover your needs?

Second stage. Proposals: open questions

- Would you like to improve your activities / needs?
- How do you think they could be improved?
- Do you think that technology could help you?

Context

[Talking about people and associated professionals to the impact of dementia in their daily lives and / or professional]

First stage. Initial analysis: open questions

- Describe social context you are in to perform your activities / needs
- How is organized your environment for performing these activities / needs?
- How is organized public / private health system to help you in your activities / needs?

Second stage. Proposals: open questions

- How do you think your social context should improve to facilitate realization of your activities / needs?
- Do you think that technology could help you?

Technology

[Talking about the facilitation of technology associated with the impact of dementia in their daily lives and / or professional]

First stage. Initial analysis: open questions proposed

- Do you use some kind of technology to perform your activities / needs?
- Do you have any problems using / applying this technology? (Internet access, quality of technology, environmental conditions, personal aspects ... etc.)
- How do you communicate with your environment in order to implement your activities / needs?
- How do you receive / send information to your environment?

Second stage. Proposals: open questions proposals

- How do you think technology should improve to facilitate the realization of your activities / needs?
- Some technological solution should be created to help realization of your activities / needs?

3.7.3   Description of participants

According to the categories of end-users and considering a wider category of Ageing Professionals, comprehensive of doctor, head nurses and, in general, experts in ageing (e.g. services coordinator), FUB collected a total of **27 questionnaires**.

Based on the categories identified in table 1, end-users involved by FUB are:

User Group	Enoumeration and subgroup description
PLWD	6 users (PLWD)
Caregivers	6 caregivers
Ageing Professional	1 doctor (family doctor) 1 doctor (neurologist - gerontologist) 1 head nurse 2 nurses 1 neuropsychologist
Social worker	8 Social Professionals
Admin	1 Foundation Manager

3.7.4   Results

In order to define a need detection model, different levels of analysis are considered, referred to:

1. Person
2. Activities
3. Communication
4. Technology

Following this PACT analysis form, with the aim of making the most out of it and letting the participant express themselves about their experience, knowledge and professional and/or personal wealth in Alzheimer, for the construction and improvement of the platform designed in the CAREGIVERSPRO-MMD project.

The results obtained from these questions were the following:

REGARDING THE "DYAD AND INNER CIRCLE"

The carers group expressed some concerns for the cognitive deterioration such as mood changes, lack of recognition; for alterations of behaviour and of other phenomena such as insomnia, which do not facilitate the cohabitation and incite incomprehension and isolation of the carer, fomenting their saturation and the burn-out.

From the contributions made, 5 categories that the carers group wish the platform had and strengthened were identified:

Tasks:

The cures provided by the main carers are understood as a complete attention to the person affected by the neurodegenerative disease, which is only interrupted by some situations of break or the attendance of some support groups and other institutions focused on sharing experiences. The tasks of "caring" involve their "global" dedication, including from supplying daily activities to medication administration, as well as concrete tasks of hygiene, feeding, etc.

It is interesting how the group expresses that "*aspects as important as the affection, the kindness, the communication or the simple company, are overshadowed by the routines and the everyday assistance requirements, when they are as essential as feeding*". This is a value that should be enhanced by the platform as a carer's value.

Values:

The values associated to the carer's role range from the need of feeling inner peace to do their best, to the difficulty that the sacrifice of giving up their own needs on a daily basis involves. It is unanimous among the participants that "*our role is not paid with anything; we have to draw strength and encouragement to keep going*".

What has the biggest influence when deciding whether to take the responsibility of looking after a person or not is the "moral value", considered an obligation due to the fact that the person receiving the care is part of immediate family, especially if it is a mother-daughter relationship. In many occasions this moral obligation causes a lack of a direct expression of problems to the closest surroundings, like the family, as the obligation requires the assumption of the suffering. This type of situations, as the group refers, "*which when it continues for a long time, leads to an isolation of the carer and causes isolation situations that involve a complication for the carers themselves.*"

Family recognition:

At the same time, there is a lack of family recognition toward the dispensed care, expressing *"even the fact of receiving a pension already justifies the sacrifice made by the carer",* which without a doubt implies that the communication channel between the family and the carers is even weaker.

The decline in family relationships, conditioned by the poor family recognition and especially from the maintained person, causes the appearance of a source of tension, creating a contradiction of feelings and the moral obligation of helping the family member, causing a loss of priority and attention on the individual demands and the carer's own wellness. In order to counter this tension, the carers express *"dealing with the situation with the feeling of the duty fulfilled, the self-evaluation of the well done work and the effects of their cares on the other, helping themselves to feel reassured, satisfied and encouraging themselves to keep working day after day".*

And if asking for help, other family members suggest the option of residence entry, an option which carers avoid due to *"moral conflict".* They express that in some occasions, more support is found in neighbours or friends than in the actual family.

Professional recognition:

Quite the reverse happens regarding the recognition from healthcare professionals, especially communitarian infirmary, considered *"an important point of support as the Alzheimer's family association, with groups and workshops that offer a very important support"* to the carer. These two figures, defined as *"escape mechanisms to understand and share daily experiences",* happen to be essential for carers.

They recognise that *"establishing family intervention strategies with the aim of giving more value to the carer's role, as well as working with the person with cognitive deterioration in order to guarantee the recognition and to improve the daily affective relationships"* should be done. Furthermore, the carers' group shows that it would be really convenient to *"expand information channels about carers' support in a more active way, to reach as many carers as possible from the beginning of the process".*

Recognition to carers:

Within the tasks and care support measures, they appreciate help from institutions. But at the same time, they think *"that they are very limited and are conditioned by financial resources".*

They view the accessibility to medical staff in a positive way as well as the treatment and the attention received from them, especially in the socio-sanitary assistance ambit.

To sum up, the improvement measures highlighted by them are *"a better collaboration and understanding by the family, more information in advance both for us and for the family about what they will have to do, and that we're more appreciated"*

REGARDING THE MEDICAL TEAM:

The Dementia Unit of the *Fundación Sociosanitaria de Manresa* (FSSM) could interact with the platform CAREGIVERSPRO-MMD in order to have the opportunity of checking if its utilities and sections, all of its areas and content possibility.

The focal group's moderator allowed the reflection on which papers they want to have in the platform as dementia clinical professionals. Explaining how the platform has to be useful for all its users, to the entire ecosystem around the dyad. From their professional clinical experience, they suggest to think about how the platform can be useful, from all points of view.

What role do you imagine the platform can have?

"A solution to increase the treatment adherence could exist. When the clinic informs in the platform which medicine, dose and the frequency, the platform informs the person that receives the medication and somehow involves their close circle informing about the use of the medicine. If we get to inform about the possible benefits of the medicine, this information will support the treatment's sense."

"The platform can hold quizzes that can be downloaded. The focus group's members point out that they would not be actual ladders, but specific questions that the platform would send to the user. This way, a tracking of different parameters, such as life quality, can be done. And this data can be crossed with a drug's prescription, thus being able to define clinical actions in a better way. The aim would be that as a doctor I would not have to wait for six months to know if the action or drug that I have prescribed has had the desired effect or not."

From the point of view of obtaining useful information though the platform for clinical use, the group points out that one of the things that would be more interesting to bear in mind is, for example, asking the user for information about break downs and hospitalisations while the clinician has not been in touch with them.

In the treatment adherence section, the members of the focus group point out that all the specific drugs for dementia could be included in order to have a better control. For example: Treatment starts in this date, they need renovation in that date, etc.

About pharmacological issues, the focus group's constituents comment that through the platform, cases where the treatment is stopped due to a prescription expiring without the user controlling the situation could be avoided. What could happen is that the user does not realise, so when they go to the pharmacy they can not be given the medication, causing that the user runs out of that medication. The treatment, as a consequence, is interrupted until the user contacts the prescriber. That is why it would be really interesting to have control and information about it.

Another contribution that the platform could offer would be: *"PLWD start a treatment and being able of asking for help in case they are suffering side effects, or feeling sleepier, unstable, etc."*

The platform, from the medical point of view, would be very useful to facilitate the tracking of the PLWD. It would be done on-line, becoming one more daily tracking. It should never replace the on-site visit, but there could be a possibility of making video-conferences or something similar in order to keep the user closer in case it was necessary to interact with them beyond the information sent to the platform."

The focal group members have doubts about the functioning of PLWD care. They all wonder the following: "*if the PLWD asks a question, when is he answered?".* They express that this would compromise them and would possibly complicate their lives due to the big number of PLWD, who might have a lot of questions. A possible answer to that would be imposing a number of rules in order to make the user aware of the fact that their doctor will not be on-line every single day but they will do it from time to time, and that they do not have to obligatorily answer the questions they have made. But it would be very appropriate that the doctor received warnings of the most important things. The platform can have warnings, but the platform must not enslave the doctor, it must make their task easier.

It is pointed out that it should be a complementary activity to the on-site visit. *"The thing is that the fit is often difficult. The professional will always find that person who will interact in a beneficial way, while other profiles will not though not respecting visits, calling twice a week, etc."*

The focal group members comment about it that: "*one thing is the possible suggestions about a particular issue, and something different is the very direct questions about the pathology. Then the law on data protection, the involvement in legal issues, etc. take relevance when a document is registered, as if it was an on-line visit. It must be clarified until which point it is an on-line visit or only a particular comment from a platform user and which point the figure of the physician can reach due to the legal involvements that this might have later. The clinical staff is not physically seeing the PLWD: with no doubt they might be suffering a side effect, but we cannot determine its origin. Sometimes it is not the same as to see the symptom, it cannot be identified like in the medical office; you can point out information, but not the medical visit connotations. Also, this type of direct information should only be received by the interested person. That is how it must be on an ethical level. These interactions must be private. On-line consultations are a thing, but on-line disclosure is something completely different. It is possible to inform about the effects of a specific drug, and that is a thing, but making an on-line visit about a side effect... it would be a mistake."*

It is necessary that "*the information that you wish to receive and that the user receives is perfectly assessed."* "*This information must be used for a clinical benefit, without it becoming a legal grievance or a diagnosis problem. If it is determined that a user informing about side effects it is interesting and they execute it, the information will be used to decide if an on-site visit should be arranged or not. This was not possible in the past, because this information got lost, and was equally valuable. The platform must facilitate clinical dynamics, not complicate them.*

The information obtained through the platform must be used to improve the assistance. It must be beneficial."

"Sometimes, delays in assistance might become legal problems. We can not downplay on-line contact. It has important involvements. From the moment that a clinician's action has a

consequence, we must establish borders in the platform. It can work with informative effects. The user must bear that in mind. Consultations must be eminently indicative."

Would direct consultations made by the user be useful?

"Some of them would, definitely, yes. Without substituting on-site ones and without being binding. In other words, that they have the possibility of making a consultation and the doctor to answer it, but that means exclusively that the professional answers a question, and that does not mean that they are diagnosing. The user must bear in mind that the professional is informing. Nothing else. For example: a concrete drug might cause sickness, and the professional informs about that, but that does not mean that the sickness experienced by the user is caused by the taking of the drug. That is the border. That diagnosis can not be made on-line. And even less when this remains written. And is binding."

The group points out, however, that: *"It is true that this communication and this information facilitation are used to lighten the family's burden, and that is very positive. Just for this reason, it is already worth it to have this function in the platform."*

They also think about the moderator's questions:

"We have an important amount of PLWD. We must benefit from the platform. We must identify if the PLWD in front of us is a user of the platform in order to, when needed, taking the information that they give to the platform. This means that, in a way, the platform needs to be linked to their clinical record. This way I will be able to make the most out of the platform."

Would it be useful for you that the validating and clinical scales were uploaded on the platform?

On this question, the focal group answers:

"No, it would not. Most of those scales can not be transferred to the on-line environment.

If the scale is self-administered and is about life quality or other aspects then it could be possible. A Mini-mental would be impossible, the only ones would be the self-administered ones, like possibly the Zarit one; a Barthel would be impossible, a professional is needed." "To the user it might be useful, but to the clinician it is not. The clinician is interested in having a tracking of the scales they go through. The clinician is not interested in self-administered ones."

"Another possibility is to create scales around the platform, about aspects that help to make a tracking, so that the users themselves can keep their own self-tracking."

Would adapting scales be useful to find out about daily activity?

"They should be very metric scales, very evaluable, very explicit. There is training for a MEC. If they are burden scales, or life quality scales, it could be useful. The questions should be very specific. Very.

For example: if the PLWD is asked if they can eat alone, what does that mean? That they can cut meat or that they can bring it to their mouth? Because if you cut it and the PLWD takes it to their mouth, will they be able to open and mix the yogurt? They must be very specific and closed. It would be useful if we achieved a scale without too much variety between observers.

Would controlling the visits calendar through the platform be useful? The management of medical visits?

"We control visits through phone calls, to remind the existence of the appointment. We control it taking into consideration the professional's availability, their guards, holidays, etc. The platform could remind the user; it could facilitate this job."

"Through Gowin (clinical history and on-line appointments management program) the medical visits are controlled. But it would be very useful to use the platform to manage this kind of tasks, since the real support is the paper agenda. The tool that we have needs to be improved."

"It would be interesting, for it, to cross data. But in many occasions, the paper agenda is what controls it. This function could be transferred. Vacations, guards, etc. should be taken into consideration. It would also be a territorial advantage."

"Automatic calls could also be made, reminder messages on the phone, on the platform…"

Will the PLWD be able to manage their own information? Would they be able to report their own information?

"*That would be very useful, because in many occasions we need information to complete the file, which when obtained, is really useful to facilitate it as soon as possible without waiting for the next visit. For example: if the PLWD takes a sleep examination. They will take it in an external service and it would be really useful that, once the study is obtained, the PLWD tells us that it is already available in their common file. It would imply a great advantage."*

The platform might require specific information from its users and keeping a tracking. If the clinical body requires an action from the user, the platform could generate a requirement, inform the user and watch for its execution, informing the clinical about its achievement.

"The platform cannot substitute the scale taking and the information required specifically in on-site medical visits. It does not make sense either that the scales are available to the users. The clinical will have to go through them during the visit anyway, even if the user had answered them a hundred times. Scales need to be administrated and gone through, so in this sense the platform would not save time, but it is true that according to their reports and the information facilitated by the platform, the appointment with the user will be more direct thanks to the amount of information."

"But knowing what the platform is asking for is essential. Knowing what kind of information it might require. This report will be according to the requirements prescribed. Currently, when the neurologist sees a PLWD, a nurse has previously seen them. If the information is shared, this facilitates the job a lot. It would be very useful seeing this information on the

platform because it would simplify the visit and it would speed the questions that can be asked.

It takes a lot of minutes to know "how has it been", if "have they eaten well", etc. If that information is already recorded, it is perfect. That they bring it prepared from home."

"Due to electronic prescription (which is not very agile) modification issues, the platform could also facilitate this process, in other words, currently, the PLWD calls saying that a medication has worked and you need more to be prescribed. If you do not modify the electronic prescription, they will not be able to go to the pharmacy and get it. Currently what we do is modify it, leave it in the secretariat and the person has to come and get it and then take it to the pharmacy. When it is just a bar code. That is it. If it could be enabled to the platform, then take the pone or the tablet to the pharmacy and just show the bar code, we would save a lot of time and problems. Just like a plane ticket. It would be a fantastic service. Every time we have a treatment that expires between visits, the person has to come just to go to secretariat and take it. If a system that facilitated this process existed in the platform, we would speed this process up and solve a lot of travel problems. In the end of the day it is just a bar code."

REGARDING SOCIAL WORKERS

The analysis with these professionals regarding the impact of neurodegenerative illnesses on the dyad's and/or the professional's everyday life and how the platform could incorporate improvements and boost abilities is started by talking about how the Alzheimer is a sickness in which a first diagnosis is established and from then, a series of control visits are scheduled, which will be done during specific periods that might take place between 3 months and a year. *"It is obvious that the PLWD and the caregiver enter a long period of loneliness, especially due to the widening of the medical visits."* Some point out that *"initially, there is a lack of guidance and specific useful information to facilitate these first meeting processes between the dyad and the diagnosis."*

The group identifies the need of *"palpable information directed to the dyad, especially to the PLWD, the carer and the family. In an ictus case, the PLWD and their families receive detailed information, both written and verbal when receiving the diagnosis, about everything that might happen and that needs to be taken into account. However, it is not like this when it comes to PLWD diagnosed with Alzheimer or with a cognitive deterioration illness, and their families."*

On the other hand, it is pointed out that usually the carers are people who also suffer pathologies, *"they are usually 60 year old women and their health is not excellent, which implies a risk factor for them. That is why their burden and surroundings need to be perfectly identified in order to organise it so that they can receive help and also be taken care of." "This is identified as a key point since taking care of the carer, the person with cognitive deterioration is also being taken care of."*

"There are stages in which the PLWD does not allow being taken care of since they do not recognise what is happening to them, they are not aware of their needs or real problems. This makes it much more difficult for the carer, worrying them and uncertainty, for example:

how can you transmit a carer to an Alzheimer PLWD (maybe their partner in life) who cannot go out on their own, who cannot light the fire without supervision, whose daily activities need to be supervised?"

"Surely it all implies a both physical and emotional overstrain that can deteriorate the carer as well as the PLWD. Therefore, the PLWD and the carer are a dyad, which is a relational unit that mixes emotions, burdens, responsibilities and challenges that have to be assumed by its both members, although progressively tipping towards the carer, who will have to assume most of the tasks and cares, trying to coordinate and involve their closest circle."

Regarding the activities:

The group expresses how the neurodegenerative illness' impact affects PLWD and professionals' everyday life.

Usually, "the carer does not accept what happens to the PLWD." Many reactions of the person who is taking care are related to thinking that they are just trying to annoy them and do not understand that the family member affected by Alzheimer does not have the same perception of reality that they used to have.

Participants unanimously express that "the carer cannot, does not know, does not want to share what they are going through with the family because sometimes assumes it is his or her only responsibility, unique and non-transferable. Taking care of the sick person is a moral obligation that they need to assume lonely and quietly. Frequently, they lose communication with their closest surroundings, leading to a point where the burden or pressure reaches unhealthy levels. Then the carer might fall ill.

A dynamic that generates a "non-communication" of needs and problems begins, causing isolation and even more pressure on the carer.

There are two important aspects for the carer regarding their daily activities and that professionals identify as important to take into account.

"First of all, finding break moments (to breath, even if it is just to go peacefully to do the daily shopping…) and secondly speaking, sharing and knowing and being aware of all the support points that they have around them."

Helping to understand that they need these spaces, moments and breaks on a daily basis is crucial for the carer to be successful with their caring tasks. But often, the moral obligation imposed and misunderstood causes the assumption of a suffering that "has to be felt", assuming that it is normal and valorising a lot if it is recognized. Socially, there is a recognition that identifies and values the burden. How to break these taboos? The group thinks there are two things the platform should work on:

"Explaining the process that will take place during the illness, and that there is not a big enough reason to focus all the burden on a single person due to the fact that the cared

person will change and will generate some unintentional problems that will have to be assumed step by step and with enough success guarantees."

"Individual education and advice is very important, but the group sessions (usually organized by associations of PLWD' families) are even more positive. Group spaces can be used to share and vent, but they are rarely done". Being able to directly relating with people in similar situations can break barriers, stereotypes, help sharing feelings, "*a space where the carers can find a relief when they realize that they are not the only ones suffering problems that, until then, they identified as exclusive and unique. Identifying their own problems in third parties approaches the affected person's point of view on the problem to its solution, by getting closer to others."*

At the same time, experts from the interviewed group point out that the most frequent problems shown by carers when taking care of a person who suffers dementia are:

"Behavioural problems (aggressiveness), lack of resting, always having to be careful with the PLWD, repeated questions and behaviours by the PLWD (they take off their diaper repeatedly, they ask the same question once and again…)."

