How do AYAs evaluate the usability of an health monitoring app with the intent to monitor their health-related quality of life on a regular basis?

Investigating the usability of a patient monitoring application

Kevin N. Netteb
Snr 2044453

Master Thesis
Communication and Information Sciences
Specialization New Media Design

School of Humanities and Digital Sciences
Tilburg University, Tilburg

Supervisor: dr. Nadine Bol
Second Reader: prof. dr. Emiel Krahmer

July 2021

Abstract

In recent years, AYAs have been the focal point of multiple studies regarding their unique predicament within oncological care. AYAs are patients diagnosed with cancer between the ages of 15 and 39 years. Patient health monitoring tools provide the opportunity to assess a patients health-related quality of life. However, in comparison to patient health monitoring tools geared towards patients, tools geared towards AYAs have not been in abundance. Hence, this study attempted to contribute by assess the usability of a patient health monitoring tool targeted at AYAs. In order to conduct the research, AYAs were asked to participate in interview/think-aloud sessions in which they were asked to use the monitoring tool and provide their opinion.

Keywords: AYAs, SYMPRO, usability, monitoring, information

Introduction

A huge advantage of patient access to information and communication with care providers is that it allows patients to take matters into their own hands and provide clinicians with information regarding their own health-related quality of life (HRQoL; Duman-Lubberding et al., 2017). Hence, within the current climate of clinical care, various clinicians look towards recent advances in technology to potentially remedy patient monitoring issues post operation (Ramkumar et al., 2019). Patient health monitoring makes it possible to constantly assess patients who either suffer from continual illnesses or to assess their situations post treatments (Szydlo & Konieczny, 2015). According to Oldenmenger, Baan and Van der Rijt (2018), the internet provided the opportunity to track symptoms as reported by patients in real-time. Sneha and Varshney (2008) emphasized the importance of patient health monitoring to the healthcare sector, because in this sector the right decisions need to be made based on the right information at the most appropriate time. A further development for patient monitoring is the utilization of handheld devices. According to Cox et al. (2011) these devices have improved and provided the opportunity to track patients' health and their side effects to treatment. Kluge (2020) described this using the term 'eHealth', in that it allows for health care access using modern technology when contact between patients and care providers is not direct and done electronically. Additionally, Wilson and Mooney (2020) recognized the benefits of health monitoring and how ineffective it would be to wait for a patient's health to decline to a point that it could result in hospitalization.

Though many research articles focused on the helpfulness of health monitoring for all patients, there were quite a few articles that targeted a specific group. In particular, because of the long-term effects of cancer, it could be more valuable for oncology patients to regularly be assessed on their symptoms (Oldenmenger et al., 2018). Bearing in mind the high numbers of tumor and treatment-related complications, McGregor et al. (2020) stressed the importance of recognizing cancer-related symptoms and to track them, as it has caused a reduction in emergency visits and an improvement in the patient's survival.

Multiple subgroups under the oncology patients umbrella have been recognized. One such group, consisting of adolescents and young adults (AYAs), refers to patients diagnosed with cancer between the ages of 15 and 39 (Van der Meer et al., 2020). One of the reasons why AYAs have been the focal point in numerous articles is because the age range captures a unique transition from guided (pediatric) to self-managing (adult) health care (Low & Manias, 2019). In addition, according to Wong et al. (2020), adolescence and adulthood are stages in an individual's life that allow for the exploration of different measures to maintain good health and avoid ailments now and later. Erickson et al. (2018) also stressed that self-management should be improved among AYAs, as it vital to improve their long- and short-term health. Moreover, multiple reports have stressed that among patients diagnosed with cancer, the overall survival outcomes has been found to be lower for AYAs compared to younger and older patient groups (Ferrari et al., 2021; Stoneham, 2020; Van der Meer et al., 2020; Telles, 2021). According to Pugh and McCann (2017), another reason why AYAs would require focused support is because cancer could return, whereas they could also experience continual disease and either physical, emotional or social difficulties because of it (e.g., hair loss or low self-esteem).

