SMART4MD

REPORT ON
USER-CENTRED
DESIGN ADAPTATION STAGE (WP2)

FOCUS GROUPS / INTERVIEWS
December 2015 – February 2016

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1) ABSTRACT

The SMART4MD project aims to develop and test an mHealth application specifically tailored to people with mild dementia. The SMART4MD application that is currently being developed will be uploaded to tablets given to people with mild dementia and their carers to be trialed for 2 years in practise.

Before the development of the first prototype of this application, the first stage of user-centred research stage was carried out during December 2015 - February 2016 among 6 project partners. This stage included focus groups or interviews with people with mild dementia, their carers and healthcare professionals. Altogether, 41 people with mild dementia, 38 carers and 25 healthcare professionals participated in the discussions. A semi-structured guide was used for the focus groups and interviews. The following topics were addressed in all groups:

- daily activites of people with mild dementia;
- familiarity with current technology/devices used among people with dementia and carers, and their frequency of use today;
- applications/websites and categories of content used most frequently by people with dementia and reasons of their usefullness;
- potential usage of current features of Pow Health platform and the reasons why;
- other suggested features for SMART4MD application;
- SMART4MD platform usage requirements and motivation;
- ethics/privacy/information sharing.

The findings revealed that eventhough the majority of people with dementia use only TV, radio and simple mobiles now, they are willing to use tablets with the tailored SMART4MD application. However, the application needs to be simple to use with a possibility to be personalised. Secondly, as a motivation to use it, it does need to include not only the treatment functionalities and content (reminders, practical steps for improving their conditions), but also try to include other daily activities and other interesting content, such as memory games, photos, videos, calls with the family, etc. Both carers and healthcare professionals stated that this application would be very helpful for them in their activities with people with dementia, however, usage of the application and sharing possibilities with the healthcare professionals do need to take into account their time constraints.

Based on this report, a list of requirements for SMART4MD application will be drafted which will be a starting point for the development stage of the first real prototype of the SMART4MD application. The first prototype will be then exposed to the second stage of focus groups/interviews with people with mild dementia, carers and healthcare professionals. The aim of the second stage is to cover mainly issues related to usability, user experience and personalization.

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2) ABOUT THE PROJECT

This project builds on an existing innovative patient support tool to develop an mHealth application that is specifically tailored to people with mild dementia. The tool should improve the quality of life of people with mild dementia and their carers; first, by helping them to adhere to the treatment, second, by allowing carers and healthcare professionals to monitor people with mild dementia more easily. We hypothesize that this will slow down the people with dementia' cognitive and functional decline, avoid carers getting exhausted and reduce costs of emergency care.

This project comprises two phases: first, we use digital accessibility tools to re-design the existing application for people with mild dementia. The development is steered by people with mild dementia, carers and healthcare professionals, through user-centred design. Therefore, we collect feedback on daily activities, technology usage, features, content, usability and personalization of the application through 2 stages of focus groups and interviews until the design and content is perfectly adapted to the users' needs. In the next phase, we will pilot the optimised SMART4MD application by comparing its effectiveness between 1 100 users dyads (person with mild dementia + carer) and 1 100 controls that will not be using the application. This will show both the clinical and social benefits for people with mild dementia and carers, as well as financial benefits for the healthcare system. We estimate that successful delivery of the pilot will increase people with dementia' adherence to treatment (10 %-points), while improving the quality of life of carers and people with dementia. It is estimated to save healthcare providers €1,818 / patient / year in care costs and to generate revenue of over €18 million / year for the consortium (Year 5).

These are the following objectives for the SMART4MD project:

Objective 1: Design a new version of the Pow Health platform (called the SMART4MD platform) that can be comfortably and reliably used by people with dementia with mild dementia, validated by at least 80% approval rate in focus groups and small scale patient trials.

Objective 2: Show the *medical benefits* of using the new SMART4MD platform:

a) Increase treatment compliance by mild dementia people with dementia from 50%[1] to 60%.
b) Reduce functional decline of people with dementia during the first 24 months from diagnosis by 10%.
c) Monitor and improve the quality of life for mild dementia people with dementia
d) Monitor the mental well-being of carers

[1] R. Brady and J. Weinmann, "*Adherence to Cholinesterase Inhibitors in Alzheimer's Disease: A Review*", *Dement. Geriatr. Cogn.*, **2013**, *35* (5-6): 351

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Objective 3: Show the *economic and financial benefits* of using the SMART4MD platform:

a) Reduce costs wasted on unused medicine by 50%.
b) Reduce costs associated with people with dementia failing to attend appointments by 75%.
c) Reduce costs associated with readmission of people with dementia to hospital (for resurgent conditions due to lack of treatment adherence) by 30%.
d) Provide overall efficiency savings to the healthcare system of 10% of dementia budget.

Objective 4: Develop *sustainable business models* for large-scale commercial roll-out of the SMART4MD platform in different scenarios and regions. Include *financial models* for investment, based on risk-sharing between relevant stakeholders and provide projections for each stakeholder's *return on investment* to complete the economic argument.

The below table lists all participating project partners on this project.

