CAPABLE

Cancer Patients Better Life Experience

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Deliverable Type		
R	Document, report	**[X]**
DEM	Demonstrator, pilot, prototype	
DEC	Websites, patent fillings, videos etc.	
OTHER		
Dissemination Level		
PU	Public	**[X]**
CO	Confidential (Consortium members including the Commission Services)	
CI	Classified Information (Commission Decision 2015/444/EC)	

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Versions History

Version	Date	Author	Comments
1.0	16th August 2021	UPM	First version with integrated protocols and document structure
2.0	19th August 2021	UPM	Results of patient interviews
3.0	23rd August 2021	UPM	Results of health professional interviews
4.0	24th August 2021	UPM	Final version to be revised
5.0	27th August 2021	BITSENS	Revised version
6.0	31st August 2021	UNIPV	Final submitted version
7.0	25th September 2021	UPM	Updates on NKI studies
8.0	10th October 2021	NKI	Updates on NKI studies
9.0	23rd October 2021	UPM	Final candidate release
10.0	27th October 2021	BITSENS	Revised version
11.00	30th October 2021	UPM	Final document version

Executive Summary

This document presents the results of the second evaluation and validation iteration of the CAPABLE prototypes as defined in previous deliverable D7.1.

In this validation process, an updated version of the WP6 prototype has been evaluated applying the two methods presented in D7.1:

- **Interviews with patients and relatives.** These interviews aimed to collect a feedback from the end users of the Patient App: Melanoma and Kidney cancer patients during the treatment phase. Given the broader applicability of the app to any type of cancer patient, this iteration included also other types of oncological patients, cancer survivors (treatment finished since no more than 2 years) and experts in patients' needs, such as caregivers. Overall, 17 patients and 2 caregivers have have been interviewed.
- **Interviews with healthcare professionals (HCPs).** These interviews aimed to collect overall feedback about both doctors' and patients' solutions, understand if the clinical and patients' needs are covered, and revise the core functionalities that have been proposed in the current prototype. A total of 11 health professionals have been interviewed.

The structure of this document follows the presentation of the results of the 2 executed studies. The protocols of each study are attached in the annex. The document also presents the general conclusions from these validation activities and the next steps to follow in the future developments in order to satisfy the user experience needs found in this process.

The work has been performed using different technological tools that made it possible to carry out these studies that normally are face to face, but that at the moment, due to the COVID-19 and recommended social distancing, in some cases were not possible. Those tools are:
- Conference system Zoom and Microsoft Teams.
- Online survey engine based on Limesurvey, used for the interviewer as guide.
- Collaborative functionalities of invisionapp[1] to inspect the prototype.

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[1] https://www.invisionapp.com/)

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1.Interviews with patients

Participant's profile

The WP7 team interviewed 19 participants selected from the AIMAC network of patients (7), from ICSM hospital (7), and from NKI hospital (5): 17 were patients and 2 were caregivers. The gender distribution was almost balanced (57,9% female, 42,1% male), the participants were adults with an average age of 53,5 year (St. Dev 12,1, Min 29, Max 73). Six of them suffered from renal cell carcinoma, 5 from melanoma, 3 from breast cancer, 1 Non-Hodgkin Lymphoma, 1 Acoustic Neuroma, 1 bladder cancer and 2 did not suffer from cancer but were a caregiver of pancreatic cancer patients. Six of the 17 cancer patients survived the treatments, 11 were still under treatment. 82,5% of the users lived together with the family (wife/ husband and/or children) or flat mate (just in one case), and 15,8% of people reported to live alone.

In general, all the participants were opened to new technology. They used the internet on a daily basis, for entertainment and for searching the web. Most of them used the internet also for work and, in the last year, they saw the increment of the usage of teleconference systems due to the pandemic. All the participants have a smartphone, 47,4% iOS and 52,6% Android based devices. According to the study protocol the participants from AIMAC and MAUGERI (n=14) also reported their opinion about the importance of specific habits to maintain a good health status. The following chart shows the overall results.

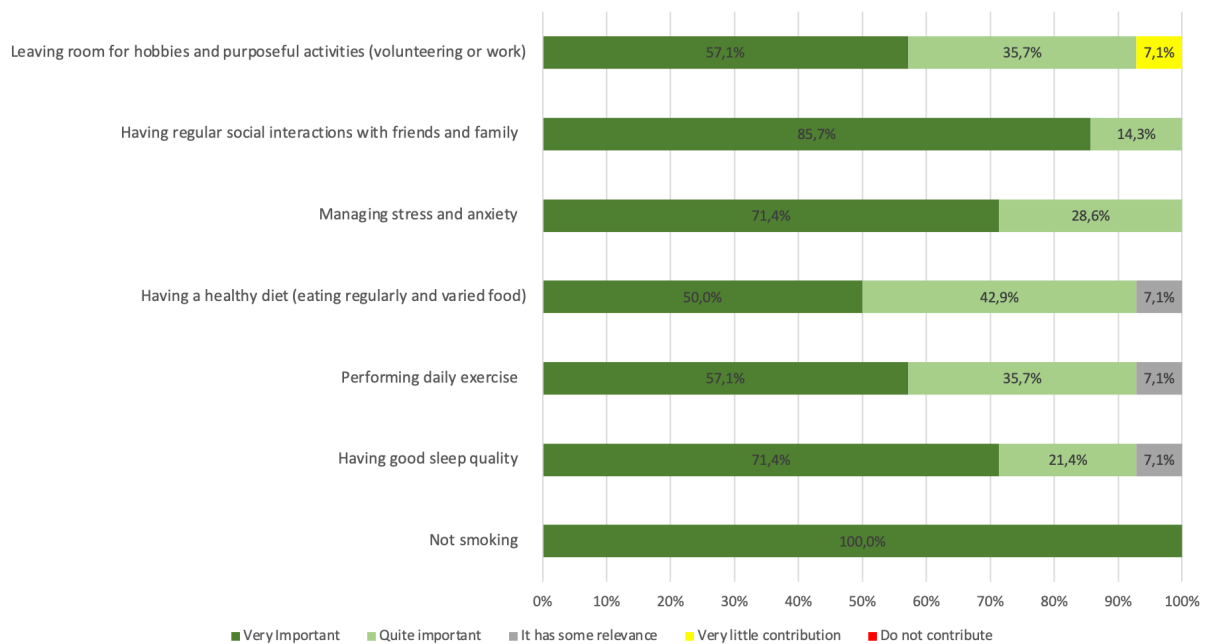### Importance of healthy habits to mantain good health status

Figure 1: Chart of the importance of healthy habits, AIMAC and MAUGERI, n=14)

In general, the participants consider that health status is not only based on a diagnostic of a disease, and that it is important to adopt healthy habits. The dimensions that received

lower score were to adopt a healthy diet, and to perform regular exercise. Differently from the previous study the management of stress and anxiety received higher score.

Overall feedbacks on the system

According to the scheduled protocol, the overall CAPABLE concept has been presented and an introduction of the app has been given to the interviewed people. The following sections detail the answer about the two presented topics.