Thus, the emergence of patient health monitoring tools, especially on handheld devices, have resulted in many opportunities for ubiquitous assessment of a patient's HRQoL, particularly the ones diagnosed with cancer. However, a few questions arise as a result of this development, particularly with regards to what makes these tools so effective. Saeed, Manzoor and Khosravi (2019) stressed the importance of making these tools user-friendly to allow patients to experience ease-of-use and have control over measures to circumvent errors. Additionally, Saeed et al. (2019) stated that lack of user-friendliness in patient health monitoring tools could have further complications, especially for patients living individually who health-wise could benefit from these tools. Hence, patients health monitoring tools need to provide patients with a proper user experience (UX). One of the essential components of UX is usability. Adinda and Suzianti (2018) referred to usability as a benchmark that measures the quality of the system utilized by users to achieve their objectives based on the items effectiveness, efficiency and satisfaction. With regards to eHealth, according to Broekhuis et al. (2019), usability is a crucial trait that is generally defined as the degree to which effectiveness, efficiency and satisfaction can be achieved by specific users in a specific context. Similarly, Andrade et al. (2019) defined usability with regards to patients health monitoring tools as a way to achieve patient care with effectiveness, efficiency and satisfaction, according to the IEC 62366-1 standard. According to Van der Weegen et al. (2014), these three variables can be assessed through frequency of errors (effectiveness), task completion time (efficiency) and a survey that rates the satisfaction.

To potentially remedy lack of usability within patient health monitoring tools, Rodriguez-Ascaso et al. (2007) proposed a set of UX guidelines, where they combined human factors (e.g., privacy) with the ongoing stages of a patient health monitoring tool (e.g., service deployment). They explained that in the spirit of user-centered design, these human factors should be examined at every stage (Rodríguez-Ascaso et al., 2007). The guidelines were subsequently divided into trust and usability themes. The ‘trust’ theme consisted of groups such as confidentiality and privacy, legal aspects, availability and privacy, integrity and safety. On the other hand, the ‘usability’ theme consisted of groups such as installation, setup, configuration and maintenance, user interaction, user education, interoperability, among others. According to Rodríguez-Ascaso et al. (2007), to provide proper UX, these particular design guidelines should be implemented.

All things considered, the objectives of this current study is to firstly gain more knowledge on usability and to assess what is required to make a patient health monitoring tool more effective. Secondly, the goal is to assess how the usability of a particular patient health monitoring tool is experienced by AYAs. The particular application that will be used to research usability in this study will later be introduced as a case. Especially in recent years, there have been studies in which certain support tools geared towards AYAs were the focal point. For example, Baggott et al. (2012) evaluated a diary tool for AYAs, which focused solely on tracking symptoms. Interestingly, Hanghøj et al. (2020) provided recommendations for creating AYA monitoring tools as a result of a usability test of an app geared towards AYAs either in treatment and in follow-up. With that in mind, an attempt will be made to generalize the results of this study to other monitoring tools by providing an outline that denotes the strengths needed to provide AYAs with a proper UX. Moreover, this study will attempt to document the feedback that AYAs have for that application in an effort to develop it further. When reviewing potentially similar articles with regards to patient health monitoring tools directed towards AYAs, the result amount was less than expected. Consequently, this literature review highlighted the need for more studies that bear AYAs in mind due to their unique predicaments and studies that denote strengths that could provide them with a higher UX. Thus, this study has been structured as a way to contribute to the low amount of studies involving health monitoring tools geared towards AYAs and studies that denote guidelines that could potentially make these tools more effective.

Hence, the following research question have been phrased as a way to encapsulate the main objective of this study while including its main concept, namely "*How do AYAs evaluate the usability of an health monitoring app with the intent to monitor their health-related quality of life on a regular basis?*".

