

Usability and Usefulness Testing of a Symptom Management and Coaching System for Cancer Patients treated with Immune Checkpoint Inhibitors: a Comparative Qualitative Study

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Abstract

Background: The prognosis for patients with several types of cancer has substantially improved since the introduction of immune checkpoint inhibitors. However, patients may experience symptoms both from the cancer itself and from the medication. EHealth applications can help support patients, their informal caregivers, and care providers during cancer treatment and follow-up. A prototype of the eHealth tool Cancer Patients Better Life Experience (CAPABLE) was developed to facilitate symptom reporting, patient education, and wellbeing interventions, aimed for melanoma and renal cell carcinoma patients treated with immunotherapy.

Objective: To evaluate the CAPABLE prototype by conducting tests to assess usability, user experience and perceived acceptability amongst end-users, and secondarily to assess any agreements or differences in the results of our wide range of participants.

Methods: This usability study was executed by interviewing patients with melanoma, renal cell carcinoma or other cancer types. Participants were asked to give their opinion on the concept of the tool, to perform think-aloud tasks and to complete the System Usability Scale and a Perceived Usefulness questionnaire. The interviews were analyzed by independent coding. The extracted usability problems were mapped to an eHealth Usability Problem Framework.

Results: We included 21 participants in the study, aged 29 to 73 years; 13 melanoma or renal cell carcinoma patients who had received immunotherapy and 8 patients with other types of cancer who had not received immunotherapy. In total, 76 usability issues were identified. Most usability problems were in the task-technology fit category of the framework. Critical problems regarding the symptom monitoring functionality were mainly found by participants who had received immunotherapy.

Conclusions: Despite identified usability issues, participants responded positively in the perceived acceptance and usefulness questionnaire regarding the evaluated tool. Further analysis of the usability problems indicates that it was essential to include participants who matched the target end-users. Participants treated with immunotherapy, specifically with previous experience in immune-related adverse events encountered critical problems with symptom reporting that would not have been identified if

these participants were not included. For other tasks and functionalities, it seems likely that loosening the inclusion criteria would have resulted in sufficient feedback without critical missing usability issues. Clinical Trial: Not applicable.

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Original Manuscript

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Original paper

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Background:

The prognosis for patients with several types of cancer has substantially improved since the introduction of immune checkpoint inhibitors. However, patients may experience symptoms both from the cancer itself and from the medication. EHealth applications can help support patients, their informal caregivers, and care providers during cancer treatment and follow-up. A prototype of the eHealth tool Cancer Patients Better Life Experience (CAPABLE) was developed to facilitate symptom reporting, patient education, and wellbeing interventions, aimed for melanoma and renal cell carcinoma patients treated with immunotherapy.

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We included 21 participants in the study, aged 29 to 73 years; 13 melanoma or renal cell carcinoma patients who had received immunotherapy and 8 patients with other types of cancer who had not received immunotherapy. In total, 76 usability issues were identified. Most usability problems were in the task-technology fit category of the framework. Critical problems regarding the symptom monitoring functionality were mainly found by participants who had received immunotherapy.

Conclusions:

Despite identified usability issues, participants responded positively in the perceived acceptance and usefulness questionnaire regarding the evaluated tool. Further analysis of the usability problems indicates that it was essential to include participants who matched the target end-users. Participants treated with immunotherapy, specifically with previous experience in immune-related adverse events encountered critical problems with symptom reporting that would not have been identified if these participants were not included. For other tasks and functionalities, it seems likely that loosening the inclusion criteria would have resulted in sufficient feedback without critical missing usability issues.

Key words: eHealth, oncology, qualitative research, usability

Introduction

The prognosis for patients with several types of cancer has substantially improved since the introduction of immune checkpoint inhibitors [1–4]. However, patients may experience symptoms both from the cancer itself and from the medication, including immune-related adverse events, as well as the stress of the disease and treatment on their mental wellbeing [2–5]. EHealth applications can help support patients, their informal caregivers, and care providers during cancer treatment and follow-up [6,7].

For example, eHealth applications in cancer treatment are used to facilitate timely symptom reporting by the collection of patient-reported outcomes, by providing information for patients and caregivers on diagnosis, treatment and side-effects, and by giving patients access to home interventions for physical and mental wellbeing [8,9]. While there's conclusive evidence on the impact on eHealth on perceived support and knowledge levels, there are inconsistent findings for outcomes related to quality of life, self-management and physical or mental wellbeing [6,10]. These potential benefits of eHealth applications are partially dependent on their ease of use, perceived usefulness and eventual user acceptance [11].

It is known that user-centered design (UCD) processes for these types of eHealth applications may benefit system usability and user acceptance [12]. Better usability can lead to benefits such as enhanced user wellbeing and reduced risk of harm [13]. A significant part of UCD is evaluating applications using a Usability Evaluation Method (UEM). Most UEMs highlight the importance of doing so with the intended end-users of the product in order to accurately extract and understand usability problems of target users [14]. The International Organisation for Standardisation (ISO) standard for health and wellness apps states if the app is specifically designed to cater to individuals with a particular health condition, testing should involve participants with that condition [15]. However, the characteristics of the intended end-users for health applications might not be strictly defined, or the intended end-users might consist of a broadly-defined, heterogeneous patient population [16]. Thus, it is not always clear which user characteristics should be considered when recruiting representative participants. In addition, it may be difficult for researchers to find patients who fit a particular profile, forcing them to adjust their inclusion criteria.

Prior to this study, we developed a prototype of the eHealth tool Cancer Patients Better Life Experience (CAPABLE). This tool facilitates symptom reporting, patient education and wellbeing interventions [17]. The prototype was developed in an iterative manner based on user-centered design principles [6]. The tool is intended for melanoma and renal cell carcinoma patients treated with immunotherapy, and their healthcare providers. During development, we aimed to consider various aspects of implementation for these different patient populations in different countries. The pilot study of CAPABLE will focus on these specific patient populations [18]. However, it is intended to be useful for a more general population of patients with cancer who are undergoing treatment. It is not known whether certain usability problems would only be evident to patients whose condition closely resembles patients in the trial, or if a broader group of patients would lead to identification of a broader range of potential usability issues. This is particularly relevant for systems like CAPABLE, intended for use by patients with serious health complaints, who ethically should only be asked to participate in tasks where their time and effort are truly needed.

Therefore, we aimed to evaluate the CAPABLE prototype by conducting tests to assess usability, user experience and perceived acceptability amongst end-users. A secondary objective of the study is to assess any agreements or differences in the results of our wide range of participants in the usability

studies, considering the different countries, hospitals, and patient populations.



Methods

The CAPABLE prototype was developed by a multidisciplinary Consortium, as part of the CAPABLE Project [17]. The overall aim of the project is to explore the effect, usability and feasibility of the CAPABLE tool in a pilot study with melanoma and renal cell carcinoma patients, during treatment with immune-checkpoint inhibitors [19]. This usability study was performed as part of the user-centered design process, through a think-aloud approach where potential end-users, patients, caregivers, were asked to execute scenario-based tasks using the CAPABLE prototype [20,21].

Recruiting and inclusion

Three recruiting organizations participated in the study, the Netherlands Cancer Institute-Antoni van Leeuwenhoek (NKI-AvL) in The Netherlands, Istituti Clinici Scientifici Maugeri (ICSM) in Italy, and the Italian Association of Cancer Patients, Relatives and Friends (AIMAC).