On this topic, the group starts a round of examples about how carers have found easy and imaginative solutions to specific problems. They identify the creation of a data base with small advice as important, where everything that the socio-sanitary and family ecosystem collects as knowledge is shared and transmitted and submitted to different points of view.

Regarding the context:

On this aspect, the interviewed group thinks that *"it is very important that the close circle is informed, so that they become identifiable support points and are constantly aware of what happens (financial issues, medication, management of resources...)."*

The way in which families are encouraged to do an estimate, both economical and logistical, is explained, but this is harder when there is not an identifiable or well defined family nucleus.

"The lack of resources in front of dealing with the problem, especially when there is just a single carer, makes the task far more complicated. Sometimes, carers happen to be ashamed of sharing what is happening to the PLWD, especially because of "what will they think". Clearly, this can lead to a bigger risk both for them and the PLWD."

"Family surroundings, the dyad's close circle, must be boosted in order to making them aware of the daily tasks, letting them know that they can help even if it is just in a precise and particular moment."

The intimate circle surrounding the dyad can be of potential help, but most times, socio-sanitary professionals do not encourage this role. The main carer has needs that usually are very far from what the family can give. "*Identifying well the close circle and knowing how to manage it would help to share tasks, even if they are very concrete, in order to release some burden from the main carer and making help more effective."*

A dyad's basic needs must be firstly identified, and an effort needs to be made to find out who might be the main characters of the close circle, who might have a key role. In this

sense, socio-sanitary professionals might identify some concrete problems which usually are different to those identified by the main carer. A good problem and need identification method must be established in order to help the dyad in a more effective way.

"There are common basic needs in all carers, who professionals identify as: Firstly, having open communication with the close circle to avoid the carer's isolation. Secondly, keeping the close circle supportive as a team and not letting them give their back to problems."

"For that, it is essential to capture the moment in which the intimate circle proves to be close and shows willingness (children, friends, associations...) so that socio-sanitary professionals find it easier to connect it directly to the main carer's needs, avoiding the reach of the disconnection moment which tends to happen due to the illness' complexity or, in some occasions, the natural isolation of this processes mentioned above."

In order to deepen in the identification of the intimate circle and of how it can take an active part with the problem, it is pointed out that *"extended and open, not individual interviews to family members and friends should be done."*

There are also other carers, such as the role of the "expert carer" that can really help other dyads. They are carers who, with their experience, can help other carers to take decisions and solve problems. Being able to connect and get benefits from this relationship should be supported. *"Identifying expert carers and making them participate in order to suggest solutions the surrounding problems would truly help to unblock hard situations."* The creation of a group of expert carers would help other carers to be effectively aware of many problems, bringing great knowledge. This fact would mean a possibility of expanding the carer's support group.

Regarding technology:

Regarding the facilitation of technology associated to the neurodegenerative illness' impact, it is suggested to the group if they find difficulties on a daily basis when using technology to make the information transmission between professionals easier. It is interesting how they mention that *"currently we go to the houses just using pencil and paper and, later, the information is introduced into the clinical course and the information is shared during clinical sessions, between professionals."*

But it is noticeable how this information introduced in the clinical file is only available for a part of the professionals related with a dyad, and that for example it would be really interesting and useful for the social worker to be able to access: *"as a social worker, the medical team's information is not available for me, I know nothing about the woman who asks for help to take care of the PLWD, and I start from the very beginning. This is clearly very distressing for the carer."*

Identifying correctly who is involved in this support process for the carer would be very important; having this information and organizing it would help the social worker to be able to know where to find the necessary resources in order to guarantee the solution to a concrete problem.

TREATMENT versus TECHNOLOGY

The adherence to the treatment is around the 30% and, in cases of advanced dementia, it is only a 10%.

During the first stages, the group finds key points focussed on increasing people's adherence:

"When the first diagnosis is done, the family members receive the information to know what the medication is for. They are told that it is not a cure, but that it slows down the process, and this leads to a bigger awareness of the family. They are also put in contact with other Alzheimer families."

"But the adherence should also be strengthened during the medication's prescription period by using strategies that remind the PLWD's close people all the benefits of the medicine. This way the putrpose and the use of the drug would be stronger, increasing the adherence. They have extra information because they have the facility of calling if anything happens. They can keep a daily contact with the hospital's professionals. However, the professionals' group discusses if the families can really have this option (of having direct access).

But just knowing that they can call, that they can make contact, gives safety to the PLWD. That's why the professionals' group is suggested to identify which type of communication would help each person. Are there other ways that could help? We cannot restrict ourselves to a single way of communicating or giving information.

They identify that the information could also be transmitted through e-mail, virtual visits, etc. An analysis should be done on this issue so that the platform could share this information.

3.7.5   Conclusions

FIRST APPROXIMATION TO THE SYSTEM OF METACATEGORIES AND FOCUS GROUP'S EMERGING CATEGORIES

The following table is a first approximation to the group of meta-categories and categories that have emerged from the focus groups' information. On a methodological level, there have been created 4 thematic areas (People, Activities, Contexts and Technology), including questions directed to working on each one of them.

Subsequently, after the data analysis, an emerging categories (inductive) and meta-categories system has been built. To do so, the Glaser & Strauss (1967) "*constant comparisons*" system has been used. It combines the coding of inductive type categories through the basic data items that explain the phenomenon we want to address.

This information has been classified and grouped by comparison, contrast and ordination, in nucleus of shared meaning. Data traceability has been always maintained, so that each category allows identifying the set of units of meaning associated. With all this, we're looking for the participants' attitudes, perceptions and opinions, rather than looking for generalizations or transfer to other fields or contexts. Therefore, the different involved groups' points of view are reflected.

A total of 6 meta-categories and 30 categories have been identified

METACATEGORY	CATEGORIES BY GROUP		
	MEDICAL-HEALTHCARE	SOCIO-SANITARY	DYAD
0. PLATFORM'S OVERALL CONCEPT (Black box)	MA.0	SS.0	DD.0 DD.0.1
1. PLATFORM'S AIM	MA.1 MA.1.1	SS.1 SS.1.1 SS.1.2	DD.1 DD.1.1 DD.1.2
2. PLATFORM'S USE	MA.2	SS.2	DD.2
3. COMMUNICATION SYSTEM AND CHANNELS	MA.3	SS.3	DD.3
4. BUILDING OF SYNERGIES	MA.4	SS.4	DD.4
5. EMERGING VALUES (that the platform must have and enhance)	MA.5.1 MA.5.2	SS.5.1 SS.5.2 SS.5.3	DD.5.1 DD.5.2 DD.5.3 DD.5.4

IDENTIFICATION OF METACATEGORIES AND CATEGORIES

METACATEGORY	CATEGORIES BY GROUP		
	MEDICAL-HEALTHCARE	SOCIO-SANITARY	DYAD
0. PLATFORM'S OVERALL CONCEPT (Black box)	0. Registration and experience studying space	0. Platform as a cohesive core, connector and disseminator	0. Reference and anchor point at double level: for private use and for taking care of the PLWD 0.1. Humanization and empowerment of the dyad regarding the illness
1. PLATFORM'S AIM	1. Conducting of global and integral studies - Sharing cases - Sharing solutions - Source of informational resources 1.1. Decision making	1. Supply of resources at two levels: a) professionals; b) PLWD-dyad, and of different typology: - Informational and formative resources. Sharing cases and solutions - Logistical Resources - Emotional Resources 1.1. Sharing cases/solutions	1. Supply of different types of resources: - Informational and formative resources. Knowing/Disseminating cases and sharing solutions - Logistical Resources - Emotional Resources 1.1. Specific information about: - Cures

		1.2. Decision making	- Treatment - Evolution 1.2. Decision making

2. PLATFORM'S USE	2. Tracking at double level:
	  a) PLWD;
	  b) dyad
	Regarding:
	  - Agenda
	  - Warnings
	  - Prescriptions
	  - Drugs
	  - Data cross
		2. Tracking and evolution of the PLWD-dyad. Improvement of the clinical record's management.	2. Tracking of the dyad's both nucleuses. Everyday management's improvement (tasks).

3. COMMUNICATION SYSTEM AND CHANNELS	3. Fluid and direct contact with the PLWD, through two modes:
	  - on-site
	  - on-line
		3. Knowing the dyad's surroundings/context:
		  - Detecting synergies to unite the dyad's immediate surroundings.
			3. Contacting other professionals, other dyads, other experts, etc.

4. BUILDING OF SYNERGIES	4. Cohesion between professionals in the dyad's pro and benefit.	4. Cohesion between professionals in the dyad's pro and benefit.	4. Support for carers from:
			  - medical-healthcare staff
			  - Socio-sanitary
			  - Family
			  - Surroundings: from other carers, to experts, etc.

5. EMERGING VALUES (that the platform must have and enhance)	5.1 Rigour 5.2 Accessibility	5.1 Rigour 5.2 Accessibility 5.3 Clarity	5.1 Recognising the task done 5.2 Inner peace 5.3. Sense of duty/Moral obligation 5.4. Perseverance, steadiness

To define the meta-categories, we started off with analysing how each category was working, observing that the following needs for the platform appeared in a natural way:

- **Platform's overall concept**: This meta-category is defined as 'how should the platform be?'

The fact that focus groups answer unanimously, a space where what people know, experience or ignore can be evoked, was analysed. While being a space to register all of this knowledge, experiences and information, it is also a connecting link for professionals both from the clinical side as well as from the carer, considered also a professional of healthcare.

- **Platform's aim**: This meta-category is defined as the ultimate goal that the platform should achieve. The groups agree unanimously and consider that it should be a base of cases, solutions to different situations, resources (not only informative but also logistic and emotional), where solutions to cares and to evolutionary moments that will eventually happen can be found, and at the same time, all this information would facilitate decision making since those could be shared.

- **Platform's use**: Defined as "what type of functionality would you give it" to enrich the meta-category of the platform's aim. Participants from the groups identified very enlighteningly aspects such as: a double level tracking of the PLWD and the dyad, as well as of an agenda, warnings, prescriptions and pharmacological control; that it could be used by the dyad to keep its tracking and that it allowed medical-healthcare and socio-sanitary professionals to observe their evolution or difficulties and have a communication channel between them.

- **Communication system**: Defined as one of the most important meta-categories by all of the groups, it is what allows the platform to have a smooth and direct communication with the PLWD, both on on-line and on-site levels, allowing to know the dyad's surroundings and context in order to detect their needs and help with their closest environment, while it allows the dyad to be in contact with the evaluations and tracking by the professionals.

- **Building of synergies**: It is defined as a value that the platform should provide, the cohesion between professionals and the dyad, and the dyad with the medical, socio-sanitary, family staff or other groups of experts in order to unify efforts for everyone's benefit.

- **Emerging values**: It is defined as a meta-category that should give rigour, accessibility and clearness to the platform as well as recognition to the cares that each group perform.

In this emerging values meta-category, regarding the dyad's category, the categories of sense of duty/moral obligation/perseverance and steadiness do not regard to the platform's characteristics but to those that it should grant or provide the carer with, when making use of it.

3.8 UHULL Report

3.8.1 Introduction

In order to improve the CAREGIVERSPRO-MMD platform, individual semi-structured interviews were held with people with dementia or mild cognitive impairment, caregivers and professionals in order to gain their input and feedback on the design, development and user-friendliness of the platform prior to the pilot study.

3.8.2 Methodology

A mixed method, user-participatory research design was adopted. Individual, semi-structured interviews were carried out in order to gain in-depth feedback from key stakeholders. Participants were interviewed between June to July 2016, and interviewed in various locations depending on the participant. For people with dementia and caregivers, interviews took place either in their own homes or in a local meeting centre. Professionals were interviewed at the University of Hull and at the Hull Memory Clinic.

Participants were explained the purposes of the research using the Participant Information Sheet (see the Appendix) and were given the chance to ask any questions. Each participant gave informed consent and understood that taking part in the research was voluntary. During the interview process, participants were asked to complete a demographic

questionnaire, which included answering questions such as their date of birth, gender, work status, dementia diagnosis, number of years caring. The demographic questionnaire was tailored to each type of participant group (see description of participants in 2.1 below). Participants were then shown a series of short demonstration videos, showing them how to use the platform. We then demonstrated the actual platform to participants by logging them into the platform using a Mac laptop. Each participant group have their own unique account, to demonstrate the different functions of the platform to meet the needs of the different users. We gave participants around 30 minutes to trial the platform. Participants were then asked a series of statements that they had to rate based on a Likert scale of 1-10 (1 being 'strongly disagree', 10 'being strongly agree'), on how they found using the platform. Finally, participants then completed a semi-structured interview, providing qualitative feedback on the design, content and user-friendliness of the platform. Again, each participant group were asked different questions according to their role in the platform.

The University of Hull actively participated in the development of the protocol for this study as well as in the development of the testing materials, such as questionnaires, consent forms and participant information sheets. Ethical approval to conduct this research was obtained by the University of Hull. Approval was also sought from Line Mangers to interview professionals and from the Butterflies Memory Loss Support group.

3.8.3   Description of Participants

Three participant groups were selected;

1. People with dementia or mild cognitive impairment living in the community
2. Caregivers of people with dementia or mild cognitive impairment
3. Professionals working in the field of dementia care

These groups were selected as they reflect the target audience of the platform. Four people with dementia or mild cognitive impairment, five caregivers and six professionals were interviewed (N=15). People with dementia and caregivers were recruited through the Butterflies Memory Loss Support group; a charitable organisation run in Hull and East Riding of Yorkshire. Professionals were recruited through the University of Hull and the Hull Memory Clinic.

3.8.4   Results

People with Dementia[19]

Open Questions from Personal Information Questionnaire

Question 1. Have you ever used an application or a webpage about memory disorders? What was your experience?

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[19] Please note that one PLWD did not manage to complete the testing session because their attention was distracted even during the demonstration videos.

One person reported previous experience with websites for Parkinson's disease, but no experience with websites for memory problems or dementia. Two people reported no previous internet experience.

Question 2. What means do you use for managing of your personal medical data and treatment plan?

One person reported that they record their clinical appointments on a computer. They also have a Lifeline device, smoke and heat alarms, and a carbon monoxide detector. The second person owns a smoke alarm. The third person relies on their caregiver for remembering medical appointments.

Question 3. How the internet and ICT technologies might support you or meet your needs on treatment management?

Two people supported the view that they are not sure or aware of how internet could help to meet their needs. The third person reported that technology, such as a touchscreen device, would be good in theory for reminding people's medications; however, this would require them to carry touch screen or phone with them all the time.

Question 4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)

People (N=2) provided a negative response because they could not find any positive effects. A third person reported that games would be interesting to train their brain as long as they are familiar with the game.

Question 5. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.)

Two reported no interest in online games. Another person reported that they would be interested in games which train the brain, such as cross-words.

Open Questions from Platform Questionnaire

Question 1. How could we improve the design? (Colours, fonts, layouts, etc).

Colours: The smiley faces are helpful (N=1). One person reported that 'the colours are reasonable' but a bigger contrast between the font size and the background would be helpful.

Font size: Three people reported a bigger font size is necessary. Some signs, such as little arrows to control who can see your information (public/friends/private) should stand out more (N=1). A larger screen, or creating more pages to present the same amount of

information would be helpful (N=1). The option to enlarge the screen would also be helpful (N=1).

Question 2. Please indicate which tasks/steps were more difficult to complete.

One person could not provide a reply to this answer because the font size was too small and they could not use the platform[20]. Another person argued that it was difficult to understand the purpose of 'Circle'. Completing the questionnaires in the 'Circle' and searching for friends was difficult (N=1). They would prefer to be able to type someone's name to find them.

Question 3. What were your expectations regarding the platform?

People (N=3) could not provide an answer to this question because they were not sure how the platform could help.

Question 4. What features would you like to add in or remove from this platform?

One person reported that my 'Circle' should be separated from 'Treatments'. The second person could not provide an answer because they were not sure what the platform is about. A third person believes that it would be interesting to add food recipes in the platform, or to be able to share food recipes with other users. In addition, video communication and video calls could be very helpful for contacting people who live away (N=1). One person reported that it would be helpful if the platform could show the date and time.

Question 5. What kind of self-reported questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).

One person was not keen in using the questionnaires because they feel it is embarrassing to share any problems and conditions they have. The second person reported they could complete online questionnaires if they owned a device (e.g. computer), but they did not feel they have a problem that they should monitor. Although the third person was not interested in questionnaires, they would not mind to complete any questionnaires which might be useful for health professionals.

Questions 6 & 7. How do you understand what is a social network and its benefits?

Could you describe in your own words what is a health online community and its benefits?

On person was familiar with using social networks (Facebook) and online health community' pages within this network, such as the 'Butterflies Memory Loss Group' page. The second

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[20] Please note that this person was wearing his glasses during the whole testing session.

person was not familiar with social networks. The third person believes that social communication is very important to them.

Question 8. How sharing your experiences with others and ask for support makes you feel?

One person reported that, although they could share information with others, the sharing function to select who can see your information is necessary. For example, they would not like to share information about medical information. A second person would feel embarrassed to share information with people they do not know. The third person was not worried about sharing information in the platform and believes that sharing information is important to seek help and advice from others.

Question 9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?

The 'Friend' section could be useful to seek help when needed (N=1). Two people reported that they would not have any problems to share this information with others, including caregivers, doctors and other health professionals.

Question 10. Is treatment adherence important to you? How a web platform could help?

One person believes that alerts and reminders would not be helpful because they prefer to use calendars and they are used to them. The same person believes that alerts and reminders could be helpful for people living alone. The second person believes that alerts and reminders could be helpful for future memory problems. The second person also reported that alerts and reminders would not be useful to them now because they do not have any memory or medical problems. The third person believes that alerts and notifications in the platform could be 'better than nothing'; however, a loud alarm for notifications would be useful because people cannot use the platform all day long.

Caregivers

Open Questions from Personal Information Questionnaire

Question 1. Have you ever used an application or a webpage about memory disorders? What was your experience?

The majority of people (4 out of 5) responded in a positive way, and reported that they have experience in using websites for memory problems. Three people have used the Alzheimer's Association and the Butterflies Memory Loss Support Group's websites. Two of them have used also Google search engine to search for problems related to dementia. The third person reported previous experience only with websites for physical problems, not related to memory problems or dementia. Another person reported no previous experience with applications and webpages.

Questions 2 & 7. What means do you use for managing of your people living with dementia medical data and treatment plan?

What means do you use for managing the treatment of your people living with dementia?

People reported that they use calendars (N=2) or just try to remember and remind to their loved ones their appointments (N=2). To manage medication, they use Nomads (N=1) or a tray in a basket (N=1).

Question 3. How the internet and ICT technologies might support you or meet your needs on treatment management?

The platform could be useful for reminding their loved one's medication and appointments (N=2), but they would prefer any reminders and alerts to be received via familiar devices to them, such as phones (N=1). Monitoring PLWD mood would be helpful as well (N=1). Another person was unsure for the usefulness of a platform because people who have to use it on a frequent basis. One person reported that they do not believe that Internet or ICT devices can help them more than the means they are currently using (calendar and tray) because their loved one would not be able to understand their use. For the purposes of treatment management, it would be helpful if the platform shows the date, time and weather to people in order not to miss their clinical appointments.

Question 4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)

All people (N=5) believe that there might be positive effects of games on the platform, especially if these games provide memory and brain training (N=2). A positive effect is being in contact with other people through games, if team/collaborative games are available (N=1).

Question 5. What other computerized means do you use for risk detection and conditions prevention?

Three people reported that they use vibrating smoke alarm systems, placed under their pillow. One person mentioned that they have their doorbell connect to a wireless device, which flashes and produces a loud sound when someone rings the doorbell. Handle rails are also used in steps and toilets (N=1). Heat sensors and smoke alarms are placed inside the house (N=1). Finally, two people reported that they own a lifeline pendant alarm. They can press a button on the device, and medical help will arrive.

Question 6. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).