What do you think of the CAPABLE approach? Would it be useful?
The overall concept proposal received positive feedback, most of the patients understand the potential of CAPABLE to innovate the clinical practice. Most of the participants consider it as a tool to better communicate with the clinical teams and to access to relevant information in an easy way.

Information provision Participants valued the goal of information provision greatly, indicating that the information about disease, side-effects and treatments would be helpful, especially at the start of their treatment.

Activities and information to support physical and mental wellbeing The idea to have a coaching system as a daily companion was also well accepted by the participants, in order to provide counseling and psychological support. The participants were specifically interested in information about nutrition and physical activity, specifically how to stay fit during treatment or how to regain strength after a hospitalization. One participant expressed needing a real-life person to stimulate doing activities related to physical and mental wellbeing, and expecting barriers in doing activities provided by a mobile application.

Remote patient monitoring All participants were interested in remote patient monitoring. The main perceived advantage would be to report the symptoms without contacting or bothering a clinician directly, and being contacted by a clinician when necessary. Some participants understood that the expected benefit could be a quicker response from the clinical team and the possibility to be better followed up, even remotely. It should be clear how often the patient should report their symptom, and when clinicians read and respond to patient-reported data.

Some criticisms have been raised on the privacy and on the feasibility of the system: one user thought that a concept like CAPABLE is too much challenging and that Artificial Intelligence techniques are not so developed to be used in the clinical practice. Another patient had the feeling that he could feel hyper controlled by a system like this, and that effective communication cannot be achieved by digital technologies.

Do you understand the purpose of the CAPABLE app? What do you think?
More than half (10/19) of the participants declared that the app can be a useful tool to be used to track subjective and objective data and get support and trusted clinical information. Five patients also highlighted the benefit to have an overall data history in the system that may help patients and clinicians too. Other patients (n=5) consider very relevant the holistic approach of the digital intervention proposed by CAPABLE, and consider the emotional support and the promotion of healthy habits as an interesting asset that can extend the more standard clinical care focused just on the cancer treatments. Three patients also identified some criticalities of the app: it can request a training to the patient, it can be an additional burden to follow the requested activities and could generate fear while reading information of possible side effects and detailed information on the cancer journey.

Unobtrusive tasks (think-aloud method)

Participants were asked to open a link to the Invision app prototype, share their screen and perform specific tasks. They were asked to describe what they were seeing in the interface, to tell their opinions and to comment on possible problems or potential improvements. The interviewers took notes and/or analysed the audio-recordings accordingly, with an emphasis on the feedback, the interactions with the prototype and whether the participants were able to complete the specific tasks. The patients executed the following 5 tasks:

- Task 1: Open the app, complete the Introduction, inspect the Homepage, read an Inbox message proposing a specific set of activities (walking every day for 30 minutes, namely the so-called *30x30 Nature Challenge*), and report to have walked 30 minutes.
- Task 2: Report an Itch symptom and see the suggestion of the system in the Inbox.
- Task 3: Report a fever symptom and simulate a caregiver entering "not feeling well at all" in place of the patient.
- Task 4: Perform a deep breathing exercise to improve sleep.
  - Revise the proposed activities in the goal page
- Task 5: Read a content on the side effects of immunotherapy
  - Revise the proposed contents

These tasks were performed in two different ways, according to the Covid restrictions and patients' availability:
- The patients interviewed in a face-to-face meeting at the hospital used a PC to access the prototype and the interviewer directly observed the user performing the tasks
- The patients interviewed through a teleconference system shared their screen and the interviewer observed the browser of the user.

Task 1 (introduction + home + message + report)

Introduction. In general, all users were able to go through the introduction. Going through the introduction was deemed easy for the users. Six users provided suggestions on the content of the introduction texts and questions.
Home page. The home page was well understood, except for the "Vital Functions" section. It was not clear what vital functions are, how they differ from "Lifestyle data" and what should be added manually. Two users tried to launch flows that were not implemented in this prototype, such as chronology and adding physiological measurements.
Inbox (30x30 Nature Challenge). Three users needed to receive suggestions to go to the message page to continue the proposed flow. The presentation of the Capsule *30x30 Nature Challenge* was not well understood by some users (n=5). The interviewers needed to explain the purpose and the requested activities.
Report of 30x30 Nature Challenge. Two users did not understand the need to go back to the home page to continue the flow and to report about the 30x30 Nature Challenge. Six users did not understood the flow of reporting the Challenge by selecting it in the daily plan. Some users did understand that the functionality referred to start a Walking activity. However, most of the users consider the task easy and intuitive.

The following table presents a list of issues that emerged during the evaluation of this task.

Table 1: Feedback from participants on task 1

Feedback from patients and caregiver on Task 1
Introduction
• Balance contents between coaching and monitoring symptoms and support cancer, there are also some repetitions.

- Text is too long. Replacing text with video might be better to show visually how functionality works. People might stop reading if text is too long.
- Provide some notes on privacy management in the intro.

Selection of hobby's
- The list of hobby's is not reflecting the real world, most of the possible hobbies are missing and there are hobbies that are quite strange from a typical patient (e.g., Thai Chi)
- Give the possibility to select more than one hobby.

Home page
- Unclear what vital functions are, how they are measured and if patients have to input manually or synchronized automatically.

30x30 Nature Challenge
Inbox message
- Unclear what the 30x30 Nature Challenge is at the moment of accepting the challenge, expected that this will be better explained in the app.
- The Italian translation of the term "CAPSULE" ("Pillola di benessere") is not clear.
- Users should be in control of the frequency of the proposed CAPSULEs.

Reporting the activity
- Some users did not get to go back to the home page after the activation of the capsule, and needed instructions on how to report the 30x30 Nature Challenge in the Homepage.
- When user start reporting the capsule it is not clear that is a reporting of a performed activity, some users thought that is to start the activity.
- Participants expect manually registering doing an activity such as the 30x30 Nature Challenge as optional, and expect that doing activities will be tracked automatically by their smartwatch.

Rating the activity
- Useful to ask the reasons for rating the 30x30 Nature Challenge negatively.
- Provide feedback on different suitable CAPSULES if the 30x30 Nature Challenge is rated negatively.

Other suggestions
- One user suggests to have push notification in the phone to receive reminders
- Chronology need to be developed, many users tried to access that section.

Task 2 (Report an Itch symptom and review the suggestion of the system in the Inbox)

Home page. All the users were able to identify the proper button in the menu.
Body figure. Four users tried to select a body part in the overall body figure and initially were not able to continue the tasks. The interviewers indicated that this functionality was not yet implemented in this prototype and suggested to press "Skip". Despite this functionality not being implemented yet, most users think that the use of this functionality will be intuitive. The rest of the reporting task was completed successfully by all the users.
Symptom list. One user reported rash instead of pruritus.
Symptom descriptions. Users that actually experienced Itch as an immunotherapy side-effect, indicated that they would have found it difficult to choose one of the descriptions (n=2). Patients might experience a combination of descriptions (itch was not continuous, but was at night, with redness and swelling, or the itch is mild, moving throughout the body, but without redness or crusts). In these cases, it will be difficult for the patient to choose one description.
Symptom overview. One usability issue was found in the final summary page of the report, where some users were not able to scroll the page.
Inbox message Two users did not like the feedback of the app (to use emollient). They did not trust the feedback and would prefer to receive this information directly from the doctor.