We aimed to recruit three participant groups; individuals diagnosed with melanoma, those with renal cell carcinoma, and participants (or their caregivers) diagnosed with other types of cancer. For each participant group, our goal was to recruit seven to nine participants. The recommended number of participants varies in literature, ranging from five participants to ten participants. We chose seven to nine participants per group to reduce the risk of missing usability problems while being sensible to time and resource constraints [22,23]. The inclusion criteria and recruitment strategies are described in *Table 1*. Written informed consent was obtained from all participants. This study was approved by the Institutional Review Boards of the Amsterdam UMC.

Table 1 Inclusion criteria and recruitment strategies across the three participating centers.

	NKI-AvL	ICSM	AIMAC
Participant	Adult patients	Adult patients	Adult AIMAC members or their informal caregivers
Diagnosis	High risk (resectable stage III) or advanced (stage IV and unresectable stage III) melanoma	Renal cell carcinoma	Any type of cancer
Treatment	During or after treatment with immune checkpoint inhibitors	During or after treatment with immune checkpoint inhibitors	Any type of treatment
Language	Sufficient understanding of the Dutch language	Sufficient understanding of the Italian language	Sufficient understanding of the Italian language
Recruitment	Purposive sampling strategy to obtain a sample that varied in age. Participants were invited by their treating clinician.	Purposive sampling strategy to obtain a sample that varied in age. Participants were invited by their treating clinician.	Open enrolment recruitment from volunteering patient network

The CAPABLE prototype

The CAPABLE prototype was developed by a multidisciplinary consortium with a user-centered design approach. During the kick-off of the CAPABLE project, preliminary interviews were done with patients to gain a first understanding of their needs for an eHealth application. Next, semi-structured interviews were conducted at NKI and ICSM with potential end-users, including patients, caregivers and healthcare professionals, to elicit their specific needs and requirements [7]. With these results, the system specifications and requirements were identified and translated into functionalities of the prototype. A preliminary usability testing round using heuristic evaluation methods was performed using a static prototype.

We used the Invision software to create a full clickable prototype of the CAPABLE application. See Figure 1 for an excerpt of the app screens [24].

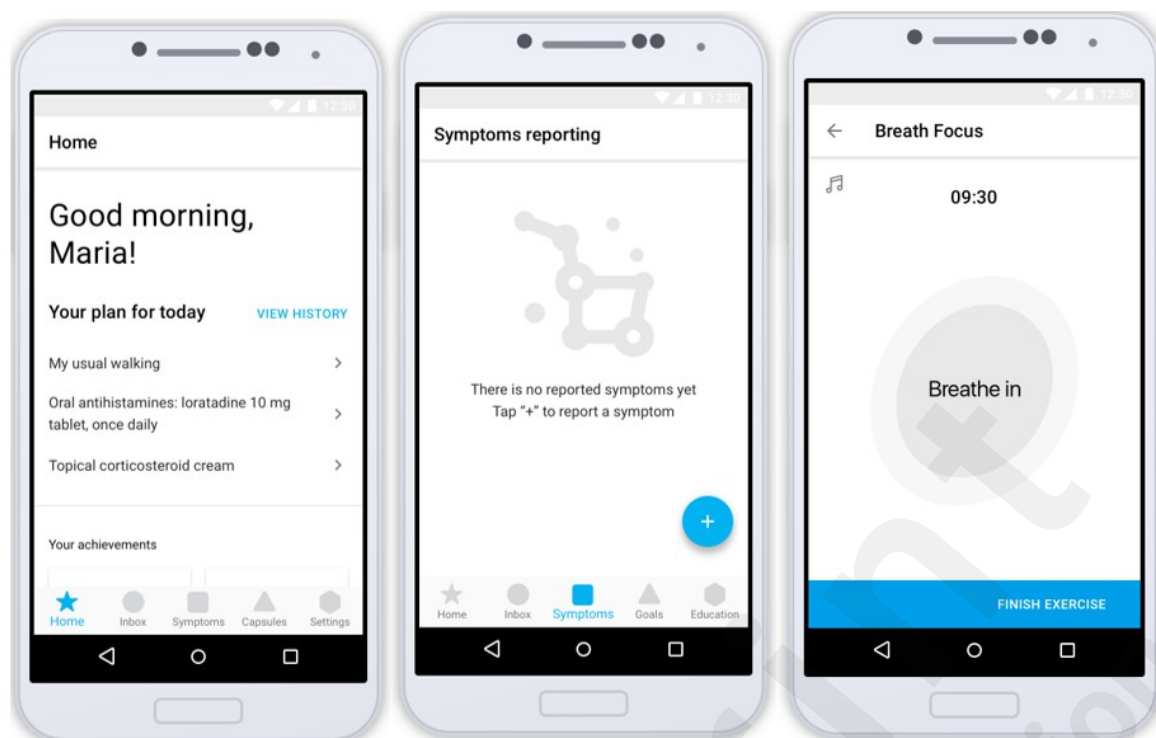


Figure 1 Excerpt of app screens from the CAPABLE prototype.

The mobile application for patients consists of five different sections to facilitate symptom reporting, wellbeing interventions and patient education.

- Homepage - contains a daily plan for patients to follow, including their hospital appointments, links to patient questionnaires, and suggestions for wellbeing interventions.
- Inbox - contains messages, recommendations and reminders regarding their symptoms and wellbeing interventions.
- Symptom reporting - allows users to report their symptoms.
- Goals – provides wellbeing goals such as improving sleep, physical wellbeing, and mental wellbeing, and offers corresponding theory-driven digital behavior change interventions including breathing exercises, meditation, and walking activities [25].
- Education - contains information about melanoma and renal cell carcinoma, treatments including targeted therapy and immunotherapy, side effects, supportive care, and nutrition.

Interviews

The interviews were performed by two research teams. The interviews at NKI-AvL were performed in Dutch by two female PhD candidates with prior interviewing experience [I.F and S.G]. The interviews at ICSM and AIMAC were performed in Italian by a female researcher [V.T], a male senior researcher [M.O] and a research assistant with previous experience as a healthcare professional [F.D]. Two participants from NKI-AvL had participated in a previous interview with the NKI research team to elicit specific needs and requirements for the CAPABLE tool. The researchers had no clinical relationship with nor did know the remaining participants. A collaborative training session was held with all interviewers to streamline the usability evaluation methods used in the interviews as much as possible.

Due to the COVID-19 pandemic, interviews were done online using video-conferencing tools Microsoft TEAMS and Zoom. The interviews were recorded using the screen- and audio capture functionalities of these tools. The planned duration of the interviews was 45-60 minutes. The interviews were conducted in three phases. See *Multimedia Appendix 1* for the interview protocol.

Phase I: Introduction

The interview started with completing a baseline questionnaire on patient demographics, and the user experience with smartphones and technology. This was followed by a short presentation about the CAPABLE system and a few open-ended questions regarding the participant's opinion on the proposed goals and functionalities of the mobile application. Then, the interviewer explained the concept of the think-aloud phase of the interview. The participants were informed that the purpose of this phase is to evaluate the app's performance, and that the method required them to talk about what they are doing and thinking whilst using the app.

Phase II: Think-aloud tasks

The participants were asked to complete five tasks in total. These tasks were developed in cooperation with research team members and the developer. The tasks were the following:

1. Go through introduction, check notifications, and report an activity.
2. Report an itch symptom in the patient role.
3. Report a fever symptom in the caregiver role.
4. Find and perform a deep breathing exercise.
5. Find and review information about skin toxicity.