Participant no.	Participant organisation name	Participant short name	Country
1 (Co-ordinator)	Anglia Ruskin University	ARU	UK
2 (Participant)	Alzheimer Europe	AE	Luxembourg
3 (Participant)	Athena ICT	ATH	Israel
4 (Participant)	Pow Health	POW	UK
5 (Participant)	Universidad Politecnica de Madrid	UPM	Spain
6 (Participant)	South Essex Partnership University NHS Foundation Trust	SEPT	UK
7 (Participant)	Consorci Sanitaria de Terrassa	CST	Spain
8 (Participant)	DEX Innovation Centre	DEX	Czech Republic
9 (Participant)	Servicio Andaluz de Salud	SAS	Spain
10 (Participant)	Blekinge Institute of Technology	BTH	Sweden
11 (Participant)	University College Leuven Limburg (Katholieke Hogeschool Limburg)	UCLL (KHL)	Belgium

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3) METHODOLOGICAL APPROACH

User-centred design is typically described as a multi-stage problem solving proces. In the case of SMART4MD, it comprised of two different phases or stages. The first phase has looked at the context of use of the application and user requirements. This phase focused on the people who will use the application, in particular it aimed to better understand their needs, preferences and experiences of and attitudes to technology. It has also looked at motivational aspects such as what they would use it for and under what conditions they would use it. People with mild dementia, carers and healthcare professionals were involved in this phase. This section reports on the methodology used for this first stage.

a) Planning for focus groups/interviews

Prior to conducting the focus groups, all WP partners agreed on a number of relevant organisational, methodological and ethical issues. Several discussions were held in regards to:

- organisational issues, including the number of focus groups that should be conducted, the minimum number of participants of focus groups and interviews and the different stakeholders that should be included;
- the ethical issues that should be taken into account before, during and after the focus groups/interviews
- the development of a semi-structured guide for moderators. It was agreed that the guide would help to collect information in a systematic way, but that all researchers would use it in a flexible way that was adapated to the pace and needs of the group;
- the development of an information sheet that would be sent to all participants in advance to the focus group and also presented again at the beginning of the discussions (please see Annex);
- the most appropriate way of getting informed consent from all participants of the focus groups.

Agreement was also reached on the topics that would be adressed during the focus groups/interviews. These included:

- daily activites of people with mild dementia;
- familiarity with current technology/devices used among people with dementia and carers, and their frequency of use today;
- applications/websites and categories of content used most frequently by people with dementia and reasons of their usefullness;
- potential usage of current features of Pow Health platform and the reasons why;

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- other suggested features for SMART4MD application;
- SMART4MD platform usage requirements and motivation;
- ethics/privacy/information sharing.

Six partners from five different countries have conducted the focus groups/interviews.

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6 (Participant)	South Essex Partnership University NHS Foundation Trust	SEPT	UK
7 (Participant)	Consorci Sanitaria de Terrassa	CST	Spain
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9 (Participant)	Servicio Andaluz de Salud	SAS	Spain
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b) Focus groups/interviews with people with mild dementia and their carers

As for people with mild dementia and their carers, either focus groups or interviews have been set up as techniques to gather valuable feedback during this user-centred stage. Inclusion criterias for the people with mild dementia to take part in the focus groups were the following: age 55+, memory problems, living at home and having a carer. Participants of focus groups were recruited through various channels, including cooperating memory clinics, departments or medical centres, other healthcare professionals, relevant local stakeholders, and through a general promotion among public.

To protect participants from harm, researchers decided to use the same term used by them to refer to dementia. This was particularly relevant in some of the countries where still often people with dementia are still not fully disclosed their diagnosis. Often the term preferred and used by participants was memory or cognitive problems. In most cases, the focus groups included both people with dementia and carers in the same group.

At the beginnning of the groups, participants were provided with information about the project and were given opportunities to ask questions about the project and about the focus groups. They were also reminded of the voluntariness of the participation, and other relevant ethical issues such as anonymity and confidentiality were also adressed. Permission to audiotape the discussions (if applied

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by some partners) and to take pictures was sought from participants in written or orally. Also, no information discussed and noted down or audio taped during the focus groups were attached to any specific participant´s name, and this was due to sensitivity and anonymity issues.

c) Interviews with healthcare professionals

As for healthcare professionals, interviews were a preferred technique to gather their feedback during this user-centred stage. The main inclusion criteria for healthcare professionals was that they had to have a direct daily contact with people with mild dementia and their carers. Therefore, participating healthcare professionals included general practicioners, neurologists, geriatrists, and psychiatrists who were recruited from cooperating medical centres, memory clinics, local engaged dementia medical centres and individual healthcare proffesionals in the dementia field.

d) Approach to analysis

As focus groups and interviews were conducted in the local language, it was decided that each local research team would produce a summary of the main and most reccuring findings. All sumaries were collapsed in an excel table. The analysis was performed using a thematic approach. Two researchers looked at the summaries and identified common trends and relevant differences between the countries that had participated in the study.

In addition, each partner offered all participants of their focus groups and interviews to send them the summary of their local notes and findings if they wished to review all notes and their quotes, and decide if there was any which they did not want to get published later.

e) Focus groups/interviews factsheet

Country/ Partner	Czech Republic DEX	Belgium UCLL	Spain CST	Spain SAS	Sweden BTH	UK SEPT	TOTAL	AVERAGE
PEOPLE WITH MILD DEMENTIA								
Date(s) of focus groups/interviews	22.1.2016	26.1.2016	15.12.2015	20.1.2016	10.12.2015	28.1.2016	N/A	N/A
Location of focus groups/interviews	Komunitní středisko Kontakt, Liberec	Geetbets	Terrassa, Barcelona	Mental Health Service, Regional Hospital Carlos Haya, Málaga	Day Center in the South Sweden	Harland Centre, Southend-on-sea, Essex	N/A	N/A
Number of people with dementia in focus groups	11	7	7	4	7	5	41	7
Average age of people	76	75	72	75	69	67	N/A	73

