

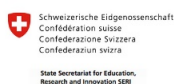
MedGUIDE

ICT Integrated System for Coordinated Polypharmacy Management in Elders with Dementia

D3.1 Wizard of Oz 1st evaluation in controlled environment

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Contributing partners :	CCARE, HU-UAS, IVM, MAT

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Acronyms used in this deliverable

CCARE	ConnectedCare Services B.V
HU-UAS	Stichting Hogeschool Utrecht / Utrecht University of Applied Sciences
IVM	Stichting Instituut voor Verantwoord Medicijngebruik
MAT	AgeCare (Cyprus) LTD – Materia Group
KARDE	Karde AS
VIGS	Vigisense SA
TUC	Technical University of Cluj-Napoca

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1 Executive summary

In the proposal, MedGUIDE's main objective is defined as a holistic monitoring platform which integrates various variables and distributed data sources describing the elders: (i) activity of daily life and lifestyle such as physical activity, sleeping patterns, movement habits, nutrition and social interaction aspects and (ii) medication intake and adherence to the prescribed therapy. The MedGUIDE platform will leverage on information from the local care network ((in)formal caregivers), self-reporting and information that can be automatically collected using sensors.

The MedGUIDE project conducted an evaluation of wireframes (as presented in D1.2 "1st version of system architecture, user interface and service design") as the first step of evaluation. Based on the results from these analyses the design and development team has been iterating on the findings and has developed a clickable mock-up.

After a successful preliminary testing of the wireframe designs as reported in earlier deliverables, we were able to develop an interactive prototype for evaluation, using the Figma platform. The implementation on the Figma-platform allowed end-user interaction in a very realistic way. Therefore, the Wizard of Oz technique as foreseen in the proposal was replaced by participative evaluations for usability and-user experience tests and heuristics evaluations of mock-ups as no simulation was needed.

The purpose of this deliverable is to document the methodology of and the results from Task 3.2 'MedGUIDE piloting and evaluation in controlled environment' from WP3 'System integration and field trials validation', in order to ensure an iterative development process that will consistently receive feedback from the end-users on its suitability, usability and appropriateness. The evaluation process was set up based on the defined scenarios and use cases, whilst the recruitment process was carried out based on well-defined eligibility criteria (Chapter 4.1.4).

2 Previous work and implications in a nut-shell

The mock-up that is to be piloted in the second iteration is based on the wireframes¹ that were developed in the project after initial end-user investigations (first mock-up). The Balsamic platform² was utilised to create the wireframes.

This evaluation is part of WP3 System integration and field trials validation, Task 3.2 [M10-M18] MedGUIDE piloting and evaluation in controlled environment (Lead: KARDE, Participants: IVM, MAT, HU-UAS).

This first mock-up illustrated a set of initial concepts that the MedGUIDE solution could be built on. The end-user feedback provided the project with feedback concerning a variety of aspects, such as layout, navigation, interaction, content, infographics, communication, etc. Two images of the wireframes are shown in Figure 1. For more detailed images we refer to D1.2 1st version of MedGUIDE system architecture, user interface and service design.

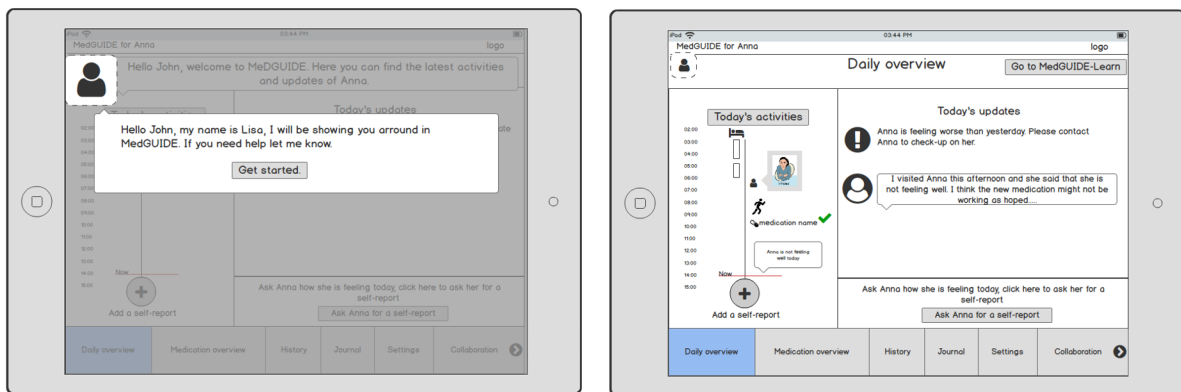


Figure 1. Two examples of wireframe prototypes from the first iteration. The presentation is skeleton-like and there is no real interaction

The wireframe pilots resulted in a rich set of feedback that has now been implemented in the second mock-up. The second mock-up represents a design that resembles real user interfaces, and it is implemented as a clickable mock-up on the Figma platform³. For the second iteration, each of these mock-ups were translated into native languages in the end-user participant countries.

The mock-ups in English can be found via the following links:

- **Caregiver's⁴ mock-up:** [https://www.figma.com/proto/omXJLqKicleBJB0ef0Xd8m/MedGuide-Mockup---Caregivers-\(EN\)?scaling=contain&node-id=242%3A37669&redirected=1](https://www.figma.com/proto/omXJLqKicleBJB0ef0Xd8m/MedGuide-Mockup---Caregivers-(EN)?scaling=contain&node-id=242%3A37669&redirected=1)
- **PwD's mock-up⁵:** [https://www.figma.com/proto/iKxDpnk3K4sYAiAcEEG8VK/MedGuide-Mockup---Senior-\(EN\)?scaling=min-zoom&node-id=168%3A7767&redirected=1](https://www.figma.com/proto/iKxDpnk3K4sYAiAcEEG8VK/MedGuide-Mockup---Senior-(EN)?scaling=min-zoom&node-id=168%3A7767&redirected=1)

¹ A wireframe is a skeletal presentation of a website or an application.

² <https://balsamiq.com/>

³ <https://www.figma.com/>

⁴ By caregiver we mean the professional, like GP and pharmacist and the (in)formal caregiver, like home care nurse and family of the PwD.

⁵ PwD = Person with Dementia

Detailed description of the design rationale of the mock-up can be found in D1.3 Final version of MedGUIDE system architecture, user interface and service design.

The combined graphical design and interaction design were meant to resemble a realistic end-user application that will be easy for the end-users to evaluate and comment on. In Figure 2, four images show the "design language" of the mock-up solution.