Phase III: Final questionnaires and comments

After the think-aloud phase of the interview, the participants were asked about their final opinions, suggestions, or functionalities that they missed in the app. Then, we administered the System Usability Scale (SUS) survey, a 10-item questionnaire [26]. Finally, the participants were asked to fill an 11-item questionnaire on Perceived Usefulness, based on the Technology Acceptance Model [27]. For both questionnaires, each item contains a statement which the participant is asked to rate based on a five-point scale, ranging from Strongly agree to Strongly disagree (*Multimedia Appendix 2*).

Data Analysis

Qualitative analysis

Coding of interview recordings

The interviews were audio and video recorded. The Dutch NKI interviews and the Italian ICSM/AIMAC interviews were analyzed using several steps of reviewing, coding, and revision, described in Figure 2. The coding was done by the same researchers who conducted the interviews [S.G. and I.F.], plus N.v.B., an MSc in Medical Informatics. The coding was done in English. These steps resulted in two codebooks; the Dutch NKI codebook and the Italian ICSM/AIMAC codebook.

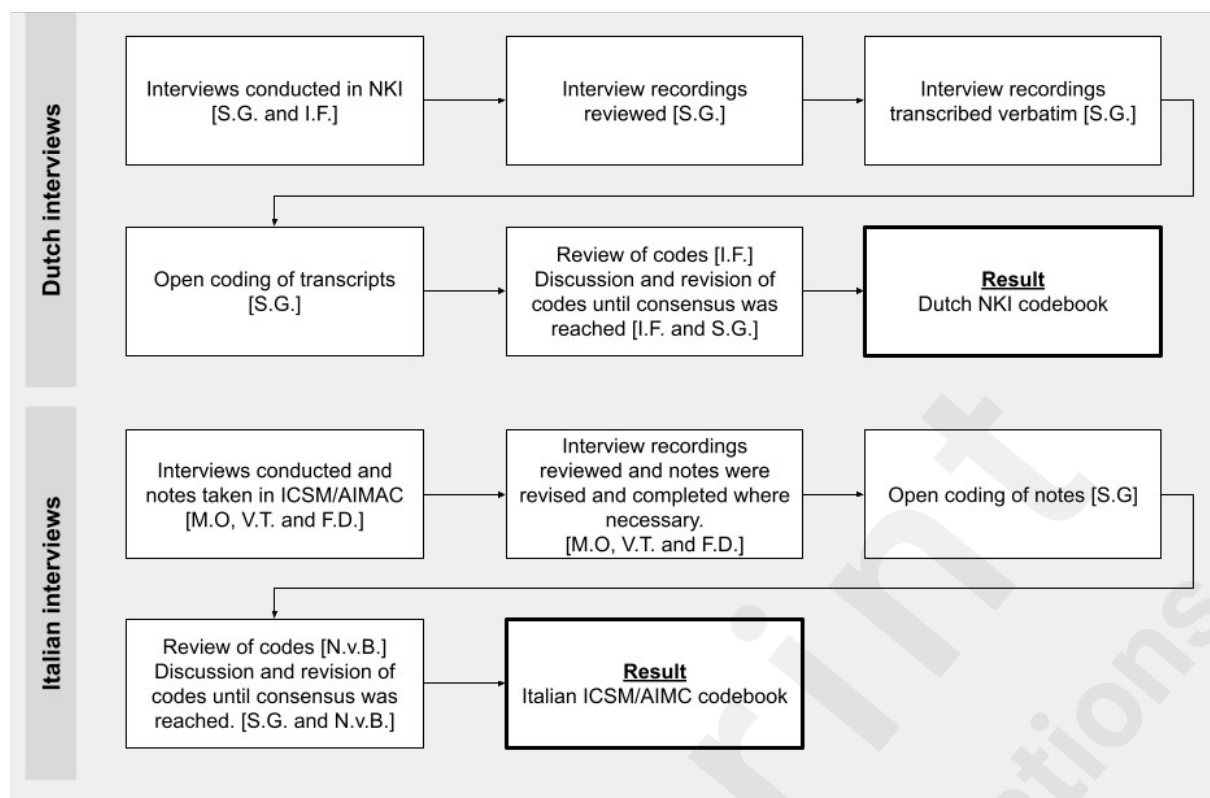


Figure 2 Steps executed for the coding of interview recordings.

Data quality check

We conducted a data quality check before merging the two codebooks. The reason for this check was that two distinct research teams performed the interviews, and the raw data used to code the interviews varied, with the Italian interviews being coded using interview notes and the Dutch interviews using transcriptions. Two Italian interviews and two Dutch interviews were transcribed and independently coded by researchers from both research teams (S.G. and V.T.). The codes based on the transcript and the codes based on the notes of the respective Italian interviews were compared, to assess whether coding based on notes and coding based on transcripts was comparable. In addition, the independently coded interviews were compared to ensure whether the interpretation of the data was similar between the two research teams. Transcripts were considered comparable if both reviewers agreed that there were no substantial differences or omissions in the codes results.

Unifying the codebooks and analysis of the usability problems

After merging the two codebooks, we revised the codes to come to a unified final codebook. Finally, several steps were taken to extract and analyze the usability problems found in the interviews. See Figure 3.

