



Deliverable Number: D8.4, version: 1

Report on Advisory Board Activities



CAREGIVERSPRO-MMD PROJECT





Document information

Project Number	690211	Acronym	CAREGIVERSPRO-MMD
Full title	Self-management interventions and mutual assistance community services, helping patients with dementia and caregivers connect with others for evaluation, support and inspiration to improve the care experience		
Project coordinator	Universitat Politècnica de Catalunya- BarcelonaTech Prof. Ulises Cortés, ja@cs.upc.edu		
Project URL	http://www.caregiversprommd-project.eu		

Deliverable	Number	D8.4	Title	Report on Advisory Board Activities
Work package	Number	8	Title	Project Management

Date of delivery	Contractual	31-12-2016	Actual	15-01-2017
Nature	Report <input checked="" type="checkbox"/> Demonstrator <input type="checkbox"/> Other <input type="checkbox"/>			
Dissemination Level	Public <input type="checkbox"/> Consortium <input type="checkbox"/>			
Keywords				

Authors (Partner)	Cristian Barrué (UPC), Ulises Cortés (UPC)			
Responsible Author	Cristian Barrué		Email	cbarrue@cs.upc.edu
	Partner	UPC	Phone	+ 34 93 413 40 11



Document Version History

Version	Date	Status	Author	Description
0.1	11-12-2016	Draft	Cristian Barrué (UPC)	Creation of the document, gathering of AB reports
Final	15-01-2017	Final	Ulises Cortés	



Executive summary

This deliverable documents the liaison that has taken place to date with our Advisory Board (AB) and summarizes their contributions to the project.

AB provides non-binding strategic advice to the management of CAREGIVERSPRO-MMD. CAREGIVERSPRO-MMD is a best practices consortium that uses a combination of research, technology, and medical practice to achieve project objectives.

Our AB brings expertise in various areas that are key for the project. They review deliverables and participate in meeting with the whole consortium to discuss our progress and next steps.



Table of contents

1	INTRODUCTION	6
1.1	ADVISORY BOARD MEMBERS	6
2	REPORT OF LUIZA SPIRU	10
3	REPORT OF ESME MONITZ-COOK	10
3.1	DELIVERABLE D.1.2, VERSION 1.0	11
3.2	CAREGIVERSPRO-MMD: PROTOCOL D4.1	12
3.3	DELIVERABLE D.1.2, VERSION 1.0	12
3.4	SUGGESTIONS GOING FORWARD	13
4	REPORT OF STELLIOS PANTADEPOULOS	15
4.1	D2.1 PACT ANALYSIS AND FOCUS GROUP REPORTS - COMMENTS	15
4.2	D3.1 DETAILED SYSTEM ARCHITECTURE (v1.6)	15
5	REPORT OF ESTEVE ALMIRALL	17
5.1	DELIVERABLE D7.5 BUSINESS PLAN	17
5.2	DELIVERABLE D4.5 SOCIAL MEDIA PLAN	18
6	REPORT OF IGNASI COLL ROLDUÀ	19
6.1	D.7.3, VERSION 2.5. & D.8. 3, VERSION 1.2.	19
7	FUTURE ACTIVITY	19



1 Introduction

The CAREGIVERSPRO-MMD Advisory Board is a non-binding counselling body providing advice and guidance for the development of the project to ensure high quality and excellence. The AB will address CAREGIVERSPRO-MMD strategic issues relevant for the project development, ensure high quality results and impact of project activities, enhance the scientific relevance of the dissemination actions providing advice for the scientific content of the project.

The AB will seek inputs from key stakeholders through interviews (or Board meetings) to guide key design decisions. CAREGIVERSPRO-MMD covers their participation in consortium meetings.

They produce executive reports on some strategic deliverables and those reports are included in this document. Management Board uses those results in order to enhance ethical, scientific and technical decisions.

