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Accessibility Report

CAREGIVERSPRO-MMD PROJECT

Document information

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Project coordinator	Universitat Politècnica de Catalunya- BarcelonaTech Prof. Ulises Cortés, ia@cs.upc.edu		
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Authors (Partner)	Antomarini Marco (COO), Cesaroni Francesca (COO), Petrone Mariangela (COO), Scocchera Francesca (COO)			
Responsible Author	Scocchera, Francesca		**Email**	f.scocchera@cooss.marche.it
	Partner	COOSS	**Phone**	+39 071 50103 1

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Executive summary

This deliverable is intended to provide recommendations for improving the CAREGIVERSPRO-MMD platform in terms of usability and accessibility. Identifying the users' characteristics and capabilities, as well as the things they want to do with the platform, will allow to tune the CAREGIVERSPRO-MMD technical specifications to their needs, thus ensuring both functionality and usability.

D1.1 is the main output of T1.1 "Relevant conditions for usability", a 33 months iterative process which will benefit from other WPs results for its completion. At this initial stage of development, D1.1 presents some preliminary accessibility features derived from the partners' expertise and an extensive literature review.

Data and information have been gathered through a series of consequential steps consisting of:

- Identification of characteristics (age, culture, educational level...) and conditions (clinical, psychological and behavioural symptoms) which can affect the users' capabilities to use the CAREGIVERSPRO- MMD platform;
- Analysis of the expected impact of these conditions on the use of CAREGIVERSPRO-MMD;
- List of the suggestions and adaption measures to improve the platform usability and accessibility.

Meaningful usability features have emerged from the "Treatment Adherence Review", resulting from T2.3, which is annexed to D1.1 in its full version.

The list of features to improve accessibility will be updated to reflect feedback from focus groups (WP2-Platform enhancement and Design adaptation), from the progresses in the platform adaptation (WP3 - IT development and integration) and from the users' testing (WP5 - Pilots Operation).

List of Acronyms

Acronym	Title
UA	User Analysis
AA	Activity Analysis
AUI	Adaptive User Interfaces
BITV	Barrierefreie-Informationstechnik-Verordnung Test
CSS	Cascading Style Sheets
CTIC	Centre for the Development of ICT in Asturias, ES
EARL	Evaluation And Report Language Overview
ICT	Information and Communication Technologies
PACT	People, Activities, Context, Technologies analysis
PLWD	People Living with Dementia
QoL	Quality of Life
SMIL	Synchronized Multimedia Integration Language
TAW3	Testo Accesibilidad Web
UNCRPD	UN Convention on the Rights of Persons with Disabilities
WaaT	Web accessibility assessment Tool
WAI-ARIA	Web Accessibility Initiative - Accessible Rich Internet Applications
W3C	The World Wide Web Consortium
WCAG	Web Content Accessibility Guidelines

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1 Introduction to Usability

When developing an ICT (Information and Communication Technology) based products or services, their design should be driven from user requirements and capabilities rather than from technological logics, to ensure that they have real value for end users, are matched to users' skills and fit for the purpose they were designed for. The challenge is to ensure that the product will contribute to the quality of life and independent living of its intended users.

This approach goes under the name of *usability*, which comes from the field of Human Factors (or Ergonomics) aimed at putting a human being at the centre of design, rather than technology or products. A user-centred design should:

- identify the users that need that product/service;
- identify the characteristics that the product/service must have in order to meet the needs of these users;
- involve the users in the design process;
- consider effectiveness, efficiency and safety criteria [33].

When people's needs and capabilities are considered for the design and implementation of a product/service, there are many benefits in terms of effectiveness, efficiency and safety, which can be easily measured and demonstrated through quantitative indicators. Important benefits are: ease of use, satisfaction and commitment, i.e. usability aspects targeting the users' subjective area, which can be difficult to measure. Feedback on the product/service usability and accessibility is a key factor in determining their likely success or failure, and tailored techniques should be used to gather information on the user satisfaction and to set usability goals against which the product/service may be evaluated.

A user-centred approach also contributes to significantly reduce accessibility problems, development costs, as well as the need for redesign and recall. On the contrary, when human aspects are not considered, this often leads to the development of inaccessible and non-ergonomic products/services. The lack of accessibility and ergonomics puts great barriers in the daily life of people with specific needs and even excludes them from many activities.

This deliverable is intended to provide recommendations to guarantee the CAREGIVERSPRO-MMD platform usability and accessibility. It will evaluate the users' profile and match their characteristics and capabilities to the existing technical CAREGIVERSPRO-MMD platform specifications, with the aim to ensure high-level functionality and usability.

2 "Design for All" vs. "User Sensitive Inclusive Design" in web development

ICT have profoundly changed people's lives. Software development products have shown to support and improve people's daily activities and raise their standard of living. The Web provides a unique opportunity for people with disabilities to communicate, participate, interact and benefit from it. Accessibility and ease of use for people with special needs, including physical or functional limitations, visual deficiencies, cognitive and learning disabilities has attracted a lot of attention during the last few years. An increasing number of governments are legislating towards promoting and enforcing equality of opportunity and of access for everyone within the economy and society (Inclusion) [14], also in terms of access to ICT and the evolving Information Society (eAccessibility) [13]. Access to information on the web has been also recognized as a human right by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) [43]. However, developed products and services often lack accessibility. Although well-defined standards exist aiding the development of accessible products, developers are often not adequately aware of the deficiencies and the boundaries that people with disabilities face while using a software application.

The "**Design for All**" principle requires researchers and designers to consider all potential user groups of systems, including the elderly and disabled. However, the "design for all" is a very difficult task, in general. Web pages that comply with general accessibility guideline sets may still fail to be accessible for some users. Lack of context, information overload and excessive sequencing when reading the information are some common problems for the visually impaired users [45]. Providing access to people with certain types of disability may make the product significantly more difficult to use by people without disabilities or people with a different type of disability [26]. Moreover, there are cases where the "Design for All" cannot be applied due to the special nature of a product/service (e.g. the inclusion of blind people in driving). Thus, new methodologies appeared, in order to enforce the inclusion of specific user's needs and preferences in the design process, namely "**User Sensitive Inclusive Design**" [27]. According to the principles of "User Sensitive Inclusive Design", "inclusivity" such as focusing on a specific target group of users, is a more achievable, and in many situations, more appropriate goal than "universal design" or "design for all". This is because the range of functionality and characteristics of the user groups in many cases can be so great that it is impossible in any meaningful way to produce a small representative sample of the user group, nor often to design a product that is truly accessible by all potential users. Some research findings [45] claim that personal accessibility evaluations of web pages often improve the web experience of disabled users and improves the whole website development process. They also report that web developers may define or retrieve user profiles and evaluate their designs against them, when developing web sites for specific audiences. User profiles allow users' disabilities and functional limitations to be considered through the design and development process.

The CAREGIVERSPRO-MMD platform will be designed and developed on the "User Sensitive Inclusive Design" approach, towards addressing the specific needs and preferences of the end-users. More specifically, the interface of the CAREGIVERSPRO-MMD will be adaptable to the needs and preferences of the direct end-users, which in our case are PLWD, their caregivers and the health professionals. At this stage of development, the usability study has focused on the functional implications that given characteristics and symptoms can determine on usability and accessibility issues. Specific needs for each target groups will be identified during the project progress, with contributions from WP2, WP3 and WP5.

3 Adaptive interfaces for PLWD

Adaptive User Interfaces (AUI) have been widely recognized as a promising means towards accessible technology [16], [34],[37],[49]. Identifying individual and situational user needs and providing dynamically personalized user interfaces can overcome significant barriers of use. People with cognitive disabilities can benefit from information and content presented in a way they are familiar and comfortable with.

A major challenge for adaptive web interfaces is the development of **user profiles** that consists of each user's cognitive and physical abilities. Currently, some research has been conducted towards the definition of user models/profiles describing user characteristics in detail, including also cognitive parameters. An indicative example is the VERITAS Virtual User Model [21], which describes a large set of physical, cognitive and behavioural characteristics of a person, including possible disabilities, functional limitations, the affected/problematic (due to the disabilities) tasks as well as possible use of assistive devices. However, there is no standardized definition of a user model/profile yet, so developers of adaptive user interfaces use different profiles for their systems. The adaption of the actual user interface based on the user profile is also still challenging. Adapting the user interface for different user needs in an automated way is still being researched. When adapting the interface to user's needs and characteristics, it is important to adjust this interface it in a way that it looks good on different devices with different resolutions and interaction paradigms and in a way that it is optimized for the individual user. Another issue is the conversion of content into another format like EasyToRead [12] or symbol language. Although some research is being made in that direction, no automated solution has emerged so far. For this reason, a specific user profile should be created for each product.

4 User Analysis

User needs are a central factor in a usability study, meaning that a relevant match between the physical and cognitive abilities of the user and the requirements for using the platform should exist. There is no such thing as an average user: age, gender, cultural and ethnic differences, cognitive and sensory abilities, mobility problems make users different in their needs and expectations.