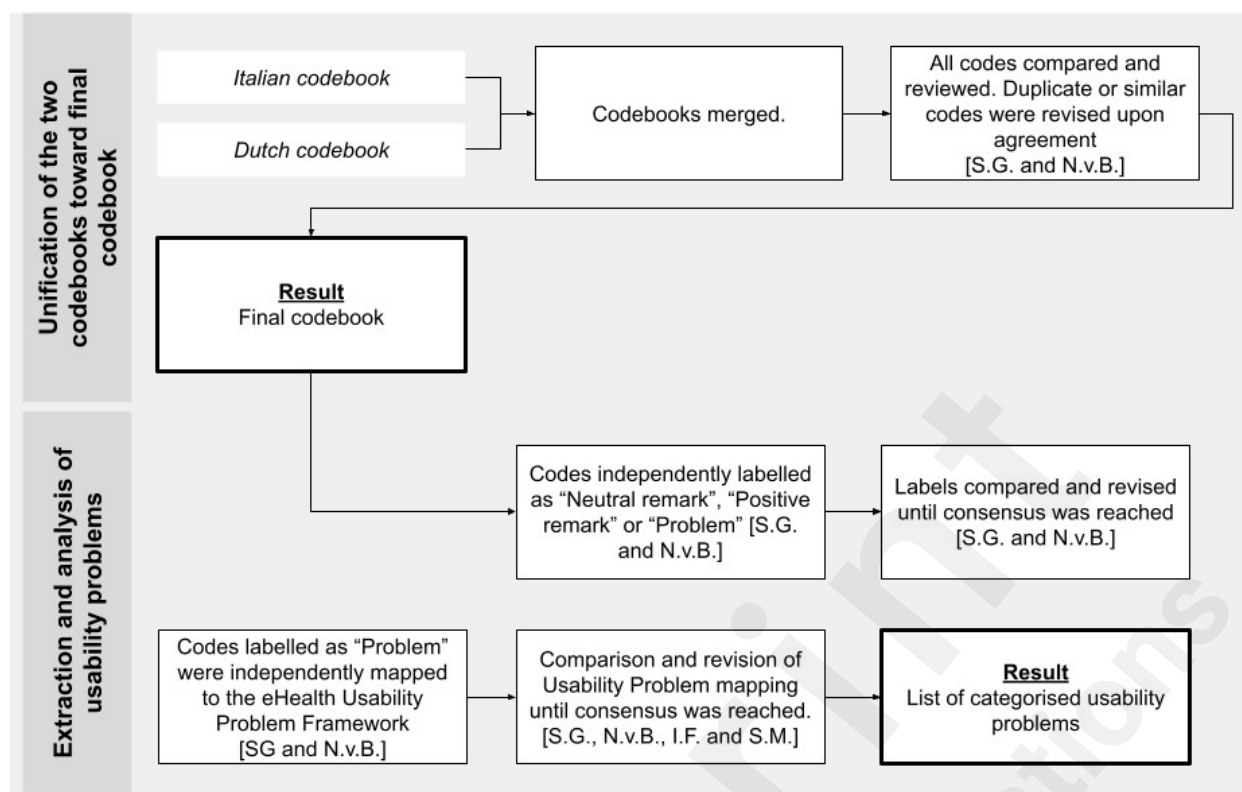


Figure 3 Steps executed for merging the two codebooks and analysis of the usability problems.

First, we labelled all codes as “Positive remark”, “Neutral remark” or “Problem” to allow us to focus on the usability problems indicated by the participants. Next, we mapped the “Problem” codes in the codebook to an eHealth Usability Problem Framework developed by Broekhuis et al. [9] This framework specifies 21 usability problems in the following categories: basic system performance, task-technology fit, accessibility, interface design, navigation and structure, information and technology, guidance and support and satisfaction. This mapping process was done by S.G. and N.v.B. in three different cycles, independently mapping and comparing the mappings reaching consensus. Any discrepancies were discussed with I.F. and S.M. The qualitative analysis was conducted without the use of any specialized software.

Quantitative analysis

The participants’ characteristics were analyzed using descriptive statistics. We assessed the effectiveness of the participants performing the tasks according to three measures: 1) completed with ease, 2) completed with difficulty, 3) failed to complete. We defined completed with difficulty as completed while needing to receive hints from the interviewer. Giving hints was done to ensure that the participant would have the opportunity to review all content of the app and allow the researchers to obtain additional information about the usability of the application regardless of the completion status of the task. The SUS survey and Perceived Usefulness questionnaire results were analyzed using the SUS scoring algorithm and frequency analysis to evaluate the perceived usability and usefulness of the CAPABLE app.

Results

Participant characteristics

We conducted 21 interviews in total. The interviews took place between June 2021 and April 2022. The average age of the participants was 53 years. We interviewed 7 melanoma patients, 6 renal cell carcinoma patients, 6 patients with other types of cancer (breast cancer, urinary cancer, lymphoma

and vestibular schwannoma) and 2 caregivers. See Table 2 for an overview of the participants' characteristics. The participants with melanoma and renal cell carcinoma were treated with immune-checkpoint inhibitors. All participants used a smartphone and were familiar with mobile applications. Five participants mentioned having used a health-related mobile application before.

Table 2 Participants' characteristics.

	Treated with immunotherapy?	
	Yes (n=13)	No, N/A (caregiver) (n=8)
Gender, n		
Male	6	6
Female	7	2
Age, years		
Mean (SD)	52 (11)	56 (14)
Range	32-71	29-73
Type of cancer, n		
Melanoma III-IV	7	
Kidney I-II	4	
Kidney III-IV	2	
Breast I-II		1
Breast III-IV		2
Lymphoma		1
Urinary IV		1
Vestibular schwannoma I-II		1
N/A (caregiver)		2
Treatment status, n		
On treatment	8	4
Off treatment	5	2
N/A (caregiver)		2
Living situation, n		
Alone	2	1
With relatives	11	6
Shared housing		1
Type of smartphone, n		
Android	6	5
iOS	7	3

Task completion

We measured the effectiveness of the participants performing tasks by completion rates. See Table . Participants found Task 1, *go through introduction, check notifications and report an activity*, and Task 3, *Report a fever symptom in a caregivers' role*, the most challenging. Task 5, *find and review information about skin toxicity*, had the highest completion rate. Participants that were not treated with immunotherapy seemed to struggle more with the symptom reporting tasks (Task 2 and Task 3).

Table 3. Task completion, efficiency per group.

	Task 1 <i>Introduction & homepage</i>		Task 2 <i>Symptom reporting & response inbox (Itch as patient)</i>		Task 3 <i>Symptom reporting & response inbox (Fever as caregiver)</i>		Task 4 <i>Coaching, goals & activities</i>		Task 5 <i>Patient education</i>	
	Treated with immunotherapy?									
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Completed with ease	8 (62%)	5 (63%)	11 (85%)	4 (50%)	10 (77%)	3 (38%)	9 (69%)	5 (63%)	11 (85%)	8 (100%)
Completed with difficulty	5 (38%)	3 (37%)	2 (15%)	4 (50%)	3 (23%)	5 (62%)	4 (31%)	3 (37%)	2 (15%)	0 (0%)

Usability problems

The participants identified 76 distinct usability problems and proposed fifteen additional features missing in the CAPABLE application. The first task ‘Go through introduction, check notifications and report an activity’ resulted in 31 issues; the second and third task ‘Report an itch symptom in a patients’ role’ and ‘Report a fever symptom in a caregivers’ role’ resulted in 24 issues; the fourth task ‘Find and perform a breathing exercise’ resulted in 16 issues; and the final fifth task ‘find and review information about skin toxicity’ resulted in 12 issues. Eight problems recurred in multiple tasks.

Table 3 shows an overview of the eHealth Usability Problem Framework [28] and the count of usability problems found per usability factor. The category with the highest number of usability problems is the task-technology fit category, which relates to the match between the system on one hand, and the user, their context of use and their health goals on the other hand. Of these, 23 usability issues were found by both participants that received immunotherapy and participants that did not receive immunotherapy, 31 issues were solely found by participants who received immunotherapy, and 22 issues were solely found by participants who did not receive immunotherapy. Table 5 shows an overview of all usability issues that were indicated by more than one participant, resulting in 32 problems. See Multimedia Appendix 3 for the complete table of usability issues. We discuss the usability problems that participants most frequently indicated during the study in the following section.

Table 3 Usability problems, count per usability factor and usability factor category (number of distinct usability problems found per category)

Usability factors	#issues found by both groups	#issues found only by immunotherapy group	#issues found only by non-immunotherapy group	#total issues
Basic system performance	1	1		2
general system interaction	1	1		2
Task-technology fit	6	9	7	22
fit between system and context of use	1	2	1	4
fit between system and health goals	3	2	3	8
fit between system and user	2	5	3	10
Interface design	2	5	4	11
design clarity		2		2
interface organization	1	1	1	3
readability of texts	1		2	3
symbols, icons, and buttons		2	1	3
Navigation and structure	4		1	5
navigation	3		1	4
structure	1			1
Information and terminology	6	3	6	15
health-related information	4	3	5	12
system information	2		1	3
Guidance and support	1	7	1	9
procedural health-related information	1	6	1	8
procedural system information		1		1
Satisfaction	3	6	3	12
satisfaction with system	2	2	1	5
satisfaction with system's ability to support health goals	1	4	2	7
Total	23	31	22	76

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Table 4 Count of usability problems indicated by at least two participants, divided by immunotherapy yes / immunotherapy no.