Theoretical Background

Patient health monitoring

It would appear rather important for both patients and care providers to tread carefully during the process after cancer diagnosis. Many symptoms can appear, for instance as a result of treatment, during this process which can be damaging to a patient's quality of life and have a lasting impact if not identified at a timely matter (Fridriksdottir et al., 2017). To identify these potentially damaging symptoms in a timely matter is a rather significant topic of discussion, especially when patients are not always in direct communication with caregivers. In recent years, the development of eHealth has attempted to provide solutions for patients in such predicaments and to empower them. Lettieri et al. (2015) discussed growing patient empowerment through self-management due to eHealth, which refers to the availability of healthcare services, attributable to technologies such as the Internet. Self-management has been defined as the possibility to control management over symptoms and consequences of living with cancer (O'Malley et al., 2020). The objective of tools made available through eHealth is to track and communicate information during care (Van der Cingel et al., 2021).One example to provide updates regarding a patient's symptom information is so-called patient-reported outcome (PRO), which provides a boost to symptom control and contact between patients and caregivers (Basch et al., 2016). According to Duman-Lubberding et al. (2017), PROs can be beneficial because it presents a measure for patients to feasibly provide information regarding their own health in an attempt to identify issues. Many self-monitoring tools have been created to detect symptoms in a timely manner and respond accordingly. For instance, as reported by Wilson and Mooney (2020), "in-home management of symptoms" has minimized occurrences where a decline in a patient's health ultimately led to visits to the emergency department and further hospitalizations. Moreover, Oldenmenger et al. (2017) conducted a study using an online application that allowed patients to score the pain that they had experienced, and additionally to receive online consultation. Ultimately, their results showed a rather significant decrease in patient reported pain intensity. Over the years, there have also been developments in developing mobile monitoring tools. Within eHealth, this component is called mHealth, which describes mobile applications created for patients with the intent to inform, educate and monitor them (Almahdi, et al., 2019). For instance, besides Szydlo and Konieczny's (2015) presentation of the TeleCARE system, they also presented the handheld version called TeleCARE Mobile, as a tool for patients to monitor their symptoms. At the time of their study, they were conducting tests with actual patients and received the support of experts within the medical field. The few examples that were given, show not only the development of different components within digital healthcare but also the advantages of these monitoring tools. However, what these articles do not describe, is what exactly makes these tools useful. More specifically, they do not describe what guidelines these tools adhere to, to be of significance to patients diagnosed with cancer.

Usability in eHealth

Thus, it remains to be assessed what traits a patient monitoring tool should have for patients to find it useful, specifically those diagnosed with cancer. Interestingly, Maramba et al. (2019) identified usability as a fundamental trait for mHealth applications due to its evaluation of the degree with which these apps succeed in adhering to patient's needs before being implemented as 'health intervention'. Similarly, Henshall et al. (2019) stressed the importance of usability for e- and mHealth because it evaluates the usage and effectiveness of apps intended to prompt patients to, for instance, self-manage symptoms during treatment. Multiple articles have been written that either tested an app (or numerous apps) geared towards patient self-monitoring or identified guidelines (based on prior research) that would need adherence to be useful for patients diagnosed with cancer. For example, in an article by Smith et al. (2019), the researchers tested a self-management tool for patients diagnosed with cancer called iConquerFear, geared towards patients with fear of cancer recurrence. In this study, they identified key aspects that could result in better usability such as having an easy navigation, more balance between text, audio and visual, clear feedback, less clicks and more accessibility (Smith et al., 2019). Additionally, Mirkovic et al. (2014) conducted a study focused on the usability of the Connect

Mobile app. The results of their study showed a significant amount of areas that could be improved, most notably more understandability, minimalistic design choices and better accessibility (Mirkovic et al., 2014). Conversely, Rodriguez-Ascaso et al. (2007) did not test an app but provided a set of guidelines for a proper user experience (UX) of which usability is a key component based on both human and lifecycle factors (see Appendix A). These guidelines will be compared to the patient health monitoring tool used in this study to assess the extent to which this tool adheres to these UX guidelines (e.g., privacy, ethics) or not. As previously mentioned, there have been numerous articles that focused on assessing the usability of mHealth apps geared towards patients diagnosed with cancer. However, in recent years there has been an increase in literature focused on a particular group of patients diagnosed with cancer that find themselves in a unique situation that could warrant digital healthcare support.

AYAs and eHealth

The group referred to in the previous sentence are so-called AYAs, which stands for adolescents and young adults (Ries et al., 2016). These AYAs are patients that have been diagnosed with cancer between the ages of 15 and 39 (Van der Meer et al., 2020). There are many, quite significant reasons why, in recent years, researchers have specifically focused on AYAs, their diagnoses and their way of living during and after cancer treatment. Much has been researched about so-called AYA survivorship with regards to the impact cancer diagnosis and treatment can have on AYAs while they progress through the rest of their lives. According to Holland et al. (2021), due to the timing of cancer diagnosis and treatment, the lives of AYAs could be impacted on a mental or physical level, among other things. Thompson et al. (2009) elaborated on the impacted aspects of the lives of AYAs, most notably their self-esteem, plans regarding education and beyond, and body image. Additionally, many researchers have highlighted the impact cancer diagnosis could have on their transition from pediatric to adult care (more self-managing) and during their later transition into survivorship (Nathan et al., 2011). Furthermore, Psihogios et al. (2019) highlighted a significant decline in recommended follow-up procedures (post-cancer), which could have long term negative consequences for AYAs. However, when reviewing articles regarding usability of mHealth apps specifically geared towards AYAs, results were quite scarce. The aforementioned developments in the lives of AYAs during treatment and during follow-up has been a topic of discussion in recent years. With recent developments within the field of digital healthcare (specifically self-monitoring), it would appear that this could play a significant part in the life of AYAs. A study by Walsh et al. (2020) did outline a few key components that could be implemented in mHealth apps geared towards AYAs. More specifically, the key components were the inclusion of AYAs in its development, integration of these apps into digital healthcare systems, data security, consistent reports on AYA's age range and evaluation of costs needed to realize mHealth apps for AYAs (Walsh et al., 2020).