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with dementia								
Sex distribution among people with dementia (%)	73 % men / 27 % women	43 % men / 57 % women	29 % men / 71 % women	50% men / 50% women	43 % men / 57 % women	100% male / 0% female	23 / 18	56 % men 44 % women
CARERS								
Date(s) of focus groups/interviews	22.1.2016	26.1.2016	15.12.2015	20.1.2016	17.6.2015	28.1.2016	N/A	N/A
Location of focus groups/interviews	Komunitní středisko Kontakt, Liberec	Geetbets	Terrassa, Barcelona	Mental Health Service, Regional Hospital Carlos Haya, Málaga	BTH, Karlskrona	Harland Centre, Southend-on-sea, Essex	N/A	N/A
Number of carers in focus groups	12	5	7	4	6	4	38	6
Average age of carers	59	55	63	40	55	65	N/A	57
Sex distribution among carers (%)	8 % men/92 % women	20 % men/80 % women	43 % men/57 % women	75% men / 25% women	0 % men/100 % women	25 % male / 75 % female	9 / 29	24 % men 76 % women
HEALTHCARE PROFESSIONALS								
Dates of interviews	11. 1. 2016 + 12. 1. 2016 + 29. 1. 2016	18. 1. 2016 + 21. 1. 2016	17. 12. 2015 + 18. 12. 2015	21.1.2016 + 22.1.2016	11. 6. 2015 + 23. 6. 2015	1.2.2016	N/A	N/A
Locations of interviews	Liberec 2x + Praha 1x	Genk	Terrassa, Barcelona	Neurology Service and Mental Health Service, Regional Hospital Carlos Haya, Málaga	Karlskrona	Harland Centre, Southend-on-sea, Essex	N/A	N/A
Number of interviews	3	5	4	2	5	6	25	4
Average age of healthcare professionals	42	40	41	48	NA	45	N/A	43
Sex distribution among healthcare professionals (%)	33 % men / 67 % women	20 % men / 80 % women	25 % men / 75 % women	100 % men / 0 % women	0 % men / 100 % women	33 % men / 67 % women	7 / 18	28 % men 72 % women

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The average number of people with mild dementia in focus groups was 7. The Czech Republic had the largest group with 11 participants with dementia. The overal mean age of all was 73. Participants in the UK and Sweden were slightly younger than in the rest of the countries. More men than women participated in the focus groups (56% vs. 44%). In the UK and the Czech Republic the participation of men was relatively high.

The average number of carers in focus groups was 6. The Czech Republic had the largest group with 12 carer participants. The overal mean age of all was 57. Participants from Spain, Málaga were much younger than the rest of the countries. 76% of carer participants were female.

The average number of healthcare professionals interviewed was 4. Of all, 72% were female.

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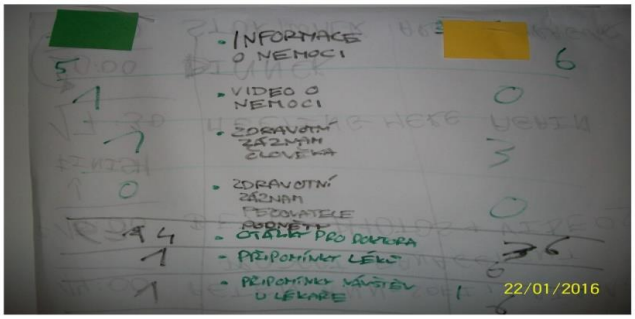
4) SELECTED PHOTOS FROM FOCUS GROUPS / INTERVIEWS



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5) FINDINGS

a) DAILY ACTIVITIES OF PEOPLE WITH MILD DEMENTIA

Most of the people with mild dementia carry out one or more of the following everyday activities - watching TV, going for a walk and calling their family members. In addition to these, a substantial amount of participants reported that they read newspapers and do mental exercises and puzzles to keep their brain active.

b) FAMILIARITY WITH CURRENT TECHNOLOGY/DEVICES USED AMONG PEOPLE WITH MILD DEMENTIA AND CARERS, AND THEIR FREQUENCY OF USE TODAY

Technology devices are not used extensively by people with mild dementia. Most of them use only TV, radio and their mobile phones daily. They use these mainly at home. Carers, on the other hand, are more familiar with the use of computers and a substantial number of them use or are familiar with using tablets. Still, not every carer feels confident about using technology.

Most people with mild dementia felt positive about using their mobile phones. Their primary motivation to use mobiles is to stay in touch with their family. Computers and tablets are viewed less positive than mobiles, however, when compared between each other, tablets do elicit a more positive opinion in people with mild dementia compared to computers.