		Treated with immunotherapy?	
		Yes	No
	Introduction & homepage		
Task-technology fit	current list of hobbies not sufficient	2	2
	expects automatic detection of activities by smartwatch	3	1
	time of going to bed is different every day	2	
	unclear what the added value is of recording exercises/activities	2	
	allow user to write down why they did or did not like the challenge	2	
	not possible to select multiple hobbies	1	1
	need for balance between coaching, support for symptoms, and support for cancer treatment in content		2
Interface design	text is too long	5	2
	participant prefers graphical explanations to textual explanations		2
Navigation and structure	link between times of waking up/going to bed and the symptom management unclear	1	1
Information and terminology	unclear what vital functions in homepage are	2	
Satisfaction	tone in the introduction text is not appreciated	1	1
	Symptom reporting & response inbox		
Basic system performance	not clear that scrolling was necessary to view everything in screen	6	5
Task-technology fit	information missing about medication in recommendation (dosage, need for prescription, where to get it)	7	1
	symptom descriptions do not match experience of itch of the patient, would be difficult to choose	6	
	feedback missing after report	1	5
Navigation and structure	participant cannot find symptom section easily	3	1
Information and terminology	term caregiver is unclear, caregiver can be a professional or family/friends visiting	1	1
Guidance and support	Unclear if the clinician will view the report, if patient will be contacted and what is expected of patient	4	
	Missing from instructions that caregivers can report symptoms	2	
Satisfaction	symptom reporting process seems long/steps redundant	1	1
	participant does not trust the feedback from the app	1	1
	Coaching, goals & wellbeing interventions		
Task-technology fit	expects automatic detection of activities by smartwatch		3
	unclear how users can set their own goals		2
	unmet expectation of the app recommending a schedule with activities, which can be personalized	2	2
	Participant cannot find the exercise easily	7	2
Navigation and structure	Participant cannot find the exercise easily	7	2
	names of types of breathing exercises are not self-explanatory	4	1
Information and terminology	menu term 'objectives/goals' does not match with content found	2	1
	unclear how goals relate to the activities	4	
Guidance and support	Invitation for wellbeing intervention is not clear, not self-explanatory what it is and how to proceed	10	7
	content, purpose, and benefits of wellbeing interventions not sufficient currently	3	
	Patient education		
Interface design	reorganize the categories and structure of the educational content list	1	3
Navigation and structure	participant cannot find educational section easily (clicks on symptoms first)	1	3
Information and terminology	first part of the text is difficult to understand without in-depth knowledge	1	2
	education not the correct term for section	1	2
	rash and itching are not translated	1	1
Total		128	85

Qualitative assessment of usability issues

Introduction & homepage

Task-technology fit The CAPABLE app asks the user to select their hobbies from a pre-defined list. This selection is used to recommend similar activities. Participants could not find their own hobbies in this list, and were unable to select more than one hobby.

Interface design In the introduction, the text to explain the purpose and functionalities of the CAPABLE app was deemed too long by some participants (5/13 immunotherapy group, 2/8 non-immunotherapy group), and participants stated a preference for more graphical explanations.

Symptom reporting & feedback inbox

In general, it was not always clear to participants that scrolling was necessary to view everything on screen (6/13 immunotherapy group, 5/8 non-immunotherapy group).

Task-technology fit Participants experienced problems when reporting an “Itch” symptom using the symptom reporting function in the app. The app presents a set of symptom descriptions to choose from. Participants that had experienced itching due to immunotherapy found it difficult to choose one of those descriptions, as none of them matched their own experiences with the symptom (6/13 immunotherapy group, 0/8 non-immunotherapy group). During the think-aloud task, the app recommended an emollient cream for the itch symptom reported by the participants. While participants appreciated the advice, they found the message incomplete, as they were not sure what the exact dosage of the cream would be, if a prescription would be needed and where to acquire the medication (7/13 immunotherapy group, 1/8 non-immunotherapy group).

Guidance and support After reporting the symptom, participants were confused about the next steps in the process. A subset of participants from the immunotherapy group (4/13) expressed uncertainty on whether a clinician would view the report, in which cases they would be contacted by the clinician and what was expected of them as a patient.

Coaching, goals & activities

Task-technology fit The section ‘Goals’ in the app contains a list of exercises and activities. These can be filtered by their goal, including supporting mental wellbeing, physical wellbeing, sleep, and acceptance. The connection between the name of the section and the list of activities was perceived as unclear and confusing by some participants. As a result, when asked to find a breathing exercise in the app, it was not always obvious for participants to click on the “Goals” button from the homepage (7/13 immunotherapy group, 2/8 non-immunotherapy group). In addition, while participants appreciated the ability to easily select and do an exercise, it was unclear how often to do these activities and how to schedule activities in the daily plan on the home page of the app (4/21). Participants were also confused about wearing a smartwatch while the app requires manual registration of exercises such as walking.

Guidance and support Users receive an invitation in the CAPABLE app inbox to participate in an activity, such as a daily walking challenge. While users are immediately prompted to accept this challenge, most participants (17/21) found it unclear in the invitation what is expected of them, how they should proceed, where they can see the content of this program in the app, and whether and where they should register doing these activities.

Patient education

Navigation and structure Participants were asked to find information about skin adverse events due to immunotherapy. Some participants (1/13 immunotherapy group, 3/8 non-immunotherapy group) had trouble finding the correct section in the app and clicked on the “Symptom management” section instead of the “Education” section.

Information and terminology Some participants (3/21) indicated that the text in the example section shown during the interview was challenging to understand without in-depth knowledge.

Perceived Usefulness and System Usability Scale

The participants filled in a questionnaire aiming to measure their acceptance and perceived usefulness of the CAPABLE app. Overall, participants were positive about nearly all statements. For eight out of ten questions, more than 75% of participants “agreed” or “strongly agreed” (Figure 4). The statements that were most widely agreed upon were that the system would easily fit in users’ daily routine, could help healthcare professionals to follow up on patients’ wellbeing, could improve communication with the care team, could help users cope with their treatment, and could help users support their quality of life. Participants were more skeptical about the CAPABLE application helping to manage emotions such as anxiety and stress and the ability of the application to help cope with daily life problems. The results of the questionnaire were comparable between the participant group treated with immunotherapy, versus the group not treated with immunotherapy. Finally, the participants were asked to fill in the System Usability Scale questionnaire. The mean SUS score was 80 (\pm 11).

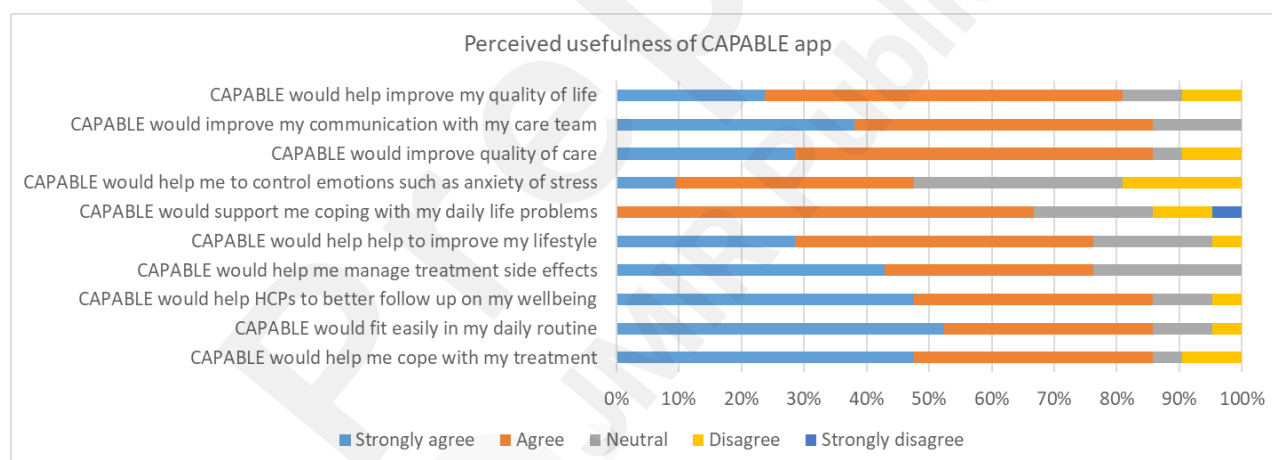


Figure 4 Stacked bar chart of the perceived usefulness questionnaire outcomes.