Two out of five people would not be interested in games on the platform because they find it a 'waste of time' (N=2) or because they are no interested in games (N=1). Another person

stated that they could try the games if they are available. Two people reported that, although they are not interested in games themselves, the games might be interesting for other people. Two people believe that they would be interested in leisure games, such as card games or time management games, while memory and brain training games, such as cross-words and Sudoku, would be interesting as well (N=2).

Open Questions from Platform Questionnaire

Question 1. How could we improve the design? (Colours, fonts, layouts, etc).

Colours: Two people reported no problems with the colours of the platform. Another person felt that there is not enough variety in colours and pictures and that there is 'no use of having white lettering on a write background, I cannot see very well, I need a bigger contrast such as black letters on white background'. The third person could not provide feedback for the colours because it is something different and new to them.

Font size: People underlined the need for bigger font size (N=4), or the option to enlarge text (N=1), while another person thought the font size is adequate. One person reported that there is not enough variety in lettering.

Layout: Three people reported that the 'Café' function could be improved because there was another word covering the word 'Café' (N=1). In addition, the word 'Café' is not very clear and the name is confusing (N=3). One person suggested to rename the 'Café' to 'Forum' or something similar. Other suggestions are to rename the function 'Private messages' to 'Messages' (N=1), separate the questionnaires from my 'Circle' function and rename them to 'Questionnaires'. Hence, symbols for private messages and alerts would be better to be replaced with words (N=1). 'Following' can be confusing for PwD (N=1). For another person, the design and layout is very clear to them.

Question 2. Please indicate which tasks/steps were more difficult to complete.

One person reported that visiting the 'Café' and finding my 'Profile' was challenging. Another person believes that PwD would need help to complete their 'Profile'. Two people believe that there are no difficult parts of the platform, once people become familiar with it, but it would not be easy to use for people with dementia (PwD).

Question 3. What were your expectations regarding the platform?

People were not able to answer this question because they have not used the platform enough (N=1), because they 'need to see it further developed' (N=1), or because it is something different and new to them (N=1). One person also reported that it could be useful for people being diagnosed with dementia in future, if they are introduced to the platform early enough. Another person reported that they expect help and information

when needed. Contacting health professionals and finding localised information is a 'brilliant idea' (N=1).

Question 4. What features would you like to add in or remove from this platform?

The selection between public or private settings, the 'Circle function', and the 'Support' section seem to be useful (N=1). One person reported that 'I like the assurance that medical people will be on the website'. Another person believes they might use the 'Café' section and they cannot see anything missing from the platform because there is no cure for dementia, and people can only get any information available. Two people confirmed that there is nothing missing from the platform, but the platform for PwD should be very simple (N=1). On the other hand, one person found it difficult to navigate around the platform. Another person believes that her loved one will not understand or will find judgemental other people in the platform if they do not know them. The 'Friends' function is not useful because not many people in their social environment 'have the same interest regarding memory' and thus, two people would prefer to be able to type names so that they can find their friends. Finally, it would be interesting to include information about opportunities to participate in research in the area (N=1).

Question 5. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).

Three people reported that questionnaires about memory and mood/how people feel would be useful. A fourth person reported that PwD might be in denial and not want to read/see information or questions about dementia. In addition, this person reported that they are not interested in monitoring their loved one's mood because this is a private information. However, one person believes that caregivers will complete these questionnaires on behalf of their loved ones, because PwD are not aware of memory loss or other dementia symptoms and thus, they would not be willing to complete any questionnaires related to dementia.

Questions 6 & 7. How do you understand what is a social network and its benefits?

Could you describe in your own words what is a health online community and its benefits?

Three out of five people were familiar with the term, which they understand as networking and getting connected with others. Another person believes that the term 'social network' refers to people 'sharing life and events on internet'. A reported benefit was contacting people who live away (N=1).

Question 8. How sharing your experiences with others and ask for support makes you feel?

One person reported that they would not like information to be public, and they approved the choice of selecting the audience for each information (public/friends/private). Another

person supported that they could share information as long as their loved one (PwD) would approve it. The third person believes that they would not share much information, but they might be interested and reply on information shared by other people. Two people would be interested in sharing information as long as they can control who can see this information.

Question 9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?

Three people believe that the idea of sharing information with a healthcare professional in the 'Circle' (e.g. a Community Psychiatric Nurse) is good. One person was satisfied with the fact that people are not obligated to complete the questionnaires. Another person believes that it could be useful for PwD to complete one questionnaire per month for their general condition.

Question 10. Is treatment adherence important to you? How a web platform could help?

All people (5 out of 5) reported that treatment adherence is important to them. Three of them believe that alerts and reminders could be helpful. The third person believes that reminders could be helpful for people who are introduced to the platform when they are diagnosed with memory problems or dementia. People being diagnosed in the past have already adopted coping strategies, and is not easy to introduce a PwD to new strategies. One person believes that the platform could be useful for them if it is used as a diary to remember clinical appointments. Finally, another person believe that phone reminder would be useful to them.

Doctors and Health Professionals

Professionals include: 1 Specialist Occupational Therapist; 1 Lecturer in nursing; 1 Pharmacist; 1 Specialist Nurse; 1 Assistant Clinical Psychologist; 1 Higher Graded Psychiatry Trainee (ST4). N = 6

Open Questions from Personal Information Questionnaire

Question 1. What means do you use for managing of your people living with dementia medical data and treatment suggestions?

Three professionals said they use an online system called Lorenzo, which is used to record all PLWD contacts, information and documentation about PLWD. One professional mentioned that the problem with Lorenzo is that it relies on people scanning in paper documents into the system, and sometimes the system lets you down. Three other professionals reported that they follow people's progress by pen and paper, and PLWD have their own case notes. One professional described how this can be problematic when going to work in different work bases or going to people's home, as they do not have easy access to their data or information. Another professional does dictations, and another one uses an online system

(SilverLink) for recording all clinical notes, appointments and letters. All professionals (N=6) send letters to General Practitioners (GP).

Question 2. What other computerized means do you use for risk detection, diagnosis and prevention?

Professionals use Lorenzo (N=2), or SilverLink (N=1), and assistive technology (N=4), such as calendars and clocks with the date and telephones with large numbers/simplified TV remote controls, fall prevention devices, navigation systems, telecare systems, e.g. 'Just checking in' system, which monitors a person's movements in their home; Lifelines (a pendant you pull on in case of an emergency), or PLWD passport (detailed personal and medical information about a person). One professional reported that they have an Occupational Therapist in their team who recommends assistive technology, like telecare.

Question 3. What means do you use for scientific contribution and accessing scientific material?

Three professionals reported that, as part of their professional role, they read scientific articles about research on the internet. Other professionals receive regular teaching for their role (N=1), attend conferences and presentations on new research (N=2), receive training on any changes in mental health law as well as regular updates from an online medical company relating to their speciality (N=1). Other professionals are subscribed to scientific journals (N=1), such as the British Journal of Psychiatry, use staff forums or meetings at a Memory Clinic (N=1), watch and read the news since dementia appears to be a 'hot topic' at the moment (N=1). They have the BBC news application on their smartphone, and are subscribed to the 'Health' section where they receive updates. Another professionals networks with colleagues or uses Google search engine to update their selves with recent research findings and new treatments. Finally, a professional said "it would be lovely to get updated about new information through email or via a website".

Question 4. Do you recommend an application or a website about memory disorders? Which ones and why?

All professionals (N=6) recommend the Alzheimer's Society website (https://www.alzheimers.org.uk/) as it has a good general source of information, it is easy to use, it is useful with plain language, it provides information on most common types of dementia, it provides information on medication and advice on social activities. Another professional recommends AT Dementia website (https://www.atdementia.org.uk/) as it has a lot of information on Assistive Technology. Ask Sara website (http://asksara.dlf.org.uk/) is also recommended to people. In this website, people are asked simple questions under different topics (e.g. 'Are you worried about having a fall?') and they are provided with a tailored report with suggestions. One professional said they found that increasingly, more caregivers are using Facebook and Twitter and so "I've been pointing towards organisations that use Facebook and Twitter in a good way that provide good snippets of information". The professional recommended the Alzheimer's Society on Twitter and the Crisis Prevention

Institute (CPI) on Facebook. Another professional reported that the problem they have is not having access to localised information easily and "websites having outdated information". People also like to use the Google search engine for side effects and benefits of anti-dementia drugs they have been prescribed. Another professional reported they would not routinely advise to look at websites – 'you have to be mindful of content'.

Question 5. What kind of resources or services do you think MND or caregivers may find useful or beneficial when using online websites?

Professionals reported possible beneficial effects of assistive technology (N=2), including gadgets, calendars, clocks, and medication boxes, information and support about how to manage particularly difficult behaviours or problems caregivers face (N=5), or information about local services, groups and events (N=4), as well as about benefits they can claim (N=1). The majority of professionals (5 out of 6) underlined the importance and usefulness of practical information and support, such as Power of Attorney for planning the future, "what are the next steps after receiving a diagnosis?", 'what if' situations, such as 'what do I do if my mum has a fall', or 'what do I do if my dad starts to wander the streets'. Another four professionals find educational material for dementia useful. Information about medication management can be helpful for caregivers (N=2). Four professionals supported the view that online forums, such as 'Talking Point' on the Alzheimer's Society, can benefit people because caregivers or PwD themselves can share information or help and support each other and provide reassurance on a long term basis, whereas clients in the NHS are seen briefly and then discharged (N=1). In addition, seeking advice and communicating with other healthcare professionals can be helpful (N=2). Other beneficial services and resources can be communicating with others (N=1) to reduce loneliness, reminiscence therapy (N=1), brain training games (N=1), and following or recording people's treatment progress on an online system (N=1).

Question 6. What design guidelines or ideas would you recommend to interface designers to make the platform PLWD-friendly and to enhance usability? Any 'must haves' and/or 'must nots'?

Professionals (N=6) suggested the platform should be simple, clear, with a dementia-friendly design, uncluttered, easy to use, very user-friendly, intuitive, consistent (does what is says), with accessible language, no adverts or 'pop ups', not too many clicks to get to something, having a search facility, no hidden buttons. Four of them reported that they do not understand the function of the three little lines at the top right of the page. One professional recommended to avoid any functions that minimise menus as it can be confusing. Another person suggested colourful words, maybe in bold or big letters, on the top of the main page for directing people to different webpages of a platform. A few privacy settings would be easier for PwD and caregivers to understand instead of having too many privacy options (N=1).

Question 7. In what way could an online website help professionals to improve the care they provide to people with dementia and their carers? (Information, socialization, support and advice, assessment of outcomes, follow therapy, etc.)

A useful website could provide information and support over a longer period of time instead of providing only short-term interventions on a face-to-face basis (N=3). A website could also reassure professionals that they have a resource that they can signpost people to (N=1), and enable communication with other PwD or caregivers (N=2). A website could also record PwD and caregivers' information because when their clinical appointments are booked for a couple of weeks later, important information might be forgotten (N=1). A website could also provide questionnaires and feedback with guidance on whether people need to seek help from their GP or a pharmacist (N=1). Another person reported that a website could help them gain a better understanding of their clients' activities and thus, professionals could help and support their clients in a more efficient way. An online website could also provide localised information about resources and events, as well as enable communication between health professionals and PwD or caregivers. On the other hand, some professionals reported they cannot see any benefits of online tools in their clients (N=2).

Open questions from Platform Questionnaire

Question 1. Enumerate parameters and information that you would like to see when you realize a medical control with your people living with dementia every 6 month

Professionals found it difficult to reply to this question. Some data for information they would like to monitor is provided in Question 9 below. One person reported that users will not able to provide all medical information that the platform asks for, such as cholesterol level.

Question 2. Please say how we could improve the design (if different for each please, indicate separately).

Colours: Pastel colours can be calming for PwD, whereas some people may prefer bold colours with big colour contrast between buttons and background colours (N=2). One professional finds the colours 'boring but clear'.

Font size: Not busy webpages and backgrounds could help people with eye-related conditions, such as cataracts or glaucoma, as well as people with hearing problems to read the content of the platform more easily (N=2). One professional reported that in the NHS they use Arial font size 12 for PLWD, as it is clear to read. In a similar way, audio instructions could be another way to support people with vision problems (N=1). Two professionals reported that a bigger font size is needed for older people, and that an option to enlarge text could be helpful. On the other hand, one professional believes that the current font size is easy to read.

Layout: The majority of professionals (4 out of 6) suggested to remove the option to "follow" friends, and keep only the "add friend" option. The layout was simply and clear (N=1). One professional suggested to remove the function that minimises the side menu because it can

be confusing for people and not know how to maximise it. Another person suggested to move functions, such as 'My Circle', to the top of the main page and use bold and big letters to indicate different webpages and functions within the platform. Less options in Privacy settings would be less confusing for PwD and caregivers (N=1). For example, people could be asked to indicate "Who can see my contact details? (this includes my telephone number, address)", "Who can see my profile? (this includes my name, date of birth, profile picture, motto, posts – exclude avatar as nobody understands what this is)", "Who can see my medical information? (this includes my medications, treatments, allergies, questionnaire data), "Who can send me friendship requests?". If the Privacy options were only 'Public / Friends / My Circle', it would be easier for people to understand and manage these settings. Three professionals found interesting that people can find friends according to their matching interests; however, a search facility to find friends could also be helpful. One person also reported that it would be more appropriate to suggest friends who attend similar groups (such as memory groups), or live in the same area. Although the function of the "Café" seems interesting, it can be misleading for PwD and caregivers (N=2) and thus, a different word, such as 'Talk', could be clearer (N=1). One professional suggested that it might be a good idea for PwD or caregiver to be able to give emergency contact details to an assigned healthcare professional from their "Circle", for example in case the caregiver is on holiday or if they became ill themselves. Two professionals suggested that caregivers may appreciate having an account that is separate or different to PwD accounts (e.g. maybe change the design or colours). One professional advised to change the way people respond to questionnaires by combining the smilies, the text and the circle in one clickable /tap area so that people will not try to tap on the face or the text, rather than the little circle. Three professionals advised that the icons/symbols may not be misleading for people and they suggested to use both a word and an icon/symbol to represent each function, for example to access private messages, use the word 'Messages' as well as the picture of the envelope, or for the notifications/alerts function, use the word 'Notifications' as well at the picture of the bell. Two professionals suggested to let people personalise the colour scheme of their account or profile. One professional would prefer their main page to include different information, such as her clients' profiles instead of a calendar, and a different main page for PwD and caregivers instead of 'What's on your mind?'. A more clinical aspect of the platform could be more suitable. One person found the word 'My Circle' confusing, whereas another person would prefer to replace the word 'Support' with 'Technical support' or 'How to…' because their first thought was that this function is about professionals providing emotional support to people. Finally, professionals (N=6) were unsure about what the '3 small lines in the top right hand corner' of the page were for.

Question 3. Please indicate which tasks/steps were more difficult to complete?

All professionals (N=6) were unable to use private messaging due to the limited functionality of the platform. For the same reason, they were unable to use the function for "Create new user", and to post their own research articles or cases in the Bibliography section. In addition, all professionals were unsure about how to message a PLWD or a caregiver on their caseload.

Question 4. What were your expectations regarding the platform?

Professionals were not able to reply to this questions because they do not have any expectations from this platform yet. However, one professional reported that the platform could provide useful information to make a diagnosis, including levels of functioning, PwD and caregivers' concerns. Providing this information before seeing PwD and caregivers can help to avoid upsetting PwD when sharing their difficulties. Also, if a person is completing information in their own home they may answer questions more honestly or accurately. Also, it would help the professional in their role to be able to have evidence to provide a diagnosis in borderline cases of dementia (i.e. someone who has mild difficulties but warrants a diagnosis of a dementia).

Question 5. What features would you like to add in or remove from the doctors' platform?

Four professionals were satisfied with the content of the platform, such as the bibliography and the caseload for PwD and caregivers. One professional suggested a short tutorial or guide could help people use the platform. Another professional suggested to build in instant video chat, so that as a community pharmacist they could give advice and support. Another suggestion is to include adding an audit trail, e.g. "Welcome back, this is what you did last time you logged on", to remind people what they have done previously on the platform (N=1). Another person mentioned that it may not be a good idea to let PwD or caregivers input their own medical information, as they may change it which could have implications for their treatment plan and interventions. Another professional underlined the importance of keeping a record of screen shots of any advice that they give to PwD and caregivers as evidence, or if there were some kind of way of storing the message that a healthcare professional has sent had advice to someone. This is in case there are any disputes in the future, for example people may remove the post or read it out of context. Two professionals would prefer to have their own personalised bibliography, and own selection of cases and articles, as well as their own online library. Moreover, sharing cases and articles with other professionals could be helpful (N=2). Another person was interested in a professional forum where professionals can discuss cases or interesting research articles, confidentially, and provide advice and support to each other. Other suggestions were to have a real-time chat (N=1), or to share PwD and caregivers' calendar with healthcare professionals so that their secretary can see their availability and organise any appointments and send them online invitations to remind these appointments (N=2). Another useful reminder could be sent to PwD and caregivers to complete certain questionnaires prior to clinical appointments (N=1). One person reported that it would be helpful for other professionals if clinicians could upload medical data in the platform, such as reports and brain scans. Tips for nutrition could also be useful for PwD (N=1).

One professional felt that the bar at the top of the page where it has private messages and alerts should be only for professionals, perhaps to talk to other professionals, or remind them appointments and events. The professional suggested that within the PwD cockpit, or PwD and caregivers' individual pages, there should be the function to contact or alert their clients. Another person would be interested in a risk section within the PwD cockpit, such as risk to self, self-neglect, self-harm, suicidal attempts, risk to others, safeguarding issues, vulnerability. Also, caregivers could update the risk section with recent events occurred that

needed reporting, and alert the professional. Professionals (N=2) would like to be provided with information for local resources and groups to recommend to their clients through the platform, as well as to obtain consent and access PwD and caregivers' profiles and forums and respond to their questions (N=2). Finally, one person suggested to provide messages or pop-up windows to users to let them know that the next page or more information will be presented to them soon, so that people know what to expect.

Question 6. Do you consider the platform can improve treatment adherence focus on symptoms related to the disease? How?

All six professionals believe that the platform could improve treatment adherence by utilising the reminders or alerts about clinical visits or about the time, quantity and colour or shape of each drug. In a similar way, the online forum (café) may improve medication adherence because people can ask support and advice about medication, for example if someone posts a message saying they have upset stomach from a new anti-dementia drug they have been prescribed, someone else may comment back advising that they had the same problem but that it went away after a couple of weeks (N=1). Another person believes that treatment adherence could be improved because PwD and caregivers gain a better understanding of medication, potential side effects and benefits. Also, this information can be easy to read and summarised on the platform, compared to the lengthy PLWD Information Leaflets that come with medication packs that may not be easy to understand or follow. One professional reported that PwD and caregivers should decide their selves whether they are interested in receiving reminders, whereas another professional expressed some concerns about whether users need to have logged in the platform to receive notifications and reminders.

Question 7. Do you consider the platform can improve control of the people living with dementia and prevent other diseases with PLWD and caregivers?

The majority of people (5 out of 6) believe that the platform could potentially help to monitor PwD. Another professional reported that this monitoring could be possible only if the reported information is accurate.

Question 8. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.)

Professionals would be interested in monitoring PwD medical adherence (N=1), levels of functioning including interests, personal hygiene and hobbies (N=2), quality of life (N=1), and memory skills (N=2). A sleep-related questionnaire could also be included, and people could be provided with sleep hygiene tips in their report (N=1). Professionals would be also interested in measuring PwD and caregivers' mood (N=2). Other people reported that questionnaires might not be a good idea because they may raise PwD and caregivers' anxiety or may upset them (N=3), or because they provide scores and numbers which 'do not really help' (N=1), or because there might be a learning effect (N=1). On the other hand, another professional believes that people would be interested in completing online

questionnaires and receive feedback. Five professionals suggested to use simple and generic questions, such as "I have been misplacing things recently", which require a simple YES/NO answer (see http://asksara.dlf.org.uk/). One professional suggested to include a Comments box at the end of the questions so that users can provide qualitative data and/or more information.