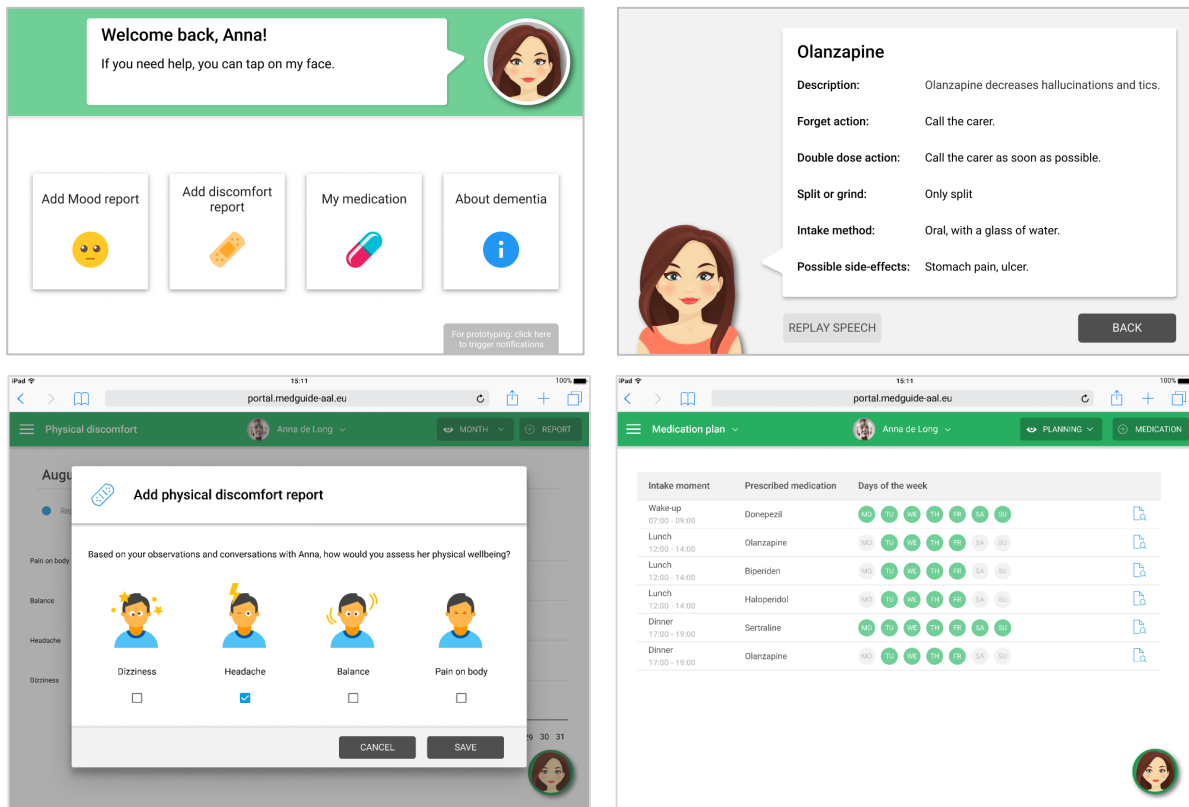


Figure 2. Examples of the interactive mock-up for the second iteration. The mock-up allows simple navigation.

In addition to these mock-ups that were part of the 1st iteration reported in this deliverable, the project has developed two initial mock-ups for e-learning: one for caregivers and one for the PwD, as described in Task 2.5 Dementia Care and Polypharmacy Management Service [M4-M28]. Only a small, initial part of the e-learning for the PwDs was integrated in the Figma-mockup, containing information about what dementia does with people, and small pieces of information about coping with dementia.

E-learning will be available as a separate tool, but will also be fully integrated in the next version of the MedGUIDE prototype and evaluated in connection with the 2nd iteration. The current status of the development that is in preparation for the 2nd iteration can be seen on:

- Caregiver's e-learning mock-up: <http://medguidelearn.wpengine.com/>
- PwD's e-learning mock-up: <https://www.figma.com/proto/4hPUDAXwB7X8bUoWevl6ED/MedGuide-Mockup---Senior-E-learning?scaling=contain&node-id=498%3A4844&redirected=1>

3 Results from the evaluation of the clickable mock-up

Here, we first present the results from the evaluations of the mock-ups. In Section 4, we provide a detailed presentation of the method of end-user involvement and research.

For this phase, the targetted number of end-users were as follows:

	PRIMARY			SECONDARY			TERTIARY
	IVM	MAT	KARDE	IVM & HU-UAS	MAT	KARDE	IVM
Testing and validation of individual services	10	8	9	7	6	6	3 pharmacists and 2 doctors

The end-user groups in the MedGUIDE project are defined as follows:

- PRIMARY: Older adults, Elders suffering of early stages of dementia wishing to self-manage their condition, and associated polypharmacy.
- SECONDARY: Formal and informal caregivers, family carer for someone with dementia, nurses, socialworkers, etc.
- TERTIARY: Healthcare professionals, doctors responsible for the treatment of dementia and of other potential associated comorbidities in elders, pharmaceutical professionals.

The actual figures are presented in connection with individual partners' results in Chapters 3.1 - 3.4.

Four MedGUIDE partners have conducted mock-up evaluations:

1. HU-UAS
2. IVM
3. MAT
4. KARDE

In this chapter, results from their mock-up evaluations are presented as summaries from all individual evaluation sessions. The evaluation data were anonymised and collected into structured excel-sheets, and then analysed and compiled to a structured overall conclusion with recommendations for the further development of the MedGUIDE solution. The individual evaluation data from the end-users are not published.

The results below should be read combined with an activated mock-up beside. It may also be helpful to read this deliverable together with the four other deliverables:

- D1.3 Final version of MedGUIDE system architecture, user interface and services design
- D2.1 Social network-based monitoring and information sharing service
- D2.4 Dementia care and polypharmacy management service – 1st release
- D3.2 MedGUIDE system prototype – 1st release

Finally, these results must be processed and prioritied into the prototype for the 2nd iteration. This work will go on in parallel with the final technology and architectural choices, development and validations.

3.1 Evaluation results from HU-UAS

3.1.1 Partner ID

Partner name: HU-UAS
Partner country: The Netherlands

3.1.2 Test population

Wireframe URL caregivers: [https://www.figma.com/proto/YlupJ3MymklcEIBQxEPQma/MedGuide-Mockup---Caregivers-\(NL\)?node-id=242%3A37669&scaling=contain](https://www.figma.com/proto/YlupJ3MymklcEIBQxEPQma/MedGuide-Mockup---Caregivers-(NL)?node-id=242%3A37669&scaling=contain)

		Comment
Number of women	4	
Number of men		
Number of PwDs (primary)		End of the month interviews are planned, May 2018
Number of formal carers (nurse, home care personnel and similar) (secondary)	4	
Number of informal carers (spouse, friend, child and similar) (secondary)		End of the month interviews are planned, May 2018
Number of GPs and pharmacists (tertiary)		

3.1.3 Parts/functionalities/features of mock-up prototypes evaluated

The clickable mock-up with the scenarios were tested We asked the professionals what they think about each page/each function in the mock-up. The end-users were able to use the mock-up with less instructions and/or help.

3.1.4 Evaluation results

Key results summarised:

- Formal caregivers (nurses and welfare worker) say the system is easy to use. Using the mock-up is easier when you use a touchscreen instead using a laptop (with mouse). The mock-up looks nice and the chosen colours are good. For the professionals it was clear enough how to navigate through the system.
- The formal caregivers mentioned some "mistakes" in how information is presented. These "mistakes" can be found below.
- The formal caregivers think the system could be useful for them, because it contains a lot of information. Nevertheless, formal caregivers wonder if they will use all the options in practice and they have some remarks on the reliability of the self-reports. Also they are not sure if the sensor-data give enough information about the different subjects.
- The administrative burden of professionals is pretty high, so for formal caregivers it would be helpful if MedGUIDE can replace some other systems.
- The avatar is not clear: Why is she there? What do I use it for? (note: the introduction was missing in the mock-up).

Most important findings that support the concept and design:

1. Look and colours are nice.
2. Agenda option is good to have; everybody in the network should use the same agenda.
3. Message function is good to have (formal caregivers will not use the group chat).
4. The explanation video is good to have. The video has to explain the system (goal) and who use the system.
5. Medication management (overview of the month) is good to have. Makes it possible to recognize patters. Gives enough information in this way.
6. Overview of the medication is good to have, but in this way maybe not recognizable (use a common way of presenting the information). Now nurses check off the medication offline, maybe the overview can be used to check off the medication.
7. Client overview gives the most important information (medication/well-being).
8. Sleep; good to see patterns, so the month is more informative then a week. Maybe it is possible to add information about the quality of sleep.
9. It is easy to navigate through the system. Gives a lot information, but should be linked with other commonly used systems.