Discussion

Principal findings

We evaluated the prototype of the CAPABLE app, a symptom monitoring and coaching system, with 21 participants divided in two groups, participants that had received immunotherapy (melanoma and renal cell carcinoma patients) and that had not received immunotherapy (other cancer types), from The Netherlands and Italy. This evaluation was executed by use of think-aloud interviews. In total, 76 usability issues were identified. Specifically, 23 usability issues were identified by both groups. The immunotherapy group found 31 additional issues, and the non-immunotherapy group found 22 additional issues.

Most usability problems were in the task-technology fit category of the eHealth Usability Problem Framework. This is reflected in problems encountered in the coaching section of the app. The participants' mental model, defined as what a user knows, believes about and expects from a system [29], did not match with the design and presentation of the digital behavior change interventions. Participants expected to be able to set their own goals, and thought that the app would suggest a recommended weekly schedule of activities that can be personalized according to their needs. Problems with task-technology fit were also encountered in creating a symptom report and with the subsequent advice given. Participants that had experienced itching due to immunotherapy found it difficult to choose one of the descriptions given to make a symptom report, as none of them matched their own experiences with the symptom. Additionally, participants felt that the advice provided was insufficient because it lacked information the prescription, use and dosage of the recommended medication, as well as whether to contact their clinician. This set of issues were mainly indicated by participants who had received immunotherapy. This is logical, since patients who received immunotherapy are more likely to have experienced a situation similar to the scenario used in the test, and could assess the fit of the application with their own lived experience.

Despite identified usability issues, participants responded positively in the perceived acceptance and usefulness questionnaire regarding the CAPABLE app. Specifically, they would expect that the CAPABLE app would facilitate at-home monitoring, help patients cope with treatment, and support their quality of life.

Overall, our analysis of the usability problems seems to indicate a necessity of including participants with the characteristics of the intended end-users for the evaluation of certain functionalities. In our case, this meant having the symptom reporting functionality evaluated by patients that had been treated with immunotherapy, specifically with previous experience in immune-related adverse events. For the other tasks and functionalities, it seems likely that loosening the inclusion criteria would have resulted in sufficient feedback without critical missing usability issues.

Comparison with Prior Work

Our study found positive perspectives from participants on measured perceived acceptance and perceived usefulness. This might seem contradictory to the number and severity of usability issues reported. This is reflected in other studies, where participants are enthusiastic about the functionalities and perceived future benefits, while simultaneously encountering difficulties during the usability evaluation [30–32]. Patients' wants and needs seem to be identified clearly in research, while a gap between user needs and eHealth tool implementation might be caused by practical considerations, the adaptability of the tool to local context, complexity factors, and health professionals' uptake of the eHealth application [33].

In addition, we investigated the impact of different user characteristics on usability problems found during a think-aloud evaluation. Previous studies have researched the impact of domain knowledge, specified as the familiarity and/or expertise an individual has with a particular topic or subject area, on finding usability problems [34]. In these studies, the output of novices and experts, with previous expertise with the software or tools evaluated, was compared. In some cases novices found more usability problems, less usability problems, or less usability problems but more severe problems, compared to experts [35–37]. However, our study would define previous domain knowledge not as previous experience with the software, but as *previous experience with the treatment (immunotherapy)* or *previous experience with certain side-effects (itch)*. Previous research found a significant difference between the novice and expert group with previous domain knowledge defined as previous pregnancy [38]. More research is needed on the impact of previous experience with a disease or treatment in the oncology field as part of the users' profile on usability evaluation outcomes.

Strengths and Limitations

This study has several limitations. We did not take health or smartphone literacy into account during recruitment. There might be a selection bias of participants agreeing to the interview as they have an interest in using their mobile phones, or invitees refusing to participate because of limited smartphone literacy. In addition, we did not purposefully recruit participants with certain comorbidities or physical or mental impairments, apart from their cancer diagnosis. However, we recruited a large and varied group of 21 participants, with varying age, different diagnoses, past treatments and countries.

The large and diverse participant group was a strength for collecting broad feedback on the CAPABLE tool and aiming to find a complete overview of potential usability issues. However, due to including participants from multiple centers in both The Netherlands and Italy, we had researchers from two different research teams performing the interviews. A limitation might be that the researchers had varying experience, which might have caused bias. However, nearly all researchers had previous interviewing experience, and a collaborative training session was held with all interviewers to streamline the usability evaluation methods used in the interviews as much as possible. In addition, we had multiple researchers involved in the coding and analysis phase of the study, to reduce the evaluator effect [39].

Finally, the raw data used to code the interviews varied, with the interviews of participants with renal cell carcinoma and other types of cancer being coded using interview notes and the interviews with participants with melanoma using transcriptions. This may have resulted in missing data from incomplete interview notes. However, we executed a data quality check, which indicated that the transcripts provided more context to the codes, but the interview notes resulted in similar codes as the transcripts.

Future work

The usability results of this study were used to improve the CAPABLE prototype. A pilot study involving the final version of CAPABLE is currently being held in The Netherlands and Italy, with different patient populations treated with immune checkpoint inhibitors, including melanoma and renal cell carcinoma patients [19]. The clinical impact and usability of the CAPABLE tool will be evaluated.

Our comparison of the usability problems generated by participants treated with immunotherapy

versus the non-immunotherapy group indicated a difference in output mainly for the symptom reporting functionality of the CAPABLE tool. This comparison was based on qualitative data. Multiple factors may have been involved in the differences of usability problems found in addition to previous experience with the treatment or side-effects, such as age, diagnosis, stadium of disease, health literacy and country. However, our findings implore future studies to focus on exploring and comparing the usability evaluation output of participants with varying previous experience. In addition, future research is needed to determine for which types of software, or which specific functionalities, there would be an added benefit or need for participants with specific characteristics.

Conclusions

While participants identified usability problems regarding task-technology fit, interface design, and overall satisfaction, they responded positively regarding the perceived impact of CAPABLE in monitoring patients from home, helping to cope with treatment, and supporting quality of life. Further analysis of the usability problems indicate that it was essential to include participants who matched the target end-users. Participants treated with immunotherapy, specifically with previous experience in immune-related adverse events encountered critical problems with symptom reporting that would not have been identified if these participants were not included. For other tasks and functionalities, it seems likely that loosening the inclusion criteria would have resulted in sufficient feedback without critical missing usability issues. Future research is needed to determine for which types of software and which specific functionalities, there would be an added benefit or need for participants with specific characteristics.