A principal concern of usability is placing the potential users at the centre of the design process. This involves identifying who the potential users are and the characteristics of these typical users. In CAREGIVERSPRO-MMD project, the direct end users are PLWD, their formal/informal caregivers and healthcare professionals. Once the users groups are identified, their characteristics and attributes have to be analysed, as they will affect their ability to use the platform. Identifying characteristics such as "memory loss" determines design parameters that must be considered for these users. In other words, the users' characteristics contribute to the functional requirements for the development of the platform.

The **User Analysis (UA)** [33] is a simple tool, which acts as a repository of design information about user characteristics, and summarizes the implications that these may have for design (Table1).

Column 1(Characteristics) lists all the characteristics of the intended users, both in terms of personal details and clinical symptoms. The list of symptoms is derived from D1.2.

Column 2 (Functional implications) provides some suggestions in order to make the platform accessible to users with specific characteristics/symptoms. Functional implications are identified, and possible solutions for user's difficulties to use the platform are sought. They can cover a wide variety of issues and be developed from literature analysis or from surveys involving the direct users.

Column 3 (Desired Product Characteristics) reports any practical ideas and suggested features to satisfy the user needs when designing the platform.

Tab.1 provides an example of what the table should result like, once filled in. It has to be considered that not all the characteristics and symptoms will give rise to functional implications, and that different symptoms can originate the same desired characteristics.

Characteristics	Functional Implications	Desired product characteristics
Personal characteristics		
Age > 65	*Simplicity of design needed*	*Self-descriptive interfaces, with all the possible actions included.*
	Attractive and interactive platform	*Appropriate graphics to enhance understanding [19]*
Gender:	*Males interact for longer periods with touch screens than females [44]*	
Cultural status:	*Plain and easy information, keys and messages*	*Labeling key buttons with signs and non verbal symbols*
Motivation in using ICT probably low	*Simple to operate and attractive*	*Use gamification to promote engagement*
Experience in using ICT	*Probably low: simple to operate, intuitive or with continuous suggestions on how to go on*	*Avoid jargon and technical language*
Cognitive – clinical symptoms		
Agnosia	*Present materials in multiple modes can help increasing comprehension [19, 18, 40]*	*Use audio prompts to signal any change of state [19, 40]*
……		
Behavioural-Psychological symptoms in Patients		
Anosognosia	*To paying attention to vocabulary used. Use medical terms (dementia, Alzheimer disease, …) for scientific contribution or caregiver's exchange. Positive not stigmatizing words*	
……		
Activities of Daily Living in People Living with Dementia and caregivers		
…….		
……		

Table 1 – User Characteristics Analysis (UA)

To complete the tool from UA above, the needs and characteristics of direct users, including PLWD and caregivers, healthcare professionals and technical staff, need to be identified. Methods such as interviews, focus groups and demonstrations will help to gather useful feedback from the above-mentioned user groups, and guarantee the compliance of their needs with the platform's functional specifications. D.1.1 will therefore be updated as the project progresses, benefitting from the PACT analysis results (WP2) and end users' experience (WP5).

The Desired Product Characteristics identified in Column 3 will indicate the usability goals against which the platform will be evaluated.

Appendix 1 reports the first usability indications, derived from a preliminary scientific literature review and from the partners' contributions.

5 Activities Analysis

Users' requirements have to be related to the tasks that the platform is facilitating or is aimed to. Matching the platform tasks and functionalities to the user capabilities and limitations is a key point to ensure its usability and acceptability: if the platform is not perceived by the users as satisfying some useful purposes, if it doesn't enable them to achieve their goals or if they do not obtain any benefit from its use, it means that its usability is low. As such, the functionality of the CAREGIVERSPRO-MMD platform may be assessed against the definition of what the user can do with it. This perspective focuses on the needs of the user groups and is driven by their characteristics, rather than by considerations of what might be technically feasible.

The **Activity Analysis (AA)** [33] is a simple tool allowing to describe the activities or tasks that each user will need to perform when using the CAREGIVERSPRO-MMD platform (Table 2). Similar to the User Analysis, Activity Analysis tool facilitates the identification of some desired product characteristics that will guide developers to improve the platform's design.

Column 1(Activities in Scenario) lists the CAREGIVERSPRO-MMD platform's functions, either as a high level overview or detailed in lower level activities that contribute to the overall task performance. The high level scenarios correspond to the 6 main services of the CAREGIVERSOPRO-MMD platform. Services, functions and contents will be added once the upcoming usability studies are completed.

Column 2 (Functional Implications) provides suggestions in order to make the tasks accessible to users with specific characteristics/symptoms. At this stage of the analysis, the focus is on the difficulties users may face in the performance of the proposed tasks, and on the way these difficulties may be practically solved.

Column 3 (Desired Product Characteristics) translates the suggestions in technical specifications, which will guide to redesign the platform. It documents any practical ideas for the design of the product and provides suggestions to make the platform satisfy the user needs.

Activities in scenario	Functional implications	Desired product characteristics
Login to the platform	*Make it simple and not confusing*	*Avoid English technical terms (pw, id, account…)*
	Privacy issues: clarify privacy issues and data protection methods in simple and accessible form	*Avoid that terms and conditions are small and illegible for the user.*
Select services from the home page	*Limit the number of functions and make them well visible and recognizable*	*Luke Wroblewski guidelines for different platform*
Social Network service:		
Build patients' community	*Make the communities easy to create, select and use*	*Clarify the differences for "circle", "contacts", "friends"…*
Clinical, psychological and behavioral screening service:		
Assess patients' treatment adherence level	*Clarify the need to save data, if it is the case* *Simple and short format for the scales, supported by visual and audio aids for their completion*	*Big "save" button? Audio-visual reminder that data have to be saved?*
Therapeutic education service:		
Provide information to the users about dementia, symptoms, psychiatric co morbidity	*Captioned videos* *Different contents depending on the dyad member*	*Interventions following guidelines in 3.1*
Treatment adherence service:		
Identify the treatment adherence level	*Provide one simple and short scale*	
Improve treatment compliance	*Include advises for caregivers (verify drug boxes, prescription renewal…)*	
Gamification service:		
Under construction	*……*	
Clinical and social report service:		
Share data with doctors/others;	*Make the data sharing automatic as far as possible, thus avoiding users' operations in this sense*	
……		

Table 2 – Platform Activities Analysis (AA)

Similar to UA, the completion of the proposed AA tool requires the involvement of the direct users (PLWD and caregivers), health professionals and technical staff to gather specific needs and conditions requiring customized design. Namely, the role and requirements of health professionals will be taken into account in terms of productivity or context, because of their crucial role. Interviews, focus groups and demonstrations will help to gather relevant feedback from the user groups and increase the compliance of their needs with the platform tasks. The AA form will be updated with information and data derived from the PACT analysis (WP2) and the users' direct experience (WP5).

The desired product characteristics identified in Column 3 will be used to set the usability goals against which the platform will be evaluated.

Appendix 2 reports some preliminary activity analysis indications.

6 Usability study results

There are two types of tasks when using a computer: operational and functional ones [40]. **Operational tasks** are related to interfacing with the machine, while the **functional tasks** are related to learning and content. It is important to make the operational tasks as transparent as possible, so that users can focus their attentions on the functional aspects – especially in a learning environment.
This chapter summarizes the suggestions emerged from the User Analysis (UA) and the Activity Analysis (AA) tools and classifies them according to their operational or functional nature.

6.1 User Analysis (UA) - Desired product characteristics

Features enhancing interface operability

☑	Use appropriate graphics to enhance understanding [19];
☑	Use bold, primary colors;
☑	Use high contrast between text and background [19] and avoid coloured text on coloured background;
☑	Highlight urgent or key information [19] to aid in selective perception [40]
☑	Make interface elements large, simple to operate and attractive;
☑	Keep menus short and easy to understand
☑	Provide keys, messages and menus in user's first language
☑	Use clear labels and signs [18, 19, 28]
☑	Label key buttons with signs and non-verbal symbols
☑	Include audio to support written material
☑	Include voice descriptions for menus and voice instructions
☑	Consider multiple modes of input, such as including captions to enhance text
☑	Allow reading out of highlighted words or sentences by synthetic speech, and automatic pop-up of pictures corresponding to words or phrases when the user taps on them
☑	Use audio prompts to signal any change of state [19, 40]
☑	Use low frequency sounds

☑	Use an interactive character, with controls allowing the user to adjust the speed and motion if animations or dynamic displays are used [19, 18, 6]
☑	Do not use menus or other text that appears and disappears [9]
☑	Minimize the number of interface elements and number of buttons per page to minimize screen clutter
☑	Design self-descriptive interfaces, with all the possible actions included
☑	Avoid multiple windows, complex or cluttered displays [19]
☑	Place the most frequently used menus firsts
☑	Arrange buttons at the bottom of the screen or one-level-navigation instead of menu structures.
☑	Include back and home buttons inside the web pages
☑	Reduce the need for fine motor coordination and two handed interactions
☑	Increase the size of clickable areas to tap [36]
☑	Allow users to enlarge interfaces and adjust text size
☑	Provide for one single key for selection whenever possible
☑	Allow warnings and messages to appear always on the same part of the screen
☑	Make menu items or keys with the same label perform the same functions (consistency);