Most important findings of the mock-ups that need improvement:

1. Overview of clients; only show clients with particularities.
2. "Double Dose Call" the text depends on who is the user of the system.
3. Look at the sequence of the medication overview, time overview, etc. Use for example an alphabetic order in medication overview and start with morning medication. Sleep pattern start at 21:00 and end at 09:00 (for example).
4. Where can users find information about what every symbol means (add this).
5. Without an explanation, it is not clear what the avatar is and what you can use it for.
6. Physical discomfort and mood report; good to have information like this. Nevertheless, how do you measure this in case of dementia? Are PwDs going to fill out the questions? What is the best way of asking? Do not ask to fill it out daily.
7. Toilet: Will the door sensor provide enough information?
8. Mobility: add more information about duration, the increase of decrease, a trend line. It would be good to combine indoors and outdoors mobility.
9. Nutrition: might not provide detailed enough information, it would be good to also know what, how much, etc. somebody eats.
10. The workload in the care network (circle) is not directly clear.

3.2 Evaluation results from IVM

3.2.1 Partner ID

Partner name: IVM
Partner country: The Netherlands

3.2.2 Test sites and test population

Wireframe URL caregivers: [https://www.figma.com/proto/YlupJ3MymklcEIBQxEPQma/MedGuide-Mockup---Caregivers-\(NL\)?node-id=242%3A37669&scaling=contain](https://www.figma.com/proto/YlupJ3MymklcEIBQxEPQma/MedGuide-Mockup---Caregivers-(NL)?node-id=242%3A37669&scaling=contain)

		Comment
Number of women	2	
Number of men	3	
Number of PwDs	1	2 PwDs will be interviewd in May 2018
Number of formal carers (nurse, home care personnel and similar)	0	
Number of informal carers (spouse, friend, child and similar)	0	
Number of GPs and pharmacists (tertiary)	4	2 pharmacists, 2 GPs (1 pharmacist will be interviewd during end of May – beginning of June 2018)

3.2.3 Parts/functionalities/features of mock-up prototypes evaluated

All parts in the mock-up.

3.2.4 Evaluation results

Key results summarised:

Most important findings that support the concept and design

PwD

1. Avatar is useful.
2. Text size is good, text is readable.
3. Information on the medication is handy ("now I don't need my magnifying glass!").
4. Information about dementia is clear and handy.
5. Introduction video of MedGUIDE system is a good idea.

GP and pharmacist

1. Positive about the look and feel of MedGUIDE. Nice colours, quiet screens. Clear information.
2. The information about sleeping pattern, medication intake, mobility and mood is regarded as usefull, mainly the monthly overviews, which show a trend.
3. Good to have insight in all the informal and formal carers that are involved in the care of the PwD.
4. Usefull to be able to monitor on side effects of medication through self reports and sensors. The GP would like to do this according to a treatment plan.

5. Useful that you can vary the notifications per patient.
6. Good that you can see from whom the report comes.

Most important findings of the mock-ups that need improvement

PwD

1. Difficult words and concepts: orally ('oraal'), cognitive ('cognitieve'), annulate ('annuleren'),; sensor devices, beacons.
2. How do I start the video?
3. It says 'back', but I want to move a page further.
4. If you have dementia you are not interested in your blood pressure. The informal carer is maybe interested.
5. Balance ('balans') is the same as dizziness ('duizeligheid') according to the PwD.
6. The light blue letters of the avatar options are not readable for the PwD.
7. How do you know you took the right medication? The system only looks at the time of intake.
8. I miss a clock when the signal comes that you have to take your medication, so you can see what the actual time is.

GP and pharmacist

1. Information: The medication list should come from the pharmacist or GP-system and not be filled in by hand. Also the information about medication should be imported from existing information systems with high quality, like Apotheek.nl or the G-standard from the pharmacist organization KNMP (NL).
2. The information about start and stop data is tricky. It has to be retrieved from a reliable source and kept up to date at all times. If you cannot guarantee this, it's better not to give this information.
3. In the menu wellbeing ('welzijn') does not cover the items that are in this menu. Also the ranking of the items in this menu is not logical. A different order would be preferred.
4. Toilet visits are not interesting for the GP. (Is more useful for a patient in the hospital or for nursing professionals).
5. Self-reports: it is important to be able to limit the self-reporting and to limit the requests for self-reports. To avoid 'stalking'.
6. Its not clear what workload means exactly. Is this the workload the caregiver fills in himself? Or others? And is this the workload only for the care of Anna? Or the general workload of the caregiver. ('Then all caregivers have a very high workload'. 'Nice that I can adjust my own workload!')
7. It has to be defined who takes action when medication is not taken, or when other urgent signals occur.
8. For the pharmacists it is not clear what their role should be. They see themselves more as consultants, than as persons who will monitor the patients.
9. The GPs state that they will delegate most of the contacts to their nurse practitioner ('praktijk-ondersteuner' or 'POH'). They want to be able to see the communication between the caregivers, but do not want to participate actively through MedGUIDE, as they are afraid of too many questions.
10. Daily overview: It was not clear how to switch from day view to yesterday and tomorrow. They would also like to see a monthly overview.

3.3 Evaluation results from MAT

3.3.1 Partner ID

Partner name: MAT
Partner country: Cyprus

3.3.2 Test population

Wireframe URL caregivers:

[https://www.figma.com/proto/z0Fxlmk7MQ6zaUwpyLu6BR/MedGuide-Mockup---Caregivers-\(Cyprus\)?scaling=contain&node-id=242%3A37669&redirected=1](https://www.figma.com/proto/z0Fxlmk7MQ6zaUwpyLu6BR/MedGuide-Mockup---Caregivers-(Cyprus)?scaling=contain&node-id=242%3A37669&redirected=1)

Wireframe URL PwDs:

[https://www.figma.com/proto/36SluBykaqpVik1IT0Q3x2/MedGuide-Mockup---Senior-\(Cyprus\)?scaling=contain&node-id=168%3A7767&redirected=1](https://www.figma.com/proto/36SluBykaqpVik1IT0Q3x2/MedGuide-Mockup---Senior-(Cyprus)?scaling=contain&node-id=168%3A7767&redirected=1)

		Comment
Number of women	10	
Number of men	4	
Number of PwDs (primary)	8	
Number of formal carers (nurse, home care personnel and similar) (secondary)	4	Home care nurses and personnel
Number of informal carers (spouse, friend, child and similar) (secondary)	2	Children of PwDs
Number of GPs and pharmacists (tertiary)	0	

3.3.3 Parts/functionalities/features of mock-up prototypes evaluated

All functionalities/features were evaluated during the evaluation sessions. The protocol, developed by the consortium, was followed. The functionalities that were discussed with the participants more thoroughly than others, were those that participants struggled with or wanted them differently. This was necessary so as to explore the way these functionalities/features should be improved in order to meet the participants' needs. However, these features differ from case to case.

3.3.4 Evaluation results

Key results summarised

Mainly the primary end-users (PwDs) as well as the secondary users (family caregivers, informal and formal caregivers who provide home nursing services) stated that it is an easy-to-use system. The main concern expressed unanimously was the cost of such system which can be a barrier for purchasing it when it will be available in the market. However, the system will help in the improved coordination of the tasks of the caregivers and their in-between communication will also be enhanced. Moreover, the clear and well-structured design of the system as well as the avatar will help caregivers to pay attention when needed to the important aspects of a patient's care and act immediately. Besides that, the MedGUIDE system enables the formal caregivers to closely monitor their patients even when they are not present, and at the same time gain the most vital and necessary information so as to provide better quality care to their patients.

Moreover, the PwDs were able to find the requested information easily with, in most cases, limited help from the researcher, even when the participants had no or limited knowledge on technology, hence no familiarity with tablets/pc and such systems. The main difficulty that PwDs dealt with was with recognising the difference between two different buttons; thus visual aids, such as different colours, might help them in these aspects.