Table 2: Feedback from participants on task 2

Feedback from patients and caregiver of the App's symptom reporting (Itch)
Body page • Image of body should be personalized (female/male) • Implement the localization of the symptoms in the body
Symptom list • The symptoms should be grouped according to body part/system, not according to likelihood to appear.
Symptom descriptions • Descriptions do not cover all potential experiences with an itch symptom. Patients might experience a combination of descriptions (itch was not constantly, but was at night with redness and swelling or the itch is mild, moving throughout the body, but without redness or crusts). In these cases, it will be difficult for the patient to choose one description.   o Frustrating to choose a grade that does not reflect their situation well.
Symptom overview • Start date is shown in overview but not in the initial symptom report. Patients may not report symptom immediately but after one or more days (an individual could prefer waiting, realizing and evaluating the symptom) • Unclear whether patients should report their symptom daily • Make scrollable page more intuitive (e.g. with a text or with a more visible scroll bar)
Inbox message • Enhance feedback with more clinical reference to make content more trustable • Be clear whether recommended medications are over-the-counter or require prescription
Other suggestions • Include in the introduction that a message can be found in the Inbox after symptom reporting.

Task 3 (Reporting fever)

This task was similar to task 2. The users were asked to include a note to their symptom report, and to mark that the symptoms were reported by a caregiver.
Home. Two users tried to insert a physiological value to the "Add Vital Signs" function in the home page. As this functionality was not available, they decided to go to the symptoms. One user went to the educational page.
Symptom overview. Eight users got stuck during the report of the symptom. It was difficult to understand that the prototype required scrolling down in the Symptom Overview to find the checkbox 'This symptom was reported by a caregiver'.
Inbox message. Six users were expecting to receive feedback after the symptoms reporting, similarly to task 2.

The following table presents a list of issues that emerged during the evaluation of this task.

Table 3: Feedback from participants on task 3

Feedback from patients and caregiver on the App's symptom reporting (Fever)
Symptom overview • Make scrollable page more intuitive (e.g. with a text or with a more visible scroll bar)
Inbox message

- Implement a proper message feedback after fever reporting. Unclear what happens with the fever report. There should always be feedback after reporting.
- Two patients initially expected the care team to monitor the symptom reports and to be contacted when their care team deems that necessary. Should be clear to the users when they should contact the care team or when they will be contacted by the care team.

Task 4 (Perform a deep breathing exercise to improve sleep).
The task consists to enter in the section called Objectives, check the specific page and select one recommended activity to improve sleep, the deep breathing exercise.
Home. 8 out 19 participants had difficulties to find the functionalities. The tab name 'Objectives' was not clear. The users identified the correct section per the interviewers' suggestion, by exclusion or by trying all the items in the menu.
Goal page. Two users had a different expectation from the 'Objectives' section. They expected to have the possibility to set up specific goals and to be able to schedule their preferred activities. In addition, five users did not find the categorization of activities by Goal intuitive. For example, in the prototype, the 30x30 Nature Challenge was solely in the "Mental Wellbeing" section and not under "Physical Wellbeing". Some users also revised the activities and were not sure to been able to perform specific activities as Thai Chi or more advanced respiration activities (e.g., the Lion breath).
Deep breathing exercise. The requested tasks were performed successfully by all the users, some initial clarifications were requested on the tutorial contents and reference links: the tutorial contains an implementation of the guided respiration instead of practical instruction on how to perform the exercise and the reference links were in English and need to be translated. Two users also suggested to link this activity with the wearable sensors, one user also suggested using haptic feedback from smartwatch as Apple IWatch. The following table presents a list of issues that emerged during the evaluation of this task.

Table 4: Feedback from participants on task 4

Feedback from patients and caregiver of the App's Capsule functionality
Goal page
The label "Objectives" in the menu is not clear and generates expectations on a more personalized, goal settings-based functionality in which a user can select goals, set reminders and personalize goals (with specific parameters, e.g. number of daily steps, number of relaxing activities / week, etc.)
- Tutorial contents need to be translated and written in such a way to explain in detail the purpose of the activities and the steps to perform the exercise correctly.   - Unclear that users had to click on "sleep" to find the breathing exercise.
Deep breathing exercise   - Add more content on when and why it's beneficial to do the exercise.   - Unclear what the rationale is of "Saving" the exercise in the app as an overview of performed activities is not available.   - Reference links need to be translated   - Consider the potential integration with the wearable sensor to have real time feedback using physiological data and haptic feedback.

Task 5 (Educational content)

The last task was successfully performed by all the participants.
Home. From a logical point of view it was suggested to move the educational button of the menu as a second item, between the home button and the inbox one.
List of educational content. Two users reported difficulties in scrolling the content and in opening the texts once they had been selected. One user suggested to reorganize the content in a clearer way: treatment, side effect, improve QoL, lifestyle.

Other comments. Two users stated that they would prefer asking questions directly to the oncologist instead of reading the content in the app. Some users suggested to send messages to the Inbox, indicating that there is relevant information available in the "Education" section.

The following table presents a list of issues that emerged during the evaluation of this task.

Table 5: Feedbacks from participants on task 5

Feedback from patients and caregiver on the educational content
List of educational content
• Change the label "Education" to "Information"
• Create a simpler structured table of content.
• Reduce the contents related to diagnostic
• Simplify the contents and make them more suitable for public audience.
• Simplify some titles, minimize texts, and make them more explicit.
• Enrich the section with contents more specific for the patient under treatment.
• Include information regarding importance of informing clinician of symptom and potential consequences of side-effect (example; diarrhea should be reported immediately, others might be less urgent).
• Add information about stress, effects of relaxation and stress on the body and wellbeing.
• Add a section on fake news.
Skin side-effect information
• Simplify texts, some text might be too scientific or not simple enough for many uses.
• Add information about when certain symptoms occur (beginning of start treatment, after certain time period).
• Include links to the source of the supporting clinical studies.

Overall easiness of the tasks

The participants scored from 1 (very difficult) to 5 (very easy) the performed tasks. The overall results are positive and average values are definitely above the positive threshold (3). The most (relatively) difficult tasks were tasks 1, 3 and 4:

- Most probably task 1 received the lowest score because of the long duration of the tasks. As a matter of fact it was composed by 4 sub-tasks and required the user to understand the overall navigation strategy.
- The reporting of fever by a caregiver caused that some users had difficulties to complete the flow because it required an additional scroll of the page.
- The objectives section generated some confusion to the users, instead of having a space to personalize goals the users saw a list of proposed activities.

The tasks that were scored as easiest is the report of pruritus (task 2), followed by the the area of the educational contents. The following table details the statistics of the easiness score.