As far as technology devices are concerned generally, their potential usage by people with dementia may be influenced by the following factors: contact with children and family, search for information and easiness of use. Some of the participants explained that interfaces need to be simple and intuitive so that any person, including those with cognitive impairment or low tech skills can use it. Some examples of how to make apps simple include: minimise the use of words and need to type, use of visual promots and voice input. Another relevant factor was that it would imply to have just one central point for information and tech support. Finally, for some groups, the app needs to be attractive and get the attention of the person. The right balance in the amount of information/ reminders was a relevant issue for many.

c) APPLICATIONS/WEBSITES AND CATEGORIES OF CONTENT USED MOST FREQUENTLY BY PEOPLE WITH MILD DEMENTIA AND REASONS OF THE USEFULNESS

Most of the people with mild dementia in the groups do not use tablets or internet frequently or have little or any experience with using them. However, during discussions, the following categories of applications/websites were cited to have good motivation for people to use them: entertainment,

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search, communication (calls, SMS), music, games/brain games, TV, radio, localization, reminders and goods/services ordering sites.

d) POTENTIAL USAGE OF CURRENT FEATURES OF POW HEALTH PLATFORM AND THE REASONS WHY

The discussions revealed that the most valuable and important parts of the current Pow Health platform, when tailored to people with mild dementia, their carers and healthcare professionals would be the following: disease information and management including mainly practical steps to improve their conditions, medication and appointments reminders, calendar/daily journal, health record sharing and contact possibilities with healthcare professionals, community network, lifestyle trackers and summary reports for healthcare professionals.

e) OTHER SUGGESTED FEATURES FOR SMART4MD APPLICATION

From other suggested features for the SMART4MD application, the following have been cited as most important: memory games and activities for cognitive stimulation, personal photos/videos, video calls/messages, online games, voice reminders, reminders for other important things (such as TV programme), localization, mood tracker and other rich content raising adherence of people with mild dementia to using such platform and application (eg. internet access, etc.)

f) SMART4MD PLATFORM USAGE REQUIREMENTS AND MOTIVATION

Generally, both people with mild dementia and their carers cited that they will be happy to use SMART4MD application if it is easy enough to use without any help and does not have too many functions, has possibilities for adaptation and personalization of interface and functionalities and if it deals with privacy issues by easy to use sharing properties. Carers would use such application mainly as a support to people with mild dementia.

There were discrepancies among the groups in relation to impact of apps in caring. For some groups, apps and in particular reminders, could potentially take some pressure off carers and have a positive impact in the relationship between the person with dementia and the carer. In other groups, however this was perceived as potentially adding more burden to the carer.

A main concern raised only by one group was about the app “taking over“ and replacing the ability of the person to function independently or to make the person more aware of his/her impairments. Most groups however perceived the app as potentially having a positive impact on the quality of life and independence. Another issue raised was the need of training and continuous motivation to use the app.

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In relation to the potential usefulness some referred to the visits with health professionals, for others the app was perceived as a potential source of information about dementia and living well with dementia, and others emphasised the relevence of social contact either with their families or with other people experiencing similar problems.

g) ETHICS/PRIVACY/INFORMATION SHARING

The majority of people with dementia do not have problems with sharing of some information through the application, but do require to have an option to be able to choose which information to share with whom. Some participants however cited that they would feel too much controlled and checked if all information were shared with carers or healthcare professionals.

Healthcare professionals prefer to see information via the tablet during the visit, as well as being informed by relevant not frequent email alerts. Nevertheless, carers have been cited to be the first instance where alerts need to be pushed to.

Healthcare professionals are worried with people with dementia and carers being able to share majority of information with them, as they would have unrealistic expectations during medical visits given the time contraints.

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6) SUMMARY

The following bullet points provide a general overview of the most important findings from this user-centred stage focused on content for the SMART4MD application.

PEOPLE WITH DEMENTIA – TOP FINDINGS

CZECH REPUBLIC – DEX

- Older generation is not used to modern technologies, not many of them use tablets and PCs now, nor applications or websites. They watch TV, use watches, read newspapers, journals, call with family, do mental exercises, go for a walk. These activities should be incorporated into as much as possible into any new technology or process to be used.
- Mobiles are a connection with a family – they like to be in contact with their children and contact with the family needs to be an important part of the application (e. g. video calls, texting etc.)
- Majority of people with dementia think they do not need reminders for anything which is in contradiction with carers´ opinion who think this exactly show that they need reminders.
- Most of the people with dementia would be willing to try the platform if there was a special training for using it at the start.
- The application needs to bring entertainmnet and richer content also for people with dementia to support everyday life, such as internet, crosswords, video calls, radio, music etc.

BELGIUM – UCLL

- Older people with dementia (75+) do not use ANY mobile devices (not een a simple mobile phone).
- People with dementia feel not confident at all that they will be able to use the app/tablet (they had less doubts when we explained it will be adapted to their needs and possibilities.
- People with dementia doubt it will add anything to their (quality of) life.
- People with dementia prefer to talk to someone in person, than via the app.
- For people with dementia, the app needs to be very simple, with large font text, and without an access code.

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SPAIN – CST

- 86 % of people with dementia do not use internet.
- The features more useful were: videos about dementia, health record medicines, health record appointments, medicine tracking, sharing information.
- Feature social is relevant.
- The technology makes life easier.
- Not necessary disease information for people with dementia.

SPAIN – SAS

- Very easy.
- Capture my attention.
- Including my hobbies.

SWEDEN – BTH

- As long as I can remember certain things myself, I do not want to be reminded all the time. I am afraid that techbology can take over so I lose the ability I have to remember.
- If I have to give a statement or analyze every day how I feel, then everyday will also be a reminder tha I am getting worse. That would be sad because we know we are not getting better.
- Very important to get the right kind of support. To feel the safety in a group of peers to dare to learn together. I would very much like it to be in the group who have the same problem as me because then I would not feel stupid.
- Using images that complement the text, or audio but you should either be able to use standard images, or use your own personal photos. Highly own medicine bottles, contacts etc.
- Help to localize thngs and places and give me reminders that give control and have a calming ffect, release stress and anxiety.