Most of the PwDs were not very comfortable with the word 'dementia' used, even though they may recognise that they forget and have memory issues; therefore, it can be more attractive for them to use the e-learning platform and read more information about their condition if the word 'dementia' was replaced with a non-official/ diagnosis term, such as forgetfulness or memory issues. However, the main advantage of the system, according to the PwDs, is the reminder functions (of medication and appointments). The PwDs also expressed that sharing how they feel (either in terms of mood or in terms of physical discomfort) with their caregivers important as well as the information accessible to them about their medication.

Most important findings that support the concept and design

1. Simple main menu and easy to find information. However, PwDs had difficulty in transferring from 'my medication' to main menu, the participants could not recognise the arrow and could not understand its function. A suggestion would be to add a 'back' button because it's easily recognisable.
2. Medication reminder was indicated as the most useful function of the system. The only information missing indicated by few PwDs was if the medication should be taken with full stomach or before their meal. The dosage of the medication (in mg or ml in case it is liquid) was indicated as missing information on behalf of professional caregivers.
3. Some participants had difficulty to see the button 'TAKE MY MEDICATION' maybe a different colour to make it more discrete. All other information presented were clear and simple to understand.
4. Mood and physical reports were easy to find and participants liked the images used. It was recommended though after choosing 'fill in a self-report' to be transferred immediately to the options of the report. Another difficulty was to understand 'SAVE' button, it would be better to be replaced with 'SEND'. Also different colours of 'SAVE' and 'CANCEL' buttons will help PwDs in distinguishing the two buttons.
5. Introductory video should include a step by step guidance on how to use the system.
6. Baseline information used in graphs is confusing on what this information represents. Also the use of darker or more discrete colours for letters in graphs.
7. It would be more helpful to see first the medication planning and then the information about the medication (if needed to click on them).

Most important findings of the mock-ups that need improvement

1. The only concern of the participants (PwDs and caregivers) was the cost of the MedGUIDE system when it will be available on the market. Other than that all functions included are useful and it is very simple to use even for people with little or no knowledge and experience with technology.
2. Lisa's messages (avatar messages) pointing out the aspects that caregivers need to pay attention to are vital.
3. Requests for reports to notify PwDs with sound in order to notice it and it would be good if the system was running in the background otherwise the PwD may not remember to open the system in order to get the notifications and requests.

4. The system helps in organising the tasks more efficiently and supports/helps a more effective way of cooperation of the caregivers' network. Important to include the type of relationship (e.g. daughter, doctor etc.) of each person included in the network.
5. Helps in comprehend the status of clients at a glance. It would be good if we can also include water intake and sugar levels, since that is important information to be included and closely monitored as well.
6. Ability to report the level of pain (in physical discomfort) that the PwD feels and in which body part the PwD experiences pain.

3.4 Evaluation results from KARDE

3.4.1 Partner ID

Partner name: Karde AS

Partner country: Norway

3.4.2 Test population

Wireframe URL Caregivers:

[https://www.figma.com/proto/fpHdxfrPV7u1uqAsgxAKh2/MedGuide-Mockup---Caregivers-\(Norway\)?scaling=contain&node-id=242%3A23535&redirected=1](https://www.figma.com/proto/fpHdxfrPV7u1uqAsgxAKh2/MedGuide-Mockup---Caregivers-(Norway)?scaling=contain&node-id=242%3A23535&redirected=1)

Wireframe URL PwDs:

[https://www.figma.com/proto/J3U2SkdaVKde0mBXs9sabm/MedGuide-Mockup---Senior-\(Norway\)?scaling=contain&node-id=168%3A7767&redirected=1](https://www.figma.com/proto/J3U2SkdaVKde0mBXs9sabm/MedGuide-Mockup---Senior-(Norway)?scaling=contain&node-id=168%3A7767&redirected=1)

		Comment
Number of women	5	
Number of men	1	
Number of PwDs (primary)	2	
Number of formal carers (nurse, home care personnel and similar) (secondary)	2	
Number of informal carers (spouse, friend, child and similar) (secondary)	2	
Number of GPs and pharmacists	0	

3.4.3 Parts/functionalities/features of mock-up prototypes evaluated

For PwD, we didn't have time to cover everything, self-reporting is missing.

For informal and formal carers all parts of the mock-up were tested.

3.4.4 Evaluation results

Key results summarised:

Most important finding that support the concept and design:

PwD

1. Easy to read
2. Liked the overview of medicines
3. Also liked the presentations of dementia
4. Liked the idea of videos
5. Navigation worked ok, but needed some guidance
6. Mostly positive to everything.

Informal carers

1. Easy and clear user interface
2. Easy to understand the graphic for e.g. medicine intake

Formal carers

A general comment about medication, which is not so directly related to the mock-up, is that in Norway there is one central automated service which packs the different medicines in the sachets for the whole country. This central does not pack medicines which is known not to work well together.

1. Nice design. Intuitively easy to understand.
2. Medication simple view. Likes the pictures. However, what if the PwD gets a copy medicine instead? And most pills are white.
3. Medication details read only tab 2. Excellent. Not only professional nurses who give medicines. Very useful for those who are not experts.
4. Likes the presentation of the care network with images of the persons. However, it could be hard to maintain the formal network because a PwD is served by very many persons, especially in large municipalities.

Most important findings of the mock-ups that need improvement:

PwD

1. The avatar was a concept which was difficult to understand. "What is girl doing there?" But the girl was accepted after explanation.

Informal carers

1. The help function could have been better. How do you give notice to the Avatar?
2. All the lists of events should be sorted from morning (at the top) to evening (bottom). OK to sort days with the recent ones first.
3. Dashboard today. Difficult to understand that clicking on the small v behind the bold day's status gives other dates. The legends should be center justified, not left justified (this also the case for other screens). Is the position of the green markers to the right (wake up) and left (lunch) in the white fields intentional? If so, what is the intention.
4. Intake history week. With red X, what medicine caused the red cross? All or one? A notification should be given to the carer.
5. Monthly views. Vertical lines will make it easier to match registrations and dates.
6. Sleeping pattern month, eating pattern month, outdoor activity month. Normal value should be indicated by a band.
7. Mood overview month. Just dots and vertical lines. Do not connect the dots.
8. Mood overview month popup. Who's report is this?
9. Discomfort add. The band-aid is not a good symbol.
10. In Norwegian, all name of months are written with small letters without a capital first letter, not Mai, but mai.

Formal carers

11. A first impression is that the system is too comprehensive. Too many details. Professional carers do not have time to look at everything. A more compact one-page summary is recommended.
12. Medication is not a task for informal caregiver. Very strongly stated.
13. Same comment as from the informal carers: All the lists of events should be sorted from morning (at the top) to evening (bottom). OK to sort days with the recent ones first.
14. A two-hour interval is a too long time slot for medicine intake. Not so much a comment about the mockup, but more a point for the critical timeliness in medication.
15. Intake history month. The red dots signal that medicine is not dispensed. In such situations, if the PWD does not take critical medicine (some medicines are more critical than others), the home service will intervene to secure that the medicine is actually taken. The monthly intake history therefore is not logic. By e.g. clicking the red dots, the caregiver should be able to get more information about the event.
16. Medication details add dialogue. Informal carers cannot do this. Must be done by professionals. Not good with double registrations. That is error prone. The system should be integrated with the medical record system, this system holds the truth. Furthermore, the major error source for wrong medication, is that nurses puts wrong medicine in the sachets. Therefore, this is a central automatic service in Norway.
17. Sleeping pattern week. Does the Data protectorate approve this registration due to privacy? How is normal value derived? May have value for medication, e.g. for sleeping medicine.
18. Eating pattern week. Little information to give time for opening of refrigerator. It would be better to know if the refrigerator was not opened the last 12 hours, than it was opened 20 times.
19. Eating pattern month. If the PwD has eaten 0 or 1 time a day, what happened. Did someone intervene?
20. Indoor activity week. Difficult to illustrate mobility. Some PwDs are very restless, they are moving all the time. We have no good answer how it should be illustrated.
21. Indoor activity month. Normal value, how is that set. Very dependent on age.
22. Physical discomfort week. The diagnoses may be a result of the PwD getting sick, not necessarily a side effect of medication.