Table 6: Easiness scores of the 4 tasks performed by the participants

	Mean	**St Dev**	**Min**	**Max**
Task 1	4,21	1,03	2	5
Task 2	4,47	0,70	3	5
Task 3	4,37	0,76	3	5
Task 4	4,37	0,76	2	5
Task 5	4,42	0,77	3	5

Final questions

During this last part of the interview four types of information have been gathered:

- Qualitative feedback on missing functionalities and how system can be improved.
- Qualitative feedback on the possibility of providing services also for the caregivers.
- Quantitative evaluation of the perceived values of the CAPABLE patient app.
- Quantitative evaluation of the overall system usability

Missing functionalities and how to improve the app.
14 out 19 participants considered that the app has all the needed functionalities. Two users suggested the need to have programmable activities and a synchronization with a calendar. Two patients suggested to provide communication with the care team, also (1) using voice messages. Other patients suggested improving the overall user experience, by improving the layout, adding colors, adding gamified elements and working more on the user's engagement.

The following suggestions were proposed for improving the app:
- Camera-functionality, to be able to provide a clinician with pictures of their skin side-effects.
- Provide more interaction between the wearable and the app.
- Exchanging information with peers with the same pathology. It would be interesting to have a second level of discussion between patients sharing the experience on symptoms management.
- Provide more guidance for the posology of medications
- Use more graphics to simplify the interaction and make navigable elements more visible.
- Track the emotional status of the users, also after the symptom reporting.
- Including more videos and animations
- Including links to lectures and scientific articles
- Including information about mental and physical wellbeing (e.g., specifically creative therapy that uses non-verbal expression like art as a means to communicate feelings and emotions, techniques to manage stress) and information about supportive care (activity centers, walk-in houses, Centre for Quality of Life (NKI)).

Informal caregivers, should they be involved?
Most of the participants liked the approach followed in task 3, to give the possibility to the caregiver to report the symptoms in the patient app. To have specific features for the caregiver, CAPABLE would need to develop a specific app for the caregiver.

In terms of privacy and visible personal or medical data, all NKI participants indicated that they would have different preferences depending on their relationship with the informal caregiver (whether they are a partner, family-member, friend or a neighbor).

Similarly to the previous interview, some participants (4) reported the fact that the caregiver will be in charge to use the app, when the patient is not able to use the app (e.g. elderly people not used to digital technologies) or because of a critical health condition.

Two patients suggested to provide specific content to caregiver on how to provide support to the patients and how to manage the burden of caregiving. For the support of the patients the users suggest providing functionalities to see the evolution of the health status and symptoms, a communication tool with the care team and specific content to support the healthy lifestyle of the patients (e.g., nutrition, physical activity), the medical prescription and an emergency button.

Perceived values

The participants filled in a questionnaire aimed to measure the acceptance and the perceived values. In general, all the proposed dimensions were well accepted but the scoring was a bit lower from the previous UX round. The most accepted sentences were that the system easily fit in the everyday life, that users would install CAPABLE in their own mobile phones and that can help doctors to better monitoring patients. The participants were more skeptical on considering CAPABLE a system that can help to manage negative emotions and to be able to help to cope with daily life problem.

The following chart summarize the statistics of the responses.

Figure 2: Chart of the perceived values of CAPABLE

Overall system usability

The last questionnaire of the interview was the standard questionnaire about system usability, the System Usability Scale[2]. The overall results are good and very similar to the previous UX study. The system received excellent scores (thresholds is 80): the overall mean score of the SUS questionnaire is 80,66 (St.Dev. 12.07, Min 52,2, Max 100) that indicates that CAPABLE has high usability. Just one participant considered the system unacceptable under the usability point of view and scored the system low. This can be seen clearly in the following chart. The lowest values have been reported on the fact that users will learn to use it quickly: some participants consider that some users could have difficulties because of their age or digital literacy. All the users (except one user) strongly agree that they feel very confident using the system, that is easy to use and not cumbersome.

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[2] https://www.usability.gov/how-to-and-tools/methods/system-usability-scale.html

System usability scale

NOT I needed to learn a lot of things before I could get going with this system.	47,4% · 31,6% · 5,3% · 10,5% · 5,3%
I felt very confident using the system.	26,3% · 63,2% · 5,3% · 5,3%
NOT I found the system very cumbersome to use.	47,4% · 47,4% · 5,3%
I would imagine that most people would learn to use this system very quickly.	15,8% · 63,2% · 10,5% · 10,5%
NOT I thought there was too much inconsistency in this system.	47,4% · 42,1% · 5,3% · 5,3%
I found the various functions in this system were well integrated.	31,6% · 57,9% · 10,5%
NOT I think that I would need the support of a technical person to be able to use this system.	52,6% · 31,6% · 15,8%
I thought the system was easy to use	57,9% · 31,6% · 5,3% · 5,3%
NOT I found the system unnecessarily complex.	47,4% · 47,4% · 5,3%
I think that I would like to use this system frequently.	47,4% · 42,1% · 5,3% · 5,3%

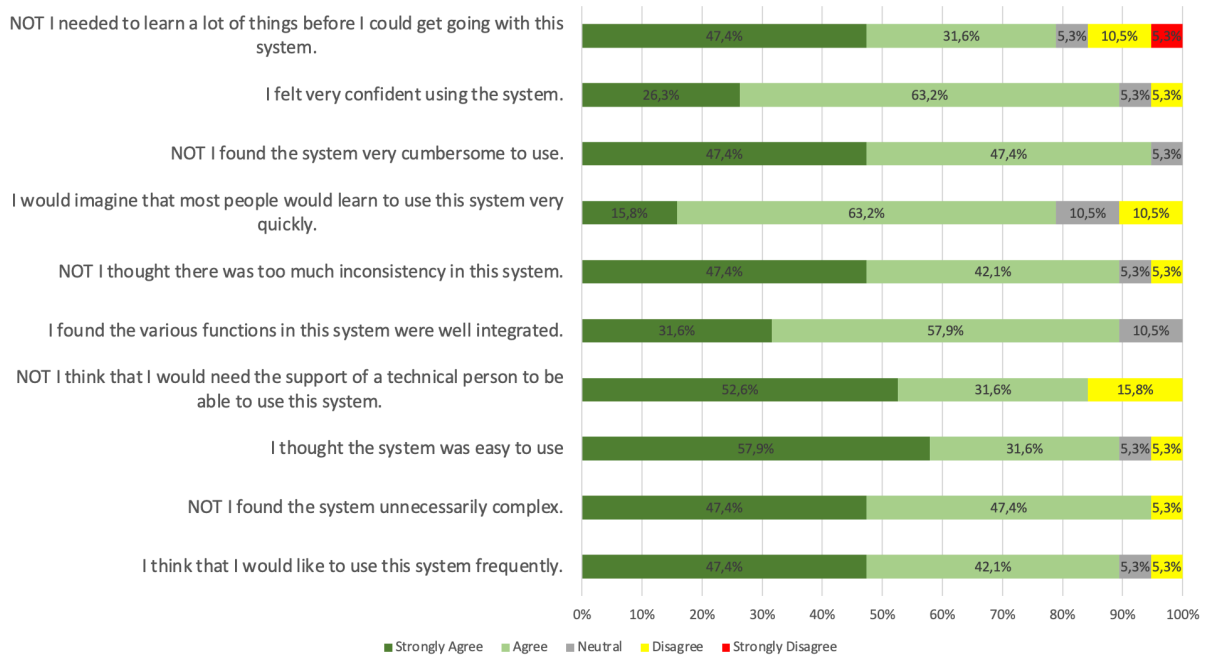■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

Figure 3: Chart of the System usability questions

3.Interviews with health professionals

Participant's profile

WP7 interviewed 11 health professionals: 18,2% Males and 81,8% Females. The average age was 37,6 (St. Dev. 14,09, Min 26, Max 64), lower than the patient's one. Out of the 11 interviewed people 54,5% were oncologists in training, 18,2% specialists in nutrition, 9,1% phycologists and 18,2% nurses.