Usability in general

Usability is important in assessing whether mHealth intervention apps adhere to a patient's needs and whether they can accomplish their objectives. Broekhuis et al. (2019) described usability as the degree to which certain users can accomplish certain goals in a certain context. According to Georgsson and Staggers (2015), to fully grasp the usability of a certain system, one would need to assess its effectiveness, efficiency and satisfaction. Additionally, according to Hastreiter et al. (2014), usability covers that which users need in a system, namely the system being efficient, its use effective and the experience satisfying. This definition of usability along with its three variables have been denoted in many articles, though it specifically adheres to the ISO 9241-11 standard (Bevan et al., 2016). These three variables will be a focal point in assessing the patient health monitoring tool in this study. Firstly, Frøkjær et al. (2000) described effectiveness as accurately and completely accomplishing objectives. Secondly, Joo et al. (2011) defined efficiency as the effort it took to achieve a goal. Finally, Bevan et al. (2016) defined satisfaction as the degree of comfortability and positivity a user experiences while using a system. In general, each of the three key variables of usability are measured similarly across multiple studies. For instance, in their article on usability, Ferreira et al. (2020) assessed effectiveness by measuring task completion, efficiency by time spent on task and amount of clicks, and satisfaction with a questionnaire. Thus, these measures will be used to measure the usability variables in this current study.

The following sub-research questions meant to support the main research question go as follows: 1) "How effective do AYAs find the patient health monitoring tool?", 2) "To what extent do

AYAs find the patient health monitoring tool efficient?” and 3) “To what extent are AYAs satisfied with the patient health monitoring tool?”.

Method

Ethics

This study received ethical approval (reference number: REDC 2019/104ab) from the Research Ethics and Data Management Committee (REDC). All participants gave their informed consent before this study started.

Materials

The self-monitoring app used to assess the usability of patient health monitoring tools was the SYMPRO application. Van Eenbergen et al. (2019) explained that SYMPRO had the following functionalities: 1) allowing AYAs to search for information on side effects, 2) give AYAs the opportunity to document side effects for oncologists to monitor, 3) spark communication between AYAs and oncologists and finally, 4) provide graphs for all parties involved to observe in multiple cycles what side effects were documented. The frequent self-reports provided oncologists with more immediate information regarding AYAs’ health and informed AYAs through an overview of their personal situation (Van Eenbergen et al., 2019).

Design

This study was conducted in cooperation with another Master’s student who was specifically researching AYAs, not SYMPRO’s usability. Because both studies were targeting AYAs, albeit with a different approach, the choice was made for AYAs to participate in one research session involving both studies. Multiple sessions were needed to reach the minimum amount of participants for both researchers. To generate a deeper understanding of the usability of SYMPRO, AYAs were asked to perform four tasks while using the application. Because of current COVID-19 guidelines, the semi-structured interviews were conducted online via Zoom. AYAs were explicitly asked during the interviews to think out loud, which means that they had to state their thoughts and opinions out loud for the researcher to understand the problem-solving process (Wolcott & Lobczowski, 2021) of AYAs while using SYMPRO. More specifically, they were asked to express what they were thinking, how they felt and the cognitive processes they underwent while performing the tasks (Vandevelde et al., 2015). The interviews were semi-structured, because this allowed the researcher to not only ask his questions but also ask questions based on responses (Kallio et al., 2016) or statements made during the think aloud. The study was conducted in Dutch.