3.5 Evaluation results: conclusions

The main conclusion from the reports is that the application is easy to use, informative and useful. Also, the design seems to appeal to the end-users.

The evaluations have also resulted in a wide spectre of comments that report minor issues, the majority of which are feasible to take care of in the development of the real software prototype for the trials in the homes of the end-users.

Special care must be taken when the design and functionality of everything connected to the medication regime is concerned. Here, potential risks connected to the usage of the MedGUIDE solution must be carefully analysed. Is the solution reliable? Do end-users understand what to do, especially the PWDs? Can we create a false feeling of safety? Can false alarms be created?

In the next phase of the project, these aspects will be analysed in depth and prioritised for implementation. In Chapter 5, some overall conclusions are to be found.

4 Protocol and data protection

The purpose of the protocol was to guide the end-user participants of the MedGUIDE project to conduct pilots of the second mock-up of the project and to advise the researchers.

The inclusion/exclusion criteria and informed consent were also part of this protocol.

4.1 Framework

In the following chapters, the protocol material is presented in detail.

4.1.1 GDPR

General guidelines are available in D5.0 (Code of Conduct) and the “MedGUIDE protocol for sharing and storing privacy-sensitive project data”. This section focuses on the General Data Protection Regulation (GDPR). GDPR is a legal framework in EU and associated countries that sets guidelines for the collection and processing of personal information of individuals, including the principles for data management and the rights of the individual person. This is new legislation, which starts in 2018.

All partners who conduct end-user studies in the MedGUIDE project must elicit necessary material and references concerning scientific work that is affected by the new regulations. This is highly relevant for the MedGUIDE project as the information gathered is about vulnerable individuals. There should not be any discussions afterwards of whether the GDPR was fully understood and respected in the project, including possible implications.

This is the sole responsibility of each end-user partner alone and cannot be claimed to be a collective responsibility or another partner's responsibility.

In the appendices, inputs to end-user information is drafted. This information must be translated and adapted to local use.

All partners in the project were asked to send a confirmation to the project coordinator and the Ethics Manager that the GDPR is read, understood, and respected in all end-user studies and corresponding data collection in the project, before the start of the second pilot.

4.1.2 Information and language

Information of the project for recruitment purposes can be provided according to the documentation (protocol) from the first pilot and recent inputs via the project's e-mail group.

All information must be presented to end-users in native *everyday* language and according to the project's overall goal. This includes project information, consent schema, and the mock-up itself.

Not repeated here. All partners have this material already.

4.1.3 Informed consent

All informants should sign an informed consent regardless of status (carer, PwD), based on given information. The material is also provided in the protocol and connected documentation for the first pilot.

Not repeated here. All partners have this material already.

4.1.4 Eligibility and exclusion criteria

Inclusion criteria

Caregiver + PwD dyads (pairs), where:

Caregiver:

- Adequate knowledge of the PwD.
- Frequent caring tasks (daily, weekly).
- Formal or informal (e.g. family, nurse, home care provider).

PwD:

- 60 years or older (exceptions acceptable).
- PwDs with memory problems, or PwDs with Mild or moderate dementia; dementia on levels 2-4 on Reisberg's scale – possible for informal caregivers to assess, i.e. not necessary to conduct MMSE or the like (Norway could not because of rules for privacy of health information in software development projects).
- Willing and able to participate and able to sign informed consent.

The stages 2-4 on Reisberg's scale are:

- 2 Very mild cognitive decline (Age Associated Memory Impairment)
- 3 Mild cognitive decline (Mild Cognitive Impairment)
- 4 Moderate cognitive decline (Mild Dementia)

The Global Deterioration Scale (GDS), developed by Dr. Barry Reisberg, provides caregivers an overview of the stages of cognitive function for those suffering from a primary degenerative dementia such as Alzheimer's disease⁶.

This scale is useful in the recruitment process thus *do not have to require information of a diagnosis* e.g. according to the MMSE scale, and will be able to explain the criteria to caregivers.

4.1.5 Methodology

The clickable mock-up replaces the foreseen method of end-user involvement (Wizard-of-Oz) as the prototype functions autonomously already (cf. Task 3.2).

Each researcher or test leader: **test the clickable mock-up yourself first. Walk through all parts and memorise it.**

The methodology of the second pilot is to involve end-users in discussions and evaluations of the provided mock-up in either personal interviews or small focus groups (sessions). The main rule should be that the PwD should have a personal helper (formal or informal caregiver) during the sessions.

In addition to the general introduction regarding what we keep developing in the project, and what the intended product/service is, it must be explained, in a suitable and appropriate way, that:

- We are not testing the end-user or her/his competency, but the product that is under development.
- The end-user cannot do anything wrong or harmful.
- "Stupid questions" and incorrect answers to our questions do not exist. Everything is relevant.
- They can interrupt or leave the session for any reason in they feel so.
- We are very interested in all inputs for improvement, so therefore, any critique is welcome.

⁶ Access point: <https://www.fhca.org/members/qi/clinadmin/global.pdf>

4.2 Interview set-up

The interview goal is to evaluate the user experience as well as the usability of the platform. Therefore both observation and a semi-structured interview will be used. In the next section we present the questions that will be used during the evaluation of the prototype.

Use the Think aloud method for the clickable mock-up. Ask questions such as: Tell me where would you start? (show me please). What do you think about ...? Is everything there what you would expect?

The mock-up for the informal and formal caregivers consists of 7 main functionalities to be evaluated. The protocol is set-up in order to guide the users through each functionality using scenarios.

The main functionalities are:

- Dashboard providing a day to day overview
- Medication intake history, providing information on the adherence
- Medication plan providing the medication that the PwD is taking
- Wellbeing provides insight into the tracked sensors as well as the self-report
- Calendar supporting the collaboration within the network
- Messages supporting the collaboration within the network
- Care network providing insight into the members of the network

The mock-up for the PwD consists of only five main functionalities to be evaluated. The protocol is set-up in order to guide the users through each functionality using scenarios.

- Notifications including
 - o medication reminder
 - o appointment reminders
 - o asking for self reports (by the system or caregivers)
- Mood reporting
- Discomfort reporting
- My medical overview providing overview of medication that needs to be taken
- About dementia providing e-learning platform

The detailed description of the scenarios and questions that were used during the evaluation of the mock-up can be found in the Appendix. The scenarios present the previously provided functionalities in the right context.

4.3 Executing and reporting the interviews

A collection of "questionnaire sheets" will be shared amongst partners to share the results of each session. Make clear notes of which "screen" or functionality is in question.

Afterwards, especially if no audio or video recording was made, transcribe your findings as quickly after the session as possible, whilst you still remember what was said and meant, but not written.

It is very important that the end-users' comments or inputs are qualitatively secured to provide us with meaningful input that can be implemented in the app. This means that detail must be elicited. Example: PwD: "This should be clearer." Researcher: "How could we make this clearer?" In other words, ask additional questions to **provide the design team with feedback that they in fact, concretely, can use to improve the design.** This is the whole purpose of the sessions.

4.4 Time constraints

The end-user sessions should not be exhausting. This is particularly important for the PwD. Their sessions should not exceed 1 hour, including introduction and necessary breaks. Keep in mind how the PwD is doing, if needed split the 1 hour session in two, and provide a longer break.

The sessions for the caregiver should not exceed 2 hours, including introduction and necessary breaks.

If a session must end (cf. hours above) before all planned themes and "screens" have been walked through together with specific end-users, make sure that the themes and/or "screens" can be evaluated by other end-users in the remaining sessions.