Previous experience with health technology
All the users have experience with patients' Electronic Health Record and Hospital information system to track the administrative processes of the patients, as well as other tools for the Hospital Information System to track care processes or request extra departmental services such as imaging or biochemical tests or other specialist visits. One participant also mentioned using PACS. The 36,37% of the participants declared to have experience in telemedicine system for oncology, specifically the KAIKU system. These participants were from the NKI hospital. 27,27% of participants also mentioned the use of Clinical Decision Support systems.

Most of the users used technology not only for job but also in their free time, to help children to study, to find information, entertainment, social network and media services. All the participants have a Smartphone, 63,7% Android and 36,4% iOS devices.

Overall feedback on the system

What do you think of the CAPABLE approach? Would it be useful?

All the participants agreed that nowadays there is a need to foster the technologies like CAPABLE, to provide home assistance and prevent adverse events. One barrier could be the elderly patients that can have difficulties to access to digital technologies (one health professional stated that he saw patients having difficulties also to open an email). Having a tool at home can reduce fear and anxieties of users and caregivers. Some criticisms have been also highlighted: patients need to be trained to use digital technologies to prevent a huge stream of communications between patients and healthcare professionals, and that not always the remote communication is effective.

Do you understand the purpose of the CAPABLE app? What do you think?

The interviewers presented the patient app as a system conceived to cover three main goals: providing information, support in mental and physical health / lifestyle and for symptom monitoring. Most of the participants agreed on the fact that a solution like CAPABLE represents an opportunity for patients going through treatment by providing information and activities. Most of the participants agreed on the added value to have a remote patient monitoring platform inside the CAPABLE system. Participants with previous experience of symptom monitoring systems noted that it can be challenging to gauge the symptom experience and severity of the symptom solely by patient-reported outcomes, without seeing the patient. CAPABLE is expected to be a supportive tool that does not interfere with the short lines of communication with the hospital, and that supports, not replaces the HCPs in management of adverse events. One key aspect of the system must be the personalization because patients have different needs, and it is very difficult to standardize the information. Furthermore, the educational materials and content need to be correctly shaped to avoid any possible misinterpretation from patients.

Some participant was sceptical about the possibility to use the CAPABLE system for remote prescription, it could not consider the adequate level of care the patients require. Some

participant reported that it would be useful to set up specific thresholds on the physiological data to trigger alarms in the health professional dashboard.

One physician considers an app like this more useful for patients in follow-up stage than during the treatment.

Do you understand the purpose of the CAPABLE health professional dashboard? What do you think?

The interviewers presented the HCP dashboard as a system conceived to cover three main goals: present and visualize patient data (sensor, questionnaires, patient-reported symptoms), provide clinical decision support, and provide prediction models.

Also, in this case the overall feedback was positive, most of the participants agree that the clinical dashboard can be an effective tool to support the job of the care team to follow-up cancer patients.

For NKI participants, it was noted that the clinical decision support might particularly be useful for more inexperienced HCPs. Specific concerns were raised regarding existing IT systems and workload. Currently at NKI, there is an extensive EHR in use. In addition, a symptom monitoring tool (KAIKU) has recently been introduced in the hospital. As such, there are concerns regarding double administrative work. It was questioned how CAPABLE will be implemented next to KAIKU, and what the impact of these apps will be on their workload.

For ICSM participants, many agreed on the fact that the biggest challenge of CAPABLE is to be able to adapt the clinical guidelines to every patient situation and to be able to also consider the human component. Some users also said that a system like CAPABLE can found difficulties to be deployed in a real clinical scenario because still there are professionals that are reluctant to these kinds of approaches, and they prefer a more classical standard care delivery. Lastly, the added value of this system is to have a unified process for all the patients and be able to perform a stratification with an easy and simple interface.

Unobtrusive tasks

At this step of the interview the interviewer asked the participant to open a specific link containing the Web Portal for health professionals[3] and the patient App prototype[4], to share the screen and perform specific tasks. The user described what they were seeing in the interface and reported possible problems and improvements. The interviewer took notes of all the feedbacks and observed also how the prototype was used and if the user was able to complete the specific tasks. The proposed tasks were 8:

- Task 1: Enroll a new patient through the Web portal for health professional (Dashboard).
- Task 2: inspect the patient app: homepage (App).
- Task 3: report a symptom in the patient app (App).
- Task 4: inspect the Capsule functionality in the patient app (App).
- Task 5: revise the educational content (the list) in the patient app (App).
- Task 6: perform a remote follow up of a patient and check the recommendation using the Web portal for health professional (Dashboard).
- Task 7: revise the prognostic models of a patients (Dashboard).
- Task 8: schedule a visit and insert new symptom (Dashboard).

As can be noticed, health professionals were requested to revise all the core use cases of the overall system, because their opinion is fundamental also in the design of the patient's app.

Task 1: Patient enrollment

All the users were able to login into the Web portal, find the button to enrol a new patient and complete the enrollment. One user had difficulties to find the next button to continue the enrollment flow.

Enrollment page 2 (steps for installing patient app). Three users did not find it clear what exactly was required to complete the steps. It was unclear whether these steps needed to be executed face-to-face with the patient. One user did not understand the need to check the steps required for the installation.

Overall workflow. For NKI HCPs, concerns related to time-constraints were raised. It was deemed unfeasible to go through the enrollment steps (filling in profile, installing app) within one regular visit. Additionally, there were questions about which fields would actually be filled in by EHR import and which fields would need to be filled in manually.

The following table presents a list of issues that emerged during the evaluation of this task.

Table 7: Feedback from participants on task 1

Feedback from HCPs on log-in and new patient enrolment (dashboard)
Enrolment page 1 • The format of date of birth should be modified (day-month-year)
Enrolment page 2 • Unclear whether the steps described are to be executed by patient or by clinician. • Unclear how exactly the patient receives his/her password and creates his/her account. • Unclear which app Menu is referred to in step 3 • Confusing that instructions for connecting devices are not shown after completing that step in dashboard.
Overall workflow • Going through steps within dashboard was deemed as easy, but it was difficult to assess how the process will be in reality, together with the patient during a visit. • Unclear if the enrollment steps and installation of the app are to be done together with patient

Task 2: Overall inspection of the patient app

The health professionals also revised the patients' app prototype. In general, all the participants were able to understand the overall purpose of the home page and of the inbox messages. Two participants noted that it was unclear at the moment of accepting the 30x30 Nature Challenge what the Challenge actually entails. One user was stuck in the message page because they did not understand the need to accept the proposed 30x30 Nature Challenge Capsule. Other users had difficulties to report a walk and had problems inserting the date in the app. Only one copy-write issue was found in the section related to the sensor data, the word 'calories' must be more specific and replaced with 'spent energy' or similar.