Features enhancing the platform functionality:

☑	Design a narrow structure [40]
☑	Insert plain and easy information, keys and messages;
☑	Use plain language in short, concise sentences [19, 18, 6];
☑	Reduce the amount of information presented
☑	Put all the info in the flow of text they are reading [28] on the display
☑	Include audio text/narration [32]

☑	Do not use colours to communicate meaning [31]
☑	Use graphics and recognizable icons to support navigation [19, 18]
☑	Avoid jargon and technical language
☑	Propose chunk materials – one idea per paragraph [18, 5]
☑	Include response systems to indicate errors in learning tasks
☑	Slow down or turn off the timed responses and eventually prompts in case of excessive delays
☑	Increase predictability and consistency across the platform
☑	Provide breadcrumbs to provide confirmation of navigation and reinforce objectives [18, 36]
☑	Provide prompts and feedback
☑	Provide user-friendly guide on internet safety and privacy
☑	Device and platform manual, including potential benefits of the platform
☑	Offer support / technical manual and training on use of the application / platform
☑	Include a welcoming personalized page providing temporal and spatial orientation details

6.2 Activity Analysis (AA) - Desired product characteristics

To start the analysis, the six CAREGIVERSPRO-MMD services the platform is conceived for were considered, to be detailed in sub-activities as the project progresses, i.e.:

- Social network service;
- Clinical, psychological and behavioural screening service;
- Therapeutic education service;
- Treatment adherence service;
- Gamification service;
- Clinical and social report service.

An in-depth analysis of the “Treatment adherence service” was carried out, nourished by T.2.3 results, already available at the time being (see Annex 3 – Treatment Adherence Review).

Other basic activities linked to the use of the platform have been included, as logging in, selecting options and services, building one’s own online community, etc.…

The AA tool will be enriched with tailored tasks once the platform is populated with new functionalities and contents; PACT analysis findings (WP2) and users' experience (WP5) will contribute to identify usability requirements. Some initial characteristics are provided, based on the impressions derived from a preliminary demonstration of the platform partners assisted to:

☑ Prefer one single big button to login, or the fingerprint

☑ Avoid technical terms (password, id, account, etc) to ask users to register;

☑ Include tutorials

☑ Avoid terms and conditions that are written with too small characters or unintelligible sentences.

☑ Include a big "save" button

☑ Insert an audio-visual reminder that data have to be saved

☑ Ensure compliance with EU and national rules on data protection and privacy issues

☑ Clarify the differences for "circle", "contacts", "friends"

☑ Include facilities to get feedback on the adherence level;

☑ Make data editing simple and immediate

☑ Provide facilities to support treatment adherence;

☑ Design pictograms, charts, colours, written action plans to organize medications and increase adherence;

☑ Allow frequent and easy exchanges with the doctors, to increase communication and treatment adherence;

☑ Provide educational material on the nature of the disease and the importance of the treatment; provide vademecum information (i.e. medication incompatibility, purpose, etc) in a simple and easy to understand way;

☑ Confirm patient understanding of the treatment;

☑ Provide varied aids to remind patients to take their medication (phone call, text messages, reminders…);

☑ Suggest strategies relying on automatic associative processes;

☑ Make medication intake reminders comfortable and non-irritating;

☑ Provide reminders, alarms, information systems to minimize the caregivers' risk of confusion and inaccuracy in the medication management

☑ Provide caregivers with information about medication management;

☑ Include advises for caregivers (verify drug boxes, prescription renewal…);

☑ Support the caregiver with aids and strategies to improve and facilitate the medication management;

The UA and AA provided some preliminary suggestions, which can be the basis of an exhaustive list of usability requirements. T.1.1 is an ongoing activity, closely linked to WP2 and WP5 results. This document aimed to give a methodological guide and to identify some available tools to support this approach. Additional data will be needed to complete the study and the involvement of users is expected to consistently contribute in this sense.

7 Other design considerations

Although there is no set rubric for designing for users with cognitive disabilities, there are several valuable suggestions that encompass both accessibility and usability metrics for users with cognitive disabilities. Some suggestions that not only improve usability for all users but may also provide a measure of accessibility for an underserved population are presented.

Often making a page visually interesting and easy to read makes *listening* to a page using a screen reader extremely difficult, as the use of graphical spacers and tables can disrupt the reading order of related text. The use of database driven text and Cascading Style Sheets (CSS) can create pages that satisfy the needs of both visual and aural users while still making it easy to change information and textual data. Additionally, style sheets help to convey context, allow for graceful degradation, and make it available for a greater number of possible browsers to read the code properly [41], [7].

Developers should provide user with the means to control as many aspects of the website as possible. The use of CSS (Cascading Style Sheets) can be used to provide control of how information is presented. CSS can be used to change font and font size; change the line height or space between lines of text; increase the size of "clickable" areas; allow for mouse over highlighting of text for easier reading; change the background colour of a page; and invert colours and increase contrast on the page [18], [6], [36].

Content might be displayed in EasyToRead [12] format or enriched with symbols so that the content is easier to understand for people with cognitive disabilities. AUI would provide interfaces that offer improved and optimized navigation mechanisms which would be tailored for the current user. Common state of the art approaches in AUI are based on user profiles and describe the capabilities, abilities and knowledge of the user. Profile servers can analyse the content and structure of the page requested and create a web page that is optimized for the user. Some approaches monitor user's interaction with the web page and update user profile if any problems with the usability, navigation or the content are detected.

Some parameters that should be considered when developing AUIs for people with cognitive impairments are provided, to complement the list provided at chapter 6:

- Identify pre-knowledge necessary for a user to successfully utilize the site [19].
- Provide definitions and explanations for unusual or technical terms – take advantage of the ABBR and ACRONYM tags in HTML [19], [18].
- Ensure that alerts and feedback remain on screen until the user removes them [19].
- Optimize search facilities; include tolerance for misspellings and typos [28].
- Ensure that webpages are compatible with screen readers and other assistive technologies [19].
- Use meaningful headings [18], [39], [5].
- Make line length not exceed 70-80 characters [18].
- Avoid large white gaps caused by full justification typesetting [18].
- Avoid or provide alternatives for non-literal text and colloquialisms [18].

- Include plenty of white space on the page [36], [18], [5].
- Avoid pull down menus
- Offer users a choice of "long" or "short" content so that they can determine the level of detail that they require [118, [40].
- Design for working memory limitations [5], [3]. Reduce the standard 7 ± 2 maximum elements guideline for short-term memory to 4 ± 2 [40].
- Use bulleted lists whenever possible [18].

Accessibility analyses may also benefit from a big amount of available technical suggestions. A good roundup of human interface guidelines for different platforms also exists, indicating sizing features: Luke Wroblewski (www.lukew.com) provides some useful indications in this sense:

- Avoid font sizes smaller than 16 pixels (depending of course on device, viewing distance, line height etc.).
- Reduce the distance between interface elements that are likely to be used in sequence (such as form fields), but make sure they're at least 2 millimetres apart.
- Buttons on touch interfaces should be at least 9.6 millimetres diagonally (for example, 44 × 44 pixels on an iPad) for ages up to 70, and larger for older people.

Further sources and technical references will be explored and detailed during WP2 activities.

8 Web accessibility standards and automatic conformance assessment

When developing accessible web content, it is also suggested to follow well-known accessibility standards such as the Web Content Accessibility Guidelines (WCAG) 2.0 [48], which cover a wide range of recommendations. Following these guidelines will make content accessible to a wider range of people with disabilities, including blindness and low vision, deafness and hearing loss, learning disabilities, cognitive limitations, limited movement, speech disabilities, photosensitivity and combinations of these. Following these guidelines will also often make web content more usable to users in general.

Cognitive Accessibility User Research [46] is another initiative of W3C describing the challenges of using web technologies for people with learning disabilities or cognitive disabilities. The research describes challenges in the areas of attention, executive function, knowledge, language, literacy, memory, perception, and reasoning. It is organized by user groups of the following disabilities: Aging-Related Cognitive Decline, Aphasia, Attention Deficit Hyperactivity Disorder, Autism, Down Syndrome, Dyscalculia, Dyslexia, and Non-Verbal Disability. Additional user groups may be added to future versions. Cognitive Accessibility User Research provides a basis for subsequent work to identify gaps in current technologies, suggest strategies to improve accessibility for these user groups, and develop guidance and techniques for web authors.

8.1 Software tools for automatic web accessibility assessment

There is a large number of software tools performing accessibility evaluation of web sites based on the guidelines of popular accessibility standards, such as WCAG 1.0, WCAG 2.0, Section 508, etc. Recently some tools supporting the WAI-ARIA (Web-Accessibility Initiative - Accessible Rich Internet Applications) guidelines have also appeared. The most common technologies that are checked include Cascading Style Sheets (CSS), XHTML, PDF, images, Synchronized Multimedia Integration Language (SMIL), and Scalable Vector Graphics (SVG). The automated checking on a single web page is the most common feature supported. However, some tools support evaluation of groups of pages or entire web sites. The report of the evaluation results may include step-by-step evaluation guidance, displaying information within web pages or more formal report types, such as EARL-based reports [1]. Some accessibility evaluators also provide repair functionality by changing the source code of the web pages, helping with captioning audio or video content, or converting the document into accessible mark-up.