1.1 Advisory Board Members

The CAREGIVERSPRO-MMD Advisory Board has the following members:

Clinical specialist
<p>Luiza Spuru (female), MD, PhD. Professor of Geriatrics, Gerontology and Old Age Psychiatry since 2013, Chair of the Department within “Carol Davila” University of Medicine in Pharmacy in Bucharest since 2004. Head of the University Department of Geriatrics within “Elias” University Emergency Clinic Hospital in Bucharest since 2003. President of the Ana Aslan International Foundation (AAIF), established in 2000 in Bucharest – an NGO dedicated to create, develop and deliver state-of-the-art education & research programs and medical services in the field of brain aging. She is the Executive President of Ana ASLAN International Academy of Aging – the educational forum of AAIF.</p> <p>She acquired three specializations: internal medicine (1994), geriatrics gerontology (1998) and old age psychiatry (2003); She is also certified in the Management of Health Care Services (2003). Her professional expertise covers multiple and diverse competences, from basic domains such as molecular medicine and neuro-psychopharmacology, through the up-to-date diagnostic techniques & treatment methods of memory diseases, towards integrating the innovative IT&C solutions for the senior patients; everything under the paradigm of integrated, preventive and personalized approach – the essence of Longevity Medicine. Experienced in managerial, academic, editorial and research activities - by coordinating EU funded R&D projects on the development, promotion and use of assistive technologies solutions for seniors, especially for those with special cognitive needs; when acting as principal investigator in clinical trials, by editing the Brain Aging International Journal and through organizing numerous scientific educational events in the field of Cognitive Impairment, Dementia and Brain Aging Research.</p> <p>She created and implemented the curricula of Geriatrics and Gerontology in the</p>



University Medical Program as a new, officially recognized, 5 year specialty in Romania (in 2001); Established the first Alzheimer Unit in Romania in 1999 – in accordance with most modern European standards of care in AD. Coordinated the creation of a new Curricula and Syllabus in Brain aging and delivered training courses for more than 3,500 specialists and nurses between 2010-2013. Has authored 3 treatises on Geriatric medicine, 6 guides on the diagnosis and treatment of Alzheimer’s disease and related dementias, having over 150 published articles in international journals and books of proceedings. From 1996 has been involved in more than 20 EU funded research projects as medical expert and coordinator / project manager.

Appointed EU Commission Expert as evaluator & rapporteur for the project applications under EU calls - FP6, FP7, AAL and Horizon 2020. Invited to act as Vice-Chair during the Ethic Review of MSCA-IF-ST-2014. Accredited by the European Alzheimer’s Disease Consortium and Alzheimer’s Europe as an international expert in cognitive impairment and dementia diagnosis and treatment. National Representative of the European Association for Predictive, Preventive and Personalized Medicine since 2010. Appointed and acting as the President of Specialist’s Consulting Commission of Geriatrics-Gerontology for the Romanian Ministry of Health since 2009. Member of 22 international professional associations.

Social specialist

Esme Moniz-Cook (female) PhD, has been practising as a Clinical Psychologist for thirty years, specialising with older people (dementia), since 1987. She is Professor (Hon) of Clinical Psychology and Ageing at the Institute of Rehabilitation, Hull York Medical School - University of Hull and Consultant Clinical Psychologist (Lead Psychologist for Older People) with Humber NHS Foundation Trust.

In 1991 established and actually leads the Hull Memory Clinic that was set at the interface of primary and specialist care which continues to date with some 86 GPs and primary care practitioners. This clinic hosts an Early Psychosocial Intervention programme for older people and their families and a `Drop-In` and training facility, the latter which won the BUPA 2004 award for care of older people.

In 1999 she developed, was coordinating Chair and now co chair of INTERDEM a pan European Interdisciplinary Network of research - practitioners whose focus is on Early Intervention in Dementia. The evidence base for Early Psychosocial Intervention in dementia across Europe has been published by Jessica Kingsley in a co-edited book (2009) and a key article on outcome measurement in dementia care was published with INTERDEM co authors (2008)

The content of her primary research was on the management of behavioural problems in dementia care settings, staff training and psychosocial intervention. Currently leads a NIHR Programme award which will develop and implement an interactive web based staff training intervention on the management of challenging behaviour in dementia for care home staff and community mental health nurses supporting family carers.