UK – SEPT

- Interface need to be very simple and intuitive, so that people with low tech skills and cognitive impairment can use the app. To this end, minimise use of words and need to type and instead use visual prompts and voice input. If the app is this easy to use, people with dementia felt if WOULD be useful in a number of ways.

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- A key advantage of the app is that it would be a single resource for various tech support – reminders, calendar etc. (see point 3). Having just one central point of information would make it easier to remember to turn it on, take it to healthcare appointments etc.
- People with dementia liked the idea of medication reminders. They wanted an audio memor prompt (beep or similar) to remind them to take meds. But it is important that this would not be switched off till after the meds have been taken. They also felt a remibder about appointments would be useful. In connection with this, they particularly liked the idea of a place to ote in advance (by voice memo), things to raise with the healthcare professional when they mean to talk about particular symptoms and so on in appointments but then forget to mention them when the time comes. Would also like a place to record what healthcare professional says in appointments so they can remember that afterwards, too. Could be voice memo, too.
- They liked the idea of a journal and/or mood tracker. This should be voice input based as typing/spelling becomes difficult. In the main they did not want to share this ind of information with others though, apart from healthcare professionals.
- They liked the idea of being able to access information on the condition and hints and tips at ways of coping. Although such information is on the web, some of those present could not use the web easily. So an app which takes them in a very simple way to these resources would be very welcome. They were more interested in this than in a social function (the privacy was a concern here).

CARERS – TOP FINDINGS

CZECH REPUBLIC – DEX

- Memory activities for people with dementia on the platform are one of the most important features.
- Daily status shared by people with dementia each day would not be 100 % real as they might press more negative smileys than reality if they want to see the family and vice-versa.
- No information about carers on the platform (such as health information of care) due to perosnal information protection.

BELGIUM – UCLL

- Receiving alerts will increase the workload of the carer, but will also give reassurance that in case there is a problem, they will know/will be notified.
- Would use it mainly for support in patient care, not really for themselves.

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- Communicating (via forum e. g.) with other carers is an advantage.

SPAIN – CST

- Functions that can be customized to the people with dementia.
- The carer has to be able to block certain functions.
- All of carers would use this tool (but only a bit) – you could have organized and archived medical history, contact with your doctor.

SPAIN – SAS

- Easy.
- Capture their attention.
- Security.

SWEDEN – BTH

- Important to create a context and to give the patient the opportunity to be able to orient themselves in space and time.
- Difference between the function and the realization of the function given personalization. Date and time, for example, displayed in different ways as a clock, image, colour indication, hourglass etc.
- To receive reminders just in time. Do not know that you will be there at 13:00, but rather – now you are gonna get dressed.

UK – SEPT

- Often proxy users of computers/digital tech on behalf of people they care for. Also like playing games online. Some Skype. But not all carers are very competent in digital tech themselves. They need good support in using computers etc. Relatives cannot always explain how to use even if they can use tech themselves. And do not want to bother others with continual questions. People with dementia especially need a strong motivation to se tech in order to get over the difficulties in using it.

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- A reminder functon on an app is welcomed as it takes some pressure off carers who otherwise have to keep reminding the patient. This can cause tension in the relationship – carers accused of nagging. But need not to avoid having too many alerts as otherwise people begin to ignore them.
- Would like information support to help carers cope with stresses and strains of caring for someone with MD. Advising how other people manage.

HEALTHCARE PROFESSIONALS – TOP FINDINGS

CZECH REPUBLIC – DEX

- All healthcare professionals welcomed the project and application idea to support people with dementia mainly.
- Memory tests and activities should be a very important part of the application.
- No e-mail notifications, no real-time answers, only weekly summary reports and answers accessible online on some website to work with the information

BELGIUM – UCLL

- App would help to have all information on a patient in one location.
- Advantage tat patient´s progress/decline will be monitored daily (and can be checked whenever needed).
- Do not think people with dementia will be able to/motivated to use the app (they asked whether we investigated beforehand the need of people with dementia to use this).

SPAIN – CST

- All healthcare professionals would use the platform.
- The tool is designed to use the carer, most of the functions are more useful for the carer (e. g. education, health record) or for healthcare professionals (e. g. diaries and trackers).
- If it is difficult to use and more than help it would be a furden for the carer.

SPAIN – SAS

- Useful if people with dementia can be able to use it.

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- It must be so easy,
- It will be more useful for carers.

SWEDEN – BTH

- The function must be fail-safe and going to rely on. Can technology help to provide security, it leads to increased well-being. The anxiety has a neative effect on the cognitive functions.
- I do not think anyone would opt out of the technology if they got it. I have not met anyone who does not want modifying drugs, and this tool is a type of modifying drugs.
- The reminders that are used should connect back to learned behaviors earlier on, such as alarm clock sound and function.

UK – SEPT

- All health care professional use commputer/digital technology however feel that they are not very competent. In their view the key to motivate people with dementia to use technology would be that it should be very user friendly and should be very easy to access.
- Medication reminders, appointment reminders and reminder functions are very helpful. A popular suggestion was Voice Reminders. A balance needs to be achieved with the number of functions that the App does as too many functions may put people off from using it.
- Regarding support for carers in addition to information on disease management having a contact list of services like local Altheimer´s society, Age concerns, Dementia nurs/GP would be very helpful.