4.5 Audio and video recordings

Ask for the permission to audio or video record the sessions. The consent must include this choice and the information must explain why the recording is made, not given to anybody else than the researcher team, and that these will be deleted immediately after the transcription of findings. No audio or video material must be "floating around" unless informed consent is given, and the uses of the audio/video material is explicitly agreed upon.

4.6 Data storage

All data storage and data analysis must be made anonymous and respect the agreed methods of data storage to avoid unintended data transmission to third countries, for example in connection with back-up services or cloud-based database services. The MedGUIDE project has a dedicated policy concerning this ("MedGUIDE protocol for sharing and storing privacy-sensitive project data").

5 Conclusions

Overall, the results show that we are on the right track concerning the design of functionalities and the user experience.

The four partners' evaluation results in Chapters 3.1 – 3.4 show that the interaction design will only need some basic improvements, many of which will follow when we move to a real software prototype.

One example is navigation. In a real environment, a coherent navigation with sufficient alternatives (e.g. back, home etc.) will be part of the user interface "template" that is generic for most views. Also, the language and expressions will be carefully crafted to communicate well vis-à-vis the end-users, when the real software prototype is created for trial use in each country. Finally, the visualisations of self-reporting results as well as the sensor data trends will be designed to display the contents more gracefully.

There are also some major issues that should be solved before the final solution is presented to end-users. Three of these are: options, integration, and patient safety.

Options in our software solution would mean to allow the end-users to choose for example how the timelines are organised (oldest to newest events, or the other way around), whether to display the avatar or not, choose which main functionalities or which content they wish or are able to see and use, etc. A person with beginning dementia may benefit from the e-learning part, whilst one with more severe dementia would not.

Integration would mean to create functional "bridges" to other systems that are used for and around the PwD. One example is the calendar and messaging functionality. Many caregivers are already using calendars, both for themselves (e.g. G-mail) and for those they are caring for (e.g. dedicated reminding technologies for people with dementia; day and night calendars etc.). They might not want to add one more calendar in the daily portfolio of calendars. Also, integration between medicine dispensers and the MedGUIDE system should be seamless and secure.

Patient safety is about the descriptions of the medicines (names, photos, and use), and prompts to report medicine intake. Anything about medicines is the business of professional caregivers (pharmacists and GPs, and should not be described or monitored by laymen. Also, to count on the PwDs' self-reports may introduce real health risk as they may forget the intake facts, or simply not want to take the medicine, but tell the system "the truth with modifications".

The next steps in the project include prioritising the findings and choosing the most important ones for implementation in the prototype for the real trial.

6 Appendix

6.1 Mock-up and tasks

Main "angles" into the mock-up analyses should be arranged per theme, such as 'About dementia', 'Messages', 'Care network', 'Today's update', etc.

For both groups, first introduce the application. To ease the evaluation especially for the PwD, it may be useful to print a small "poster" of the theme that is under evaluation and keep it visible during the session, so that the end-user knows where she/he is in the thematic structure of the app. For example, when the PwD looks at the "screens" under the theme 'My medical overview', keep this text and the icon of this menu choice displayed on an A4 sheet. Change the sheet when the theme changes. Alternatively use other methods, such as projection of the theme on a canvas, or just write the theme on a white board.

PwD: Because not all functionalities are working, introduce the app by letting the end-user walk through the scenarios. Introduce the app by letting the end-users walk (navigate) through a small number of "screens" in the app using the scenarios. This will give the participant a general impression of the app.

Introductory video

My medical overview

About dementia

Contact

Caregiver: For the caregiver, we have also prepared scenarios through which the caregiver will walk-throughs of the following themes, and conduct the session by letting the end-user navigate through the "screens" under each of the three themes below. Help the end-user if she/he "gets stuck". The items to be evaluated are highlighted in the scenarios.

When the final clickable mock-up is ready for the evaluation sessions, you might want to collate a memory sheet for yourself covering thumbnail images of all "screens" under each theme.

Introduce the app by walking (navigating) through a small number of "screens" in the app, to give the participant a general impression of the app.

For the caregiver, use the scenarios/thematic walk-throughs of the following themes, and conduct the session by letting the end-user to navigate through the "screens" under each of the three themes below. Help the end-user if she/he "gets stuck".

Introductory video

Dashboard

Medication intake history

Medication plan

Wellbeing including sensors and self-reporting (PwD)

Calendar

Messages

Care network

When the final clickable mock-up is ready for the evaluation sessions, you might want to collate a memory sheet for yourself covering thumbnail images of all "screens" under each theme.

6.2 Interview set-up for PwDs

6.2.1 Introduction

Explain the goal of the project, and the goal of MedGUIDE. What will it do for the user and how will it help.

Ice-breaker: PwD

We would like to start by getting to know you.

- Can you tell me your age?
- What are your hobbies, and activities you find important in life?
- Do you take medication on a daily basis?
- Do you ever struggle taking your medication on time?
- Do you use any technology? If yes, what kind of technology do you use? (mobile phone / tablet / computer / laptop / television / radio/ other)
- Do you have access to internet?

Introduction: Mock-up

As previously mentioned we are developing a mock-up, and we would like to receive your input. The design you will evaluate is work in progress. Note, you are looking at images it is not an actual app, and therefore functions will not be working. It is not yet a finished prototype, and we are looking for feedback in order to improve it. During the test, do not forget there are no wrong answers, you are the expert of your own experience.

In front of you, you can see the prototype as introduced previously. We would like to ask you to test the prototype by going through the different functions you can find. Don't worry, if you get stuck or need help, we are here to support you. If you get stuck- it is not your fault, it's a prototype you can get stuck.

For the mock-up we have created, we have provided names for you and your loved ones. In the mock-up you will be Anna the Long and your children's names are Johnny and Eva.

Scenario 1: Introduction and home screen (PwD)

A home care professional introduced you to MedGUIDE, she has explained that she would like you and your loved one to use it. MedGUIDE will support you in your health and medication management. It will help you and your loved one to get better insight into how you are doing. The first time you open MedGUIDE, you will get an introduction by Lisa the virtual assistant.

- View the introduction, note the video is not working yet.
- Finish the introduction.

Questions:

- What is your first impression?
- What do you think of the look and feel / visual clarity?
- What should the introductory video contain?
- What do you think of the information presented?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?

- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 2: My medication

Yesterday you were at the general practitioner and he prescribed you a new medication called 'Olanzapine'. He says it will help to decrease tics you've been suffering from lately. The home care professional has added this medication to your medication-list in MedGUIDE. You are curious to know more about the medication and possible side effects.

- Look up information on the medication 'Olanzapine'.

Questions:

- What is your first impression?
- What did you think about the medication overview?
- What do you think of the information presented? Is it enough? Do you miss anything?
- Was it easy for you to find the information about the medication?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3a: Medication reminder

Task researcher: Go back to the home page, and click on "For prototyping click here to trigger notifications". Click on " Medication notification, with/without pillbox".

You've just had dinner and now you're watching TV. Suddenly, you get a message from MedGUIDE you see/hear the message. You view the message where MedGUIDE tells you it's time for your medication.

- Take a look at the message

Questions:

- What is your first impression?
- What do you think of the way you are reminded of your medication?
- Was it easy for you to indicate that you've taken your medication?
- What do you think of the information presented? Was it enough? Did you miss anything?
- Do you think the reminder can help you in your medication management?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3b: Mood report

Task researcher: Go back to the home page, and click on "For prototyping click here to trigger notifications". Click on "Mood report by caregiver".

Johnny, your son, is wondering how you're doing now that you have received new medication. The home care nurse told him you could feel a little more down because of the new medication. He asks you to fill in a mood report via MedGUIDE. You decide to share how you are feeling using MedGUIDE.