Task 3: Symptom's report

The participants also revised the symptoms reporting functionalities. In general, all the users were able to complete the flow. The different modalities to report a symptom were appreciated (selecting an area from the body or going directly to a list). However, there were critical comments on both the symptom list and the following symptom descriptions (for Itch). The users liked that the app is providing immediate feedback to the patient. One user did not get the need to go to the message to read the suggestions on how to manage the symptom. It was suggested to ensure that patients read the Inbox, to redirect them

to the inbox immediately after finishing a symptom report or to give a pop-up asking to go to the inbox. One user considered the top menu of the messages (the filters) too much intrusive and unclear. One user asked how to report two symptoms together.

The following table presents a list of issues that emerged during the evaluation of this task.

Table 8: Feedback from participants on task 3

Feedback from HCPs on symptom reporting functionality (App)
Symptom list • The list is not complete, gastro-intestinal symptoms missing for example. • The symptoms should not be grouped according to likelihood to appear. Patients will not be aware of the likelihood to appear. The symptoms currently seem randomly sorted. Similar symptoms are not close to each other in the list.   o Group symptoms more logically for patients, for example: symptoms affecting skin, head, torso, mood, etc.
Symptom descriptions • Symptom descriptions are not sufficient for patient to describe symptom. Will be difficult for patient to choose 1 description, for example itch can be mild but moving throughout whole body, but without redness or crusts, which is currently not possible to report.
Symptom overview • Start date is shown in overview but not in initial symptom report. Patients may not report symptom immediately but after a day (process of individual of waiting, realizing and evaluating symptom). • Unclear whether patient should report symptom daily.

Task 4 Capsule functionality.

The participants also revised the Capsule functionality. They were asked to find and execute the deep breathing exercise. This module was well accepted, even if there were some problems during the navigation in understanding the proposed content. In fact, one user got lost in the goals menu. Two users identified a mismatching between deep breathing and the Italian translation 'respirazione di base'. Other users asked an explanation on the Lion's breath practice. Some users also asked why the Wellbeing area does not include information on nutrition and adequate hydration. One health professional also stated that elderly users may have difficulties to perform the breathing exercise. It was noted that from a clinician point of view, the process of selecting these particular interventions was unclear.

Task 5: Find and review the educational section of the app (specifically information on skin toxicity)

All the participants were able to navigate in the educational section of the patient app, just one user had problem with the scrolling of the page and one user tried to open an educational content that is not available in the prototype (related to sleep). Two users suggested to change the name of the section from Education to info/information or FAQ (Frequently Asked Questions). One user did not understand the order of the section related to the goals. Five health professionals commented on the added value to have a trustable source of information and avoid patients search by themselves the information in the web. One user also suggested to avoid information conflict between the information provided by the app and the one provided by the healthcare team.

While reviewing the skin toxicity content, participants appreciated the visualization of risks with figures. It was noted that the section contained a lot of information, but that it will fulfill the information need of a specific group of patients.

Task 6: Perform remote patient follow-up, review a recommendation, and prescribe medication

During this task the participants had to select the patient 'Maria Rossi', enter in the patient overview page, manage a recommendation related to a reported symptom, and then inspect all the information available in the dashboard related to the selected patient.

Seven participants, specifically all the NKI participants, have problems with the flow of performing remote patient follow-up. Intuitively, many of them first try to open other sections of the dashboard before clicking on the recommendation. The current flow was not logical. Currently, the users see a red alert, and are immediately shown a recommendation when clicking on the patient. However, they are not informed what the original red alert was for, and they are not redirected to the patient-reported data. They would like to review the patient-reported data before reading the recommendations for treatment. As many participants first tried to open other sections of the dashboard, the recommendation disappeared in this prototype. To solve this issue, it was suggested to move the Symptoms tab before the Measurement tab, and to show or replicate the recommendation in the Symptom section, as in most cases the symptoms are the triggers for the recommendations. The following table presents a list of issues that emerged during the evaluation of this task.

Table 9: Feedback from participants on task 6

Feedback from HCPs on remote patient follow-up, visualization of a recommendation and prescription of a medication
Patient list • Unclear in-patient list why patient Maria has a red status
Treatment page • One participant got lost and did not click on the recommendation, thus needing help to continue   o Unclear where to find the recommendation • Flow is not logical, currently the user sees a red alert, and a recommendation is immediately shown when clicking on the patient, without being informed what the alert is for or reviewing patient data
Recommendation • Meaning was unclear of level of evidence and grading of recommendation
Prescription pages • Unclear how prescribing will work with currently used EHR • Unclear what "happens" with prescription after prescribing

Task 7: Find and review a survival prediction model
Three out of 11 participants had difficulties to find the proper button to launch the prognostic models. While for most users it was clear how to access the Survival model, it was not clear how to interpret the survival model itself. It was unclear whether the Survival model was on the overall patient population, or specifically on the current patient. It was also unclear how the features were used in building this model.
Two users stressed the fact that this information must not be shown to the patient. It was suggested to add a reference publication to provide more details on the models. One user suggested to use these models to train health professionals.
The following table presents a list of issues that emerged during the evaluation of this task.

Table 10: Feedback from participants on task 7

Feedback from HCPs on Survival prediction model
Page of AI model selection • Predictive models are quickly found
AI model 1 (Survival model) • Add the performance of the survival model

• Unclear whether feature importance is based on specific patient or from general population.	
• Add month 6, month 12 and month 24 in graph.	
Comments on using the model in practice	
• Unclear what the aim of the survival model is for doctors, and when to "use" the survival model	
• Showing a survival model for treatment choice does not fit with their perception of CAPABLE as a symptom monitoring system	
• Showing a toxicity model with risk of severe toxicity would fit with their perception of CAPABLE as a symptom monitoring system.	

Task 8: schedule a visit and report a symptom.

All users were able to complete the tasks. It was initially unclear for two users whether to report the tachycardia in the Measurements tab or in the Symptoms tab. One user had difficulties scrolling through the patient list page. The following table presents a list of issues that emerged during the evaluation of this task.

