# METHODOLOGICAL APPROACH FOR FOCUS GROUPS AND USABILITY TESTING WITH PEOPLE LIVING WITH DEMENTIA

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SMART4MD is an app and platform developed under European Commission, H2020 Project 643399 for people living with dementia to manage their health and improve their quality of life.

The project used focus groups, design guidelines based on COGA research, and userability testing to help adapt the platform for people living with dementia . The following is a summary of the methodology used. Full details of the focus groups is in the focus groups report (D2.3) for the project. It should be noted that the prototype also used design patterns and guidance based on the advice of the COGA task force.

## FOCUS GROUPS - METHODOLOGICAL APPROACH

The first phase has looked at the context of use of the application and user requirements. 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.

1. Planning for focus groups/interviews

Prior to conducting the focus groups, all 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, and to make sure both the particpents and any gardians have given informed concent
* 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 and the reasons why;
* other suggested features for SMART4MD application;
* SMART4MD platform usage requirements and motivation;
* ethics/privacy/information sharing.
1. 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 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.

1. 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.

1. 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.

## USABILITY TESTING - METHODOLOGICAL APPROACH

In the SMART4MD project the principles for Agile software development are influencing the whole design and adaptation process. The inclusion of users and early and continuous testing of software, where changing the requirements based on user feedback with continuous improvement is an important part of the Agile methodology.

During the second round of user testing (focus groups/interviews/observation) of the prototype further involvement of users in order to ensure that undiscovered usability problems would be removed from the final application.

The following steps were taken in order to conduct the user testing:

* Preparation (ethical issues, information sheet, informed consent, guide for the moderator, recording, etc.)
* Focus groups/interviews/observations with patients and carers (inclusion, why, how, when, whom, how many, structure)
* Interviews with healthcare professionals (why, how, when, whom, how many, structure)
* Iteration of feedback between focus groups to enable better practices and adaptation
* Post-events activity
* Focus groups / interviews factsheet

### Focus groups/interviews/observations with people with mild dementia and their carers

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During this second round of focus groups, the aim was to get feedback from the users about the prototype of the application developed. A series of focus groups and interviews were held in Czech Republic, Spain, Belgium and Sweden during October and November 2016. Focus groups attempts to use the potential for positive synergy in group work to gain more useful data than could be obtained from an equivalent string of individual interviews. Separate questions were developed for PWDs, caregivers and health professionals in order to get feedback of as many aspects as possible of the application’s design. The initial focus group was held in Sweden, including six persons with dementia and two caregivers. The feedback from this focus group was used to improve the prototype and improve how well the questions prepared for the focus groups were understood by the participants and identify if there were any topics missing. As a result, an additional question was added to the later focus groups.

Tablets containing the application were given to the users and questions were being asked about the design (including the functionalities). The feedback given by the PWDs, the caregivers and health professionals during the focus groups and interviews was synthesized and the result is featured in a later section of this report. [[1]](#footnote-1)

A combination of different methods were merged to conduct the second round of focus groups, in order to ensure the efficiently use of time and resources (including project partner work capacities, users and logistical resources). The following methods were used:

* Task analysis (as far as requirements, routines and processes are concerned)
* Interview techniques (as far as prepared questions are asked)
* Classical focus group methods (as far as users are encouraged to discuss)

### Interviews with healthcare professionals

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### Usability Strategy

Usability Testing was used during the second round of focus groups in order to determine the usability of the SMART4MD prototype and to find ways to improve it (“formative testing”) based on the feedback of the end users, and the struggles they went through during the focus group.

Nielsen (1993)2 states that User Testing with real users is “the most fundamental usability method and is in some way irreplaceable, since it provides direct information about how people use computers and what their exact problems are with the concrete interface being tested.”

The main objectives of the usability testing are:

1. Measure the usability of the prototype, in order to determine whether it is already acceptably high.
2. Identify optimisation potentials, in order to increase the usability of the SMART4MD application.

In the case of SMART4MD end users performed some pre-defined tasks using the prototype and then will use interview techniques in order to find out which aspect of the interface and functionalities derailed a successful performance of the pre-defined tasks. Also, the internationally accepted standard DIN EN ISO 9241 will be used to measure usability. According to DIN EN ISO 9241, usability could be measured assessing the following parameters:

* **efficacy** is the extent to which the user is able to achieve the respective goal(s). Hence, efficacy is a relative measure, ranging from 0% to 100%. A common operationalisation of efficacy is the percentage of tasks completed successfully by the user.
* **efficiency** is the efficacy of the user, divided by the amount of resources the user needs to spend in order to reach this efficacy. A common measure of efficiency would therefore be the time to complete each task.
* **satisfaction** is the user’s “subjective reaction” to the interaction with the product (ISO 9241). User satisfaction is an emotion which results from the user comparing his expectations of the system to his actual experiences with it. Satisfaction can therefore only be measured by asking the user about his feelings towards the system.

In order to assess these parameters quantitative metrics will be collected during the second round of focus groups. Also subjective metrics including questions asked during the execution of the focus group, after each task completed, as well as general questions about overall satisfaction and experience with the application. The following table show the metrics collected:

|  |  |  |
| --- | --- | --- |
|  | **Metrics** | **Measurements** |
| **Performance Metrics** | * Task success
* Time-on-task
* Errors
 | *Effectiveness*: percent of task completed; ratio of successes to failures.*Efficiency*: time to complete the task; percent of number of errors; number of repetition or failed commands. |
| **Issues-based Metrics** | * What prevents task completion?
* What creates confusion?
* What produces an error?
* Why a user performs a wrong action?
* Why a user misinterprets content?
* Why a user does not understand navigation?
 | *Satisfaction*: satisfaction with function and features; number of users expresses frustration;  |
| **Behavioural Metrics** | * Positive and negative comments
* Suggestions
* Confusion
* Frustration
 | *Satisfaction*: satisfaction with function and features; number of user expresses frustration; positive attitudes towards the use of the system. |

### Approach to analysis

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### Notes

Based on the consortiums experience in working with people living with dementia, and of the nature of the user group the partners agreed on the following additional guidelines

1. Have a large observer to participant ratio so you can monitor the individual participant, where they struggle and what they say.
2. Usability tests should be a mix of groups and one on one interview.
3. When a participant does not manage and the observer offers help, the observer should try and help with words and note what words were effective in helping the user understand what to do.
4. Ask people things about their performance during the session but we have to be aware of their real performance during the execution of the task using quantitative measures.
5. Ask users to complete the task as far as they can without asking for help. If they need they can ask their caregiver for help to complete the tasks.
6. Also try and check if the back navigation confuses  people

**For each task:**

1. For each task, the common starting point should be the home page
2. Identify any sections were the user is struggling.
3. Are terms and icons understandable? If the user needs help what term was helpful?
4. What sections made the users mode improve? What sections did the user’s mode worsen?
5. Ask is there something that would make this task easier or better for you

How do they get back to the start/home page at the end the task (ask them to go to the start page)

See SMART4MD.eu for more details

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1. Note that, not all the sections that were presented to people with dementia, carers and health professionals for feedback were complete. For example, the section “About dementia” in the final version of the app will contain a number of sections relevant to people with dementia. In each of them, there will be background information about the section and several links from where the person will be able to find national / local information. For the focus groups and interviews, only the headings of each section were shared with participants. [↑](#footnote-ref-1)