Question 9. Is treatment adherence important to your people living with dementia? How a web platform could help?

All professionals (N=6) believe that treatment adherence is important for PwD.

See Question 6 about how a website could help treatment adherence.

Additional questions:

Question 1. What are the barriers or facilitators for people with dementia/ older people accessing the Internet?

Barriers: Three professionals reported that the majority of elderly people do not own a computer or tablet, or that "they do not really know what to do with it even if they had it". In addition, most elderly people do not have an internet access (N=2), and internet for them is 'an unknown entity'. Two professionals believe that the cost of having Internet connection and buying a device could be an issue and having to buy an application may put people off. The procedure of going online and the ability to search for information may be daunting for older people, especially for people that have not used technology devices or Internet before (N=2). One professional mentioned that when someone has cognitive decline, they struggle to learn new information. The amount of information available online may confuse older adults, and it is difficult to know which website or internet source can answer your questions, or what search terms you should use to gather the information you need (N=3). The speed of internet connection may have an effect, for instance, if the connection is too slow, people can get frustrated and are more likely to stop accessing online sources (N=2). Security concerns might be another barrier for elderly people to visit websites, such as Facebook. Internet access and download limits might also affect elderly people's internet usage, especially if they reach the limits and cannot access internet (N=1). One more barrier for older people could be remembering passwords and keeping them in safe places (N=1).

Facilitators: Two professionals underlined the importance of simplicity on websites and applications; with a simple and easy to read layout. Another facilitator is the device, because people are more likely to be engaged with tablet computers with larger screens (N=1). On the other hand, smartphones screens are smaller, while laptops are heavier than tablets to carry (N=1). Three professionals believe that helping older adults set up an account in social media might be another facilitator. In a similar way, older adults might be benefitted from receiving education and training on how to use ICT devices and applications (N=3), as well as on their potential benefits, such as quality of life improve (N=1). Finally, support workers can

provide devices and internet access in memory groups and cafes so that people can familiarise themselves with technology (N=1).

Question 2. What are your thoughts on PwD and their caregivers sharing information on an online platform?

Four professionals supported the view that there should be no risk as long as people are aware of what their share; however, shared information should be monitored in case they bring people in vulnerable position when sharing personal information, such as their address, or financial information, such as where they keep their money. Monitoring the platform would reassure caregivers that PwD would not be vulnerable to others (N=3). One professional was concerned about PwD capacity to give consent after a certain stage, and about caregivers' rights to share personal information on behalf of PwD. If the caregiver has Lasting Power of Attorney for the PwD, then the caregiver might be covered legally to share things in the PwD best interests. Two professionals suggested that you could have a function where you 'report' inappropriate activity. One professional suggested that people who sign up to CAREGIVERSPRO-MMD platform should sign an agreement, such as 'terms and conditions'. Two more professionals underlined the importance of protection and vulnerability. Finally, one professional was concerned about how health professionals can manage situation where PwD are upset from the outcome of a completed questionnaire, such as being at risk of a heart attack.

Question 3. Any other comments or suggestions?

One professional suggested to test the platform with people to find potential gaps or unnecessary steps. Another professional suggested to be mindful of medical and legal issues.

Questionnaire results		Avg	stDev	StEr
People with dementia				
P1	D001	3.167	3.779	0.658
P2	D002	2.6	2.313	0.403
P3	D003	3.933	3.14	0.547*
Caregivers				
C1	C001	5.931	3.585	0.634
C2	C002	7.138	3.378	0.597
C3	C003	3.31	2.466	0.436
C4	C004	8.897	1.472	0.26
C5	C005	9.724	0.996	0.176*
Doctors				

D1	P001	5.8182	3.7497	0.7086
D2	P002	5.5	3.648	0.689
D3	P005	5.318	3.92	0.741
D4	P007	2.368	2.852	0.539
D5	P008	5.5	4.014	0.759
D6	P009	5.16	4.0278	0.7612*

*Please note that PwD and caregivers could not provide a response (N/A response) for the private communication questions (3 items) due to the limited functionality of the platform and the lack of participants' data/health information in the platform. For the same reason, 3 out of 6 doctors/health professionals could not provide a response for private communication questions (3 items), 5 out of 6 doctors/health professionals could not provide a response for managing disorders and treatments (3 items), one person could not reply on managing evaluations questions (3 items), and on creating new cases questions (3 items). Therefore, N/A responses were excluded from numerical results.

In addition, one PwD did not manage to complete the testing session because their attention was distracted even during the demonstration videos.

3.9 COOS Report

3.9.1 Introduction

COOSS, as a non-profit private company providing health and care services to elderly and disabled persons, brinks in various user groups to support the Focus Group approach in CAREGIVERSPRO-MMD. Both face-to-face and group meeting took place in various sites. The following sections provide a description of the participants, discuss the methodology used and present the results.

3.9.2 Methodology

In order to collect feedbacks and opinions around the CaregiversPro version and to achieve the new development requirements for the CAREGIVERSPRO-MMD platform, COOSS selected a panel of end-users to involve, both through Focus Groups and individual face-to-face interviews.

The Focus Group were the following:

Site	Place	Date	Participants	Moderator
Ancona	COOSS office	31/5/2016	1 psychologist 6 researchers in Ageing	M. Antomarini
Falconara	Daily Center Visintini	1/6/2016	1 psychologist 2 caregivers	M. Antomarini
Falconara	Daily Center Visintini	8/6/2016	1 psychologist 1 doctor 1 head nurse	M. Antomarini

The face-to-face interviews were the following:

Site	Place	Date	Participants	Moderator
Ancona		10/6/2016	1 helper	F. Scocchera
Falconara	Daily Center Visintini	13/6/2016	1 user	M. Petrone
Camerano	Daily Center Visintini	30/6/2016	1 user	F. Scocchera
Ancona		12/7/2016	1 helper	F. Cesaroni

Focus group and face-to-face interviews have followed the same process: participants have been introduced to the project's scope and activities by a member of COOSS staff involved in CAREGIVERSPRO-MMD. The platform has been initially presented with a PPT presentation. Videos have been also showed, for their whole duration (in Focus Group) and as extract of main parts (in face-to-face interview).

After that, with the support of a tablet or a PC, participants have been asked to go through the platform's functions in order to test them; caregivers and ageing professionals have been asked to define if and how the solution proposed may affect the PLWD daily life, how it may support the caregivers, and how it could be integrated in their daily work.

At the end of the demonstration, questionnaires have been submitted; some participants completed them in real time, with a support (namely in face-to-face interviews), others participants filled the questionnaire in later on, sending copy by mail or paper. The investigation has been conducted in anonymous way, so no privacy requirements have been asked to the participants.

3.9.3   Description of Participants

According to the categories of end-users and considering a wider category of Ageing Professionals, comprehensive of doctor, head nurses and, in general, experts in ageing (e.g. services coordinator), COOSS collected a total of **16 questionnaires**.

Based on the categories identified in table 1, end-users involved by COOSS are:

PLWD	2 users
Caregivers	2 psychologists 2 caregivers
Helper	2 family members
Ageing Professional	1 doctor 1 head nurse 6 experts researcher in ageing

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3.9.6   Results

PLWD

Open Questions from Personal Information Questionnaire

Q1.Have you ever used an application or a webpage about memory disorders? What was your experience?
None of the respondents have ever used an application or a webpage about memory disorders. So, no cases have been experienced.

Q2. What means do you use for managing of your personal medical data and treatment plan?
Respondents referred exclusively to paper version documents concerning personal medical data, information, diagnosis, examinations, up to treatment plan. In rare case, e-mail messages are used to communicate with the General Practitioner, but always managed by children.

Q3. How the internet and ICT technologies might support you or meet your needs on treatment management?
Respondents agreed in looking at ICT with the scope of getting easier the relationship with the General Practitioner, as an opportunity to avoid visits or mobility (e.g. to obtain prescriptions). One of the respondents also referred to ICT in terms of reminds and alarms for medical appointments.

Q4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
One of the respondents (with limitations in mobility) would expect the opportunity to get an occupation during the day and spend the time of the day passed at home ("…something to do at home, to help me pass the time, especially during the long week-end…"). One of the respondents would expect the opportunity to be in contact with friends and health professionals, as well as to receive immediate rescue in case of need ("…I'm fine but I'm worried not to be able to call for help if I feel sick…").

Q5. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).
Respondents agreed in games like crossword, rebus and sudoku, also considering some kind of socialisation forum (for the younger interviewed).

Open Questions from Platform Questionnaire
Q1. How could we improve the design? (Colours, fonts, layouts, etc).
Respondents have visual impairment, so they asked for bigger fonts, clearer (black instead of white) and easy to read texts. Also, as they are not familiar with ICT (they do not have PC) and devices (e.g. mouse), they have difficulties in scrolling down the pages (one of the respondent suffer of arthritis), so too long screen were not easy to browse for them.

Q2. Please indicate which tasks/steps were more difficult to complete.
From a 'technical' point of view, they were confused by the too many colours and by the long list of items to select (get immediately boring to read the long list of symptoms). From the 'content' point of view, they needed to be assisted during the whole demonstration.

Q3. What were your expectations regarding the platform?
One of the respondents would expected to see photos and pictures of family members (e.g. children, nephews) and also asked for the opportunity to call them through the platform (namely, one of the users previously experienced such an option in a pilot).

Q4. What features would you like to add in or remove from this platform?
One of the respondents asked to add photos and pictures of family members. But in general they were not able to provide further comments as they started get anxious with the demonstration of more complex tasks (e.g. café), especially because they were not able to interact with the platform autonomously.

Q5. What kind of self-reported questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
Q6. How do you understand what is a social network and its benefits?
Q7. Could you describe in your own words what is an health online community and its benefits?
Respondents were not able to provide answers to those 3 questions.

Q8. How sharing your experiences with others and ask for support makes you feel?
Respondents agreed in positive effects of sharing experiences with other, namely concerning their health and conditions. One of the respondent referred to the opportunity to avoid and fight loneliness when talking with others; one of the respondents referred to the importance of the network (friends, neighbours, family members) to help each other in case of need.

Q9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?
Respondents have in general great trust towards the General Practitioner so they agreed, and agree in principle, of any solution or information given to the General Practitioner with the aim to improve their health conditions. Even more, for one of the respondents, the opportunity to provide the General Practitioner with automatic information generated by the platform, is highly appreciated as enhances the feeling of security and monitoring.

Q10. Is treatment adherence important to you? How a web platform could help?
Respondents were not able to provide answers to this question.

Caregivers

Open Questions from Personal Information Questionnaire

Q1. Have you ever used an application or a webpage about memory disorders? What was your experience?
Respondents referred to scientific web pages (Centro Alzheimer.org; Fatebenefratelli - Brescia - Alzheimer; Libera Università di Anghiari - La Memoria, etc.) as a mean to obtain information about latest researchers, about innovative methods to approach the PLWD, about strategy to work to maintain the memory, about the psychological aspects of dementia.

Q2. What means do you use for managing of your people living with dementia medical data and treatment plan?

Respondents referred mainly to face-to-face interview with the PLWD, with submission of evaluation tests; in some case, the interview is also managed by phone. As concerning documentation, the management of information occurs mainly by paper version; one of the respondent declared to be under training for a new approach of management and sharing of data though on-line format.

Q3. How the internet and ICT technologies might support you or meet your needs on treatment management?
Respondents (all formal caregivers) appreciated the approach of the platform, namely in terms of an opportunity: to share opinions, to launch doubts and questions, to look for psycho-educational materials, to find training opportunity, to search for thematic in-depth analysis, to participate to experienced forum.

Q4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
Respondents referred to socialisation as first and primary effect for the PLWD. They also agreed upon the positive effects generated by the sharing of information, the mutual help amongst caregivers, the answers provided by different specialists and stakeholders, the psycho-social-behavioural support, the scientific and educational resources. One of the respondent is, anyway, sceptic in providing family members with full access to evaluations, diagnosis and therapies of the PLWD, not only because the unnecessary full understanding but mainly for a sense of respect and protection of the PLWD's privacy.

Q5. What other computerized means do you use for risk detection and conditions prevention?
None. One respondent mentioned the bi-monthly tele-monitoring of CVD PLWD.

Q6. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).
Respondents agreed in the personalisation of every intervention, to be tailored according to the PLWD, in ICT environment or not. One respondent pointed out the difficulty for some PLWD in accessing the platform, as a general principle, and foresaw the possibility only for minor NC disorders.
One respondent pointed out the requirements in terms of visual, cognitive and auditive incentives, suggesting exercises able to stimulate the emotions, the colour perception, the word-matching, the auditive recognition. As concerning writing, this need to be stimulated by hand-writing, as the keyboard risk to get lost important residual abilities.

Q7. What means do you use for managing the treatment of your people living with dementia?
Paper documents and archives.

Open Questions from Platform Questionnaire
Q1. How could we improve the design? (Colours, fonts, layouts, etc.).
Respondents suggested:
- Bigger fonts
- Images with captions
- Serene images
- Representative images (pubs or pictures of '50, even of PLWD history)

- Less visual features to avoid confusion (too much boxes as graphic layout)
- Less dark colours (the black screen is unpleasant)
- The visual impact is not clear (to organise better contents/spaces)

Q2. Please indicate which tasks/steps were more difficult to complete.
Respondents had no problem in browsing and completing tasks, but they were sceptic about the capacity to do it by the PLWD/user. One respondent claimed that the research of contents is time consuming and a more 'elementary' structure would help to immediate access and find with is looked for.

Q3. What were your expectations regarding the platform?
Respondents agreed in finding the platform a useful tool for the caregiver, able to:
- inform
- help to manage the stress
- promote the communication
- provide practical and operational information (the primary scope) about how to deal PLWD (e.g. how to cope with aggressive behaviours)
- enhance the acquisition of social and relational skills needed by the helping relationship
- offer information about services and structures of the territory
- provide a psychological, social and behavioural support

Q4. What features would you like to add in or remove from this platform?
Respondents provided different suggestions:
- to offer the platform only to caregiver, with a view to provide them with practical answers to their doubts and difficulties in managing the PLWD
- to prevent the access to discussions amongst caregivers and/or doctors to the PLWD
- to allow a better and more direct connection amongst caregiver and related PLWD (now it seems to be disconnected and out of the dyad approach)
- to enhance the comprehension of the real needs of the caregiver, considering as primary goal the provision of practical tools and hints useful to deal with the PLWD.

Q5. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
Respondents agreed with the questionnaires monitoring the anxiety and depression of the caregiver. They also suggested the inclusion of questionnaires and exercises for the residual abilities of the PLWD.

Q6. How do you understand what is a social network and its benefits?
Q7. Could you describe in your own words what is an health online community and its benefits?
Respondents did not put lot of attention to those questions; one respondent described the Social Network as a tool for socialisation and information that reveals to be useful if well organised and managed, and the Health Online Community as a group of individuals sharing the unique need of information and contents as concerning a specific need (health), together with the need of socialisation and psychological support.

Q8. How sharing your experiences with others and ask for support makes you feel?

Respondents agreed in the importance of sharing the experiences, the doubts, the burden and the information. A key aspect was, actually, the opportunity to collect all tests, evaluations and information to allow a shared and more complete assessment and monitoring of the PLWD, by all the stakeholder composing the "equipe". This is useful not only to reduce the burden but mainly to ensure a more effective assistance and intervention.

Q9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?
Respondents had no specific opinion on that. One respondent referred to the importance of such a function to support health specialist in the definition of degenerative diagnosis; but any reference to a prevention purpose or effect must be avoided.

Q10.Is treatment adherence important to you? How a web platform could help?
Respondents provided different opinions about TA, which seems to be a very delicate topic:

- the platform should avoid to deal TA with PLWD in order to avoid confusion in therapies;
- the platform should allow the therapeutic revision by the doctor in order to provide the caregiver with an always updated general frame of therapy;
- the section related to TA has to be thought for the caregiver mainly, avoiding anxiety and feeling of failure for the PLWD;
- the TA should be dealt considering the effects about information and training of the caregiver as regard the importance of the therapy.

Further comments issued during demonstration
During the Focus Group with caregivers, further free and open comments were collected.

"In general, the proposed solutions, focusing more on the support of the caregivers than to the PLWD, has the potential to be a significant contribution to support the care activity provided informally at home, in close integration with the human-based traditional care intervention. This for two reasons: at first, the platform, as it is now, can be managed mainly by persons without cognitive problems, as it asks for abilities that a PLWD lose very soon. Secondly, it is hard to imagine a PLWD able to go through the platform's functions, looking for social interactions and managing its daily life on it. Particularly, the treatment management tool seems to be a little bit "risky", because the cognitive degeneration does not allow the PLWD to properly define his/her level of adherence".

"Concerning the doctor's set of functions, it seems to be a useful toolbox, but it has to be tuned to him/her daily working activity. First of all, the category of expert addressed has to be clearly stated: who's meant to use it? A GP? A Psychologist? As it is, it seems to be more suitable for a specialised medical expert than for a GP: first of all, for a simple reason of numbers (GP's has too many PLWD and it is not reasonable to imagine him or her monitoring in remote hundreds of PLWD so in deep), secondly for a practical reason, which is the possibility given by the platform to reduce the face-to-face visits without reducing the PLWD monitoring. The possibility as well to monitoring in real time the caregiver status is a key point of strength of the platform because is a key component of an expert's interventions normally."

"The platform seems a powerful tool to allow caregivers to find solutions, tips and suggestions for very concrete circumstances that may happen during the care activity; PLWD can have unexpected reactions and caregivers may not be able to identify the proper behaviour to manage it. From this point of view, the possibility to interact with other caregivers seems to be the most effective function, with potentially the faster and deeper impact in the dyad's routine"

"A deeper attention shall be given to the users' side of the platform: a PLWD only in a very early stage of disease is able to interact with tools like this; with the time, the support of a person in interacting with the platform is mandatory; to support the users in managing the tool and to avoid any risk of wrong, unexpected or even dangerous use of it."

"Two scenarios could be imagined after the test of the platform: in the first scenario, the use of the platform is established by and agreement among the doctor and the family: the expert (specialist?) invites the family to use the platform in order to facilitate the interaction and to provide real-time support to the dyad; such an agreement seems to be mandatory to convince the family to adopt the platform in daily life, because otherwise a partial or not proper use of it does not provide any valuable information for the doctor.
In the second scenario a PLWD with reduced abilities is imagined, and his/her use of the platform progressively decreases; this scenario may happen quite soon therefore it would be better to imagine the caregivers working on the platform instead of the users; in this sense a suggestion may be the possibility for the caregivers to introduce and profile the cared person instead of let the users profiling by themselves and manage their profile directly."

"A caregiver has few time to interact with the tool during the care activity, so the suggestion goes in the direction to empower the mobile application more than the platform for the use via PC. In fact, a professional caregiver may need to find a solution for a critical situation during the care intervention, so the possibility to quickly check the mobile phone may be more useful. The remote monitoring may be applied in a structured context, as a daily centre: families could interact with the centre from home, facilitating the awareness of the experts about the dyad situation so to identify more suitable and personalized services."

Helpers

Open Questions from Personal Information Questionnaire

Q1. Have you ever used an application or a webpage about memory disorders? What was your experience?
None of the respondents have ever used an application or a webpage about memory disorders. So, no cases have been experienced.

Q2. What means do you use for managing of your people living with dementia medical data and treatment plan?
Respondents referred exclusively to paper version documents, as well as phone calls and e-mails to the General Practitioner.

Q3. How the internet and ICT technologies might support you or meet your needs on treatment management?
One of the respondents declared to be not enough digital literate to be able to answer.