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Conflicts of Interest

All authors report no conflict of interest.

Multimedia Appendix 1

Think-aloud interview protocol

Multimedia Appendix 2

System Usability Scale and perceived impact questionnaire

Multimedia Appendix 3

Overview of all usability problems and suggestions

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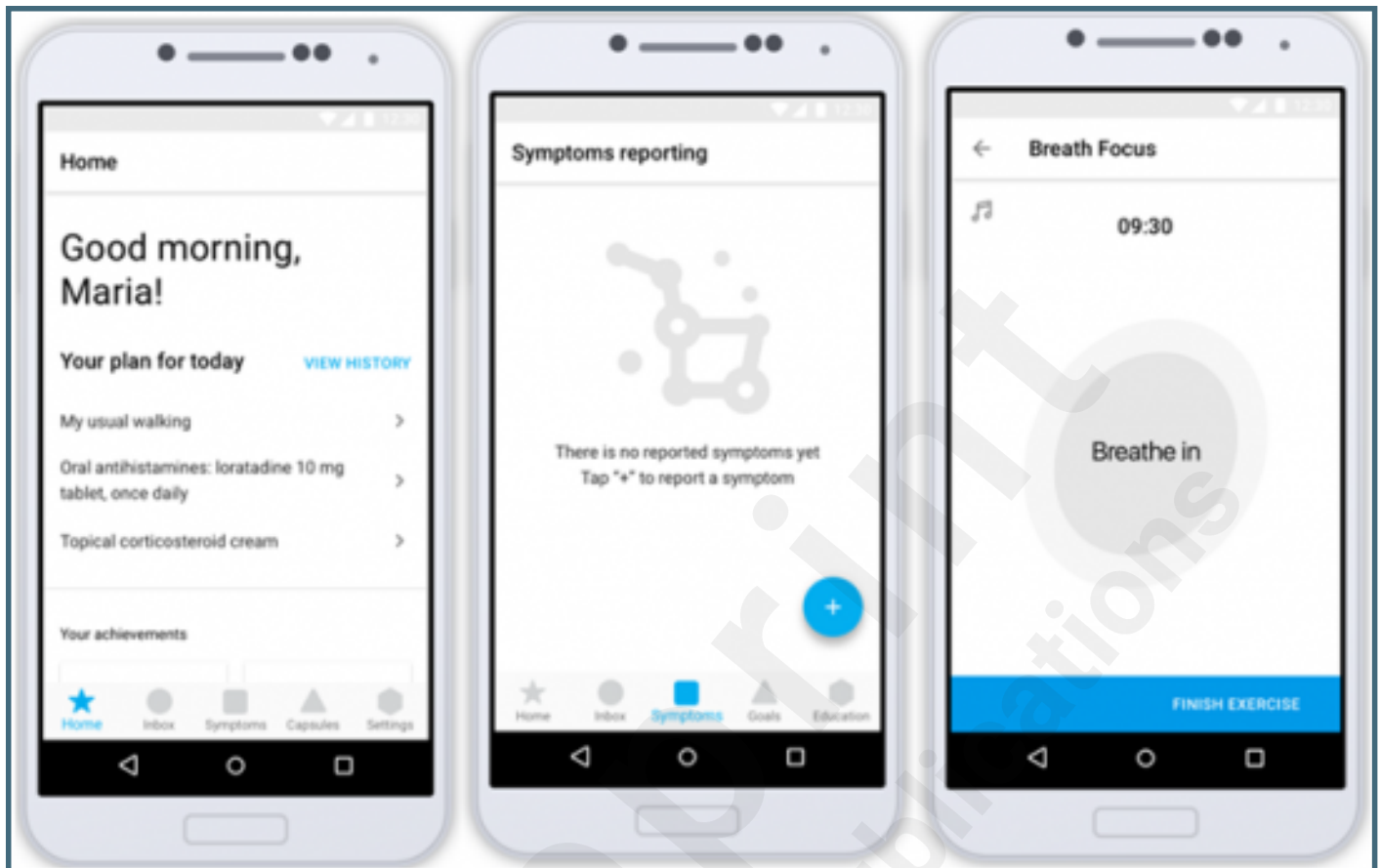
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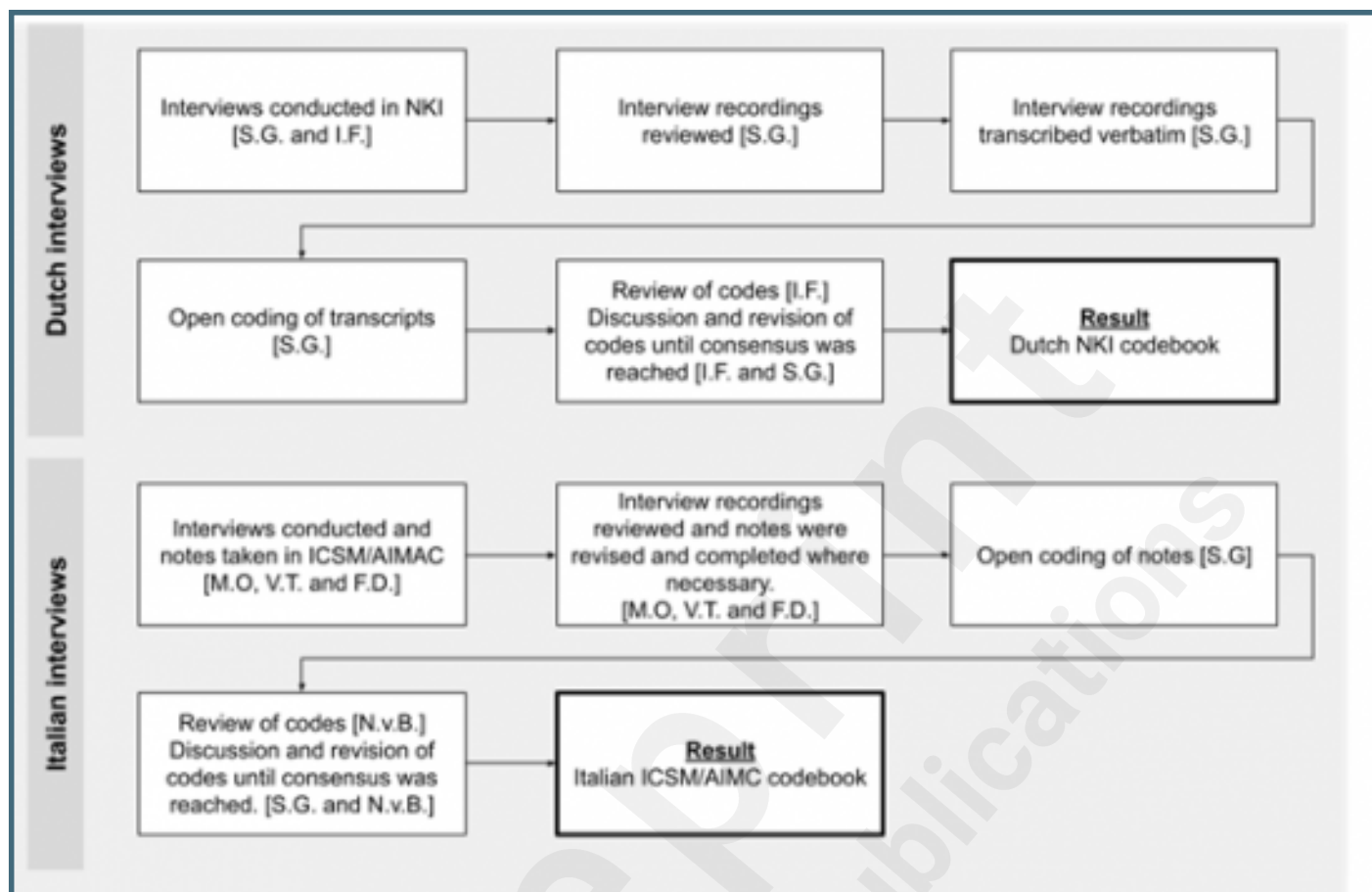
Supplementary Files