SUGGESTED FEATURES – TOP FEATURES

CZECH REPUBLIC – DEX

- Memory games and activities.
- Video calls, private messaging with family + doctors (questions for doctors).
- Reminders of medicines and appointments + their lists.
- Personal and family photos + other richer content (internet, music).

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BELGIUM – UCLL

- Easy way to watch photos and videos and communicate (from/with family members and friends) are the main motivator for people with dementia to use the app.
- Reminders of appointments and visits will be useful.
- Reminders not as written messages, but spoken with video (not only speech).
- Combine with a watch or bracelet that vibrates (because older persons may have hearing problems and thus will not notice the reminders) or with a light signal together with a bell ringing.
- Easy way for charging the battery (which at least will have to last for one entire day) + solution in case they forget to charge.

SPAIN – CST

- Guidelines for disease management (the most important for carers).
- Online games (with voice) – carers.
- Photos (carers).
- Contact with other professionals (not only doctors, e. g. other neuropsychologist) – healthcare professionals.
- Links of cognitive stimulation – healthcare professionals.

SPAIN – SAS

- Videos with disease information.
- Reminders.
- Share record with my doctor.
- Keystroke with photo to call the family.
- Access to my hobbies (personal area).

SWEDEN – BTH

- Reminders to take medication.
- Create a structure throughout their daily lives.

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- Communication and contact with others. Both professionals and carers but also people with dementia in the same group of diseases, which ultimately may result in that they are safe in using technology (community approach).
- Personal images linked to other functions such as reminders, daily schedule etc.
- Localisation (help to find both things and finding their way around).

UK – SEPT

- Information about dementia and suggested ways of coping/managing symptoms.
- Calendar – reminders appointments (also reminding what appointment is about).
- Medication reminder but must link to dosset box or onnly switch off after medication taken. Otherwise reminder goes, people switch off but then forget again before they have actually taken the medication.
- Appointment reminder coupled with voice memo function which can remind patient/carer of issues they want to bring up in the appointment.
- Mood tracker of journal via voice memo of how patient is feeling day to day. Both as way of making sense of dips in mood and also as a way of unburdening.

TOP QUOTES

CZECH REPUBLIC – DEX

- Mobiles are a connection with family and children (people with dementia).
- People with dementia think they do not need reminders, but carers said this exactly shows they really need them (carers).
- Easy connection to PC for download and third party software, memory tests, Skype, phone calls, emergency, application to recognize if the patient felt down etc. (healthcare professionals).
- Carers would feel stressed to know the patient feels bad and cannot visit him, it would not be 100 % real anyway what they pusthed about their mood as the might push more negative mood just to be able to see the family e. g. (carers).
- Include journal to calendar – carer could go through activities they did and train people with dementia´ memory (healthcare professionals).

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BELGIUM – UCLL

- We are old and have rigid fingers, we cannot learn to use these devices anymore (people with dementia).
- Men like to read the newspapers, women prefer to read magazines (carers and healthcare professionals).
- Do not overload people with dementia with information, it will cause them stress (healthcare professionals).
- Believe that the app will be more helpful for carers than it will be for people with dementia (healthcare professionals).
- Receiving alerts will increase the workload of the carer, but will also give reassurance that in case there is a problem, they will know/be notified about it (carers).

SPAIN – CST

- This tool will serve for future generations (carers).
- In people with dementia with Mild Dementia, it could be difficult to use (healthcare professionals).
- A tool is very useful for carers (healthcare professionals).
- It could help the carer stress (healthcare professionals).
- Medicine reminders give autonomy to patient and liberate carer.

SPAIN – SAS

- This devices confuse me (people with dementia).
- I need something that capture my attention (people with dementia).
- Overall it could be easy, very very easy.
- It will be useful it it is easy and captures the attention of people with dementia.
- I want to select who receives the information (carers).

SWEDEN – BTH

- As long as I can remeber certain things myself, I do not want to be reminded all the time. I am afraid that technology can take over so I lose the ability I have to remember.

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- If I have to give a statement or analyze every day how I feel, then everyday will also be a reminder that I am getting worse. That would be sad because we know we are not getting better.
- Functions must be fail-safe and reliable. Can this technology help to provide a sense of security, it leads to increase well-being.
- The structure is the most improtant thing – that you have a daily schedule visible and that the pad helps me through the day. Highlight what is done and to check what has been done. Personalized custom. Focus for some persons but for others that may not be necessary. In the first basic setting so it shall nonetheless be simple with few features to not reinforce the feeling of being odd and stand out.
- Should there be different permissions? Rights? Can of course be fights about who has changed what? Is there a traceability of who has done what?

UK – SEPT

- Carer, talking about a value of a medication reminder: „I think it would take the onus off me, getting it in the neck every time I ask him to take them."
- Patient talking about usefulness of being able to save a voice memo to tablet reminding him what to mention when he sees healthcare professional: „I think, I must tell him about this symptom or that symptom when I see him and then you go in, and you forget."
- Patient talking about the app: „If it was user friendly, it could have huge benefits."
- Patient: „Important thing is to have a single source of information."
- Healthcare professional about the App: „It has to be very easy to access and too many functions on the App can put people off from using it."

In addition to the bullet points above, an additional summary of interesting findings is presented below:

TECHNOLOGY/APPLICATION:

- Add mental exercises, cognitive stimulation.
- Most people with dementia have simple mobile phones as the newest technology used.
- Although people with dementia expressed that they feel positive about using technology, most of them prefer to use simple technology such as mobile phones mostly to communicate with their family.
- People with dementia expressed a positive feeling about using tablets, but they need to be easy to use and independently used, without the need to ask others how to use it.