Technical specialist

Stelios Pantelopoulos (male) M. Sc. (spantelopoulos@singularlogic.eu) Senior Software Engineer, is since 1999 the Head of European R&D Projects Department at SingularLogic (www.singularlogic.eu). The department is responsible for the involvement and the participation of the company in European and National co-funded projects. He has been involved in more than 50 research projects having different technical and non-technical roles namely Software Engineer, System Analyst, Exploitation Manager, Technical



Manager and Project Coordinator. He has over twenty years of experience in managing multi-people teams, and his field of expertise includes e-Health Solutions, Business Software Applications, Energy Efficiency systems, Internet of Things Platforms, Mobile Application Services, Software Development Frameworks, etc. He has also acted as external Technical Expert at EU Level is several topics either as a Scientific Advisor or as Proposals Evaluator, or as R&D Projects External Technical Reviewer. Between 2001 and 2003 he was the Vice-President of Research and Development Committee of the Federation of Hellenic Information Technology & Communications Enterprises (SEPE).

Ethics specialist

María Casado (female) PhD, Professor of Philosophy of Law at the University of Barcelona. She is the director of the Bioethics and Law Observatory, Barcelona Science Park and director of the UNESCO Chair in Bioethics of the University of Barcelona. Founder and director of the Master in Bioethics and Law of the University of Barcelona. She coordinates the Consolidated Research Group “Bioethics, Law and Society”, of the Generalitat de Catalunya. She coordinates the Education Network in Bioethics (AECID), the Iberonetwork group of the International Association of Bioethics, the research network for establishing Programmes for Joint Teaching of Bioethics (ALFA) and the Thematic Network in Bioethics and Human Rights of the Generalitat de Catalunya. She was awarded with the Narcis Monturiol medal for her scientific and technical contributions. She has authored more than 63 journal papers, 17 books and 38 book chapters. She has coordinated 33 research projects national and international with main focus in bioethics and legal aspects of healthcare. She is member of the European Global Bioethics Association, the National DNA Bank Commission of Experts, the Ethical Board of the European Human Embryonic Stem Cells Registry, the Bioethics Commission of the Universitat de Barcelona and the Assistive Ethical Committee of the Hospital of Barcelona.

From December 2016 Prof Casado has been replaced by

Ignasi Coll Rolduà (male) MM, Holds Master in Geriatrics and Gerontology from the Universitat Autònoma de Barcelona (UB) & Master's Degree in Bioethics and Law from the Univesitat de Barcelona. He is especially aware of the bioethical problems associated with the elderly, he collaborates with the Observatory of Bioethics and Law at the Universitat de Barcelona, where he studied a master's degree and is currently a tutor. Regular collaborator of the Internal Medicine service of the Hospital of Barcelona, in addition he is member of its Committee of Ethical Assistance. He is also a Member of the Ethics Committee of the Universitat de Barcelona.

With more tan 25 years of prectice he is an specialist in Alzheimer's, Palliative care, Dementia, Depression, Hypertension and, Pluripathology.

Innovation/Business specialist

Esteve Almirall (male) PhD, holds a PhD in Management Sciences (ESADE), a MRes in Management Sciences, a MCIS, DEA and MRes in Artificial Intelligence (UPC). Most of his career has been devoted to Information Technologies, especially in consulting, banking and finances where he worked for more than 20 years in executive and board level



positions in IS, Organization and Marketing. As an entrepreneur he actively participated and founded several start-ups in the field. Moreover, Esteve has an MBA, a PDD from IESE a Diploma in Marketing from UC Berkeley and a GCPCL Diploma from Harvard B.S. Esteve is passionate about the intersection between technology and innovation and how IT is changing the way we innovate from the individual inventor to ecosystems, from owning and buying innovations to benefiting from innovations created by others by aligning incentives and motivations. Therefore, he is very active in fields such as Smart Cities, Innovation Ecosystems, Innovation in the Public Sector or User Innovation (particularly Living Labs). He has coordinated several large EU competitive projects and participated in more than ten of them as main researcher. He is often busy collaborating and organizing workshops, Open Data Challenges and conferences in these areas. Esteve is a well-known speaker in fields such as Open Innovation in the Public Sector, Smart Cities or Living Labs in Europe, the US and Asia. He also serves as a World Bank consultant and Council member of the ENoLL (European Network of Living Labs), a member of the OIPSG (Open Innovation Policy and Strategy Group) of the European Commission and server as an expert for several organizations, cities and the European Commission. Esteve has more than 30 publications in journals and conference proceedings, including top level journals and well-known magazines such as HBR (Harvard Business Review) and advised several PhD and Master thesis.

The AB will mainly interact with the PB members.