Figures

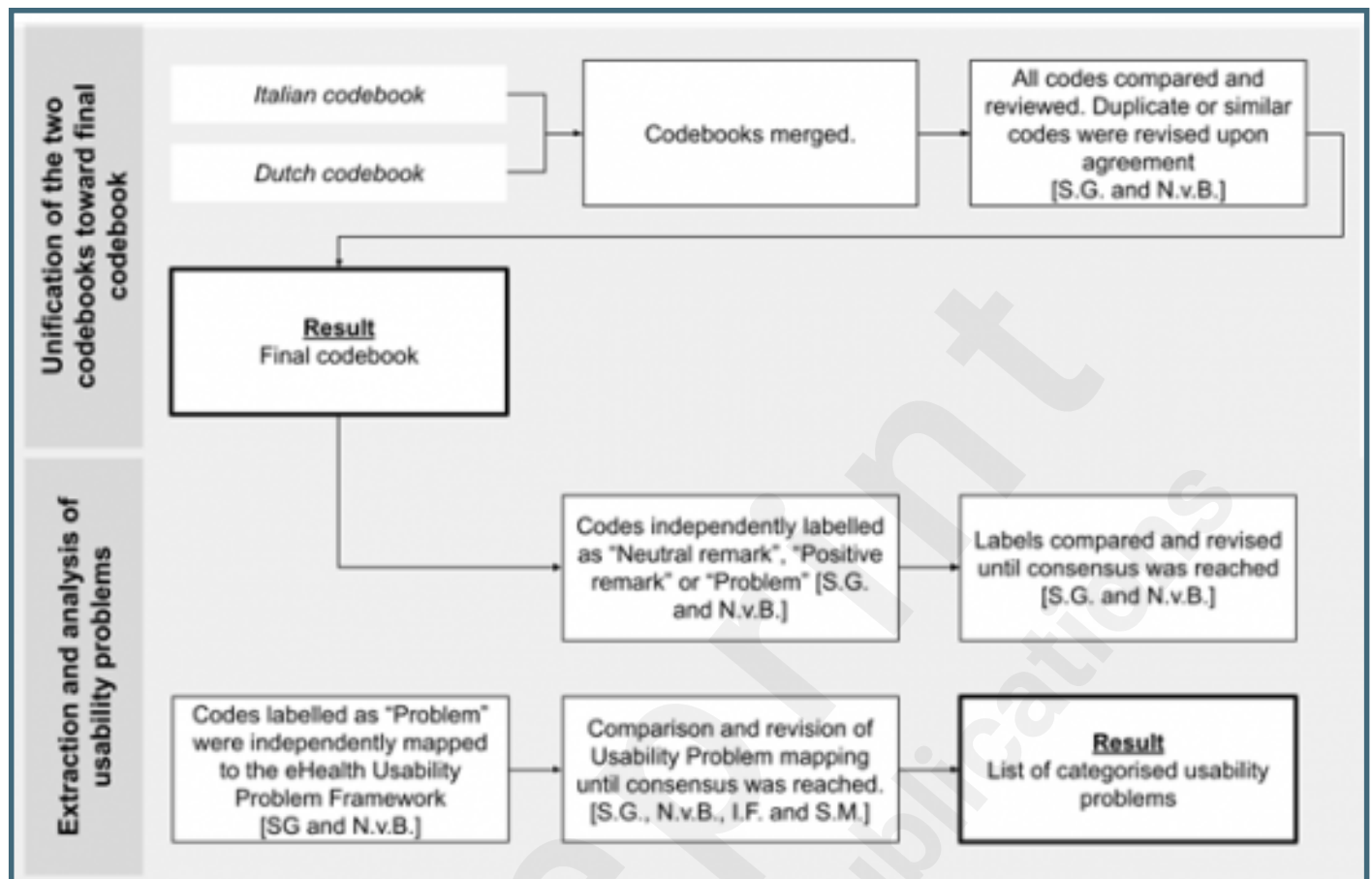
Excerpt of app screens from the CAPABLE prototype.



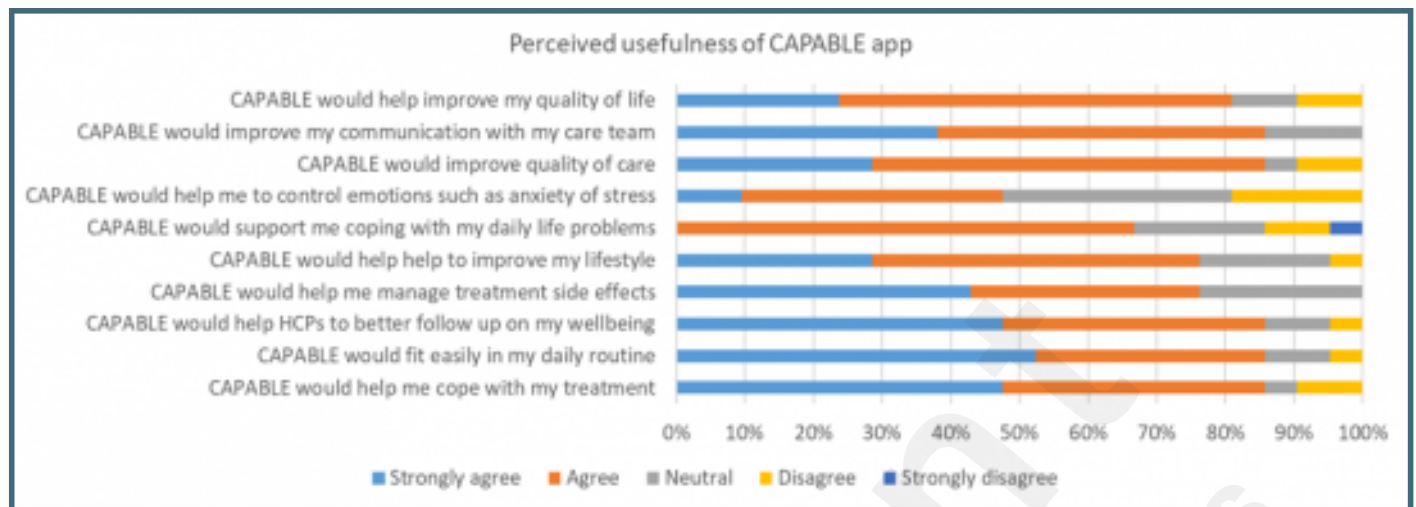
Steps executed for the coding of interview recordings.



Steps executed for merging the two codebooks and analysis of the usability problems.



Stacked bar chart of the perceived usefulness questionnaire outcomes.



Multimedia Appendixes

Think-aloud interview protocol.

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System Usability Scale and perceived impact questionnaire.

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Overview of all usability problems and suggestions.

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