Table 11: Feedback from participants on task 8

Feedback from HCPs on planning a new visit and reporting a new symptom
Visit schedule
• Show a confirmation message for the visit schedule.
• Include option to press "Plan visit in 3 weeks" instead of selecting specific date.
Symptom page
• Initially unclear whether to report pulse/heartrate at Measurement page or Symptom page.
• Advice given to patient (of emollients) is not shown in this overview, it should be included.
• Exact patient-reported symptom description is missing from the symptom page, the grade alone is not sufficient.
• Specific name of HCP should be included, not just that it is reported by 'a' clinician
• Create a bigger button for new symptom report and export of the data.
Report of new symptom
• Should be clear that there are two separate symptom lists, with different symptom descriptions, for patients and for HCPs.
Other tabs in clinician dashboard
• Measurement tab – make it clearer that these are sensor measurements, not measurements done by HCPs.
• Measurement tab - unclear what the source of data is, unclear how often the measurements are synchronized. Measurements should be optional for patients (such as sleep) as patients might not want to be monitored that extensively.
• Questionnaire results - dashboard should show all potential answers to questions in questionnaire.
• Questionnaire results – show alerts based on quality of life questionnaires (for a certain worrying threshold).
• Questionnaire results - add also the cut-off values to explain the scoring of a reported questionnaire.

Overall easiness of the tasks

The participants score from 1 (very difficult) to 5 (very easy) the performed tasks. The overall results are positive and above the positive threshold (3). The most critical tasks was task 6, related to the recommendation and to the inspection of the patient data. All the participants agreed that task 1 and task 5 are very easy to perform.

Table 12: Easiness of the performed tasks

	TASK 1	TASK 2	TASK 3	TASK 4	TASK 5	TASK 6	TASK 7	TASK 8

Mean	4,82	4,78	4,64	4,67	5,00	3,55	4,27	4,73
St Dev	0,40	0,44	0,50	0,71	0,00	1,13	1,01	0,47
Min	4,00	4,00	4,00	3,00	5,00	1,00	2,00	4,00
Max	5,00	5,00	5,00	5,00	5,00	5,00	5,00	5,00

Final questions

Similarly to the patients' interview schedule, in last part of the interview four types of information have been gathered:

- Qualitative feedback on missing functionalities and how the system can be improved.
- Qualitative feedback on the possibility of providing services also for the caregivers.
- Quantitative evaluation of perceived values of the CAPABLE systems.
- Quantitative evaluation of the overall system usability.

Missing functionalities and suggestions to improve the app.
All the participants were satisfied with the presented functionalities, and they thought that CAPABLE is a quite complete system.

The following suggestions have been provided to complete the system:
- Include the functionality for patients to upload photos in their symptom reports.
- Provide a section for the psychological support
- Integrate EHR data
- Visualize other health events of the patients
- Integrate with the medical prescription system, already available in Italy.

The users also reported the following ideas to improve the system:
- To provide a help functionality in the app and in the clinical dashboard
- Possibility to use a calendar to share events between patients and care team (for visits, surgery etc.),
- To provide a more 'evident' graphical solution for the clinicians, richer in graphical elements.

The NKI participants also provided the following comments regarding workflow and use of the CAPABLE system
- HiX (EHR) should be used as main EHR, and CAPABLE should be a complementary support system.
- Using CAPABLE and KAIKU (symptom monitoring system currently used in practice) simultaneously would be redundant.
- Data integration between HiX and CAPABLE should be reliable
- Try to prevent additional "double" administrative work for HCPs

Informal caregiver, should be involved?

All the participants agreed on the usefulness of the functionality to give the possibility to a caregiver to report a symptom. Other suggested functionalities were mostly related to the full access to the app to see performed activities, the mood, and the symptoms. Also, nutrition and lifestyle habits were considered very important dimensions of the patient to be monitored by the caregiver.

Perceived values
The participants responded to a questionnaire aimed to measure the acceptance and the perceived values. All the responses received a positive score, but some dimensions were less scored by the health professionals: there was some criticisms in thinking that the system easily fits in the health professional work routine, about the fact that the app can

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help to manage negative emotions and on the idea to access the system using their personal mobile phone. The most accepted sentences were the idea that CAPABLE could improve the quality of care, improve the communication with patients, help patients to manage side effect and improve the QoL.
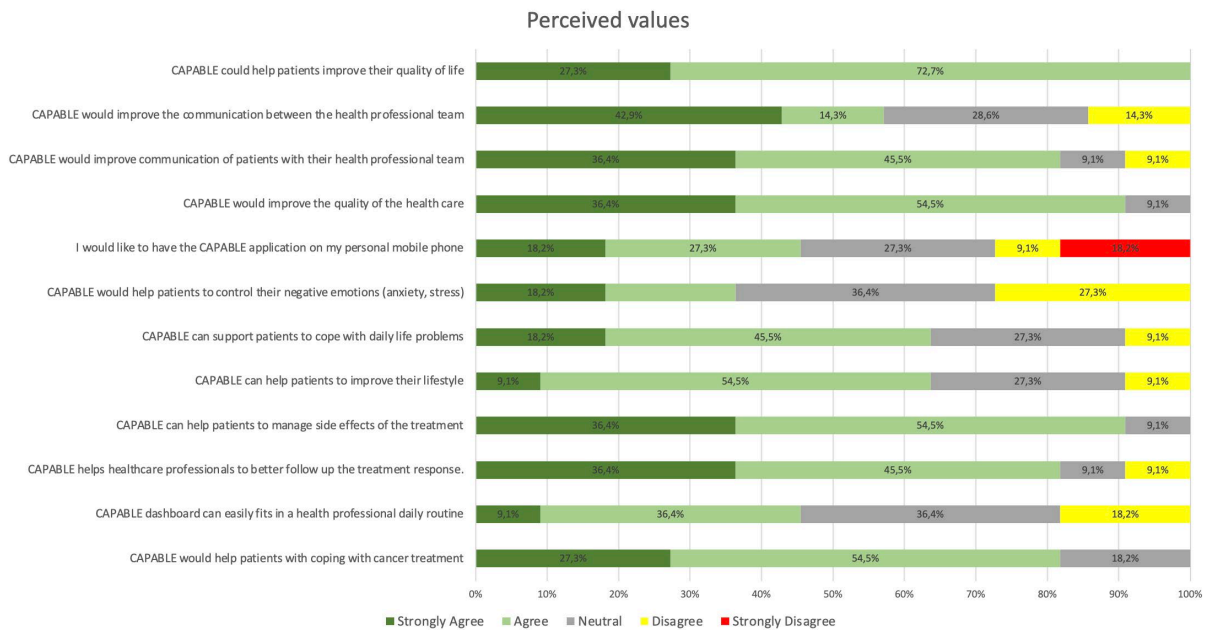

Figure 4: Chart of the perceived values of CAPABLE

Overall system usability

The last questionnaire of the interview was the standard questionnaire about system usability. The overall results are good. The system received good scores (thresholds are between 68 and 80): the overall mean score of the SUS questionnaire is 82,95 (St.Dev. 9,61, Min 67,5, Max 95) that indicates that CAPABLE has high usability. This result is higher than the scored received in the previous UX study. Differently from the patients all the users scored positively the usability of the system and the data has lower variability.

From the analysis of the single metrics of the questionnaire it is possible to notice that the dimensions that received higher scores were about system (no) complexity, the learnability of the system and the (no) need to have a technical support to use the system. This is the opposite trend of the previous study. The dimensions that received lower scoring were the idea that most of the users will learn to use the system quickly, the idea to use the system frequently and to feel that the functionalities was well integrated: even if with lowest scores the average value is positive.