- Let Johnny know how you're feeling today.

Questions:

- What is your first impression?
- Was it easy for you to report your mood?
- What did you think about the different report options (not so good, okay, good)? Were there enough? Would you like more? If so, what kind?
- Do you think you would share how you are feeling with your caregivers using MedGUIDE?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3c: Reminder for a walk

Task researcher: Go back to the home page, and click on "For prototyping click here to trigger notifications". Click on "Upcoming appointment notification".

It's a nice and sunny Sunday morning. You've just taken your morning medication, ate breakfast and you're just about to pour yourself another cup of coffee, when you get a notification from MedGUIDE. MedGUIDE is reminding you, that you will go for a walk with Johnny and Eva today. You are looking forward to it.

- Take a look at the message.

Questions:

- What is your first impression?
- Was it clear enough?
- What do you think of the information presented? Is it enough? Did you miss anything?
- What do you think of this type of reminder of appointments made? These appointments could be social appointments but also doctors appointments coming up that day.

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 4: Physical discomfort

The GP said it would be good to keep an eye out for the effects and side-effects of your new medication (Olanzapine). You think the medication is giving you stomach pain, just like the possible side effects indicated. You want to let your caregivers know about this.

- Fill in a physical discomfort report and let your caregivers know that you experience pain.

Questions:

- What is your first impression?
- Was it easy to fill in the report?
- What do you think of the information presented? We're there enough options?
- Did you miss anything? Would you expect to do anything else?
- Do you think you would share how you are feeling with your GP using MedGUIDE?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 5: Learn about dementia

You have been talking with you GP about dementia. He suggested if you would like to know more about it, to check out what information MedGUIDE can share with you. The MedGUIDE App offers you to learn about different aspects that go along with dementia like how to stay fit and healthy. You are curious to read more.

- Look up information about severe dementia.
- Click to watch the video about severe dementia.

Questions:

- What is your first impression?
- Do you think you would like to use the information shared via MedGUIDE about dementia, technology and health?
- What do you think of the information presented? Was it clear enough?
- What do you think of the idea of the video presenting information on a specific subject?
- Did you miss anything? Would you expect to do anything else?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Evaluation questions

- Is the prototype easy to understand and read?
- What do you think of the avatar? Do you think it could help you/ guide you?
- Do you think the app is easy to use?
- Is there something that should absolutely be changed to improve the general impression, understandability, or appearance? In that case, what?

- Is there something that should be improved in MedGUIDE? In that case, what and why?
- Would you personally use this system/service/app if it was commercially available? Why, or why maybe not?

6.3 Interview set-up for informal caregivers

Ice breaker Informal

We would like to start of by getting to know you.

Can you tell me your age?

What is your relationship with the PwD?

What kind of care and support do you provide him/her?

Do you ever worry about him/her?

How do you try to keep track of his/her wellbeing and medication intake?

Do you use any technology? If yes, what kind of technology do you use? (Mobile phone / tablet / computer / laptop / television / radio / other)

Do you have access to internet?

Introduction mock-up

As previously mentioned we are developing a mock-up, and we would like to receive your input. The design you will evaluate is work in progress. Note, you are looking at images it is not an actual app, and therefore functions will not be working. It is not yet a finished prototype, and we are looking for feedback in order to improve it. During the test, do not forget there are no wrong answers, you are the expert of your own experience.

In front of you, you can see the prototype as introduced previously. We would like to ask you to test the prototype by going through the different functions you can find. Don't worry, if you get stuck or need help, we are here to support you. If you get stuck- it is not your fault, it's a prototype you can get stuck.

For the mock-up we have created, we have provided names for you and your loved ones. In the mock-up you will be Johnny de Long and you are caring for your mother Anna the Long.

Scenario 1: Home screen and introduction video (informal)

A home care professional introduced you to MedGUIDE. She has explained that she would like you and your loved one to use it, in order to track the medication use, and wellbeing of your loved one. It will help you get better insight into how your loved one is doing. The first time you open MedGUIDE, an introduction video will be shown.

- View the introduction, note the video is not working yet.
- Move on to the dashboard.

Questions:

What is your first impression?

What do you think of the look and feel/visual clarity?

What should the introductory video contain?

What do you think of the Dashboard and the information presented?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 2a: Medication management

After the introduction you can start by exploring MedGUIDE. In the dashboard you can see the update of today's medication. You can see if your loved one has taken his/her medication. You are interested to see the medication intake for today, but also for the last month.

- Check the medication intake for today and last month.

Questions:

How would you assess the intake of the last two days?

Do you think Anna's adherence is decreasing the last two weeks?

What do you think of the medication intake overview? Will this provide the needed information? Or do you want to see more or less details?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 2b: Medication plan

You can also find out what medication your loved one is taking and read more information. The information about the medication is provided by MedGUIDE is provided by the professional or the pharmacist. Your loved one has started taking new medication Olanzapine, and you would like to know what the medication does, and how often he/she should take it.

- Check the medication plan, and find out what Olanzapine does, and how often it should be taken.

Questions:

On which days and which moments should Olanzapine be taken?

What are the possible side effects of the medication?

Would you like to read more or less details about the medication taken by your loved one?

What do you think of the medication plan, will this help you in supporting your loved one?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3a: Tracking the wellbeing of your loved one:

On some days you are worried how your loved one is doing. Within MedGUIDE you are now using sensors that will help you get insight into the daily living and sleeping pattern of your loved one. You would like to know if there have been any changes lately.

- Check the Wellbeing sleeping pattern of your loved one (Anna) of the last few days
- You want to better understand how to interpret the sleeping pattern, click on the avatar/face to get more information.
- Explore other wellbeing patterns you would be interested in?

Questions:

Do you see any changes in the sleeping pattern in the last few days?

What do you think of the information provided for the sleeping pattern?

What do you think of the overall wellbeing patterns you can view? Do you think it is too much or too little information?

Do you think the wellbeing patterns will help you get better insight into how your loved one is doing?

Are there any aspects that are not clear or difficult to understand?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3b: Tracking the wellbeing of the PwD

Next to the sensors you can also track and share how your loved one is doing. You can see on a daily and weekly basis how he/she is feeling. You can also see if your loved one has reported any discomfort in the last few days. These reports can give you a better understanding on how your loved one is doing. You would like to ask Anna to share how she is feeling.

- Check the mood changes of your loved one for the last week. Ask Anna to share how she is feeling, by requesting a mood report.
- Check if your loved one (Anna) has reported any discomfort. Add a report on the physical discomfort of your loved one (Anna).

Questions:

Do you see any changes in the mood in the last week?

Did your loved one report any dizziness today or yesterday?

What do you think of the reported information on the mood?

What do you think of the possibility to ask Anna for a mood report?

What do you think of the reported information on the physical discomfort?

What do you think of the idea of reporting how Anna is feeling today?

Observation:

- Did the user experience any difficulties when navigating?

- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 4: Collaboration in the care network

With all members who are caring for your loved one you share the MedGUIDE Calendar, messages and network map. This will give you an update of the newest appointments coming up, but also the last messages provided by other caregivers.

- Add an appointment to the group agenda
- Check if there are any messages sent today

Questions:

What do you think of the agenda?

What do you think of the way to add an appointment?

Do you think an agenda can be useful to share within your care network? Why?

What do you think of the group messages?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario4b: View care network members

Check the last appointment made, and see if there are any new messages. To get a good overview of the care network and see how everyone is doing, you can view the network, and view their roles.

- Check what Johnny de Long role is, and how he is experiencing his care load.

Questions:

What do you think of the overview of the network?

What do you think of the information provided on the network members?

Would you be interested to know how others are experiencing the care load in the network?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Evaluation questions:

- Is the prototype easy to understand and read?
- What do you think of the avatar? Do you think it could help you/ guide you?
- Do you think the app is easy to use?
- Is there something that should absolutely be changed to improve the general impression, understandability, or appearance? In that case, what?