Many tools, such as the Foxability [15], WAVE [47], HERA [4] and Hera-FFX [20], have been developed based on the WCAG 1.0 guidelines. However, WCAG 1.0 presented weaknesses due the fact that they were based on technologies of the past decade, specifically HTML. Thus, WCAG 2.0 was proposed to solve WCAG 1.0 problems and made WCAG 1.0 obsolete. After the establishment of the WCAG 2.0 guidelines, many evaluators were extended in order to support WCAG 2.0.

AChecker [17]is an open source web accessibility evaluation tool developed by the Adaptive Technology Resource Centre at the University of Toronto. It supports a variety of international accessibility guidelines like Section 508, Ley Stanca (Italy), WCAG 1.0 (levels A, AA and AAA) and 2.0 (levels A, AA, and AAA), and BITV 1.0 (Germany). AChecker presents results in three categories: known problems, likely problems and potential problems.

Worldspace FireEyes [11]**Error! Reference source not found.** is a free web accessibility evaluation tool introduced by Deque Systems, Inc evaluating the compliance of a web site according to standards such as WCAG 1 (Priorities 1, 2 and 3), WCAG 2 (levels A and AA), Section 508 and contains some dynamic rules that test for WAI-ARIA compliance. The FireEyse also includes features such as: color contrast analyser, dynamic report filtering, interactive issue remediation and transcripts of all pages visited in a session. Worldspace FireEyes is fully JavaScript aware and handles event-based page content. It works as a complement of the Firebug Firefox extension.

Total Validator [42] is another accessibility validator supporting WCAG 1.0, WCAG 2.0 and Section 508 standards. It includes a HTML validator, an accessibility validator, a spelling validator, a broken links validator. There is a web version, a Firefox extension, and a desktop version of the tool available.

TAW3 [9] is an accessibility validator developed by the Spanish Foundation CTIC (*www.fundacion**ctic**.org*). It is available in two versions: a plug-in for Mozilla Firefox and in a standalone version. TAW3 analyses websites according to WCAG 1.0 and WCAG 2.0 guidelines by providing fixes and recommendations. TAW3 results are presented with different representation of violations (problems, warnings, and not reviewed).

WaaT [29] is another tool performing automatic accessibility evaluation of web pages against on both the WCAG 2.0 standard and the WAI-ARIA guidelines. The Harmonised Methodology (HAM) [8] introduced by the ACCESSIBLE EC FP7 project was the base for the development of WaaT.

The tools above will be used to ensure the accessibility of the CAREGIVERSPRO-MMD platform.

9 To be considered

When gathering opinions and suggestions on product desired characteristics, different views can emerge with respect to a given problem, which will have to be solved in subsequent design. Additionally, conflicts can occur due to different design features being incompatible with each other, some of which may not be possible to resolve when a single product is to be used with a wide range of users. Where feasible, platform design differentiations will be considered to match the needs of specific groups, but in many cases it will be necessary to decide how such conflicts between design constraints and user needs are to be addressed. Prioritizing the relevance of the proposed features can be a first step in the design process: rating them using a 3-point scale (i.e. high, medium, low priority), can provide an initial indication of major conflicts and whether or not a solution can be found.

Product characteristics specified in this deliverable will be useful to set the usability goals against which to evaluate the platform. Usability goals represent what the users can achieve through the platform and how easily and effectively they can achieve it. Deciding upon the goals which the product must meet if it is to be attractive to users and successful in the market will be a challenging task as the project progresses. The list of desired characteristics presented in this document will be enriched with the feedback derived from the PACT Analysis (WP2) and the pilots' development (WP5), and will pose the basis for the identification of the usability goals, the measurement procedures and the criteria for success.

Much has been written and reported on usability, but accessibility remains one of the main barriers to the exploitation of innovative ICT based products and services. One of the CAREGIVERSPRO-MMD challenges will therefore consist in making the platform really accessible to its users.

10 Appendices

10.1 User Analysis (UA)

Attribute	Functional Implications	Desired product characteristics
PERSONAL CHARACTERISTICS		
Age > 65	Simplicity of design needed	Self-descriptive interfaces, with all the possible actions included.
	Attractive and interactive platform	Appropriate graphics to enhance understanding [19]
Declining sensory abilities	loss of visual acuity and colour perception, increased sensitivity to glare	Use of bold, primary colours; Make interface elements larger; Allow users to enlarge interface Increase the size of areas to touch or tap [36]
	sounds tone detection decreased [31]	Use low frequency sounds
Declining motor abilities	slower movements, poor coordination, difficulties with fine motor actions	Reduce need for fine motor coordination and two handed interactions
Gender	Males interact for longer periods with touch screens than females [44]	
Cultural status	Possible low education; Levels of education affect computer use [10] [30]	Plain and easy information, keys and messages; Labelling key buttons with signs and non verbal symbols Voice instructions to support reading material
	Reading patterns in low-literate users imply word by word reading => narrow fields of vies causes them to miss objects and information if not directly in the flow of text they are reading [28]	Put all the information in the flow of text they are reading [28]
		Include auditory function for text/narration [32]
	Colours might represent different things and be perceived in different ways in the different cultures [31]	Do not use colours to communicate meaning [31]
Motivation in using ICT	Motivation to use technology depends on appropriate training and awareness of benefits [23] [35]	Simple to operate and attractive Device and platform manual, including potential benefits of the platform
	Propose a dynamic and playful system promoting engagement and enhancing motivation	Gamification
Experience in using ICT	For low-experienced users, the system should be simple to operate and intuitive	Avoid jargon and technical language; Use an interactive character
	Continuous encouragements/suggestions on how to go on needed	Offer support / technical manual and training on use of the application / platform
	Older adults with previous computer and other technology experience are more likely to be engaged with technology ([24]	

	Low experience may require education / support on privacy and internet safety issues	Provide user-friendly guide on internet safety and privacy
Languages knowledge	Elderly users may be able to speak and understand their native language only.	Labelling key buttons with signs and non verbal symbols; Provide keys, messages and menus in Users' first language.
COGNITIVE-CLINICAL SYMPTOMS		
Agnosia	Agnosia can make the platform use difficult; present materials in multiple modes can help increasing comprehension [19, 18, 40]	Multiple modes of input, such as including captions to audio and screen readers to enhance text; Use audio prompts to signal any change of state [19, 40]; Reading out of highlighted words or sentences by synthetic speech, and automatic pop-up of pictures corresponding to words or phrases when the user taps on them;
Aphasia	Problems to process language and numbers [6] Problems in deciphering auditory or written inputs [6]; Propose visually appealing and strong graphical components; Propose short and easy sentences to make understanding easier; Avoid animated graphics as they can be distracting and increase cognitive load	Avoid multiple windows, complex or cluttered displays [19] Consider multiple modes of input; Label key buttons with signs and non verbal symbols; Use graphics and recognizable icons as navigation aids [19, 18]; Controls allowing the user to adjust the speed and motion if animations or dynamic displays are used [19, 18, 6]
Apraxia	Allow voice commands; Enlarge pictures and digital keyboards	
Attention disorders	No complex or busy interfaces ([50]; Interfaces should containing all the information that users need, to allow them to build a mental model or internal representation of the system they are using, to facilitate the acceptance of the system, and make the operations easier;	Self-descriptive interfaces, with all the possible actions included.
	Plain and easy information, keys and messages, in order not to overburden the attention system; Restrict bright colors at important details or information;	Minimize number of interface elements-simplify; Back and home buttons inside the web pages
	Reduce the amount of information presented on a display and allow blank spaces, as they help to focus attention; Minimize any distractions – in terms of design features (no pop-ups or ads)	Chunk materials – one idea per paragraph [18, 5]
Executive dysfunction	Guide the user to appropriate actions when mistakes are made; Simple to use, intuitive (planning deficit)	System responses to indicate errors in learning tasks
	Not busy interface because older adults' attention in more than one source of information is declined [25]; Interface should be familiar and easily understood, like other interventions for orientation ([38];	Minimize number of interface elements-simplify; Back and home buttons inside the web pages