One of the respondents mentioned the possibility of getting easier and quicker communication, of facilitating information sharing on what is needed among all people around ("…to make it possible that all people involved in the care process are informed: me as family member, the informal caregiver, the formal caregiver staff at the daily centre, the medical doctor, etc.")

Q4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
One of the respondents would expect an improvement in socialisation, a reduction of the isolation and an opportunity of cooperation with peers. One of the respondent would expect an opportunity to spend some time.

Q5. What other computerized means do you use for risk detection and conditions prevention?
None for all respondents.

Q6. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).
Respondents declared not to know games in healthcare application, neither their work.

Q7. How would you like to follow progress made by your people living with dementia and get informed for the activity of users related to your PLWD?
One of the respondent would like to receive information in real time, not in terms of alarms or alerts but within a framework of sharing communication and understanding, so that all people involved in care are informed and everything is planned ("…I do not expect improvements, but what I need is to be ensured that no further critical events might occur: I need to spend my time working and being sure that my mother is ok and the whole system of care (informal and formal caregivers) is working properly…"). One of the respondent precised the poor experience with ICT, and expressed the preference for very simple reminders/popups opening by themselves and warning about progresses ("… with the practice, I might learn (and appreciate) more advanced modalities...").

Q8. What means do you use for managing the treatment of your people living with dementia?
One of the respondents declared to use no means or specific tool, admitting the worry and the problem ("… this is the main problem to face right now as I'm not more sure about the adherence of the treatment of my mother…"). One of the respondents declared to take the responsibility for the treatment

Open Questions from Platform Questionnaire
Q1. How could we improve the design? (Colours, fonts, layouts, etc.).
One of the respondents expressed the preference for less colours, given the misunderstanding about coloured circle/points and asking for clearer explanation of the relationship amongst colours and roles. Also, the full name is preferred, instead of the initial.

Q2. Please indicate which tasks/steps were more difficult to complete.
One of the respondents admitted the initial confusion about circle, cafe and friends, especially for those who are registered in all ("…are friends also caregivers?"). Also, IC code in the list of treatment/medicines created confusion. One of the respondents admitted to be confused by the whole platform, being not experienced in dealing with ICT tools.

Q3. What were your expectations regarding the platform?
One of the respondent would expect to gain practical information and hints, also in terms of self-assessment of the helper contribution ("…am I doing right with my mother?"), as well as to create a better relationship with the General Practitioner ("…I cannot find him easily by phone and it is not easy to explain by phone what is happening, he is always in hurry…"). For that reason, the opportunity to let the General Practitioner the information and the whole picture in real time directly from the platform is appreciated. One of the respondents would expect something handy and easy to use, to get information and monitor progresses, also asking for proper technical preparation in order to be able to benefit from this

Q4. What features would you like to add in or remove from this platform?
One of the respondents asked for photo of the participants instead of the initial letter of the name; also, proposed to include other issues amongst the tags and interesting aspects, not strictly related to dementia and caregiving ("… not only those related with the disease or with the caregiving, but more in general, such events, wellbeing, travelling, in order to invite people to share opinions and discussion about other items and have a relief...").

Q5. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
Respondents suggested information about services available in the territory (daily centres, relief services, mutual help groups, etc.) and cognitive decrease monitoring.

Q6 .Is treatment adherence important to your people living with dementia? How a web platform could help?
Respondents agreed about the importance of TA and about a possible support provided by the platform to remind the assumption: alerts about treatment schedule, counting pills taken in a week (count-down), tricks to remember the assumption deadline.

Aging Professionals

Open Questions from Personal Information Questionnaire

Q1. What means do you use for managing of your people living with dementia medical data and treatment suggestions?
Some of the respondents referred to informative and descriptive platforms, where information about chronic diseases are stored and managed by main actors, in terms of medical data and treatments: data bases, medical records, platforms; those are the results of pilots or work in progress. Some of the respondents referred of Users Platform, with personalized health plans, training tailored on users characteristic and pathology. One of the respondents referred to traditional means such as paper, folders and archives.

Q2. What other computerized means do you use for risk detection, diagnosis and prevention?
Some of the respondents mentioned applications such as telemonitoring for falls preventions and cardiac periodic check, and more in general, telemonitoring devices.

Q3. What means do you use for scientific contribution and accessing scientific material?
Internet is the main source of information and contribution for all of the respondents, together with seminars, forums, workshops, scientific papers and pubmed.

Q4. Do you recommend an application or a website about memory disorders? Which ones and why?

Some respondents suggested the following sites:

- National and European networks (scientific sources, caregivers' community, professionals forum) as they provide the most liable information
- Web sites (www.centroalzheimer.org; www.neuropsicologia.it) for the completeness of the information and the opportunity to be re-directed to liable sources
- Previous projects and experiences (e.g. Nacodeal project: application developed within an AAL project and aiming at sustaining the daily life of people suffering of dementia)

Q5. What kind of resources or services do you think people with MND or caregivers may find useful or beneficial when using online websites?

Respondents agreed about the benefit of knowledge sharing in general, specifically mentioning:

- Exchange of experiences and case-studies with peers
- Practical advices, problem solving and good practices
- Opportunity of socialisation and sharing of personal information and experiences (not necessarily professional information, as people not well trained could not be able to use scientific sources in the proper way)
- Online Health Record
- Forum, chat and discussion spaces, non formal and informal learning opportunities

Q6. What design guidelines or ideas would you recommend to interface designers to make the platform PLWD-friendly and to enhance usability? Any 'must haves' and/or 'must nots'?

One of the respondents mentioned all items and functional requirements about usability and accessibility that need to be taken into consideration, with a special attention to personalisation of services, due to the fact that PLWD and their caregivers are not used to 'browse' and need precise and exact indication about what to do and how to do. One of the respondents suggested the implementation of games and exercises submitted by experts also during face-to-face visit and monitoring. One of the respondents referred to forum, spaces to share experiences (e.g. informal learning) and all activities related with socialisation.

Q7. In what way could an online website help professionals to improve the care they provide to people with dementia and their carers? (information, socialization, support and advice, assessment of outcomes, follow therapy, etc.)

Respondents provided different suggestions:

- Social networking services and behavioural screening able to improve the therapeutic activities
- Information and training for formal carers, support and relief to familiars
- Tailored and personalised services, in order to address to the most effective care process
- Home care and remote monitoring
- Information, exchange of good practices, opinions and advices, assessment and monitoring

Open Questions from Platform Questionnaire

Q1. Enumerate parameters and information that you would like to see when you realize a medical control with your people living with dementia every 6 month

One of the respondents suggested the 'socialisation' parameters, as a quantification of PLWD and caregivers' accesses to the platform.

One of the respondents pointed out the difficulty in standardization of medical controls, due to the several stages of dementia and severity.

Q2. Please say how we could improve the design (if different for each please, indicate separately).

Respondents provided different suggestions:

- Greater attention to the intuitivity of the platform, as not all are familiar with social network
- A more friendly design and layout, avoiding too much confusing colours and icons and with more explanations about rules in using colours (e.g. Yellow for user, green for caregivers, blue for the doctor, rose for neighbours and friends, etc.)
- Adoption of the 'traffic light logic' (green is ok, yellow attention, red is no), especially with smile icons.
- Presentation of a landing page, after sign in, providing the general framework of all information, functions and services
- Bigger icons, able to substitute long texts

Q3. Please indicate which tasks/steps were more difficult to complete.

One of the respondents mentioned the evaluation as the less intuitive, because coloured smiles are confusing instead of helping. One of the respondent mentioned adding contacts and treatments, as well as the assessment of PLWD conditions.

One of the respondents admitted to have experienced difficulties in dealing with the whole platform, adding that from the point of view of a General Practitioner, it would imply to totally change the system of recording and storing information and foreseeing an interaction with the platform only for younger and digital literacy caregivers.

Q4. What were your expectations regarding the platform?

Respondents mentioned:

- to offer different services (social, educational, clinical) targeted to the main users (people with dementia/caregivers/healthcare professionals)
- to provide help in the organisation of circle and in management of friends, giving the function to filter those living in the neighbour, in order to have occasion to meet them (not only through the platform)
- to pay more attention to the user profile and characteristics, in terms of usability and accessibility
- to find out more games and more opportunities of entertainment
- to have a more intuitive design, not so closely related with the layout logic of most common social network.

Q5. What features would you like to add in or remove from this platform?

Respondents suggested:

- user oriented game development related to dementia prevention and intervention
- charming layout, easier and intuitive
- an initial 'orientation box' appearing once signed in, providing information in terms of space and time (e.g. who are you, where you are, which date is today, etc.)
- the opportunity to 'see' the password is under typing, when logging in
- easier management of activities

Q6. Do you consider the platform can improve treatment adherence focus on symptoms related to the disease? How?
Some of the respondents answered yes, thanks to:
· closer interaction between PLWD and clinicians and social workers
· daily list of the prescriptions, as summary of the whole medical treatment for the day, including alert in the main timeframe (breakfast, lunch and dinner time).
· visual and audio-visual reminders, with immediate and in-real-time feedback
· graphic reminds and icons

One of the respondents answered no, without providing any additional explanation.

Q7. Do you consider the platform can improve control of the people living with dementia and prevent other diseases with PLWD and caregivers?
Most of the respondents answered yes, with condition that it is devoted to mild and moderate stage of dementia (otherwise other services have to be included) and that the 'triangle' user-caregiver-medical is enhanced and facilitated.

One of the respondents answered no, without providing any additional explanation.

Q8. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
Some of respondents suggested:
· collection and processing of personal behavioural data, through gamification and exploitation of social networks' services
· memory games, cognitive exercise, information about possible services to activate in case of need;
· articles, appointments, and events for the caregivers (is there any restriction in publishing a link or the text of an articles?)
· short and easy-to-fill-in scales, to assess anxiety, depression or confusion;
· evaluation of results from games/exercises/activities of users and constant comparison
· assessment test in line with the monitoring and evaluation system implemented by National Health System

Q9. Is treatment adherence important to your people living with dementia? How a web platform could help?
Some of the respondents mentioned the contribution of the platform in getting easier the contact and the monitoring by the doctor; treatment adherence to be assessed and pharmacological details of prescription are crucial for the doctor, but need for an easier and feasible solution to be managed by the PLWD themselves. Some of the respondents mentioned reminders, with special attention to the support given to the caregivers in terms of advices and hints about how to encourage and motivate the PLWD to stick the therapy assigned.

Further comments issued during demonstration
During the Focus Group with caregivers, furthers free and open comments was collected.

"It is necessary to verify the possibility to integrate the platform with tools and applications already in use by doctors and experts, otherwise it will imply an additional effort instead of a

simplification of the daily work. The involvement of General Practitioners is not easy, maybe specialists, like psychiatric, are more interested to be involved. But pay attention not to interfere with medical doctor activity (e.g. amongst doctors or specialists)."

"It is essential the agreement amongst family and Medical Doctor as it is not feasible to imagine family members that spontaneously and freely access and interact with the platform without an opinion or an involvement of a clinical professional inviting them to do it."

"In a Residential Facility, the platform could be adopted as educational tool if it is able to concretely facilitate the communication with family, whilst it is difficult to imagine in health intervention (namely with major cognitive disorders) a more intensive and complete use of the platform."

"In case of severity stage of dementia, the conditions of the PLWD do not allow to interact with the platform, so the active presence of the caregiver is crucial, as the one engaged in providing and uploading information in the platform, in communication with the medical side."

"It appears to be an appropriate tool when informing about variation in the caregiver status, in terms of stress and burn-out, but considering that the subjective dimension is dominant and it can reduce the objectivity of the assessment tool."

"In case of emergency or urgency, the icons related to ALARMS are a delicate issue, as there are legal and ethical implications that must be cleared, described and agreed upon. Also, the TA is a difficult issue, as in case of severity stage, the PLWD is not able to manage the treatment adherence and the caregiver has to intervene."

"The platform seems to have a great potential but is not enough developed; too much functions and activities are missing in order to provide a clear identification of the potential impact."

3.10 Overall Interview Results and Additional Requirements

People Living With Dementia - Demographics
Part A: About you
From the total 16 PLWD who participated in the first interview cycle in June-July, 2016, 9 males were and 7 females. Their average age was 78.68 years old (SD = 5.34), while they had first diagnosis 4.46 years (SD = 2.50) before the time of the interview. People with Major Neurocognitive Disorders were not recruited, so participants were split among the other two categories, 9 people with MND, 6 with mild to moderate conditions and one case reported no Neurocognitive Conditions.

9 people reported they were wholly retired from work and another 7 reported they were under social pension (implied not fully retired). The main type of Employment Status (if not retired) was not filled by most participants, but 2 implied employee status and 1 self-employed and contractor.
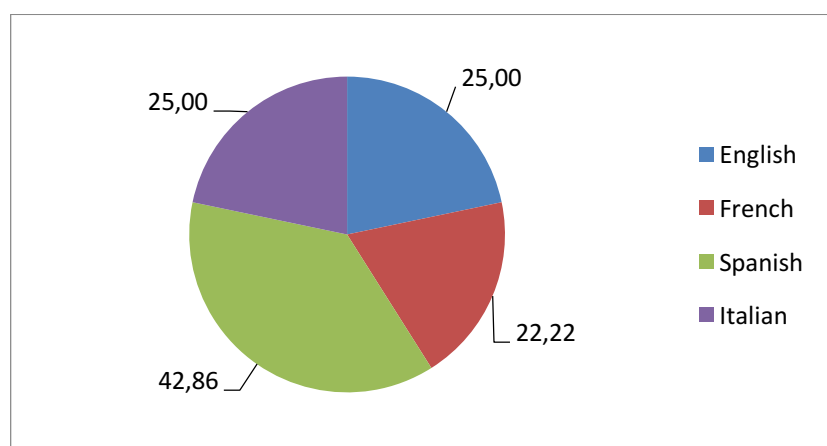
Figure 7. Spoken languages strongly depends on the site's country

A lot of people in the participants group (N=9) lived alone at the time of the interview, 6 people live with another person and 7 live with more than two people in their household. One third of them live at their homes independently, but the two thirds live at home with health care provided by family member (N=9) or a professional carer (N=1).
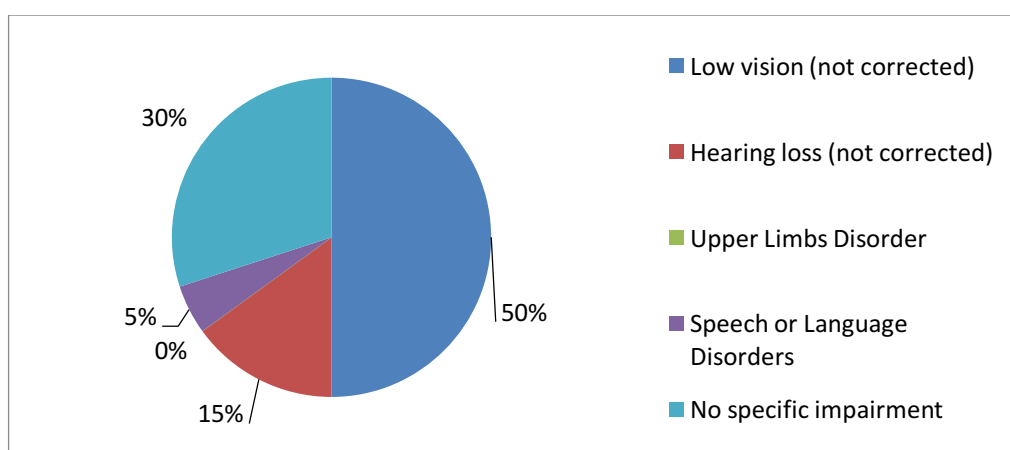
Figure 8. Frequencies of visual, acoustic, or motor Impairments

An important part of the demographics questionnaire is related to impairments other than cognitive. Figure 8 presents the frequencies of the visual, acoustic and motor impairments reported during the interviews. According to participant's responses, the most common impairment was low vision (50%), followed by hearing loss (15%). One third implied no specific impairment and one case reported Speech or Language Disorders.

Part B: Use of Technology/Communication means

The 70% of participants stated that they do not use the Internet. From only the two people who make use of the Internet, one stated communication (email, video chat, etc.) but the other one stated a wide list of activities like communication, Online Shopping/Selling, News Reading, Social Networks, Social Networks and Looking for medical advice. It is interesting to note that from those two people, one uses a personal computer and the other one uses all kind of devices (PC, Tablet/iPad, Laptop and Smartphone). Thus, we can assume –for now- that people who use the Internet may not face difficulties in using any kind of end-device.

In the question 'What other means of communication do you use for socialization with other people living with dementia?' the answers were divided equally between 'Club (reading, games, craft, sport…)' and 'Memory workshop (in a institution) or day hospital'. Similar answers were given in the question about means of communication with doctors and your caregivers. The 50% (N=13) responded that they have face to face meetings at home or doctor's office. The other half (N=14) said they communicate through telephone and only one reported mail conversation.

People use different for treatment management. The 22% (N=4) has no preparation and the 30% do not prepare the treatment themselves but the caregivers.

Part C: Gamification and Games

An interesting part of the interview is dedicated to attitudes against games and gamification. The 68% of participants do not play games and 18% said they play once a week and 12% said they play every day. From those who play games, two had positive experiences, one reported negative experiences and the other two reported in barriers using games.
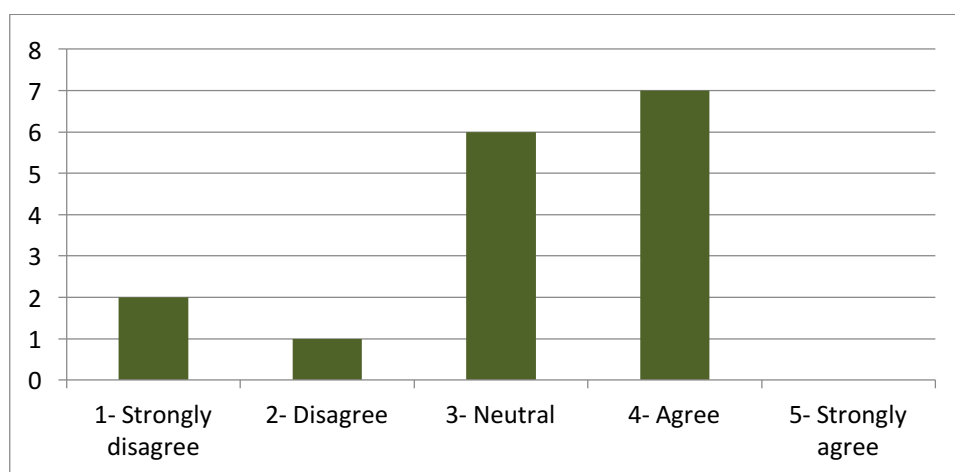
Figure 9. Responses to 'I believe that a game-like experience from an application or a webpage would motivate me to participate'

Figure 9 presents how participants responded to the statement: 'I believe that a game-like experience from an application or a webpage would motivate me to participate'. The 18% of participants were negative (Strongly disagree or disagree), the 37% were neutral, but the 43% believe that game-like experiences could motivate them to participate. Although PLWD were not negative to having gamified experiences from the platform, the majority of them do not expect to be benefited more from the gamification component (68%).

Part D - Semi-Structured Interview

Most people reported no previous experience in using an application to learn about cognitive diseases and others reported no previous internet experience. Personal medical data are managed with an agenda or with professionals (ie: pharmacist) and those data, including clinical appointments are stored on local computers. In some other cases, respondents referred exclusively to paper version documents.

Some PLWD participants did not know, or were not sure how the internet and ICT technologies might support them on treatment management. But others agreed that with ICT it could be easier the relationship with the medical professionals, as an opportunity to avoid visits or mobility and also it would be helpful to have reminds and alarms for medical appointments or receive an immediate rescue in case of need.

About games, they said they would like having games and could play games (stimulation games, crosswords, sudoku….). An interesting opinion that games would be interesting to train brain as long as users are familiar with the game was reported. Respondents agreed in games like crossword, rebus and sudoku, also considering some kind of socialisation forum. But an important part of participants reported no particular interest in games.