System usability scale

NOT I needed to learn a lot of things before I could get going… — Strongly Agree 45,45% | Agree 54,55%

I felt very confident using the system. — Strongly Agree 36,36% | Agree 63,64%

NOT I found the system very cumbersome to use. — Strongly Agree 63,64% | Agree 18,18% | Neutral 18,18%

I would imagine that most people would learn to use this… — Strongly Agree 9,09% | Agree 63,64% | Neutral 27,27%

NOT I thought there was too much inconsistency in this… — Strongly Agree 36,36% | Agree 63,64%

I found the various functions in this system were well… — Strongly Agree 9,09% | Agree 72,73% | Neutral 18,18%

NOT I think that I would need the support of a technical… — Strongly Agree 63,64% | Agree 36,36%

I thought the system was easy to use — Strongly Agree 54,55% | Agree 45,45%

NOT I found the system unnecessarily complex. — Strongly Agree 72,73% | Agree 27,27%

I think that I would like to use this system frequently. — Strongly Agree 18,18% | Agree 54,55% | Neutral 27,27%

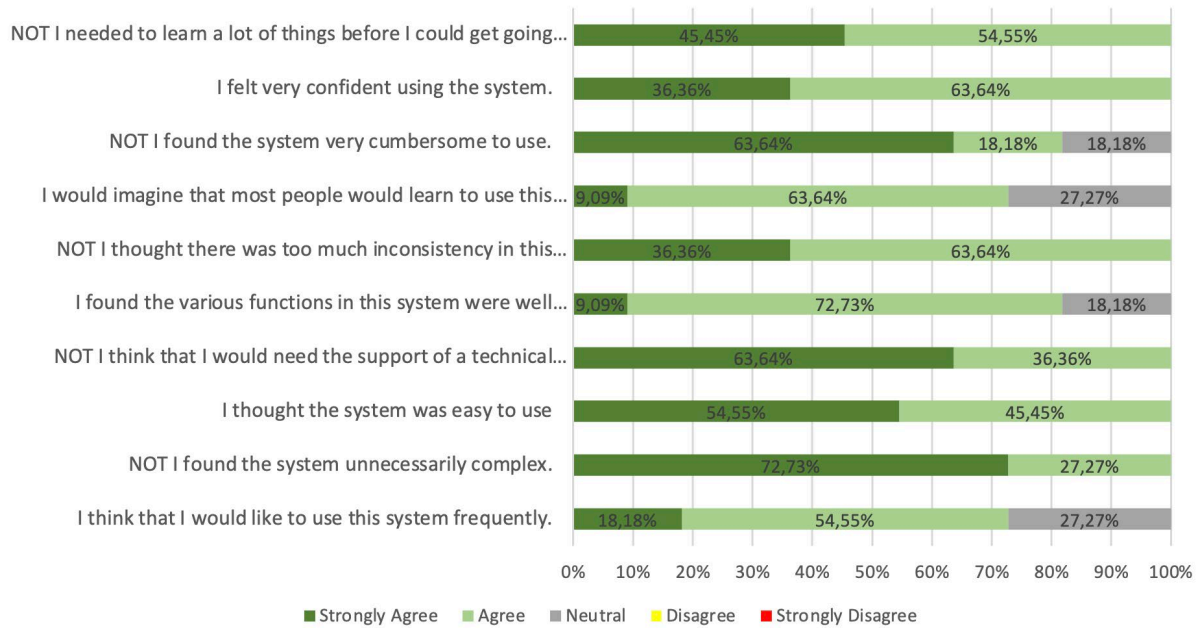Legend: ■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

Figure 5: Chart of the System usability questions

4.Conclusions

During this second iteration WP7 set up an exhaustive set of interviews that globally involved 21 participants distributed as follow:
- 17 patients and 2 informal caregivers selected from the AIMAC networks and from ICSM and NKI Hospital
- 11 health professionals from ICSM and NKI hospitals

Two different types of protocols have been applied, according to the participant profile (see documents in the annex).

The overall results demonstrate that CAPABLE is a usable (patient app 80,66 and clinical dashboard 82,95 out of 100 in the SUS scale) and acceptable (average of 4,1 in patients, 3,8 in health professionals out of 5 of a specific scale of perceived values). The proposed tasks, even if more complex than in the previous study of February 2021 (Reported in D7.3) received an average score of "very easy" (health professional 4,56 and patients 4,37 out of 5). Aside from the quantitative results a list of issues has been generated to improve the app (100) and the clinical dashboard (35) as documented in the annex (Analysis of the issues of the prototypes). The issues were classified as: 1) general design problem that requires a better refinement of the functionality, 2) copy writing issue when related to the contents of the Graphical User Interface, 3) usability issue when related to the difficulties that user found to complete the proposed tasks. The last category includes also the suggested improvements.

The interview took longer than expected (around 1 hour and 15 minutes) basically because some tasks had a higher level of complexity than expected and many screens to analyze. Many quantitative and qualitative information has been gathered with different types of perspective. All these feedbacks will be used to improve the current version of the prototype and to release other versions to be further validated in the next iteration at month 32 (D7.5 Third interim usability and acceptability report).

The consortium right now planned a set of activities to address all the inputs. A preliminary work of systematization of the issues has been done and is presented in the annex, where a list of issues has been organized for the two revised prototypes: the patient app and the web dashboard for the healthcare professionals. Again, User Centered Design demonstrated a very good approach to refine the prototypes and to give to the Consortium a precious feedback on how to improve the system and what could be the impact on the real end-users.

5.Annexes

The following chapter provides links to other documents that are related to the work performed in this deliverable. The Subsections contain the link to the protocol that have been implemented (interviews with patients and health professionals) and a table that recap all the issues on the prototypes that have been identified thank to these activities. Additionally, the links to the prototypes are provided.

Protocol of the patient and health professional interviews

https://drive.google.com/file/d/1ttO0DKj1uVY3SLLeszqY5Gl9TRt5hUOW/view?usp=sharing

Analysis of the issues of the prototypes

https://docs.google.com/spreadsheets/d/1hhUN63sMO6H7vZrslreN2kCUMsHtBb0q1CHg0CqV3DM/edit?usp=sharing

Links of the prototypes

The following table details the link to see the prototypes used in this 2nd evaluation.

Table 13: Links of the prototypes

	Task 1	Rest of the tasks
Italian APP	https://invis.io/Q411B3GZXFGM	https://projects.invisionapp.com/share/Q411B3GZXFGM#/screens/454795540
Duch App	https://invis.io/F611B3GUPMTR	https://projects.invisionapp.com/share/F611B3GUPMTR#/screens/454796004
English App	https://invis.io/CE118W9CFST9	https://projects.invisionapp.com/share/CE118W9CFST9#/screens/454229097
Clinical Web Tool	https://invis.io/2511A4IPP9GQ	https://invis.io/F311B3WE8T4Q