	Restrict bright colours at important details or information (inhibition deficit);	
Temporal/spatial disorientation	Reduce the complexity of all the operations: simple functionality is more acceptable than systems with a large number of features;	Reduce the amount of information presented on the display; Arrange buttons at the bottom of the screen or one-level-navigation instead of menu structures. Simple interface with not many buttons per web page
	Propose an agenda in the homepage with the day's date, the time of day (morning, afternoon, dinner time,…), localization (city) and weather (to indicate how to dress appropriately according to the weather/temperature…).	Include a welcoming page personalised providing temporal and spatial orientation details
Thinking and reasoning disorders	Give users flexible times to complete the tasks. Think and respond to online stimuli requires longer times [40]	Slow down or turn off the timed responses and eventually prompts in case of excessive delays
	Present information –simply and avoid cluttered or crowded screens; Present one item at a time Minimize any distractions – in terms of design features (no pop-ups or ads);	Avoid multiple windows, complex or cluttered displays [19]
	Problems to identify information and integrate them into meaningful chunks [36]; Make contents become more appropriate and advanced as information are provided (Advancement system)	
Memory loss	Minimize the memory load; Use short words in positive form (easier to understand); Use designs that people are familiar with e.g. CIRCA a reminiscence platform was designed to look like an old fashioned music player [2] Keep the same design for the homepage;	Use plain language in short, concise sentences [19, 18, 6]; Use clear labels and signs [18, 19, 28] Minimize buttons and on screen features displayed to minimize screen clutter Keep menus short and easy to understand
	Because of working memory problems- Research suggests when items are presented one after the other – people with dementia picked the last item as it was in their immediate memory (Astell et al 2009); Navigation during tasks is difficult for people with memory problems [30]; Games stimulate memory [22] Problems in processing sequential operations [19] Let users know if they made the correct choice and help them to get back on track when they make errors [19, 18, 40] Limit the number of options to prevent cognitive overload [18]	Increasing predictability and consistency across the platform Randomizing the presentation of items could be considered; Voice descriptions available for menus, and voice instructions Breadcrumbs to provide confirmation of navigation and to reinforce objectives [18, 36]

	Use familiar imagery to aid in memory retention [40]	
	Make recognition prevail on recalling: reduce the amount of information presented on a display and allow blank spaces, as they help to focus attention; Ensure that the same actions have the same consequences; Avoid repeated questions.	Most frequently used menus placed first One single key for selection whenever possible; Warnings and messages should appear always on the same part of the screen; Menu items or keys with the same label should perform the same functions (consistency)
	Improper or ambiguous navigation can create confusion [19] Provide ways to backtrack or start over in navigation [19] Use word game and rhymes to help memorization Avoid simultaneous tasks [40]	Consistency needed: standardize controls, features and navigation Provide prompts and feedback Design a shallow or narrow decision structure [40]
BEHAVIOURAL-PSYCHOLOGICAL SYMPTOMS		
Anosognosia	Difficulty to pay attention to vocabulary used. Use medical terms (dementia, Alzheimer disease, …) only for scientific contribution or caregiver's exchange. Positive and not stigmatizing words.	
Anxiety	Touch screens reduce older adults' anxiety about technology; Positive words, encouragements, valorization (to patient and caregiver). Soothing colours. Importance to place date and localization. Clear and consistent information to prevent misinterpretations.	
Appetite/eating disturbances		
Delusions	Positive words, encouragements, valorization (to patient and his caregiver). Soothing colours.	
Depression or dysphoria	Risk of harassment due to users' inappropriate behavior. Tocontrol information from posts and messages with a content engine.	
Disinhibition / Social behaviour disorders	For people avoiding social interaction: Games promote social interaction among players when using real time verbal communication	
Elation or euphoria		
Hallucinations	May compromise the platform usability	
Irritability or labiality	Simple to operate, intuitive. Soothing colours.	
Motor and behavioural inertia, apathy, indifference	Attractive design. Interactive character.	
Night-time behaviours / sleep-wake cycle disruption	Agenda with date, time of day, hour, … (for example: time of sleep). Soothing colours.	
Repetitiveness/motor disturbance	May compromise the platform usability	

Sexual behaviour disorders	Control information in posts and messages by using a content engine to spot inappropriate language/behavior.	
Verbal/physical aggressiveness / Agitation	Simple to operate, intuitive. Soothing colours.	
ACTIVITIES OF DAILY LIVING		
Eating		
Drinking		
Dressing		
Hygiene		
Bath / Shower		
Toilet		
Transfers	Use tablets rather than a computer	
Mobility	Use tablets rather than a computer	
Orientation-Time	To propose an agenda in the homepage with the day's date, the time of day (morning, afternoon, dinner time, etc)	
Orientation-Place	Localization (city) and weather, with recommendations on how to wear appropriately for the weather.	
Communication	Visually appealing, bright colours, strong graphical components; Propose short and easy to understand sentences Words should be easy to understand	
Using the telephone	Simple to operate, intuitive	
Houseworking/Gardening	Weather?	
Shopping	No adaptation required	
Managing finances	No adaptation required	
Games/Hobbies	Daily contents adapted to hobbies	
Transport	No adaptation required	

10.2 Activity Analysis (AA)

Activities in scenario	Functional implications	Desired product characteristics
Login to the platform	Make it simple and not confusing;	1 single big button to login, or a fingerprint; Avoid technical terms (pw, id, account…) to ask users to register; Tutorials
	Privacy issues: clarify privacy issues and data protection methods in simple and accessible form	Avoid terms and conditions that are written with too small characters or unintelligible sentences; Compliance with EU and national rules on data protection and privacy issues
Select services from the home page	Make the home page attractive, not confusing and with positive statements; Limit the number of functions and make them well visible and recognizable	See suggestions from UA
Social Network service:		
Build patients' community	Explain the importance of the online community to encourage its use; Make the communities easy to create, select and use;	Clarify the differences for "circle", "contacts", "friends"
Increase awareness about self-help and mutual aid	Make communication channel with the community members immediate and attractive, to enhance its use and encourage conversation	
Prevent patients' isolation	Easy and immediate communication possibilities with reduced text/writing requests	See UA suggestions
Clinical, psychological and behavioural screening:		
Assess patients' treatment adherence level, QoL and well-being, symptoms of dementia and psychiatric comorbidity	Simple and short format for the scales, supported by visual and audio aids for their completion; Avoid text-based feedback;	
	Clarify the need to save data, if it is the case	Big "save" button; Automatic reminder; Autosave; Audio-visual reminders/notifications that data have to be saved.
Therapeutic education:		
Obtain information from the users about dementia, symptoms, psychiatric comorbidity;	Make the navigation easy and the contents immediately recognizable; Provide simple, adapted and personalized information	
Personalize interventions through predictive algorithms.	Avoid anticipating future too much; Limit the need for user intervention as far as possible (i.e. make the system more automatic as possible)	

Treatment adherence services:		
Identify the treatment adherence level	Provide a simple tool to assess treatment adherence	Include facilities to get feedback on the adherence level; Make data editing simple and immediate. [Annex 3]
Improve treatment compliance	Users at an early stage of dementia may be capable of managing their medications with little assistance [Annex 3]	Provide facilities to support treatment adherence; Design pictograms, charts, colors, written action plans to organize medications and increase adherence. [Annex 3]
	Poor relations and scarce communication with the medical doctor are risk factors for non adherence	Allow frequent and easy exchanges with the doctors, to increase communication and treatment adherence. [Annex 3]
	Difficulty to understand medical advices and information about disease and treatment, as well as to get enough information from the medical doctor	Provide educational material on the nature of the disease and the importance of the treatment; [Annex 3] Provide vademecum information (i.e. medication incompatibility, purpose, etc) in a simple and easy to understand way; Confirm patient understanding of the treatment. [Annex 3]
	Difficulty to memorize instructions; establishing a routine or cues strongly associated with medication taking actions can improve medication adherence.	Provide varied aids to remind patients to take their medication (phone call, text messages, reminders…); [Annex 3] Suggest strategies relying on automatic associative processes. [Annex 3]
	Tracking whether the medication was taken or not is as important as reminding to take the medication	Make medication intake reminders comfortable and non-irritating. [Annex 3]
Support the caregivers in the treatment management	Possible difficulties and confounding factors when performing the management of care recipient medication for regimen complexity	Provide reminders, alarms, information systems to minimize the caregivers' risk of confusion and inaccuracy in the medication management. [Annex 3]
	Lack of complete information on the treatment because excluded by the medical appointments for privacy reasons	Provide information about medication management;[Annex 3] Include advises for caregivers (verify drug boxes, prescription renewal…). [Annex 3]
	Medication management is potentially stressful for the caregiver	Support the caregiver with aids and strategies to improve and facilitate the medication management. [Annex 3]
Gamification service:		

Increase the interest of end-users on using the platform	Agenda with weather, date, hours, city, game each day, day advice…. Include quizzes with multiple choice questions; Base them on hobbies and preferences; Use appropriate rewarding schemes.	
Clinical and social report service:		
Share data with doctors/others;	Make the data sharing automatic as far as possible, thus avoiding users' operations in this sense; Provide social and legal information	
Improve treatments	Useful data: where to find help?;	
Obtain feedback from doctors	Make the doctors' feedback clear, possible through icons and without too technical sentences; The link with doctor should not be systematic: provide doctor online once a month (?), for advice and interaction;	

10.3 Treatment Adherence Review[1]

10.3.1 The patient with Alzheimer

Alzheimer's Disease

Alzheimer's disease (AD) is the most common cause of dementia. According to WHO it may contribute to 60-70% of dementia cases. This means that about 32 out of 47.5 million people with dementia suffer from AD worldwide (an estimated prevalence of 40 million patients worldwide, although it may be much higher if we consider that the disease may begin years before the firsts apparent symptoms). The current lifetime risk of AD is estimated to be 10,5%.

Patients with AD suffer from deterioration in memory, thinking, behaviour and the ability to perform everyday activities not associated with normal ageing. It is one of the main causes of disability and dependency among older people worldwide.