Finally, some participants had forgotten how to use the platform and could not answer to open questions, they feel tired or they thought that those questions were too intrusive

People Living With Dementia – Platform

Closed Questions

In most usability-related questions participants living with Dementia reported no major problems in performing the required tasks based on the predefined scenarios, but the interface did not always appear as being intuitive. Moreover, values in statements of the type: 'I prefer a different design for…' over 5 simply means that new platform designers should provide a deferent interface to fulfil the needs of PLWD. A highlight in this one is the 7.07 in average given at the statement 'I prefer a different design for searching and connecting with other users' and the 6.72 in average given at 'I prefer a different design for online questionnaires and reports'. Thus, searching, questionnaires and reporting appear to be the less popular interface designs and need to be totally redesigned.

Table 14. Responses of PLWD in the usability questionnaire

Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)		
Question/Statement	**Mean**	**SD**
I encounter no problems logging into the system	4	3.13
I found logging into the system intuitive	4.46	2.84
I prefer a different design for login	6.58	3.20
I encountered no problems in locating and updating my profile	5.3	2.40
I found locating and updating my profile (my account) intuitive	4.1	2.23
I prefer a different design for profile management	5.18	2.71
I encounter no problems managing disorders and treatments	2.90	1.70
I found managing disorders and treatments intuitive	3.41	2.27
I prefer a different design for the management of disorders and treatments	6.7	2.35
I encounter no problems in searching and connecting with other user profiles	4.27	2.57
I found managing connections with other users intuitive	4.75	2.7
I prefer a different design for searching and connecting with other	7.09	2.34

users		
I encounter no problems managing posts and wall messages	4.2	1.87
I found managing posts and wall messages intuitive	4.5	2.02
I prefer a different design for managing posts and wall messages	5.72	2.49
I encounter no problems participating in an online questionnaire about adherence evaluation and reading the report	4.27	2.24
I found participating in an online questionnaire and reading the report intuitive	4	2.08
I prefer a different design for online questionnaires and reports	6.72	2.10
I encounter no problems communicating privately with users like doctors, other people living with dementia, caregivers, helpers and social workers (send personalized message, friendship request or invitation)	4.5	1.87
I found private communication with other users intuitive	4.57	1.71
I prefer a different design for private communication with others	6.4	0.89
I encounter no problems in creating a new ticket and uploading a file	4.2	1.98
I found creating a new ticket and uploading a file intuitive	3.5	2.07
I prefer a different design for creating a new ticket and uploading a file	5.5	2.44
I encounter no problems in actively participating in the café.	5.9	2.28
I found actions related to the Cafe intuitive	4.1	2.02
I prefer a different design for the Café.	5.62	2.77
I completed all tasks related to my role in the platform	4.1	1.96
I can use this platform on my own	2.83	1.85
This application was user-friendly	3.58	2.31
Did the platform respond at your expectations?	3.7	1.82
Do you understand the notion of circle in the platform?	3.09	1.70
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	4.63	2.37

Open Questions

Contrast and colour issues were reported. Splitting the information into multiple pages was reported as a helpful way to present the same amount of information without information overload. There were some issues related to the different mental models PLWD have regarding social networks. They reported the need to type someone's name in order to find him/her. Thus, they may not understand the basic functionality of an online social network in which you find similar profiles of people to invite to your circle and that knowing in advance the names of people may not be possible. So, people may feel safer if they will be able to transfer existing social structures into their online social network.

Missing platform functionality was not reported because, as responders could not find what functionality could fulfil their needs or they see no connection of Internet services with their actions towards healthcare prevention.

Caregivers and Helpers – Demographics

Part A: About you

From the caregivers group, 2 were Males and 18 Females (Total 20 persons) with average age 55.66 years old (SD = 13.64). Apart from 15 persons who were responsible for one person, the rest of Caregivers had 30.83 individuals to take care of. In the majority of cases, home was the place of caregiving services (80%) and the rest 20% was a Day Care Institution. The 60% of caregivers were relatives and members of the family. Four caregivers were working part-time (20%) professionals and another two were working full time (10%). Caregivers reported no not-corrected impairments.

Part B - Use of Technology/Communication means

Caregivers use a wide range of end-devices and make use of different Internet services. Communication (80%) and online entertainment (66%) are among the most popular online activities. A more detailed list of Internet activities can be seen in Figure 10. They use more than one device types for Internet connection: 76% of caregivers use PC, 71% use a Smartphone (Android/iPhone) and tablet and laptop share a 5% in user's preferences.
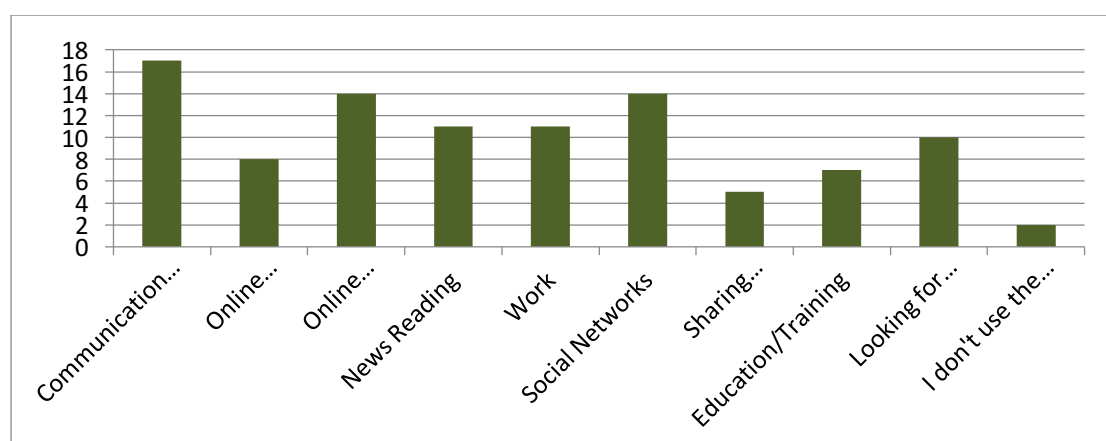
Figure 10. Responses of Caregivers to the question: 'What do you use the Internet for?'

The most popular ways of communication with doctors and other caregivers is face-to-face meetings at home or at offices and telephone conversations. Almost half of them (45%) use mails also.

Part C - Gamification and Games

Gaming penetration is relatively good and much better than PLWD, having one third playing games daily, another 33% not playing games at all (33%), 28% to play once a week and only to play in a monthly basis. This results are strengthened by the fact that 57% have positive experiences from gaming and only one person reported unchallenged experiences. Moreover, only one person reported barriers in playing games. 62% of caregivers agree that a game-like experience from an application or a webpage would benefit more and motivate them to participate, while a group of 5 people (23%) disagree on those two points.

Part D - Semi-Structured Interview

Caregivers were aware of scientific web pages about memory disorders (like Centro Alzheimer.org, Fatebenefratelli - Brescia – Alzheimer, Libera Università di Anghiari - La Memoria, etc.). Their activities in those websites was related to obtaining information on innovative methods for approaching PLWD, strategies for memory maintaining and various psychological aspects of Dementia.

Most caregivers were mainly counting on face-to-face interviews with their PLWD for managing medical data and treatment plan. Responders agreed that Internet and ICT technologies can help in sharing experiences and personal opinions, in making questions in experienced forums and looking for educational and training materials. Moreover, they have reported the psycho-social-behavioural support, but mentioned also the need to respect and protect of the PLWD's privacy.

Regarding risk detection and conditions prevention, most caregivers did not report any known computerized mean. One respondent mentioned the bi-monthly tele-monitoring of CVD PLWD. Gamification and the use of games in healthcare applications do not seem to be known to caregivers. Although they see games and game-like activities in a positive way, they are not aware of ways gamification could be connected to a socialized platform about healthcare.

Caregivers – Open Questions

Open questions helped in making comments issued during demonstration of the platform. Caregivers understand their role as a complete attention to the person affected by the neurodegenerative disease and may have different values than other user groups and those values range from the need of feeling inner peace to do their best, to the difficulty that the sacrifice of giving up their own needs on a daily basis involves.

Caregivers see their role in the platform as crucial as dementia conditions progress and do not allow PLWD to interact with the platform. They are aware of the fact that they have to communicate with doctors and other medical professionals for a lot of issues, ranging from appointment to treatment management and actually see an invitation by medical professionals as essential step to participate into a lot of the platform activities. They also appreciate any help provided by the institutions, but they find this help to be very limited and conditioned by financial resources. Thus, the platform could provide additional help at almost no cost in a daily basis.

To this end, caregivers see enough room for development and they expect much more functionality to be added in future versions of the platform in order to provide a clear identification of the potential impact.

Caregivers have identified certain features of the platform that requires modification, like font sizes, colour contrast and variety in content and modalities in presenting the information. Some reported that they cannot do some tasks on their own, like the profile

completion and the participation in the Café. Others reported no problems, but they concern about the possibility PLWD to face difficulties in performing in-platform tasks.

Caregivers – Platform

Closed Questions

Caregivers responded well in almost all questions related to the platform. The average score in all questions of the type "I encountered no problems in…' was found equal to 7.07. Similar results were found for intuition (7.05 in average for statements of type 'I found … intuitive). On the other hand, there is enough room for improvements according to the 5.98 average score in the statements of type: 'I prefer a different design for …'. The highest score was recorded by the statement related to the posts and wall messages. We need to design a messaging system simple and useful, but also to train users how to locate receivers for their posts.

Regarding the usefulness of the platform to delay institutionalization for people living with dementia caregivers are cautiously optimistic with an average score of 6.44 (SD = 3.35). In overall, the old version of the platform did not respond well in caregivers expectations (M = 5.81, SD = 2.97). Although the 62% of the caregivers group agree that game-like experiences from an application or a webpage motivate them to participate, the 8.44 (SD = 2.42) in the question 'Would you like to participate in this platform as a game character' possibly indicate that after a hands-on experience with the platform they may find a clearer connection with the gamification approach.

Table 15. Responses of caregivers in the usability questionnaire

Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)		
Question/Statement	**Mean**	**SD**
I encountered no problems in locating and updating my profile (my account)	6.94	2.79
I found locating and updating my profile (my account) intuitive	7.69	2.15
I prefer a different design for profile management	5.69	3.32
I encounter no problems managing disorders and treatments	6.81	2.76
I found managing disorders and treatments intuitive	7.56	2.56
I prefer a different design for the management of disorders and treatments	6.25	3.34
I encounter no problems in searching and connecting with other user profiles	7.69	2.70
I found managing connections with other users intuitive	7.88	2.66
I prefer a different design for searching and connecting with other users	6.81	3.64
I encounter no problems managing posts and wall messages	8.63	2.68
I found managing posts and wall messages intuitive	6.69	3.28
I prefer a different design for managing posts and wall messages	7.88	3.32
I encounter no problems participating in an online questionnaire about adherence evaluation and reading the report	7.38	2.99

I found participating in an online questionnaire and reading the report intuitive	7.38	2.80
I prefer a different design for online questionnaires and reports	5.50	2.97
I encounter no problems communicating privately with users like people living with dementia, doctors, other caregivers, helpers and social workers (send personalized message, friendship request or invitation)	6.30	2.26
I found private communication with other users intuitive	6.00	2.83
I prefer a different design for private communication with others	4.80	3.22
I encounter no problems in contacting other caregivers in the café	7.06	2.38
I found contacting others in the café intuitive	6.75	2.84
I prefer a different design for contacting other in the café	5.31	3.30
I encounter no problems in actively participating in the café.	5.75	3.07
I found actions related to the Cafe intuitive	6.44	2.92
I prefer a different design for the Café.	5.56	2.97
I completed all tasks related to my role in the platform	7.25	3.00
I can use this platform on my own	7.63	2.19
This application was user-friendly	7.69	2.30
How useful you consider the platform to follow up people living with dementia?	6.94	2.98
How useful do you consider the platform to delay institutionalization for people living with dementia?	6.44	3.35
Did the platform respond at your expectations?	5.81	2.97
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	8.44	2.42
Do you understand the notion of circle in the platform?	7.33	2.87

Open Questions

Caregivers reported a wide range of issues, from faced psychological conditions, the feeling of duty to self-evaluation issues that need to be addressed. Great impression was made by the fact that they feel isolated and they have to deal with the unwillingness of other family members to provide help.

Apart from 'moral conflict' issues, caregivers expressed their expectations on the communication and support features of the platform. They made direct indications related to the font size, the used colours and the layout of the interface designs. The name Café created some confusion to a part of caregivers as they already knew the term 'Forum' and this made them wonder on the differences between those two. People likes symbols and smiley faces, but they reported the need to have for each icon a textual description given at the same time. Although they found that the platform can meet some of their expectations, they will appreciate managing contacts. It has been reported that questionnaires about memory and on how people feel would be useful if included in the questionnaires section of the platform. Others said that there is nothing missing from the platform, but the interface design should be simpler.

People appreciated the fact that they were given the option to choose whether a new message or post would be available in a private circle or in a wider community of people.

The interest on applying control over the personal information was reported on various occasions during the open interviews. One of the most important features of the present and future platform would be the treatment adherence according to the participants. They also highlighted the importance of reminders, especially for those having memory problems.

Doctors – Demographics

Part A: About you

19 doctors and other medical professionals, including geriatricians and experts from various allied professions (5 males and 14 females) took part in this interview, aged 42.5 in average (SD = 7.59). Apart from the four languages (Spanish, Italian, English and French), Catalan and Russian were reported as spoken languages. All medical professionals reported an institution as a place of work and they average number of PLWD they are responsible for was 4.25 (SD = 3.2). Half of them were responsible for less than or equal to 25 people at the time of the interview. Others were responsible for less than 50 (10%), less than 100 (15%) and more than 100 (15%). Having in mind that the time those people can devote on offering professional services to individuals is inversely proportional to the number of PLWD they support, we can easily understand that business processes within the platform should be fast enough to be considered useful and efficient.

Responders in this group were very experienced, having 36% of them with more than 20 years of professional experience, another 36% 10 to 20 years of experience and only the 15% had less than five years. Almost half of them (52%) offer their professional services in a hospital or clinic, while the 42% work in other places such as Research & Development department or the FSSM (Dementia Unit of the Fundación Sociosanitaria de Manresa). One person works in the home of people living with dementia and another one reported the local mental health community as a physical place of offering services.

Regarding the use of Technology/Communication means, responders gave a balanced range of activities having contacts, ordonnance and professional reading the three most performed activities. The frequencies of all professional activities can be found on Figure 11.
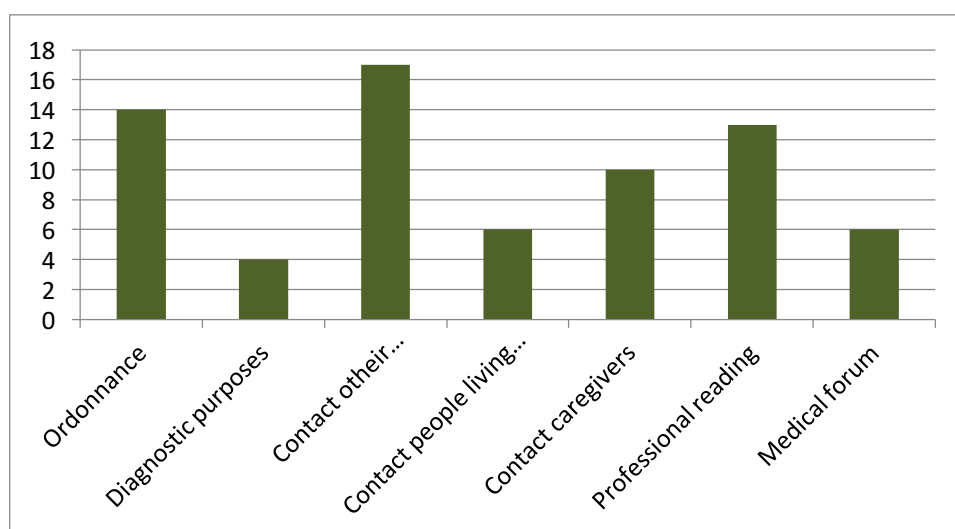

Figure 11. Clinical activities medical professionals use the Internet for

In the multiple response questions asking what means of communication do you use for socialization with other doctors and healthcare professionals and also for the dyads, responders reported multiple ways and means of communication. Emails and phone calls are featured at the first two places of the list in Figure 12. Differences between other professional sand dyads are focused on seminars and forums which are clearly used as a mean of communication with other professionals. Thus, those features (seminars and forums) should be considered as appropriate ways to communicate with other professionals within the platform and keep others means of communication for between dyads and professionals.
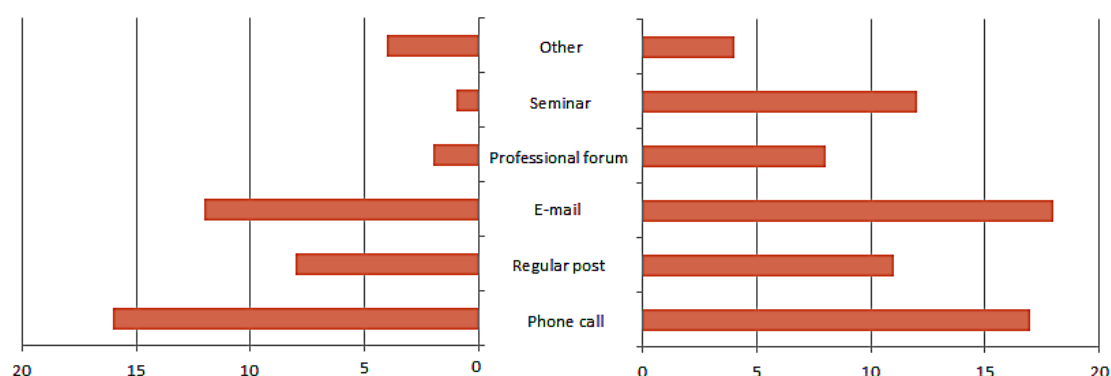
Figure 12. Popular ways and means of communication: a) for doctors, experts and others medical professionals (right) and b) for the dyads (left)

58% (12 out of 19 responders) said they like to play games. One third (33%) of them reported they play once a week, another 33% once a month and the rest every day. From the people who reported gaming activities, 58% had positive experiences and the rest 42% reported nonchalance experiences. An impressive portion of medical professionals (79%) believe that a game-like experience from an application or a webpage would motivate their people living with dementia and their caregivers to participate in the platform. Only 21% disagree or strongly disagree on this statement.

The positive attitudes professionals have on the use of games in a healthcare platform is shown in the responses to the next statement 'I believe that a game-like experience from an application or a webpage would benefit more', in which 63% agree or strongly agree on this statement, 15% gave a neutral response, another 15% disagree and only one person strongly disagrees.

Part D: Semi-Structured Interview

Some professionals reported they do not currently use ICT to detect, prevent or diagnose disease. Others mentioned applications such as telemonitoring for falls preventions and cardiac periodic check, and more in general, telemonitoring devices. But most agree that Internet is a resource for scientific contents (via PubMed), national websites, seminars, workshops scientific publications, books (see Table 16). A website or an online platform can help them by giving information on treatment adherence, giving a means of monitoring caregiver's burn-out and to follow behavioural disorders with various scales (like for treatment adherence, psycho-behavioural disorders, nutritional intake, Body Mass Index, a follow-up of weight, activity daily living, etc.).

Another interest, according to responders, is to have professional information on the disease (news, recommendations, links with interesting professional sites, etc.) and share it with PLWD and their caregivers but these massive consultations must be taken by dyads as eminently indicative. Professionals should proceed with diagnosis and consolation with caution. This could be addressed using visual indications and textual descriptions in the interfaces to notify dyads that direct consultations by doctors and other medical professionals should be considered more useful and secure than massive or 'blind' consolation.