2 Report of Luiza Spiru

N/A

3 Report of Esme Monitz-Cook

CAREGIVERSPRO-MMD - Self-management interventions and mutual assistance community services, helping patients with dementia and caregivers connect with others for evaluation, support and inspiration to improve the care experience. Grant agreement 690211

REPORT BY: Professor (Dr) Esme Moniz-Cook

University of Hull & Humber NHS FT; *INTERDEM* founder chair (now Co-chair)

AS: Scientific Advisory Board member for CAREGIVERSPRO-MMD

DATE: 22nd December 2016

Background

This report is written based on my perusal of:

1. CAREGIVERSPRO-MMD: Summary of Deliverable D.1.2, version 1.0 –Dementia and psychiatric comorbidity symptoms handbook –Received on 15th December 2016 during attendance at a meeting 15th -16th December 2016
2. CAREGIVERSPRO-MMD: Pilot study Operational Manual - Protocol D.4.1 – i.e. the first deliverable of WP4 received on 16 December 2016; “Multicentre pilot study to determine the benefits of CAREGIVERSPRO-MMD platform use based on the information and communications technology (ICT), dedicated to the support and assistance of dyads living with neurocognitive diseases including persons living with mild cognitive impairment or mild to moderate dementia and their primary caregivers”
3. CAREGIVERSPRO-MMD: Proposal Part B Sections 1-3 page 1-71 and sections 4-5 received on 7th December 2016
4. Presentations by work package leads and discussions at a meeting in Ancona Italy 15th-16th December 2016.

Conclusions

Overall I note that many of the current deliverables are completed in a timely manner. My recommendations (in the next section) are made for work going forward. Next I will summarise my observations on the material I have read and heard about.



3.1 Deliverable D.1.2, version 1.0


1. CAREGIVERSPRO-MMD: Summary of Deliverable D.1.2, version 1.0 –Dementia and psychiatric comorbidity symptoms handbook


This is a comprehensive handbook of measures.

It is surprisingly heavily weighted towards Cognitive Scales some of which are quite detailed and in my experience as a clinical neuropsychologist, rarely used as they have been superseded by other newer and perhaps more 'patient friendly' measure of cognitive function. The Hayling and Brixton Tests appear separately when they are now sold and used together as a screen measure of executive function when detailed clinical evaluation is not possible. I was surprised not to see the D-KEFS (Delis –Kaplan Executive function system) - Delis, Kaplan & Kramer 2001 nor the Behaviour Rating Inventory of Executive Function (Roth, Isquith and Gioia 2005). These are both commonly used measure of executive function in clinical neuropsychological evaluation in the UK. 2

I was surprised not to see the Sense of Competence scale Vernooij-Dassen et al 1996, a derivation of the Zarit Burden Inventory and described as perhaps more sensitive as an outcome measure for psychosocial intervention research –see *Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, de Vugt M, Mountain G, O'Connell M, Harrison J, Vasse E, Dröes RM, & Orrell M For the INTERDEM group. (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care Aging & Mental Health 12,1, 14- 25;* and the JPND programme <http://www.neurodegenerationresearch.eu/wp-content/uploads/2015/10/JPND-Report-Mountain.pdf>

My understanding of the purpose of this deliverable is follows: *'Identification of symptoms will be intended for both individuals as well as the related caregiver (professional or not)'* see CAREGIVERSPRO-MMD: Proposal Part B Sections 1-3 page 41 T1.2. This deliverable appears to relate to then choosing measures for the platform for people and caregivers to use adapted questionnaires themselves to act as screening for the detection of risk factors in clinical (assumed cognitive) social psychological and behavioural assessment see CAREGIVERSPRO-MMD: Proposal Part B Sections 1-3 page 42 T1.3.

 was not entirely clear from the presentations (15th and 16th December 2016) - and have not had access to D1.3 - on whether a definitive self -management list of four scales to act screens for each of the symptom domains had been selected but noted a clear agreement from all WP leads that these would a) differ from the primary and secondary outcomes that will be used in the pilot studies.

 noted that there are certain risks associated with use of some scales – albeit as screens - on the internet and clinicians responsible for this aspect of the platform will need to ensure that when the choice of scales are made (D1.3) the necessary wording is clear to cover the risks of misunderstanding by users of this platform. These screens are not diagnostic and some of these measures - such as many mood scales have words associated with hopelessness and in some cases suicidality.