Despite the fact that the symptomatology of AD varies in each patient depending upon the impact of the disease and the person's personality before becoming ill, there are three well defined stages in its signs and symptoms:

- Early stage (gradual, slow and insidious onset): forgetfulness, losing track of the time, becoming lost in familiar places.

- Middle stage (clearer and more restricting signs and symptoms): becoming forgetful of recent events and people's names, becoming lost at home, having increasing difficulty with communication, needing help with personal care, experiencing behaviour changes, including wandering and repeated questioning.

- Late stage (dependent and inactive patient, serious memory disturbances, physical signs and symptoms): becoming unaware of the time and place, having difficulty recognising relatives and friends, having an increasing need for assisted self-care, having difficulty walking, experiencing behaviour changes that may escalate and include aggression.

[1] *Treatment adherence review – Fundaciò Universitaria del Bages (FUB), Universitat de Vic – Universitat Central de Catalunya (UVic-UCC)*

In the neuropsychological domain, AD patients start with reduced performance in **episodic memory** tasks including recognition as well as free recall and paired-association learning as a consequence of the neurodegeneration in hippocampal areas (1). As the disease affects other brain regions, other cognitive symptoms appear (2,3). Although the ability to understand simple commands is usually preserved (4), deficits in **language** include impairment in semantic knowledge (verbal fluency, object naming, semantic categorization) (3) and in verbal comprehension (semantic, syntactic and metaphorical levels) (5,6). **Executive functions** depending on prefrontal cortex are also affected (7) including problem solving (3), working memory and attention (2). Simple language and motor skills are usually the last abilities affected in severe dementia (2).

All these cognitive alterations are related to the dysfunction of several neurotransmiter systems. Special attention has been directed to the cholinergic and glutamatergic systems.

Cholinergic neurones located in the basal forebrain innervate the neocortex and the hippocampus (8). This system has a prominent role in cognitive function, especially in memory, attention and emotion (9,10). When AD interferes with the cholinergic neurotransmission, cognitive functions become compromised (11–16).

It seems that in AD **glutamate** levels in the synaptic cleft are increased maybe due to alterations in the removal mechanisms (17–19). The increase in glutamate depolarises the postsynaptic neurone, altering the function of the NMDA receptor and thereby the LTP mechanisms (20,21). This mechanism may contribute to the cognitive decline in AD. Moreover, the excess in glutamate is related to neuron excitotoxicity and cell death. Indeed, the number of glutamatergic neurons is reduced in AD, especially in the cerebral cortex and the hippocampus (17).

Treatment

Although nowadays treatments do not stop AD, they allow to slow the progress of the disease (22).

Cholinesterase inhibitors (ChEIs) are prescribed for mild to moderate AD. These include galantamine, rivastigmine and donepezil (23). They bind and inhibit acetylcholinesterase (AChE), the enzyme involved in the hydrolysis of acetylcholine at the synapse (24). By doing

so, ACh increases at the synapse and stabilises or slows the cognitive decline in AD, producing small improvements in activities of daily living and behavior (25). ChEIs are usually associated with mild adverse effects, including gastrointestinal-related side effects (nausea, vomiting, diarrhea), dizziness, headache or insomnia (23). Gastrointestinal side effects are the most common and less dangerous but cardiovascular effects (derived from vagotonic effects) are more alarming: hypotension, bradycardia and syncope could also be related to a higher risk of failures and bone fractures (26–28).

Memantine, an uncompetitive N-methyl D-aspartate (NMDA) antagonist, is prescribed to treat moderate to severe Alzheimer's disease (29). It blocks the NMDA receptor when neurones are too excited, normalising and reducing noise levels in glutamate neurotransmission and avoiding glutamate excitotoxicity (30). This would improve cognitive function (31,32) by improving the signal to noise ratio and would slow neurone loss. Memantine adverse effects are usually mild and infrequent and include dizziness, headache, insomnia and constipation (33,34).

Memantine and ChEI can also be prescribed in combination (32).

Comorbidities

Comorbidity can be defined as two or more chronic conditions happening at the same time.

Several studies have linked AD with other comorbidities (35), including psychiatric (depression, schizophrenia and bipolar disorder) (36) as well as physical alterations (cardiovascular, ear, nose and throat, genitourinary, musculoskeletal/integument, metabolic, stroke) (37,38).

Bauer et al. (35) suggested that some of the comorbidities (stroke, diabetes, atherosclerosis, Parkinson's disease and possibly depression) could be considered dementia risk factors whereas others (fluids and electrolyte disorders, insomnia, incontinence, pneumonia, fractures and injuries) are supposed to be sequelae of AD.

Comorbidities are related to increased dementia severity and cognitive and functional decline (37).

The treatment of comorbidities is an important factor in AD care plan as many AD patients are routinely prescribed at least five drugs or more (39). Polypharmacy can increase the number of side effects due to drug pharmacokinetic and pharmacodynamic interactions. ChEIs can interact with many drugs frequently taken by AD patients (antidepressants, anticholinergic agents, etc.) whereas memantine seems to be less prone to drug interactions in AD (interactions concern drugs not commonly taken by older people) (40). For example, paroxetine and bupropion are strong inhibitors of CYP2D6, the main hepatic enzyme involved in the metabolism of galantamine and donezepil (41–45).

A clinical trial in development by Campbell et al. (25) will hopefully clarify this topic and its influence on adherence and tolerability.

10.3.2 The caregiver

Given dementia's chronic nature, caregivers of dementia patients are exposed to prolonged stress over long periods of time. The longer the caregiving, the greater the impact on caregiver's health, increasing physical and psychiatric morbidity (46–50). Some evidence has linked caregiving with depression or depressive symptoms (51), altered immune system function (52), elevated blood pressure (53), altered plasma lipid levels (54), higher insulin levels related to increased coronary risk (55), migraines and colitis (56) and sleep disruptions (57). As important as the treatment of the care recipient, will be the treatment of the caregiver's health problems.

10.3.3 Adherence to treatment

Definition

Adherence to treatment can be defined as the extent to which the patient takes a prescribed drug according to the times and recommendations of the prescriber.

Adherence can be broken down into: initiation (the patient taking the first dose of medication), implementation (following a treatment regimen), and discontinuation (the patient reaching the end of the treatment regimen and stops taking the medication (58,59). Similarly, non-adherence may imply: no initiation of the treatment due for example to failure to fill the prescriptions (primary non-adherence), reception of the prescription but not implementation of the treatment or discontinuation earlier than instructed (secondary non-adherence) (60). Take the medications less often than indicated seems to be the most common phenomenon (61).

Discontinuing ChEIs in patients with moderate-to-severe AD may lead to a worsening of cognitive function and greater functional impairment compared with continued therapy (62).

Adherence rates

Non-adherence rates to long term treatments for chronic diseases in developed countries are around 50% (63,64). Adherence estimates among older adults range around 20–80% independently of the pathological condition (65,66). In particular cases, adherence can be as low as 0% (67,68)

In AD patients, adherence to ChEIs ranges form 17 to 100% (68,69). The high adherence estimates in some studies could be attributable to the support received by their participants. Moreover, adherence estimates may vary between and within patients with AD. Between AD patients, those receiving only minimal assistance with their medications and those receiving physical help had the highest mean objective adherence rates, 96.7% and 92.3%, respectively (68), suggesting that early stage individuals may be capable of managing their medications with very little assistance. The 1-year discontinuation rates for ChEIs ranges between 40-65% and the 2-3 years discontinuation increases to 90% (69).

An important aspect to take into account is that AD patients can have their perception of the ability to time medications particularly altered compared to their actual performance (68), significantly over-predicting it.

Adherence assessment

When assessing adherence, some variables can be evaluated:

- Percentage of days that the correct number of doses or **proportion of days covered** by therapy (PDC). This is considered a key measure by the Pharmacy Quality Alliance (PQA, USA) in order to assess the proportion of patients meeting the **PDC threshold** (the level of PDC above which the treatment regimen has a reasonable likelihood of achieving most of the potential benefit (PQA defined a threshold of 80%) (70).

- **Medication possession ration** (the summation of the "days' supply" of medication refills across an interval). This measure has been criticised because of the variability in the calculations and the overestimation of adherence that it may account (70).

- **Gap in therapy** (percentage of prevalent users who experienced a significant gap in treatment defined as 30 days in a 6-month measurement period). This is an important measure as it may lead to an adverse event. It can be complementary to PDC.

- **Errors of omission** (failure to take the prescribed medicine each day).

- **Errors of comission** (taking too many medicines on a given day).

- **Medication Management Tasks**: the Drug Regimen Unassisted Grading Scale (DRUGS) (71) examines performance on tasks designed to simulate drug adherence behaviour: (1) identify medications correctly, (2) specify the correct dosage, (3) specify the correct timing of dosage and (4) accessing the containers (68).

- **Task Prediction:** evaluates the ability to predict their ability to perform medication management tasks through an analogue scale (0-100%) prior for each of the tasks of DRUGS questionnaire (68).