Participants

Eight AYAs participated in this study, with a mean age of 35.13 (*SD* = 6.20). Two participants were male (25%) and six were female (75%). All AYAs were Dutch. With regards to marital status, five AYAs (62.5%) lived with their partner, while two (25%) were married and one AYA (12.5%) was single. The highest education level completed, were two AYAs who completed University (25%), followed by two AYAs who obtained their Bachelor's degree (25%), one AYA completed high school (12.5%) and two AYAs (25%) completed their intermediate vocational education [MBO], while one in particular reached level 4. AYAs were asked to disclose when they were diagnosed with cancer but because of the variation in age, the answers were varied. When asked for which cancer type they were diagnosed, three selected breast cancer (37.5%), two had osteosarcoma (25%), two were diagnosed with thyroid (25%), two others with testicular cancer (25%), and among them, one AYA was diagnosed with both breast cancer and osteosarcoma (12.5%). All AYAs underwent multiple treatments. Seven out of eight AYAs had surgery (87.5%), six AYAs received chemotherapy (75%) and four received radiation therapy (50%). Additionally, two AYAs received hormone therapy, while three AYAs highlighted other treatment methods, such as bone strengthening, brachytherapy (internal radiation) or the use of radioiodine (radioactive iodine).

Instruments

During the interview/think aloud study, AYAs were asked to use SYMPRO while performing four tasks and to think out loud. After the interview/think aloud study, AYAs were asked to rate how satisfied they were with SYMPRO's usability based on 10 items, on a scale of 1 (strongly disagree) to 5 (strongly agree) per item. The scale used to rate their satisfaction is the System Usability Scale (SUS). According to Pal and Vanijja (2020), SUS is one of the most prominent scales to measure perceived usability, though it has been used in usability studies to rate satisfaction (Harrati et al., 2016). Prior research has proved the scales reliability (Cronbach's alpha coefficient commonly exceeds 0.90) and validity (Pal & Vanijja, 2020). In the aforementioned SUS, the odd numbered items have a positive tone (e.g., “I thought the application was easy to use”) and the even numbered items have a negative tone (e.g., “I found the application very awkward to use”). Perceived usability was scored between 0 and 100 and the scores were interpreted according to the Curved Grading Scale (CGS) approach (Sauro & Lewis, 2016). The interview introduction and the SUS can be found in Appendix B and the CGS table can be found in Appendix C.

Procedure

AYAs either responded to a message to the ‘AYA panel’ or to an invitation placed on www.kanker.nl by the IKNL (Integraal Kankercentrum Nederland). Before the interview/think aloud study, AYAs were sent a survey in which they were briefed, asked whether they were willing to participate and asked for consent. Those who were willing, were then asked a few demographic questions regarding their age, gender, cancer diagnoses, treatment history, marital status and highest education level achieved. At the end of the survey, they were asked to leave their email address for invitation to the interview/think aloud study. As preparation for this study, AYAs were sent an instruction in which they were asked to familiarize themselves with SYMPRO (see Appendix C). It was essential for both researchers to have AYAs use the application beforehand so they could gain a better understanding of what SYMPRO had to offer, especially if they had not used it before. More specifically, to give AYAs a better understanding of how SYMPRO could inform AYAs about their symptoms and provide responses or alerts based on those symptoms. Hence, AYAs were asked to use the application three days in a week. SYMPRO’s main feature was to document (cancer) treatment-related symptoms. Not expecting AYAs to disclose such personal information, they were instructed to fill in mock information.

During the interview/think aloud study, AYAs were asked to use SYMPRO again. This choice was made to show AYAs how their input would be processed and put out by SYMPRO and to then ask them their opinion about it. Each task was measured on time spent to measure efficiency and on task completion to measure effectiveness. In the first task, AYAs were asked to login and give their opinion on the login process and the overall look and feel of SYMPRO. In the second task, AYAs were asked their opinion about personal information. The third task had them filling in the weekly (symptom) survey and asked to state their opinion on the survey. Finally, AYAs were asked in the fourth task to evaluate their symptom report. After finishing the tasks, AYAs were shown the SUS to rate their satisfaction with SYMPRO.