3.2 CAREGIVERSPRO-MMD: Protocol D4.1

2. **CAREGIVERSPRO-MMD: Protocol D41** - the first deliverable of WP4 received on 16 December 2016. “Multicentre pilot study to determine the benefits of CAREGIVERSPRO-MMD platform use based on the information and communications technology (ICT), dedicated to the support and assistance of dyads living with neurocognitive diseases including persons living with mild cognitive impairment or mild to moderate dementia and their primary caregivers”

With Reference to Outcome Measures

I note from CAREGIVERSPRO-MMD which I received on 7th December 2017: Proposal Part B Sections 1-3 page 63 that a number of measures are outlined but these do not then appear in CAREGIVERSPRO-MMD: Pilot study Operational Manual - Protocol D.4.1. For example Objective 2a the outcome measure is ADRQL. I missed this measure in but note that there are two good ADL measures in the protocol. The same applied to Objective 3b where I am assuming caregiver QoL is not included – unless the EQ5D will be taken for both caregiver and person with dementia – at present it is taken for neither in the protocol CAREGIVERSPRO-MMD: Pilot study Operational Manual - Protocol D.4.1.

Objective 2b refers to reduction in functional decline where no measure for this is stated. An overall functional measure which may not have been considered is the Global Deterioration Scale (Reisberg et al 1982). I did not see mention of this measure of global functional decline

3.3 Deliverable D.1.2, version 1.0

CAREGIVERSPRO-MMD: Summary of Deliverable D.1.2, version 1.0 –Dementia and psychiatric comorbidity symptoms handbook.

CAREGIVERSPRO-MMD: Pilot study Operational Manual - Protocol D.4.1 - I note that my advice of 7/10/16 - to add an extra primary outcome measure (alternatives suggested were QoL-Ad and DEMQoL) to capture experience of people with dementia (you had and still have a number of measures reported by proxies and also measures of caregiver quality of life and burden) has been adopted.

3.7.2.1 Scale for primary outcomes for MCI and PLWD Subjective quality of life DEMQoL - Dementia Quality of Life Measure Created by: Rabins and Kasper, 1997. **Comment: This is one of your two your primary outcome measures so will need correction as it was NOT developed by Rabins and Kasper in 1997!**

3.7.3.2 Scales for secondary outcomes for primary caregivers Subjective quality of life SF-36v2 - Medical Outcomes Study (MOS) 36-Item Short Form 2nd version **Comment: In the**



presentations and those that indicated pilot proposals that were sent to ethics the EQ5D was definitely included. I am surprised to not find the EQ5-D as a secondary measure in this protocol

■ **8.7.4 Medications, concomitant treatments, treatment adherence, comorbidities and adverse events** - For people living with cognitive impairment or dementia (mild to moderate) and their primary caregivers, this information will be collected by doctors and codified following international dictionaries as World Health Organization's Drug Dictionary (WHO-DD), International Classification of Diseases (ICD-10) and WHO Adverse Reactions Terminology (WHOART) respectively. **Comment: Not all pilots will have doctors.**

3.4 SUGGESTIONS GOING FORWARD

1. There will need to be some intensive work done with significantly closer communication between the engineering and clinical teams to ensure that the usability of the platform is thoroughly tested before the pilots are started.
2. I strongly recommend that baseline measures and randomisation is not started until each site is completely confident that all aspects of the platform is stable and can be easily used by patients and carers. Otherwise the scientific methodology of this intervention will be compromised since the concept (intervention and content) could be undermined by the technology.
3. My understanding is that there will be a project worker to deliver the tablet and assist users to navigate this and use the manual, as well as a 'super-user' to help with navigation (phone calls etc) and presumably updating of information such as drugs as information on this and other aspects if the platform such as social opportunities in the community emerge. If I am correct then these 'interventionists' who assist with managing and updating information as well as conduct delivery of the intervention will need to be costed in for time resource, in the health economics / cost- analyses.
4. Care needs to be taken about who will assume clinical responsibility about drugs used for potentially between 9-12 drugs prescribed by differing medical disciplines for differing comorbid conditions. I suggest your ethics advisor is consulted.
5. Each pilot site may have differing contextual conditions – for example in France participants may well be recruited from a clinic whilst in the UK they may be recruited through a variety of sources and not necessarily involve a doctor. Careful contextual data will need to be included and used to understand the findings since the platform will be necessarily different across pilot sites. For example not all pilots will use the screen tools (for risk detection) within in platform unless this has been agreed by the country's ethics committee. The statistical analysis plan – which I have not seen, may need to detail how this will be done across the four sites.
6. I have recommended that given the differing contexts across the four pilot sites, that the engineers develop a high level flexible open system that can be managed at each site to suit



the participants. There will need to be close communication between researchers, the site clinician and engineers during the progress of the intervention if this is to work iteratively during pilot studies (WP4).