Numerous instruments (subjective, objective, direct and indirect) (72,73) have been developed to assess the capacity to manage and adhere to medicines. Some of them are listed below:

- **Pill counts** (taken during the first visit and some time -e.g. 30 days- later). In-home inspection has been found to be more accurate than clinic visits (74). In single pill counts it has to be taken into account that patients tend to refill their medications before the previous supply is depleted and it can result in underestimations of adherence (75).

- **Medication monitoring systems** have been used in some studies (76).They allow calculating the percentage of days that the correct number of doses was taken as well as the inclusion of both errors of omission and errors of commission.

- The **tracking of pharmacy claims data** is another method used for assessing adherence. It allows to track large periods of time without treatment (77).

- Some studies suggest that **patient self-report** and **physician report** of treatment adherence are poor measures of actual treatment adherence (78).

Factors influencing adherence

Non-adherence causes can be classified as intentional or unintentional.

According to the Rosenstock **model of health belief** (79), an individual's likelihood of realising a health related behaviour is determined by:

- Perceived **susceptibility** (perceived risk for contracting the illness).

- Perceived **severity** (perception of the consequence of contracting the illness).

- Perceived **benefit** (perception of the good things that could happen from undertaking specific behaviours).

- Perceived **barrier** (perception of the difficulties, time and cost of performing behaviours).

- **Cue to action** (exposure to external or internal factors that prompt action such as social influence or perception of symptoms). This is the most important behavioural determinant.

- Self- efficacy (confidence in one's ability to perform the new health behaviour).

Recently some other variables have been added to the model (80):

- Consideration of **future consequences** (the effect that a behaviour could have on future health and well-being).

- **Self-identity** (one's perception about him/herself: individuals who perceive themselves as health conscious tend to positively associate with healthy behaviours).

- Concern for **appearance** (motivation for appearance, attractiveness, and popularity).

- Perceived **importance** (the value a person attaches to the outcomes of a behaviour).

Non-adherence has been related to factors depending on:

- **The medical system:** the number of medical prescribers, polymedication and complexity of medication regimen (including the number of treatment recommendations to be followed and the number of medications prescribed (76,81–84). Medication complexity index (85) is a measure used in some studies (76) to evaluate each medication according to the total number of medications, frequency of doses, additional directions to be followed and mechanical actions necessary to administer the dosage.

The cost of the treatment is also a factor to consider as increased copayments have been associated with decreased adherence (86).

- **The patient:** depression and anxiety (87–90), age (82,90), vision problems (91), dexterity problems (92), problems swallowing, multiple morbidity, lack of social support or not living with a relative or couple (87), risk or fear of side effects and forgetfulness and cognitive decline (83,88). Cases of alcoholism, behavioural problems of resisting care or wandering have also been related to poor adherence (87). Insel et al. (93) report that a composite of executive function and working memory is a significant predictor of adherence. Contrary, health beliefs are thought to be a more powerful predictor of medication adherence than either clinical or sociodemographic variables by some authors (94,95).

- **Patient - healthcare provider relation:** Patients report not getting enough information from the medical doctors, having problems to understand medical advices and the information about their disease and treatment, such as confusion about generic drugs (96). This may cause that the patient is reluctant to adhere to their medication regimens. Studies suggest that patients don't ask the appropriate questions (83,97). Poor relation with healthcare providers and poor communication between them and the patient are risk factors for non-adherence too. Those who had not had their medication reviewed by a doctor in the last 6 months were all less likely to be adherent (87).

When treating older patients suffering from cognitive impairment as is the case with AD, health professionals may encounter unique challenges as they exhibit many of the risk factors for low adherence to medications, including personal (impaired memory and executive functions, depression, comorbidities, comprehension difficulties) (98,99), treatment (adverse effects) (100) and contextual factors (lack of social support) (98,99).

In the specific case of AD treatment, several studies suggest that **older** patients may be more likely to discontinue ChEIs therapy (101–103), possibly reflecting a more advanced state of the disease, perceived lack of therapeutic effects or risk of adverse effects (69).

Female patients with AD are also more likely to discontinue ChEIs treatment or to be non-adherent (103) maybe because they are less likely to receive the care of a caregiver or they experience more side effects due to their body weight (69,104).

Changes in **executive function** occurring in normal ageing influence adherence to treatment (93) and comprehension of medical information. Executive functions allow us to plan, select the appropriate strategies for the actions, focus our attention and switch between tasks. As stated above, executive functions are affected in AD patients. Regarding **cognitive decline**, some studies suggest that the more severe the cognitive impairment, the more probabilities of ChEI discontinuation (69). Others report lowest adherence in moderate dementia (inverted U-shaped relationship) maybe due to the compensatory mechanisms that those with mild cognitive impairment develop (pillboxes, etc.) and the presence of caregivers who administer their medication in cases of severe dementia (87). The cognitive impairment may also interact with the complexity in medication treatment.

Socioeconomic barriers to therapy such as having to pay a greater proportion of the prescription costs have also been reported as important factors to discontinue ChEI therapy by some studies (69,103).

Comorbidities may also have an impact on adherence to medication, with some studies reporting a positive association between them (105) -possibly due to having more frequent medical controls- and others (106) reporting lower persistence and adherence in patients with more comorbidities.

The use of rivastigmine **patch** increases patient and caregiver satisfaction with the treatment possibly because of increased tolerability (less gastrointestinal side effects) and less complexity using it (107,108).

Understanding and belief about the efficacy and side effects of medication have been shown to affect adherence in cognitively intact individuals and may also influence that on patients with dementia (98). More **frequent physician visits** may be associated with increased communication between the medical system and the patient/caregiver dyad. The increased communication can have positive effects in ChEI persistence and adherence (105).

Adherence to dementia treatment may also be influenced by the **medical professional that prescribed** it. Barro-Belaygues et al. (109) found that it was higher when the neurologist made the diagnosis, followed by geriatricians, psychiatrists and lastly by general practitioners.

Role of caregiver in AD patient's adherence

Although frequently ignored in this role, caregivers play a major role in medication management of the care recipient, performing tasks such as administering medications, working out medication schedules, avoiding errors and possible drug interactions, controlling side effects and maintaining supplies of medications (110). It is especially important in the case of AD patients because the course of the disease causes the inability of the patients to manage their own medications. A key point is when to switch from the patient's to the caregiver's control of medication (69,98). Cotrell et al. (68) suggest that the informal caregiver is accurate predicting the abilities of the patient to manage medication to be able to prompt the decision.

As in the case of the patient, caregivers may encounter some difficulties and confounding factors when performing the management of care recipient medication. Gillespie (110) identified several factors including:

- Regimen complexity. Informal caregivers managing a larger number of medications are more likely to record inaccuracies in the understanding of the medication management. Some of these inaccuracies could be reduced by the use of dosage administration aids, such as organised pill boxes.

- Some aspects of the relationship between the caregiver and care recipient.

- Unhelpful healthcare systems and practices.

- Lack of information. Caregivers aren't often present during medical appointments or medical information is not given to them due to the restrictions sharing confidential information. Generic medications are also a source of confusion. Lack of information about the medication management roles that the caregiver will do and the possible side effects of the drugs he/she administers seem to be a frequent problem.

- Responsibilities arising from the care recipients' cognitive decline.

There is increasing evidence that responsibility for medication adherence is potentially quite stressful for the caregiver (111).

Strategies to improve adherence
Interventions aimed to improving adherence may be classified according to the principles of the health belief model (80,112):

- **Perceived susceptibility/severity of disease and perceived benefit:** Educate patient on the nature of the disease and the importance of the treatment, confirm patient understanding of the treatment and work on the physician-patient relationship.

Most of the studies recommend **education strategies** to improve adherence (69,98,100).

The **quality of communication** and **frequency of interaction** between physician and patient and (or) their caregiver seem to be important determinants of both persistence and adherence (69). Medication reviews may improve adherence maybe by improving the doctor-patient relationship or emphasizing the relevance of medications (87). In fact, one of the most commonly recommended strategies to improve adherence is to build the **relationship between physician and patient** (113). According to Aslam et al (112), it could be achieved by causing a good first impression (a comfortable, clean environment and considerate and friendly staff), letting the patient share his/her story, feelings and expectations without interrupting, taking care of the non-verbal communication (eye contact) and explaining the disease and treatment in an understandable manner reassuring patient's understanding, avoiding the traditional and outdated paternalistic approach.

- **Self-efficacy:**

The use of pictograms and colours to designate periods and drugs or the use of **medication organisers** and charts (83) increase adherence. Pill boxes are useful in helping patients remain organised, especially when they take multiple medications (114) and therefore reducing the likelihood of drug errors in individuals with probable dementia. Further, Branin (115) found that older adults who expressed greater concern about their memory were more likely to rely on external props.

Providing the patient with **written action plans** for treatment (very easy with electronic medical records) may increase adherence because they remove the burden of trying to memorise instructions (116).

Increasing the **frequency of the interactions** between physician and patient can also ease the patient's perception of his/her ability to follow a treatment plan (112). Best outcomes in chronic diseases seem to be obtained when follow-up visits were programmed in intervals of ≤2 weeks.