Table 16. Online resources professionals think that could be useful for PLWD and/or their caregivers

A/A	Name of resource
1	Forum or exchange of experience
2	Sites on Alzheimer's disease like "France Alzheimer"
3	Sites of social organisation (i.e.: CLIC, CCAS….)
4	Sites in order to find a list of contacts (doctors, nurses,…)
5	Online health record
6	Information on therapeutics
7	Information on the disease and caregiving
8	Information on psycho-compartmental disorders
9	Geriatric sites
10	Information on Respite care
11	France Alzheimer or forum (by French geriatrics)
12	National and European networks
13	liable sources such as www.centroalzheimer.org; www.neuropsicologia.it)
14	Previous projects and experiences (e.g. Nacodeal project)

Other professionals focused on the use of medical and scientific data. Especially data from tracking of different parameters can be crossed with a drug's prescription, thus being able to define clinical actions in a better way (not having to wait for long time to see if the prescribed drug had the desired effect or not. In any case, only self-administered scales and questionnaires should be included into the platform (scales about life quality, behavioural screening or other aspects), as for all others (e.g. Mini-Mental, Barthel) a professional is required. Moreover, pharmacological issues could be addressed in a better way through the platform. There have been cases where the treatment is stopped due to a prescription expiring without the user controlling the situation could be avoided.

Doctors – Platform

Closed Questions

Based on the participant's responses, there were some usability issues during the platform testing as indicated by the average scores in statements of type 'I encountered no problems in...' whish was found equal to 6.44. The lowest score was achieved by the task of posting my new scientific contribution with average score 4.80. A possible explanation is that some functionality related to medical professionals may was not validated at the time of the interviews. In addition, intuition was not as high as expected (M = 6.12) and responders required a different interface design with score 5.40 in average. From as designer's point of view, the interfaces used in searching and connecting with other user profiles, communicating privately with other users and creating a new case should be totally redesigned and carefully checked as they collect the most negative scores.

Table 17. Responses of Doctors and other medical professionals in the usability questionnaire

Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)		
Question/Statement	**Mean**	**SD**
I encountered no problems in locating and updating my profile (my account)	7.61	3.01
I found locating and updating my profile (my account) intuitive	7.70	2.27
I prefer a different design for profile management	5.26	3.77
I encounter no problems managing disorders and treatments	6.75	2.14
I found managing disorders and treatments intuitive	6.19	2.61
I prefer a different design for the management of disorders and treatments	6.18	3.30
I encounter no problems in searching and connecting with other user profiles	5.71	3.12
I found managing connections with other users intuitive	5.14	3.03
I prefer a different design for searching and connecting with other users	6.09	3.28
I encountered no problems during the overview of the cockpit of people living with dementia?	7.04	3.15
I found overviewing cockpit of the people living with dementia intuitive.	6.52	3.10
I prefer a different design for overviewing of the cockpit of people living with dementia.	5.13	3.78
I encounter no problems managing evaluations	7.33	2.22
I found managing evaluations intuitive	7.57	2.11
I prefer a different design for managing evaluations	4.81	2.82
I encounter no problems communicating privately with users like people living with dementia, other doctors, caregivers, helpers and social workers (send personalized message, friendship request or invitation)	5.76	3.29
I found private communication with other users intuitive	5.31	2.77
I prefer a different design for private communication with others	5.82	3.19
I encounter no problems in creating a new case	5.74	3.81
I found creating a new case intuitive	5.37	3.61
I prefer a different design for creating a new case	4.63	3.56
I encounter no problems in posting my new scientific contribution	4.80	3.78
I found posting a new scientific contribution intuitive	5.14	3.77

I prefer a different design for creating a new scientific contribution	5.29	3.72
I completed all tasks related to my role in the platform	5.95	2.44
This application was user-friendly	6.57	2.21
How useful you consider the platform to follow up people living with dementia?	7.87	1.71
How useful do you consider the platform to delay institutionalization for people living with dementia?	5.17	3.47
Did the platform respond at your expectations?	6.24	2.93
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	6.88	3.33

Open Questions

Although it was pointed out the difficulty in standardization of medical controls (due to the several stages of dementia and severity), responders reported that the platform can improve: a) treatment adherence using alerts highlighting symptoms and giving content, b) follow, or control of the people living with Dementia and prevent other diseases but this is useful only for caregivers and not for PLWD and c) The platform may caregiver burn-out detection. Typical items and functional requirements about usability and accessibility that need to be taken into consideration were mentioned.

Regarding interface designs and taking into account that PLWD and caregivers have a low knowledge on ICT, some guidelines provided by doctors, geriatrics, experts and other medical professionals are presented in Table 18. Most of those comments and recommendations are related to the need to have greater attention to the intuitivity of the platform, the accessibility and the visual appearance.

Table 18. A collection of comments and design guidelines to improve platform design according to doctor's recommendations

A/A	Design guideline description
1	Have a design that can help PLWD and caregivers to browse
2	The design is not intuitive, not user-friendly and not fun
3	The presentation is not intuitive for PLWD and caregivers
4	Improve functionality, change the colours for bright colours, recreational, attractiveness, add icons
5	Improve the design with a more friendly design-for-all interfaces
6	Font size may be increased (eye impairment)
7	Design is too sad. It needs more colours
8	Have large icons and have message to help PLWD, caregivers to understand actions behind icons.
9	The left banner is not optimal and difficult to understand
10	Have large emoticons. Choice of emoticons colours is not optimal.
11	Have an agenda for PLWD (date, hour, season and why not weather..)
12	Not too much information in one page
13	Have a function "return"
14	Issue with pulldown menu: too difficult for PLWD and some caregivers
15	Having an icon for social information
16	Use words that are easy to understand
17	Professionals are not friends but create a section: professionals

18	Be careful with colours codes (risk of confusion…). A colour code for each user.
19	View on alerts
20	Take into account confidentiality of information
21	Let the platform to be a container of validated and clinically useful games and provide more opportunities of entertainment together with caregivers and social surroundings
22	Add audio-visual reminders and daily list of the prescriptions, as summary of the whole medical treatment for the day, including alert in the main timeframe (breakfast, lunch and dinner time).

Social Workers- Demographics

Part A: About you

13 Social Workers, all females, aged 45 years old in average participated in the interviews. The majority of the responders were experienced social workers having over 10 years of experience (77% of participants). Regarding the number of PLWD they follow at the time of the interview, we have two subgroups: one with less than 25 people (60%) and another one following more than 100 (40%).

Regarding the working place, 66% in both Day Care Institute and in a Hospital/clinic, while the Hospital/Clinic was selected by the 84% of the responders as a physical context of delivering professional services.

Part B: Use of Technology/Communication means

Responses in relation to the used communication means spread over various options. Telephone, mail and home visits are the typical means of communication with dyads and other professionals, both for communicating with other Social Workers more means were used like forums and workshops.

Part C: Gamification and Games

All participants reported a positive attitude in the possibility to use game-like experiences in the platform and actually reported they are gamers themselves. The 53% of responders reported they play games daily, 30% play once a week or once a month and only 15% do not play games at all.

Part D - Semi-Structured Interview

There is some evidence on using the Internet as a source to get information on Dementia diseases, but Social Workers still rely on traditional means of communication like papers and telephones. The use of ICT tools for risk detection and conditions prevention is not common. The interesting thing in this group of professionals is the fact that they are good ICT and Internet users and they use those computerized means more frequently for personal and professional work, but for social working, oral communication is more important.

They see the platform and the social network as the devices to break down the social isolation of PLWD, share experiences with others and facilitate communication between allied professions (e.g. Social Workers and medical professionals). They highlighted the importance of security and privacy and give room for eLearning activities within the platform. It was proposed to apply gamification in eLearning activities as well (Games that deliver information as reported).

Social Workers – Platform

Social Workers did not face serious problems in demo using the platform as indicated by the 7.05 average score in statements related to problems encountered. They found the platform quite intuitive (M = 7.28) and they do not strongly demand a redesign of the platform as indicated by the average scores in the statements of type 'I prefer a different design...' (M = 3.06). More detailed information can be seen in Table 19.

Table 19. Responses of Social Workers in the usability questionnaire

Please indicate how strongly you agree with the following statements (1= strongly disagree; 10 = strongly agree)		
Question/Statement	**Mean**	**SD**
I found locating and updating my profile (my account) intuitive	7.10	2.85
I prefer a different design for profile management	2.70	1.95
I encountered no problems during the overview of the cockpit of people living with dementia.	8.70	1.16
I found overviewing the cockpit of the people living with dementia intuitive.	8.40	1.26
I prefer a different design for overviewing of the cockpit of people living with dementia.	1.80	0.63
I encounter no problems managing posts and wall messages	7.30	3.20
I found managing posts and wall messages intuitive	6.80	3.19
I prefer a different design for managing posts and wall messages	3.80	3.08
I encounter no problems communicating privately with users like people living with dementia, doctors, other caregivers, helpers and social workers (send personalized message, friendship request or invitation)	5.40	4.27
I found private communication with other users intuitive	5.70	3.97
I prefer a different design for private communication with others	5.00	3.92
I encounter no problems in updating social information of people living with dementia.	8.40	0.55
I found updating social information of people living with dementia intuitive.	8.40	0.55
I prefer a different design for updating social information of people living with dementia.	2.00	1.00
I completed all tasks related to my role in the platform	5.50	4.01
This application was user-friendly	6.60	3.78
How useful you consider the platform to follow the social status of people living with dementia?	7.80	1.75
Did the platform respond at your expectations?	7.40	2.41
Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?	7.60	2.84

4 Comparison between sites

Although participants share common characteristics, it was found that from site to site, there were some interesting differences. The following section presents some key-points resulted from a cross-site (and thus a cross-country) analysis of the interview results for the dyads. For other users groups like professionals, the differences do not appear to be significant from the designer's point of view. Those results need to be cross-checked again in later Focus Group interview cycles and also they need to be verified by larger groups of participants.

PLWD

Participants who live with Dementia are fully retired from work in all sites and they live independently. But in Spain PLWD live with more family members (3 and 4), while in the rest countries it is more often that PLWD live alone.

From those who use the Internet, PLWD responded in a similar way on the technology-related questions, but in UHULL they use a wide range of Internet technologies and they consume more Internet-based services than in other countries.

In FUB and UHULL responders prepare their treatment to the week with a weekbox or they don't prepare their treatment themselves. On the other hand, in CHU-ROUEN and COOSS, responders reported that they take their treatment day after day, without preparation or they prepare their treatment to the day with boxes (morning; afternoon; evening).

Regarding game preferences, in FUB they play games more (83% of the responders) than in other sites in which responders do not play games so often. But, interview participants from all countries agree that a game-like experience from an application or a webpage would motivate them to participate in the platform.

Caregivers

In CHU responders reported more places of delivering services than home of PLWD or a day care institute. In FUB and UHULL most caregivers are family members, while in other countries they are spread in part time or full time professional caregivers. Moreover, in FUB caregivers is more possible to be children.

In all countries the way Internet is used appear to be similar, but in COOSS and CHU people prefer to use a personal Computer (PC) more often. In the rest sites, responders use more devices than PC (including tablets, smartphones and laptops).

Caregivers from all sites agree that games can provide motivation to them and that game-like experiences from an application or a webpage would benefit more.

Both dyad members (PLWD and caregivers) reported problems in accessibility of the current version of the platform and especially mentioned font sizes and the use of icons and pictures.

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Annex A - Questionnaires

Questions are numbered according to this rule:

- The first letter indicates the user group {P, C, H, D, S}
- The second letter indicates the Demographics or Usability test {D, U}
- The third letter indicates the part of the questionnaire {A, B, C, D}

PLWD-Demographics questionnaire

Part A - About you
PDA1. First name
{Textbox}
PDA2. Surname
{Textbox}
PDA3. Sex (* at the time of birth)
Male
Female
Other (please indicate): {Textbox}
PDA4. Age
{Textbox, block off any keystroke that is not a number}
PA5. Type of memory problem, if known (Multiple choice)
Mild Neurocognitive Disorder
Moderate Neurocognitive Disorder
Major Neurocognitive Disorder
No Neurocognitive Disorder Conditions
I do not know
Other (please indicate): {Textbox}
PDA6. Year of first diagnosis of memory problem (If memory problem known)
{Combobox control with first choice 'I do not know' and then years from 1980 to 2016}
PDA7. Mother Language (Multiple choice)
English
French
Spanish
Italian
Other (please indicate): {Textbox}
PDA8. Work Status (Multiple choice)
Unemployed
Part time employed

Full time employed
On training/education programme
Wholly retired from work
Looking after home
Other (please indicate): {Textbox}
PDA9. If not Retired, main Type of Employment Status (Multiple choice)
Worker
Employee
Self-employed and contractor
Director
Office Holder
Other (please indicate): {Textbox}
PDA10. Level of Education (according to ISCED 2011, Multiple choice)
0-Early childhood education
1-Primary education
2-Lower secondary education
3-Upper secondary education
4-Post-secondary non-tertiary education
5-Short-cycle tertiary education
6-Bachelor's or equivalent level
7-Master's or equivalent level
8-Doctoral or equivalent level
9-Not elsewhere classified
PDA11. *Number of people in your household including yourself (Multiple choice)*
1
2
3
4+
PDA12. *Living status (Multiple choice)*
Living at home independently
Living at home with health care provided by family member
Living at home with health care provided by professional carer
Living in care home
Other (please indicate): {Textbox}
PDA13. Visual, acoustic, or motor Impairments (Multiple response)

Low vision (not corrected)
Hearing loss (not corrected)
Upper Limbs Disorder
Speech or Language Disorders
No specific impairment
Other (please indicate): {Textbox}
Part B - Use of Technology/Communication means
PDB1. What do you use the Internet for? (Multiple response)
Communication (email, video chat, etc.)
Online Shopping/Selling
Online Entertainment (video/movies, games, music, etc.)
News Reading
Work
Social Networks
Sharing information (blogging, photo sharing, etc.)
Education/Training
Looking for medical advice
I do not use the Internet
Other (please indicate): {Textbox}
PDB2. Which kind of devices you prefer/feel more confident to use? (Multiple response)
Personal Computer (PC)
Tablet/iPad
Laptop
Smartphone (Android/iPhone)
Other (please indicate): {Textbox}
PDB3. What other means of communication do you use for socialization with other people living with dementia? (Multiple response)
Club (reading, games, craft, sport…)
Memory workshop (in a institution) or day hospital
Forum discussion or social network
Others (Please specify): ……………………………..
PDB4. What means do you use for communication with your doctor and your caregiver? (Multiple response)
Visit at home/ doctor's office
Telephone conversation
Mail conversation

Other (please indicate): {Textbox}

PDB5. What means do you use for self-managing your treatment? (Multiple choice)
I take my treatment day after day, without preparation
I prepare my treatment to the day with boxes (morning; afternoon; evening)
I prepare my treatment to the week with a weekbox
I do not prepare myself my treatment
Other (to specify): ……………………………………..

Part C - Gamification and Games
PDC1. How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)
I play no games
Once a week
Once a month
Everyday

PDC2. If you play digital games, can you tell us about your experiences? (Multiple choice)
Positive experiences
Negative experiences
Barriers to using games
Nonchalance experiences
Other (please indicate): {Textbox}

PDC3. I believe that a game-like experience from an application or a webpage would motivate me to participate.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree

PDC4. I believe that a game-like experience from an application or a webpage would benefit more.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree

Part D - Semi-Structured Interview (Open Questions)
PDD1. Have you ever used an application or a webpage about memory disorders? What was your experience?

PDD2. What means do you use for managing of your personal medical data and treatment plan?
PDD3. How the internet and ICT technologies might support you or meet your needs on treatment management?
PDD4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
PDD5. What kind of games would you like to play in a healthcare application? For what reason?(for skills training, leisure, socialization, etc.).

PLWD-Platform Questionnaire (after demonstration of the platform)

Part A – Perceived Usability
Please indicate how strongly you agree with the following statements (1= strongly disagree; 7 = strongly agree)
PUA1. I encounter no problems logging into the system
PUA2. I found logging into the system intuitive
PUA3. I prefer a different design for login
PUA4. I encountered no problems in locating and updating my profile (my account)
PUA5. I found locating and updating my profile (my account) intuitive
PUA6. I prefer a different design for profile management
PUA7. I encounter no problems managing disorders and treatments
PUA8. I found managing disorders and treatments intuitive
PUA9. I prefer a different design for the management of disorders and treatments
PUA10. I encounter no problems in searching and connecting with other user profiles
PUA11. I found managing connections with other users intuitive
PUA12. I prefer a different design for searching and connecting with other users
PUA13. I encounter no problems managing posts and wall messages
PUA14. I found managing posts and wall messages intuitive
PUA15. I prefer a different design for managing posts and wall messages
PUA16. I encounter no problems participating in an online questionnaire about adherence evaluation and reading the report
PUA17. I found participating in an online questionnaire and reading the report intuitive
PUA18. I prefer a different design for online questionnaires and reports
PUA19. I encounter no problems communicating privately with users like doctors, other people living with dementia, caregivers, helpers and social workers (send personalized message, friendship request or invitation)
PUA20. I found private communication with other users intuitive
PUA21. I prefer a different design for private communication with others
PUA22. I encounter no problems in creating a new ticket and uploading a file

PUA23. I found creating a new ticket and uploading a file intuitive
PUA24. I prefer a different design for creating a new ticket and uploading a file
PUA25. I encounter no problems in actively participating in the café.
PUA26. I found actions related to the Cafe intuitive
PUA27. I prefer a different design for the Café.
PUA28. I completed all tasks related to my role in the platform
PUA29. I can use this platform on my own
PUA30. This application was user-friendly
PUA31. Did the platform respond at your expectations?
PUA32. Do you understand the notion of circle in the platform?
PUA33. Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?
Part B – Open Questions
PUB1. How could we improve the design? (Colours, fonts, layouts, etc).
PUB2. Please indicate which tasks/steps were more difficult to complete.
PUB3. What were your expectations regarding the platform ?
PUB4. What features would you like to add in or remove from this platform ?
PUB5. What kind of self-reported questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
PUB6. How do you understand what is a social network and its benefits ?
PUB7. Could you describe in your own words what is an health online community and its benefits ?
PUB8. How sharing your experiences with others and ask for support makes you feel?
PUB9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?
PUB10. Is treatment adherence important to you? How a web platform could help?