7. I noted that there was some confusion about whether the pilots are considered as an observational or interventional. International ethics guidance including the MRC's guidance for complex interventions would certainly regard this as an intervention study since at the point of consenting participants the researcher will be asking them to consent to being randomised to either an intervention (tablet) vs Treatment As Usual (whatever they are receiving in their local communities).

8. This should be clarified with the ethics scientific advisor for this programme of work and the pilots should be registered as an intervention study.

9. I suggest the revised protocol is published as soon as ethical permissions are granted across all countries. I would be happy to advise on relevant journals if requested.

10. Given the additional outcome measure DEMQOL to evaluate patient experience I would be happy to put key data analysts in touch with its inventor (Prof Banerjee and/or Dr Sarah Smith) once the data is in.

11. However I note a very short timescale for data analysis and reporting at the end of this project. There is a risk that the data collected may not be fully exploited to the benefit of patient outcomes. It may be worth approaching the commission to consider an extension in reporting time.

Esme Moniz-Cook

BSc Hons Dip Clin Psyche PhD A

www.interdem.org



4 Report of Stelios Pantadepoulos

4.1 D2.1 PACT Analysis and Focus Group Reports - Comments

Deliverable Scope

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

Deliverable Comments

D2.1 is a well-structured document that describes the PACT methodology and how it has been used in making the interviews and capturing the requirements for the purposes of the project.

Some comments for the deliverable are outlined below:

- Since there are a lot of different caregivers subtypes, it was proposed (if possible) to pay more attention and reveal the specific (and different sometimes) needs of the different subtypes. And how those different needs will be covered by the platform

- Table 6 in section 2.3.5 provides a good base about “*who is going to use what*” but it needs to include some more details in each “*Description specification of Activities*”

- The management of health record through the platform as well as the adherence services are not very realistic and includes a lot of risk types, technical, managerial, ethical, procedural, etc. and we propose to the consortium to reconsider the functionalities that will be provided

- We appreciate the fact that the consortium decided to increase the number of users interviewed in order to have a better sample to validate the findings

- Sometimes there is a confusion between gamification and games (e.g. page 111)

- A prioritisation between the requirements should be provided differentiating “Must” requirements from “nice to have” requirements

- It’s not clear if avatars will be used or not in the system.

- It’s not clear (at least in this deliverable), the “*modus operandi*” of the platform. Maybe it was (or it will) included in other deliverables.

4.2 D3.1 Detailed System Architecture (v1.6)

Deliverable Scope

In this direction the current document covers three main purposes:

- to transform the user requirements and the project objectives into technical specifications to be used in the technical design, development and the evaluation processes of the C-MMD platform;

- to present a first version of the system’s architecture aligned with all the technical requirements in an efficient and effective manner;



to separate the implementation responsibilities and define the planned interfaces for each of the defined system components so as to allow the productive cooperation of the consortium members towards the final goals of the C-MMD outcomes.

Deliverable comments

It is a well-structured and very analytical document that covers all required topics for its objectives. The view of the platform is quite comprehensive, but it can be enhanced with the inclusion of some more relevant schemas and graphical pictures.

Rereading the deliverable, especially after the Ancona meeting, I believe there are several things that are not very clear and/or needs (possibly) to be modified in the deliverable. Most of them are outlined below:

- In the Screening Service: it was several comments about the questionnaires that should be included. It was advised to minimize the set of questionnaires and simplify the correlation between the data captured and the conditions of the dyads

- The treatment adherence service - as it is described and foreseen to be provided - might have several legal, ethical and operational difficulties in its implementation. A workaround had been proposed and analysed during the meeting.

- The realization of the COR3 - Clinical and social reports service, EHR integration in real life settings is advised to be reconsidered.