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- Login credentials or code inputs need to be avoided.
- Adaptation and personalization options need to be possible according to their conditions.
- It is not needed to have too many functions, just the most important are enough.
- Confirmation on what is happening is very important.
- Caregivers´ alerts have to be managed well enough (useful alerts/reminders, just in time, etc.) to avoid people ignoring them.
- Health professionals only need a weekly summary of the patient's status.

MOTIVATIONS FOR PEOPLE WITH DEMENTIA TO USE THE APPLICATION:

- Hobbies and games (Sudoku, Korsord, music).
- Reading newspapers.
- Search information (Google).
- Connect with family members.
- Adaptation and personalization.
- Easy to use without having to ask other people to help them.
- Picture gallery with personal photos.
- Communicate with their carers.

THINGS TO HAVE IN MIND:

- "As long as I remember certain things myself, I do not want to be reminded all the time. I am afraid that technology can take over so I lose the ability I have to remember."
- What they feel awkward about is the fact that everyone can know where they are and what they are doing (they feel the need for privacy).
- "If I have to give a statement or analyse every day how I feel, then everyday will also be a reminder that I am getting worse. That would be sad because we know we are not getting better"
- Music is used to "wake up the memory" and as a basis for the dialogue in the group. It also has a soothing effect.

POTENTIAL USAGE OF CURRENT FEATURES OF POW HEALTH BY PEOPLE WITH DEMENTIA AND CARERS + REASONS

- **Education:**
  - In general people with dementia do not see these as being very useful for them.

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- Carers and healthcare professionals think that: very useful to include guidelines and advise for disease management, and useful for patient care (carer), but very unuseful for people with dementia themselves.

- **Health Record:**
  - People with dementia - health records: carers and healthcare professionals think that it would be useful to have a vision of people with dementia health status for: patient monitoring,
  - In general carers and healthcare professionals think that the monitoring could be done every month or 3 months depending on the patient status.
  - Regarding carers health record, carers do not see the importance of having this feature, but in general healthcare professionals think that it would be great to know if carers could score each day how they feel to monitor the carer, because carers status could affect the people with dementia as well.
  - Medication: in general reminders of medication intake for Carers and medication intakes reports for Healthcare Professionals. Regarding reminders for people with dementia there are many opinions: could not be useful at all due to most of them take their medication when given to them by the carer, and also Carers and doctors think that reminders for people with dementia could serve to motivate them to take the medication.

IMPORTANT RELATED ISSUE TO ADDRESS: if the PWD takes the medicine but does not push the button (so doesn´t inform the app that he/she has taken the medicine) will the PWD not take it again later because he forget? How to manage that situation?

  - Appointments: Good for carers, necessary to get the reminders just in time so you can prepare but not forget, good to be able to put everything in the calendar and have a daily schedule for example if somebody is visiting.

- **Diaries & Trackers:**
  - Quality of live tracking: useful for carers to know status of people with dementia. Not relevant or/and not essential for people with dementia because as for example: it reminds you that you are getting worse all the time.
  - MCI symptom tracking: It would be useful for the doctor but it is not useful because of poor awareness of disease.
  - Lifestyle tracking: physical activity, mental activity, free time activities, therapeutic plan should be done (physical activity, food, etc.) daily plan should be done and if not

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respected by patient than he could get a bad smiley and has to write why he didn't, for example when he went to sleep etc. (not food etc.). Useful to see if you have routines (it should be easy). Always depending on the patient (hobbies, lifestyle, etc).
  - Lab Tests: Useful for the doctor (healthcare professional). Must follow the laws of confidentiality.
  - Connect to third party devices
  - Sharing: under the condition that I can decide with whom and what should be shared.
  - Social: useful for the carer. It would be great to share experiences and knowhow between people with the same problem (people with dementia and carers), a possibility to switch on for those interested, but not a standard feature
- **Communication:**
  - Notifications: useful for the carer (not all the time).

OTHER SUGGESTED FEATURES

- Memory games, photos and videos, music, guidelines for carers, calendar.

SMART4MD PLATFORM USAGE BY PEOPLE WITH DEMENTIA AND CARERS + MOTIVATION

- As a general opinion, carers and healthcare professionals think that people with dementia could use a tool like the one discussed in case it is simple enough to use.
- In general carers would use the app only as a support to people with dementia.

ETHICS

- In general people with dementia are comfortable with sharing information but they feel more comfortable if they can choose what personal information they share. Also, some have the feeling they will be 'watched' and 'controlled' all the time.
- In general Carers are comfortable with sharing information of people with dementia + carer with the doctor. Under the condition they can decide when and where and who and following security standards.
- Healthcare professionals:
  - Want to receive the information via application (as you will have all information in one place).
  - Receive alerts through email but on the right level – things that are relevant and that you can act upon. Also they think that Carers must be the first to received alerts.
  - Receive reports monthly or if there has been a change for example on QoL measures, adverse events, etc.

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- Mainly view the information at their work place through the tablet brought by people with dementia.

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7) ANNEXES

ANNEX 1

Today's Consultation about the Development of an Internet-based Health Management Tool for People with Memory problems and their Carers

About the consultation/discussion:

- The purpose of the consultation is to find out from you how to adapt an existing Internet-based health management tool to the specific needs of people with memory problems
- The aim of the tool is to monitor the evolution of dementia and promote independent living as well as quality of life.
- The consultation will be an informal group discussion lasting not more than X hours.
- No payment will be made. Sorry ☺
- Refreshments will be provided.
- Toilets are located XXXXXXXX.