Caregivers-Demographics questionnaire

Part A - About you
CDA1. First name
{Textbox}
CDA2. Surname
{Textbox}
CDA3. Sex (* at the time of birth)
Male
Female
Other (please indicate): {Textbox}
CDA4. Age

{Textbox, block off any keystroke that is not a number}
CDA5. Mother Language (Multiple choice)
English
French
Spanish
Italian
Other (please indicate): {Textbox}
CDA6. *Number of people living with dementia you are responsible for?*
{Textbox, block off any keystroke that is not a number}
CDA7. *Context/Place of caregiving services (Multiple choice)*
Day care institute
Home of people living with dementia
Hospital/Clinic
Community mental health team
Other (please indicate): {Textbox}
CDA8. Work Status (Multiple choice)
Part time employed as caregiver
Full time employed as caregiver
On training/education programme
Relative/Family
Other (please indicate): {Textbox}
CDA9. Level of Education (according to ISCED 2011, Multiple choice)
0-Early childhood education
1-Primary education
2-Lower secondary education
3-Upper secondary education
4-Post-secondary non-tertiary education
5-Short-cycle tertiary education
6-Bachelor's or equivalent level
7-Master's or equivalent level
8-Doctoral or equivalent level
9-Not elsewhere classified
CDA10. What is your relationship with your people living with dementia? (Multiple choice)
Spouse
Children
Grandchild
Parent
Brother/Sister
Friend
Neighbour
Other (to specify): ……………………………………..
CDA11. Visual, acoustic, or motor Impairments (Multiple response)
Low vision (not corrected)

Hearing loss (not corrected)
Upper Limbs Disorder
Speech or Language Disorders
No specific impairment
Other (please indicate): {Textbox}
Part B - Use of Technology/Communication means
CDB1. What do you use the Internet for? (Multiple response)
Communication (email, video chat, etc.)
Online Shopping/Selling
Online Entertainment (video/movies, games, music, etc.)
News Reading
Work
Social Networks
Sharing information (blogging, photo sharing, etc.)
Education/Training
Looking for medical advice
I do not use the Internet
Other (please indicate): {Textbox}
CDB2. Which kind of devices you prefer/feel more confident to use? (Multiple response)
Personal Computer (PC)
Tablet/iPad
Laptop
Smartphone (Android/iPhone)
Other (please indicate): {Textbox}
CDB3. What means do you use for communication with doctors and other caregivers? (Multiple response)
Visit at home/ doctor's office
Telephone conversation
Mail conversation
Other (please indicate): {Textbox}
Part C - Gamification and Games
CDC1. How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)
I play no games
Once a week
Once a month
Everyday
CDC2. If you play digital games, can you tell us about your experiences? (Multiple choice)
Positive experiences
Negative experiences
Barriers to using games
Nonchalance experiences
Other (please indicate): {Textbox}

CDC3. I believe that a game-like experience from an application or a webpage would motivate me to participate.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
CDC4. I believe that a game-like experience from an application or a webpage would benefit more.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
Part D - Semi-Structured Interview (Open Questions)
CDD1. Have you ever used an application or a webpage about memory disorders? What was your experience?
CDD2. What means do you use for managing of your people living with dementia medical data and treatment plan?
CDD3. How the internet and ICT technologies might support you or meet your needs on treatment management?
CDD4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
CDD5. What other computerized means do you use for risk detection and conditions prevention?
CDD6. What kind of games would you like to play in a healthcare application? For what reason?(for skills training, leisure, socialization, etc.).
CDD7. What means do you use for managing the treatment of your people living with dementia?

Caregivers-Platform Questionnaire (after demonstration of the platform)

Part A – Perceived Usability
Please indicate how strongly you agree with the following statements (1= strongly disagree; 7 = strongly agree)
PUA1. I encountered no problems in locating and updating my profile (my account)
PUA2. I found locating and updating my profile (my account) intuitive
PUA3. I prefer a different design for profile management
PUA4. I encounter no problems managing disorders and treatments
PUA5. I found managing disorders and treatments intuitive
PUA6. I prefer a different design for the management of disorders and treatments
PUA7. I encounter no problems in searching and connecting with other user profiles
PUA8. I found managing connections with other users intuitive
PUA9. I prefer a different design for searching and connecting with other users

PUA10. I encounter no problems managing posts and wall messages
PUA11. I found managing posts and wall messages intuitive
PUA12. I prefer a different design for managing posts and wall messages
PUA13. I encounter no problems participating in an online questonnaire about adherence evaluation and reading the report
PUA14. I found participating in an online questionnaire and reading the report intuitive
PUA15. I prefer a different design for online questionnaires and reports
PUA16. I encounter no problems communicating privately with users like people living with dementia, doctors, other caregivers, helpers and social workers (send personalized message, friendship request or invitation)
PUA17. I found private communication with other users intuitive
PUA18. I prefer a different design for private communication with others
PUA19. I encounter no problems in contacting other caregivers in the café
PUA20. I found contacting others in the café intuitive
PUA21. I prefer a different design for contacting other in the café
PUA22. I encounter no problems in actively participating in the café.
PUA23. I found actions related to the Cafe intuitive
PUA24. I prefer a different design for the Café.
PUA25. I completed all tasks related to my role in the platform
PUA26. I can use this platform on my own
PUA27. This application was user-friendly
PUA28. How usefull you consider the platform to follow up people living with dementia?
PUA29. How useful do you consider the platform to delay institutionalization for people living with dementia?
PUA30. Did the platform respond at your expectations?
PUA31. Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?
PUA32. Do you understand the notion of circle in the platform?
Part B – Open Questions
PUB1. How could we improve the design? (Colours, fonts, layouts, etc).
PUB2. Please indicate which tasks/steps were more difficult to complete.
PUB3. What were your expectations regarding the platform?
PUB4. What features would you like to add in or remove from this platform?
PUB5. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
PUB6. How do you understand what is a social network and its benefits?
PUB7. Could you describe in your own words what is an health online community and its benefits?
PUB8. How sharing your experiences with others and ask for support makes you feel?
PUB9. Do you understand that the result of the online questionnaires will serve to alert doctors or members of my circle in case of emergency? How that feature makes you feel?
PUB10. Is treatment adherence important to you? How a web platform could help?

Doctors and Medical Professionals-Demographics questionnaire

Part A - About you
DDA1. First name
{Textbox}
DDA2. Surname
{Textbox}
DDA3. Sex (* at the time of birth)
Male
Female
Other (please indicate): {Textbox}
DDA4. Age
{Textbox, block off any keystroke that is not a number}
DDA5. Mother Language (Multiple choice)
English
French
Spanish
Italian
Other (please indicate): {Textbox}
DDA6. *Place of work*
{Textbox}
DDA7. *Number of people living with dementia you are responsible? (Multiple choice)*
less or equal to 25
26-50
51-100
More than 100
DDA8. *Context/Place of healthcare professional services (Multiple choice)*
Day care institute
Home of people living with dementia
Hospital/Clinic
Community mental health team
Other (please indicate): {Textbox}
DDA9. Years of Professional Experience (Multiple choice)
Less than 5 years of experience
6-10 years of experience
11-15 years of experience
16-20 years of experience
More than 20 years of experience
Part B - Use of Technology/Communication means

DDB1. For which of the following clinical activities do you use the Internet for? (Multiple choice)
Ordonnance
Diagnostic purposes
Contact otheir professionals
Contact people living with dementia
Contact caregivers
Professional reading
Medical forum
DDB2. What other means of communication do you use for socialization with other doctors and healthcare professionals? (Multiple response)
Phone call
Regular post
E-mail
Professional forum
Seminar
Other (please indicate): {Textbox}
DDB3. What means do you use for communication with your people living with dementia and their caregivers? (Multiple response)
Phone call
Regular post
E-mail
Professional forum
Seminar
Other (please indicate): {Textbox}
Part C - Gamification and Games
DDC1. How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)
I play no games
Once a week
Once a month
Everyday
DDC2. If you play digital games, can you tell us about your experiences? (Multiple choice)
Positive experiences
Negative experiences
Barriers to using games
Nonchalance experiences
Other (please indicate): {Textbox}
DDC3. I believe that a game-like experience from an application or a webpage would motivate my people living with dementia and their caregivers to participate.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree

5- Strongly agree
DDC4. I believe that a game-like experience from an application or a webpage would benefit more.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
Part D - Semi-Structured Interview (Open Questions)
DDD1. What means do you use for managing of your people living with dementia medical data and treatment suggestions?
DDD2. What other computerized means do you use for risk detection, diagnosis and prevention?
DDD3. What means do you use for scientific contribution and accessing scientific material?
DDD4. Do you recommend an application or a website about memory disorders? Which ones and why?
DDD5. What kind of resources or services do you think people with MND or caregivers may find useful or beneficial when using online websites?
DDD6. What design guidelines or ideas would you recommend to interface designers to make the platform PLWD-friendly and to enhance usability? Any 'must haves' and/or 'must nots'?
DDD7. In what way could an online website help professionals to improve the care they provide to people with dementia and their carers? (information, socialization, support and advice, assessment of outcomes, follow therapy, etc.).

Doctors and Medical Professionals -Platform Questionnaire (after demonstration of the platform)

Part A – Perceived Usability
Please indicate how strongly you agree with the following statements (1= strongly disagree; 7 = strongly agree)
DUA1. I encountered no problems in locating and updating my profile (my account)
DUA2. I found locating and updating my profile (my account) intuitive
DUA3. I prefer a different design for profile management
DUA4. I encounter no problems managing disorders and treatments
DUA5. I found managing disorders and treatments intuitive
DUA6. I prefer a different design for the management of disorders and treatments
DUA7. I encounter no problems in searching and connecting with other user profiles
DUA8. I found managing connections with other users intuitive
DUA9. I prefer a different design for searching and connecting with other users
DUA10. I encountered no problems during the overview of the cockpit of people living with dementia?
DUA11. I found overviewing cockpit of the people living with dementia intuitive.
DUA12. I prefer a different design for overviewing of the cockpit of people living with dementia.

DUA13. I encounter no problems managing evaluations
DUA14. I found managing evaluations intuitive
DUA15. I prefer a different design for managing evaluations
DUA16. I encounter no problems communicating privately with users like people living with dementia, other doctors, caregivers, helpers and social workers (send personalized message, friendship request or invitation)
DUA17. I found private communication with other users intuitive
DUA18. I prefer a different design for private connumication with others
DUA19. I encounter no problems in creating a new case
DUA20. I found creating a new case intuitive
DUA21. I prefer a different design for creating a new case
DUA22. I encounter no problems in posting my new scientific contribution
DUA23. I found posting a new scientific contribution intuitive
DUA24. I prefer a different design for creating a new scientific contribution
DUA25. I completed all tasks related to my role in the platform
DUA26. This application was user-friendly
DUA27. How usefull you consider the platform to follow up people living with dementia?
DUA28. How useful do you consider the platform to delay institutionalization for people living with dementia?
DUA29. Did the platform respond at your expectations?
DUA30. Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?
Part B – Open Questions
DUB1. Enumerate parameters and information that you would like to see when you realize a medical control with your people living with dementia every 6 month
DUB2. Please say how we could improve the design (if different for each please, indicate separately).
DUB3. Please indicate which tasks/steps were more difficult to complete.
DUB4. What were your expectations regarding the platform?
DUB5. What features would you like to add in or remove from this platform?
DUB6. Do you consider the platform can improve treatment adherence focus on symptoms related to the disease? How?
DUB7. Do you consider the platform can improve control of the people living with dementia and prevent other diseases with PLWD and caregivers?
DUB8. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
DUB9. Is treatment adherence important to your people living with dementia? How a web platform could help?

Helpers-Demographics questionnaire

Part A - About you
HDA1. First name
{Textbox}

HDA2. Surname
{Textbox}
HDA3. Sex (* at the time of birth)
Male
Female
Other (please indicate): {Textbox}
HDA4. Age
{Textbox, block off any keystroke that is not a number}
HDA5. Mother Language (Multiple choice)
English
French
Spanish
Italian
Other (please indicate): {Textbox}
HDA6. Level of Education (according to ISCED 2011, Multiple choice)
0-Early childhood education
1-Primary education
2-Lower secondary education
3-Upper secondary education
4-Post-secondary non-tertiary education
5-Short-cycle tertiary education
6-Bachelor's or equivalent level
7-Master's or equivalent level
8-Doctoral or equivalent level
9-Not elsewhere classified
HDA7. What is your relationship with your people living with dementia? (Multiple choice)
Spouse
Children
Grandchild
Parent
Brother/Sister
Friend
Neighbor
Other (please indicate): {Textbox}
HDA8. *How many PLWD receive help from you?*
{Textbox, block off any keystroke that is not a number}
HDA9. *Context/Place of healthcare professional services (Multiple choice)*
Day care institute
Home of people living with dementia
Hospital/Clinic
Community mental health team
Other (please indicate): {Textbox}
HDA10. How many years you provide help to people living with dementia? (Multiple choice)

Less than 5 years
6-10 years
11-15 years
16-20 years
More than 20 years
Part B - Use of Technology/Communication means
HDB1. What do you use the Internet for? (Multiple response)
Communication (email, video chat, etc.)
Online Shopping/Selling
Online Entertainment (video/movies, games, music, etc.)
News Reading
Work
Social Networks
Sharing information (blogging, photo sharing, etc.)
Education/Training
Looking for medical advice
I do not use the Internet
Other (please indicate): {Textbox}
HDB2. Which kind of devices you prefer/feel more confident to use? (Multiple response)
Personal Computer (PC)
Tablet/iPad
Laptop
Smartphone (Android/iPhone)
Other (please indicate): {Textbox}
HDB3. What means do you use for communication with doctors and other caregivers? (Multiple response)
Visit at home/ doctor's office
Telephone conversation
Mail conversation
Other (please indicate): {Textbox}
Part C - Gamification and Games
HDC1. How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)
I play no games
Once a week
Once a month
Everyday
HDC2. If you play digital games, can you tell us about your experiences? (Multiple choice)
Positive experiences
Negative experiences
Barriers to using games
Nonchalance experiences
Other (please indicate): {Textbox}

HDC3. I believe that a game-like experience from an application or a webpage would motivate me to participate.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
HDC4. I believe that a game-like experience from an application or a webpage would benefit more.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
Part D - Semi-Structured Interview (Open Questions)
HDD1. Have you ever used an application or a webpage about memory disorders? What was your experience?
HDD2. What means do you use for managing of your people living with dementia medical data and treatment plan?
HDD3. How the internet and ICT technologies might support you or meet your needs on treatment management?
HDD4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
HDD5. What other computerized means do you use for risk detection and conditions prevention?
HDD6. What kind of games would you like to play in a healthcare application? For what reason? (for skills training, leisure, socialization, etc.).
HDD7. How would you like to follow progress made by your people living with dementia and get informed for the activity of users related to your PLWD?
HDD8. What means do you use for managing the treatment of your people living with dementia?

Helpers -Platform Questionnaire (after demonstration of the platform)

Part A – Perceived Usability
Please indicate how strongly you agree with the following statements (1= strongly disagree; 7 = strongly agree)
HUA1. I encountered no problems in locating and updating my profile (my account)
HUA2. I found locating and updating my profile (my account) intuitive
HUA3. I prefer a different design for profile management
HUA4. I encounter no problems managing disorders and treatments
HUA5. I found managing disorders and treatments intuitive
HUA6. I prefer a different design for the management of disorders and treatments
HUA7. I encounter no problems in searching and connecting with other users

HUA8. I found managing connections with other users intuitive
HUA9. I prefer a different design for searching and connecting with other users
HUA10. I encounter no problems managing posts and wall messages
HUA11. I found managing posts and wall messages intuitive
HUA12. I prefer a different design for managing posts and wall messages
HUA13. I encounter no problems communicating privately with users like people living with dementia, doctors, caregivers, other helpers and social workers (send personalized message, friendship request or invitation)
HUA14. I found private communication with other users intuitive
HUA15. I prefer a different design for private communication with others
HUA16. I encounter no problems in managing circles
HUA17. I found management of circles I participate intuitive
HUA18. I prefer a different design for management of circles I participate in
HUA19. How useful you consider the platform to follow up people living with dementia?
HUA20. I completed all tasks related to my role in the platform
HUA21. This application was user-friendly
HUA22. How useful you consider the platform to follow up people living with dementia?
HUA23. Did the platform respond at your expectations?
HUA24. Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?
Part B – Open Questions
HUB1. How could we improve the design? (Colours, fonts, layouts, etc).
HUB2. Please indicate which tasks/steps were more difficult to complete.
HUB3. What were your expectations regarding the platform ?
HUB4. What features would you like to add in or remove from this platform ?
HUB5. What kind of questionnaires and data-collection tools you might like to be included in the platform? (for memory, cognition, anxiety, depression, etc.).
HUB6. Is treatment adherence important to your people living with dementia? How a web platform could help?

Social Workers-Demographics questionnaire

Part A - About you
HDA1. First name
{Textbox}
HDA2. Surname
{Textbox}
HDA3. Sex (* at the time of birth)
Male
Female
Other (please indicate): {Textbox}
HDA4. Age
{Textbox, block off any keystroke that is not a number}

HDA5. Mother Language (Multiple choice)
English
French
Spanish
Italian
Other (please indicate): {Textbox}
HDA6. *How many people living with dementia receive services from you? (Input Number in Textbox)*
{Textbox, block off any keystroke that is not a number}
HDA7. Years of experience as a social worker (Multiple choice)
Less than 5 years of experience
6-10 years of experience
11-15 years of experience
16-20 years of experience
More than 20 years of experience
HDA8. *Number of people living with dementia you follow (Multiple choice)*
less or equal to 25
26-50
51-100
More than 100
HDA9. *Context/Place of profesional services offering (Multiple response)*
Day care institute
Home of people living with dementia
Hospital/Clinic
Other (please indicate): {Textbox}
Part B - Use of Technology/Communication means
HDB1. What means do you use for communication with people living with dementia, their families, doctors and their caregivers? (Multiple response)
Visit at home/ doctor's office
Telephone conversation
Mail conversation
Other (please indicate): {Textbox}
HDB2. What means do you use for communication with other social workers? (Multiple response)
Forums/Workshops
Telephone conversation
Mail conversation
Blogs
Socal networks
Other (please indicate): {Textbox}
Part C - Gamification and Games
HDC1. How often do you play digital games of any kind (e.g. puzzles, leisure games)? (Multiple choice)

I play no games
Once a week
Once a month
Everyday
HDC2. If you play digital games, can you tell us about your experiences? (Multiple choice)
Positive experiences
Negative experiences
Barriers to using games
Nonchalance experiences
Other (please indicate): {Textbox}
HDC3. I believe that a game-like experience from an application or a webpage would motivate my people living with dementia and their caregivers to participate.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
HDC4. I believe that a game-like experience from an application or a webpage would benefit more.
1- Strongly disagree
2- Disagree
3- Neutral
4- Agree
5- Strongly agree
Part D - Semi-Structured Interview (Open Questions)
HDD1. Have you ever used an application or a webpage about memory disorders? What was your experience?
HDD2. What means do you use for updating social information of the people living with dementia you follow?
HDD3. How the internet and ICT technologies might support you or meet your needs on treatment management?
HDD4. What effects would you expect from a gamified healthcare application or webpage on its users? (e.g. reduce boredom, maximize engagement time, treatment adherence, etc.)
HDD5. What other computerized means do you use for risk detection and conditions prevention?
HDD6. What kind of games would you like to play in a healthcare application? For what reason?(for skills training, leisure, socialization, etc.).

Social Workers -Platform Questionnaire (after demonstration of the platform)

Part A – Perceived Usability
Please indicate how strongly you agree with the following statements (1= strongly disagree; 7 = strongly agree)
HUA1. I encountered no problems in locating and updating my profile (my account)

HUA2. I found locating and updating my profile (my account) intuitive
HUA3. I prefer a different design for profile management
HUA4. I encountered no problems during the overview of the cockpit of people living with dementia.
HUA5. I found overviewing the cockpit of the people living with dementia intuitive.
HUA6. I prefer a different design for overviewing of the cockpit of people living with dementia.
HUA7. I encounter no problems managing posts and wall messages
HUA8. I found managing posts and wall messages intuitive
HUA9. I prefer a different design for managing posts and wall messages
HUA10. I encounter no problems communicating privately with users like people living with dementia, doctors, other caregivers, helpers and social workers (send personalized message, friendship request or invitation)
HUA11. I found private communication with other users intuitive
HUA12. I prefer a different design for private communication with others
HUA13. I encounter no problems in updating social information of people living with dementia.
HUA14. I found updating social information of people living with dementia intuitive.
HUA15. I prefer a different design for updating social information of people living with dementia.
HUA16. I completed all tasks related to my role in the platform
HUA17. This application was user-friendly
HUA18. How useful you consider the platform to follow the social status of people living with dementia?
HUA19. Did the platform respond at your expectations?
HUA20. Would you like to participate in this platform as a game character (e.g. participate in a game story, appear as an avatar to others, have goals defined in and out of the platform)?
HUA21. How could we improve the design? (Colours, fonts, layouts, etc).
HUA22. Please indicate which tasks/steps were more difficult to complete.
HUA23. What were your expectations regarding the platform?
HUA24. What features would you like to add in or remove from this platform?
HUA25. What kind of questionnaires and data-collection tools for screening of social status you might like to be included in the platform?