- For the Social Network service, it is very important to authenticate the users. We propose to have an eponymous Social Network rather an anonymous one, because we believe it is very important for those target groups to know (and to be sure) with whom they communicate and they share information.

- For the Therapeutic education service, we propose to pay attention to the validation of the content and more specifically, who is uploading content in the platform and for what reason. It needs also to be more clear how the “tailored interventions” will be performed

- For the platform infrastructure, it is not very clear if it will be one multinational instance of the platform or several national/regional platforms

During the Ancona meeting several more detailed functional and operational aspects has been discussed and analysed and both members from the advisory board have provided comments/concerns about the services applicability and suggestions to enhance the services usability. In case the consortium decide to endorse some of those concerns/proposals the deliverable should be updated accordingly in the relevant parts.



5 Report of Esteve Almirall

5.1 Deliverable D7.5 Business Plan

The deliverable presents a comprehensive market analysis finding gaps where the solution could fit in the market.

To this extent it presents the solution and describes at length the social problem of dementia and its impact. From this departure point the deliverable analyses the strengths of the solution and therefore its main selling points.

Well-known and accepted models such as the *strengths, weaknesses, opportunities, and threats* (SWOT) analysis are used to evaluate the fit and competitive advantage of the new proposal in the market.

From this description of strengths and competitive advantages, the report develops several proposals of business model highlighting the different aspects where the CaregiversPro solution could have a competitive advantage through the use of a diversity of scenarios.

CANVAS is well implemented for that and the description is detailed enough for the purpose of defining actions to implement.

Finally, the deliverable presents the most significant risk that the implementation may face both at the level of industry and product.

This part of the work is well done and I cannot find significant objections in terms of depth of the analysis or methods used.

There are however other aspects where the report falls short. A business plan is basically an implementation plan, based on an analysis of the market and a proposal in terms of value proposition and business model, but the core is an implementation plan.

Therefore, we miss this core. Actions to be taken: produce a chronogram or Gantt of the implementation and their associated financial needs and the projected Profit & Loss statements.

Another common element of a business plan is the development of a set of indicators and it's projecting through the different phases of the business. Sometimes this is presented as an alternative to detailed financial statements.

However, in our case both approaches are missing.

Therefore, our suggestion is to either change the title to Market Analysis and Proposed Solution or complement the existing doc with the typical parts of a business plan related to implementation.



5.2 Deliverable D4.5 Social Media Plan

The deliverable does a good job in terms of market and target analysis.

Particularly the target audience seems to be well defined, although it is not clear which instruments have been used and what assumptions lie behind the instruments.

Other elements such as content, publication and indicators together with their measurement are well described.

Finally, a list of social media practices is included that the project attempts to follow through the implementation of the plan.

The only two shortcomings lie again in the area of a detailed implementation with costs, objectives and resources in its associated plan.

This level of detail is needed if the project wants to put this plan into action. Therefore, it could be advisable to produce it now.

Alternatively, the project may choose to divide the Media Plan in to deliveries, one and two, being this one the first.



6 Report of Ignasi Coll Rolduà

6.1 D.7.3, version 2.5. & D.8. 3, version 1.2.

DISCUSSION:

1) **PLWD.** It should be necessary to defined all the inclusion/exclusion criteria for the “People living with dementia” group for evaluating their decisional capacity. I do understand that this group is going to be as homogeneous as possible related to their mental competence. This point is important for ...” *in case of incapacitated adults or people with dementia, a legal representative must consent to participate*”, and it should be determined the criteria to assign the legal representative.

2) **INFORMED CONSENT.** “...Each participant will sign an informed consent...”. It is very important to describe the content of the informed consent and it should be better to get a specific and a different one for each category of users, especially for PLWD, because we must guarantee that they are able to understand everything that it’s writing down at it.

3) **OPEN ACCES.** “...The data base will not be shared outside.... A small part will be openly accessible by platform users...”. It should be defined exactly what is the information it is going to be shared, specially linked to the health professional evaluation. Although it is said that “only the user, people authorised by him/her...”, all of them should know the importance of autonomy, privacy and dignity and it should be reflected in a document signed by them.

7 Future Activity

The project has conducted the two formal meetings with the AB. Despite earnest efforts to convene the complete AB, it was not possible to find a suitable date for them. We are now trying to convene them during the next plenary consortium meeting to be held in Hull, UK, in spring of 2017.