- Is there something that should be improved in MedGUIDE? In that case, what and why?
- Would you personally use this system/service/app if it was commercially available? Why, or why maybe not?

6.4 Interview set-up for formal caregivers

Ice-breaker formal caregiver

We would like to start by getting to know you.

Can you tell me what your role is within the organisation? Can you shortly describe what you do?

What kind of care do you provide to PwD?

How do you keep track how the PwD is doing?

Do you use any technology? If yes, what kind of technology do you use? (Mobile phone / tablet / computer / laptop / television / radio / other)

Do you have access to internet?

Introduction mock-up

As previously mentioned we are developing a mock-up, and we would like to receive your input. The design you will evaluate is work in progress. Note, you are looking at images it is not an actual app, and therefore functions will not be working. It is not yet a finished prototype, and we are looking for feedback in order to improve it. During the test, do not forget there are no wrong answers, you are the expert of your own experience.

In front of you, you can see the prototype as introduced previously. We would like to ask you to test the prototype by going through the different functions you can find. Don't worry, if you get stuck or need help, we are here to support you. If you get stuck- it is not your fault, it's a prototype you can get stuck.

For the mock-up we have created, we have provided names for you and your loved ones. In the mock-up you will be Johnny de Long and you are caring for your mother Anna the Long.

Scenario 1: Introduction video and overview clients

Within your organization you have started to use MedGUIDE in order to better track the wellbeing of your clients. MedGUIDE will help you get insight into the medication management such as adherence, as well as the daily live pattern of the clients. The first time you open MedGUIDE, an introduction video will be shown. After that you will view an overview of all clients, and the latest updates of these clients. You are interested to see more information about Anna de Long.

- View the introduction, note the video is not working yet.
- View the overview of clients, and visit the personal page of Anna de Long

Questions:

What is your first impression?

What do you think of the look and feel/visual clarity?

What should the introductory video contain?

What do you think of the overview of the clients, do you think this will provide you enough insight to know which client to go in detail?

What do you think of the Dashboard and the information presented?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 2a: Medication management

After the introduction you can start by exploring MedGUIDE. In the dashboard you can see the update of today's medication. You can see if your loved one has taken his/her medication. You are interested to see the medication intake for today, but also for the last month.

- Check the medication intake for today and last month.

Questions:

How would you assess the intake of the last two days?

Do you think Anna's adherence is decreasing the last two weeks?

What do you think of the medication intake overview? Will this provide the needed information? Or do you want to see more or less details?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 2b: Medication plan

You can also find out what medication the client is taking and read more information. The information about the medication is provided by MedGUIDE is provided by either the professional or the pharmacist. The client has started taking new medication Olanzapine, and you would like to know what the medication does, and how often he/she should take it.

- Check the medication plan, and find more information on Olanzapine, and how often it should be taken by the client.

Questions:

On which days and which moments should Olanzapine be taken?

What are the possible side effects of the medication?

Would you like to read more or less details about the medication taken by the client?

What do you think of the medication plan, will this help you in providing the needed care?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3a: Tracking the wellbeing of the client

MedGUIDE can provide insight into any changes on the wellbeing of the client. By using sensors you will get insight into the daily live such as for example sleeping pattern of the client. Any changes in for example the sleeping pattern or eating pattern will be presented. Before visiting the client Anna, you would like to know if there have been any changes lately.

- Check the Wellbeing sleeping pattern of the client (Anna) of the last few days
- You want to better understand how to interpret the sleeping pattern, click on the avatar/face to get more information.
- Explore other wellbeing patterns you would be interested in

Questions:

Do you see any changes in the sleeping pattern in the last few days?

What do you think of the information provided for the sleeping pattern?

What do you think of the overall wellbeing patterns you can view? Do you think it is too much or too little information?

Do you think the wellbeing patterns will help you get better insight into how the client is doing?

Are there any aspects that are not clear or difficult to understand?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 3b: Tracking the wellbeing of the PwD

Next to the sensors you can also track and share how the client is feeling. You can see on a daily and weekly basis the mood changes of the client. You can also see if the client has reported any discomfort in the last few days. These reports can give you a better understanding on how the client is doing. You would like to ask Anna to share how she is feeling.

- Check the mood changes of the client for the last week. Ask Anna to share how she is feeling, by requesting a mood report.
- Check if the client (Anna) has reported any discomfort. Add a report on the physical discomfort of the client (Anna).

Questions:

Do you see any changes in the mood in the last week?

Did the client report any dizziness today or yesterday?

What do you think of the reported information on the mood?

What do you think of the possibility to ask the client/Anna for a mood report?

What do you think of the reported information on the physical discomfort?

What do you think of the idea of reporting how Anna is feeling today?

Observation:

- Did the user experience any difficulties when navigating?

- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 4: Collaboration in the care network

With all members who are caring for the client you share the MedGUIDE Calendar, messages and network map. This will give you an update of the newest appointments coming up, but also the last messages provided by other informal and formal caregivers.

- Add an appointment to the group agenda
- Check if there are any messages sent today

Questions:

What do you think of the agenda?

What do you think of the way to add an appointment?

Do you think an agenda can be useful to share within the network of the client? Why?

What do you think of the group messages?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Scenario 4b: View care network members

To get a good overview of the care network and see how everyone is doing, you can view the network, and view their roles.

- Check what Johnny de Long his role is, and how he is experiencing his care load.

Questions:

- What do you think of the overview of the network?
- What do you think of the information provided on the network members?
- Would you be interested to know how caregivers are experiencing the care load in the network?

Observation:

- Did the user experience any difficulties when navigating?
- Where there any unexpected buttons?
- Where there any unexpected flows/screens?
- Are there functions that are hard to understand? If so, which parts?
- Are there words/terms used that the user is unfamiliar with?

Evaluation questions:

Is the prototype easy to understand and read?

What do you think of the avatar? Do you think it could help you/ guide you?

Do you think the app is easy to use?

Is there something that should absolutely be changed to improve the general impression, understandability, or appearance? In that case, what?

Is there something that should be improved in MedGUIDE? In that case, what and why?

Would you personally use this system/service/app if it was commercially available? Why, or why maybe not?

6.5 Example of text to align the consent with the GDPR

Privacy statement and consent

General information

The treatment body for all personal information in this evaluation is _____.

The purpose of the evaluation is to gather information about the use and satisfaction of various aspects of the MedGUIDE application mock-up.

This is used in the following for internal quality assurance, as well as production of improved application designs. For the latter reason, the information will also be stored for future use.

The personal data in this evaluation are available to and used exclusively by _____.

The basis for the processing is your consent to this privacy statement.

It is optional to sign this consent and you may at any time withdraw your consent without giving any reason. If you withdraw, all information about you will be deleted.

Scientific purposes

The MedGUIDE project makes regular analyses of the application, assessments and project sessions that are collected through our contact with end-users. All information recorded is relevant for such analyses. We do this primarily for internal quality assurance.

Sometimes analyses will also be conducted with the aim of providing new knowledge and increased knowledge of the application that is under development. These results may be relevant for scientific publishing.

Examples of possible research questions are:

- What kind of app functionality is important or less important for people with dementia?
- Which design criteria are the most important considering the application?

Personal data used for scientific purposes and research will always be treated confidentially. The data sets contained in such use will be unidentified upon creation. The key that connects personal data (such as name) to the reply will only be stored on an encrypted and password-protected memory stick that is locked in the MedGUIDE project partners' premises. Both the switch key and the avid-authenticated datasets will be available exclusively to _____.

Consent

Yes, I give my consent to the MedGUIDE project's Privacy Statement as described above.

No, I do not agree (evaluation cancelled)