As stated above, improving the relationship between physician and patient is a key point when trying to increase adherence. Apart from changing the perceived benefits of the treatment by the patient, it could also improve self-efficacy through **motivation**, as has been shown in the literature for some conditions (112,117).

- **Perceived barriers to treatment**: Affordable treatment options, decreased copays, simplification of treatment regimens.

Reduction of prescribed medications and simplification of their regimen have been shown to be an effective way to increase adherence (65). Combination drugs or drugs that need to be taken only once per day are recommended whenever possible in patients with chronic diseases (118). Discontinuing medications based on the altered risk-burden to benefit ratios of many therapies in patients with advanced dementia can be another option to simplify the drug regimen of a patient.

- **Cues to action:** Varied aids that remind patients to take their medication (telephone calls, text messages, medication reminder software for smart phone, reminder packaging), memory or suggestion strategies.

Many health services remind patients their appointments through the use of **text messages or telephone calls** as an effective way to improve attendance (119). The use of text messages to remind patients to take their medications has been shown to be an effective way to improve adherence in several conditions (120,121) whereas in others it seems to be ineffective (122) maybe because patients can find them annoying.

The literature suggests that older adults often rely on contextual cues and automatic or ritualised behaviours to remember to take their medications (e.g., taking pills when having meals) (115). Using prospective memory interventions to provide strategies that switch older adults from relying on executive function and working memory processes to mostly automatic associative processes (establishing a routine, establishing cues strongly associated with medication taking actions, performing the action immediately upon thinking about it, using a medication organiser, and imagining medication taking to enhance encoding and improve cuing) improved medication adherence to antihypertensive medications in patients without dementia (123). The intervention produced greater benefits for those with lower executive function and working memory, suggesting its application in patients with dementia.

Insel and Cole (76) suggest the use of **individualised the memory strategies** to improve adherence by tailoring the cues to remind individuals take medications (e.g., placing the medicines in the area an individual routinely goes, such as the coffee pot for a coffee drinker, thereby providing a visual cue). Moreover the authors propose that tracking whether the medication was taken or not is as important as reminding to take the medication: as confusion may arise tracking it in repetitive tasks (such as taking a medication every day during years). This intervention benefited participants with high and moderate cognitive functions but did not provide the same benefit for those patients who are cognitively impaired.

Caregiver's adherence to the treatment

It has been suggested that the stress of caring may compromise the caregiver's adherence to his or her own medication: Wang et al. (124) showed that nearly one third of caregivers were noncompliant by frequently or occasionally missing medication doses, and about a half was unable to fully keep appointments with health care providers. Moreover the authors suggest that the non-adherence rate of the caregivers may be even higher due to the fact that caregivers may be reporting the socially desired answer during the interviews. Consistent with the chronic stress theory of caregiving (125), care duration has been significantly associated with the decrease in caregivers' medication adherence and medical appointment keeping as well as being female and low educational level (124).

Wang et al. (124)suggest that helping caregivers find relief from caregiving duty would help to increase caregivers' health. The authors propose interventions such as:

- Providing referral resources.
- Educate caregivers for self-care (nurses).
- Recruiting other family members to help provide care.
- Using support of social groups for special activities with the person with dementia.
- Provide in-home health assessment.

10.3.4 Conclusions

Adherence to medications among people living with dementia varies from 17 to 100% depending on the study and the population. There are objective, subjective, direct and indirect forms to assess adherence but one of the most recommended is de proportion of days covered (PCO).

The caregiver takes different roles in medication management through the course of the disease and is exposed to an increasing burden of responsibilities as the disease progresses. This makes the caregiver susceptible to suffer consequences on his/her health that may need treatment too.

Regimen complexity, understanding and believes about the disease and the treatment and the relationship between the patient/caregiver and the medical prescriber seem to be some of the main factors influencing adherence. The main strategies to improve adherence to treatment include: i) provide information about the treatment and the disease; ii) work on the relationship between the person receiving the treatment and/or the caregiver and the healthcare provider; iii) increase the patient's or caregiver's sense of self-efficacy; iv) simplify the regimen and v) provide cues to prompt the action of taking the medication.

Interventions to increase adherence seem to have small size effects (67,69,98). Therefore, a combination of strategies, personalizing them (76,126) and involving the different stakeholders (112) could be the appropriate approach to achieve this goal.

Proposal for the platform

According to the findings above, the strategies to improve adherence in the platform could be:

Strategy to improve adherence	**Proposed intervention in the platform**
Provide information about the treatment and the disease.	Provide simplified and comprehensible information about the disease and the treatment (expectations, adverse effects, etc.).
Work on the relationship between the person receiving the treatment and/or the caregiver and the healthcare provider	Facilitate the contact between them.
Increase the patient's or caregiver's sense of self-efficacy	Provide calendars, pictures and diagrams about when and how to take each medication. Provide written action plans.
Simplify the regimen	Provide information to the health professionals about the different treatment options and encourage them to choose the simplest regimen. Provide information to the health professionals about the benefits/risk ratio to empower them to discontinue the treatment if necessary.
Provide cues to prompt the action of taking the medication	Send reminders to take the medication to the patient, the caregiver and the social network around the dyad.

All these actions should be directed to the person living with dementia and the caregiver and the aim should be to increase the adherence to the treatment of the person living with dementia as well as the adherence of the caregiver to his/her own treatment. An important point is when to switch from a patient directed intervention to a caregiver directed intervention to increase patient's adherence to medications. Tools like de DRUGS scale could provide objective information about the ability of the patients to manage his/her own medication in order to take this decision.

To decrease the burden of the caregiver, the platform could also involve the social network around the dyad in all the strategies.

10.3.5 References of Annex 3

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10.4 Glossary

Awareness	Conscious knowledge of one's own character, feelings, motives, desires and health status.
BITV	The BITV-Test is a reliable and comprehensive accessibility evaluation instrument. 50 detailed test steps help assessing whether information-oriented web sites are accessible for users with disabilities.
Cognitive abilities	The individual's capacity to think, reason, and solve problems. Cognitive ability is measured through tests of intelligence and cognitive skills.
Cognitive impairment	When a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe.
Comorbidity	It refers to more than one disorder or diseases that exist alongside a primary diagnosis. The additional disorders can be of psychological or purely physiological nature.
Dementia	It's an overall term that describes a wide range of symptoms associated with a decline in memory or other skills severe enough to reduce a person's ability to perform everyday activities.
Design	Realization of a concept or idea into a configuration, drawing, model, mould, pattern, plan or specification (on which the actual or commercial production of an item is based) and which helps achieve the item's designated objective.
Digital skills	The set of skills and capabilities needed to fully interact with digital devices and contents. In particular they are linked to the capability to manage information, communicate, purchase goods, create, identify and solve problems via digital devices/solutions.
Dyad – care unit	The person with dementia and the caregiver.
EARL	Evaluation And Report Language Overview

Functional requirements	The list of functions requested to a technological solution.
Gamification	Gamification is the application of game elements and digital game design techniques to non-game problems, such as health problems, social impact challenges and business.
Health Care Professionals	Health professionals maintain health in humans through the application of the principles and procedures of evidence-based medicine and caring. (*e.g.*, Doctors, Psychologists, Geriatricians, Psychiatrists Nurses)
Informal caregiver	Any relative, partner, friend or neighbour who provides a broad range of assistance to an older person or an adult living with a chronic or disabling condition.
Interface	A connection between a person and a computer
Mild dementia	A stage of dementia including increased forgetfulness, slight difficulty in concentrating, decreased work performance.
Moderate dementia	A stage of dementia including difficulty in concentrating, in remembering recent events, in managing finances, traveling alone to new locations, or completing complex tasks efficiently or accurately.
Non-Functional requirements	The list of required aspects of a given technological solutions such as shape, dimension, colour, usability and accessibility elements.
Person Living with Dementia (PLWD)	A 65+ year old individual, living with mild to moderate dementia, who is receiving professional services from a qualified medical or allied health practitioner to maintain, improve or protect their health or reduce illness, disability or pain.
Platform	A "platform" is a system that can be programmed and customized by developers in close cooperation with final users; it can provide set of services and contents, tailored to users' requirements.
Professional caregiver	A care provider associated with a formal service system (health system or welfare system), either as paid worker or as volunteer.
Social Care Professionals	Professionals intended to advance the social conditions of a community, and especially of the disadvantaged, by

	providing counselling, guidance, and assistance (care professionals, social assistants, family carers)
Social Network	An online service or site through which people create and maintain interpersonal relationships. They are used to share personal information, or to interact with specific communities.
SMIL	The Synchronized Multimedia Integration Language (SMIL, pronounced "smile")
Socialization	A continuing process whereby an individual acquires a personal identity and learns the norms, values, behaviour, and social skills appropriate to his or her social position.
TAW3	TAW is a tool for the analysis of Web sites, based on the W3C - Web Content Accessibility Guidelines; The TAW3 analysis engine is available as different tools, so the users can choose and use which better suits his/her needs.
WCAG	Web Content Accessibility Guidelines
W3C	The World Wide Web Consortium (W3C) is an international community that develops open standards to ensure the long-term growth of the Web. W3C operates under our Code of Ethics and Professional Conduct.

10.5 References

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