About your participation in the discussion:

- The consultation will be conducted in a friendly and respectful manner.
- Please share your thoughts and ideas, even if different to those of other people.
- All contributions will be valued.
- There are no wrong answers.
- It is not necessary to be technically-minded or have experience using the Internet.

About confidentiality:

- Please do not repeat anything you hear in the group to anyone else afterwards.
- We might recording and taking notes but guarantee complete confidentiality.
- No real names will be used in our reports.
- We will only use the information we collect for the purpose of this study.

About freedom of choice:

- You are free to decide whether or not you would like to take part in this discussion.
- You are free to leave at any time without having to justify your decision.
- You are free to decide whether or not to respond to a particular question.

After the discussion:

- In a few weeks' time, you will receive a summary of the findings.
- You will have the opportunity to read the summary and ask for anything you said to be deleted if you are not happy with it being included.
- Contact details of the local Alzheimer society will be provided in case you wish to discuss any issues which arose through your participation in this study.

Thank you very much for taking part in this consultation. Your help is greatly appreciated.

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ANNEX 2

Discussion guide for moderators of the group consultation involving people with dementia and carers – SMART4MD

Start of the consultation and engagement question

Good evening and welcome to this consultation. Thank you for taking the time to join us. This consultation is part of a European study called SMART4MD. This is a study that has been funded by the EU, and xxxx EU countries are participating in this study.

The aim of SMART4MD is to adapt an existing Internet-based health management tool to the specific needs of people with dementia. This tool aims to help people with dementia to monitor their condition and to promote independent living and quality of life. The tool will be used by people with dementia themselves but also their relatives (or informal carers/trusted people) and healthcare professionals. We would like to know more about what people with dementia and carers might value from this type of tool. To participate in this consultation it is not necessary to be technically-minded or to have experience using the Internet. It is more a matter of finding out what you might want from such a system to ensure that we design something that is useful and that people will want to use (including those who are not yet familiar with such technology)

This will help the team working on the tool to support you with useful features such reminders to help you take your medication on time. XXXXXX

We are having discussions like this with other groups in across Europe. (xxxx name countries). There are no wrong answers but rather differing points of view. Please feel free to share your point of view even if it differs from what others have said. We are interested in all ideas and suggestions. We might tape record the session because we don't want to miss any of your comments. People often say very helpful things in these discussions and we can't write fast enough to get them all down. We will be on a first name basis tonight, and we won't use any names in our reports. You may be assured of complete confidentiality. The reports will be collected and put in a bigger report.

Well, let's begin. Let's find out some more about each other by going around the table. Tell us your name and to start the ball rolling, what type of technology do you use in your everyday life

Question 1

We will start now with the questions about the use of technology. The first question is in relation to your own personal experiences in using technology. How do you feel about using technology?

Prompts

- How confident do you feel about using technology?
- What motivates you to use technology? What helps you to use technology?
- What prevents you from using technology?

We would also like to know about the specific devices and applications that you may have used or that you know about.

Prompts

- What, if any, devices do you use?
- How often do you use these devices?
- If you have never used any devices, what has prevented you from using them?

- What sorts of applications/websites do you use and why?
- If you have never used any applications/websites: what type of application do you think would be more relevant to you? Is there any type of application that you think you would be more inclined to use?

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Post-it notes

Now, we would like each of you to write on these post-it notes the apps/websites that you have used the most frequently. You can write up to xxx examples. This is not a test so don't worry about finding something to say or to write.

For those of you who have never used an application or website, please write on these other post-it notes (PROBABLY OF A DIFFERENT COLOUR???) the type of applications or websites that you think would be useful for you. (Or that you are more likely to use???)

We are now going to stick these post it notes onto these boards around the meeting room so that we can all see the different types of applications that the group is familiar with or would like to use.

Note for the moderator: each board can have notes for a different category, e.g. Shopping, News, Entertainment, Health, Diary/Reminders, etc.

Question 2

(*For each of the categories that were mentioned by the group).* We would now like to know about (name of the category, e.g. shopping)?

- Why is this important for you?
- How does the use of technology help you in xxx?
- What do you find most useful about the application/website?
- Is there anything that is relevant for you and that is missing or that could be improved in this application/website?

(For those who have no experience with apps/websites) If you were invited to use an application for (XXX name category) what would be important for you? How could the use of technology help you in this category?

Question 3

I would now like you to imagine a tool that you could access on XXXX and which could include the following features (XXXXXXX). A health platform is XXXXXXX

Pow Health is XXXXXX. The main features available on the platform are XXXXX.

I have listed on these boards all the features that so far are included in Pow Health. These features are based on our knowledge of what other patient groups have found useful,

(MODERATOR repeat these questions for each feature)

We would like to know how useful you think (XXXX name feature) would be for you?

Do you think you would use it? Why / why not?

Question 3

To finalise the discussion, we would like to know about your opinion of a tool like the one we have discussed today and to what extent you think such a tool would be helpful to you?

Prompts

- Do you think you (yourself) would use a tool like the one we have discussed today?
- Do you think you would use a tool like the one we have discussed today for others?
- Why would you use this tool?
- What would prevent you from using this tool?

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- Are there any additional features that you would like to have access to but which haven't been mentioned?

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