Analysis

The results of the interviews in which AYAs were asked to perform tasks in SYMPRO were transcribed verbatim. All qualitative analyses were conducted in Atlas.ti. To analyze the qualitative raw data, the grounded theory method was applied. This method highlights three stages of data analysis within which the data will be broken up, categorized based on similar themes and refined into theory (Lawrence & Tar, 2013). These three stages are referred to as open, axial and selective coding. During the initial, open coding phase, the program Atlas.ti 8 was used to analyze the raw data during open coding based on similarities. More specifically, during the analysis of the transcripts, the focus while reading the texts was on the possible recognition of particular themes. These parts of the text were subsequently broken up and grouped. To give meanings to these groups, the overall gist of these groups were translated into labels or themes. For instance, AYAs had loads of feedback on the information provided by SYMPRO, motivation to use the app while undergoing treatment and accessibility to the app, among other themes. However, these themes were broad and the amount of pieces of text per theme were quite big, due to significant feedback from AYAs. Consequently, within these themes, similarities in text were labelled into sub-themes, for example, the information theme was subsequently divided into sub-themes information clarity, variety, overload and directness. This overview of themes and sub-themes has since been translated and organized into a codebook (see Appendix D).

Results

A previously mentioned, the main research question was supported by three sub-questions, namely 1) “How effective do AYAs find the patient health monitoring tool?”, 2) “To what extent do AYAs find the patient health monitoring tool efficient?” and 3) “To what extent are AYAs satisfied with the patient health monitoring tool?”. During data analysis, different codes were generated based on the input from AYAs. The input from AYAs was subsequently interpreted as possible affordances, namely traits that SYMPRO could have. These themes were then categorized under several overarching sub-themes to provide an overview. With the focus on usability of patient health monitoring tools in mind, these themes were consequently classified based on effectiveness, efficiency and satisfaction.

Effectiveness

Effectiveness was defined as accurately and completely accomplishing objectives. This variable was measured on percentage task completion. All AYAs completed their tasks. The following codes have been classified under effectiveness, because they either contribute to improve or denote certain traits of current SYMPRO that negatively impact effectiveness. For instance, AYAs found certain features lack clarity of information, which impeded their ability to properly and completely accomplish objectives. Moreover, when exposed to certain SYMPRO notifications, AYAs experienced lack of urgency which caused them to not feel the need to always comply and complete its intended objective.

Clarity of information. According to multiple AYAs, the information was rather clear. However, a few AYAs were quite adamant that the information could have been clearer, especially for those whose reading ability was negatively impact due to treatment. They also giving suggestions for how certain informational aspects of SYMPRO can be improved. A few AYAs were particularly critical of the weekly (symptom) survey in that it, especially the first time around, could be quite ambiguous what the overall purpose is. Specifically, because this survey is a key feature to document how AYAs perceive certain symptoms and how much it impacts their daily lives, it is important to highlight what could improve it. For instance, AYA 3 suggested a disclaimer at the start of the survey "which states that there are no bad answers, but that it is meant to identify [factors that could be detrimental to one's health]". AYA 8 reciprocated this and mentioned the following: "I think if you clearly state the added value beforehand, that [the weekly survey] would be used more". The general structure of the weekly survey is the same every time, namely a few questions that ask AYAs to rate the most frequent symptoms. For those symptoms that are not included, AYAs will have the opportunity to input these themselves at the end of the survey. The inclusion of this question was met with an overall positive response, with the likes of AYA 1 remarking that it was "good to be able to input symptoms that have not been included". However, for the sake of being transparent, AYA 3 thought that it would be better if it would "let AYAs know that they can input their own symptoms later, if the ones that are being asked about do not pertain to their situation". Clarity of information is a trait that could use improvement within SYMPRO with regards to multiple features. One of these possible improvements could pertain to the alerts given by SYMPRO or the report that shows AYAs their symptom management progression. The usual approach in case of high score(s) is that SYMPRO highlights these scores in the 'Report' section in red, advises AYAs to contact a clinician and sends an e-mail that is supposed to relay this message as well. However, a few AYAs when asked about this did not recognize that in the e-mail. Rather, the e-mail was perceived as ambiguous by some and as a reminder to fill in the weekly survey by other AYAs. The current lay-out of this e-mail is a blank page with only the SYMPRO logo and no clear subject. Moreover, according to AYAs, they received the email in their spam folder. Other than that, AYAs can be advised to contact their clinician on the 'Report' page, which as previously mentioned is an extra step that some AYAs might not be willing to take. There were however quite a few suggestions on how to improve and make these alerts clearer. AYA 7 suggested quite a descriptive alert in which AYAs will be advised to contact their clinician and to either "call this number during work hours and this number during nighttime and weekends, because we noticed something that needs to be discussed". Other AYAs, such as AYA 4 and 5 thought it would be clearer to, "for privacy reasons", notify AYAs about the irregularity and advise them to login for further details and then contact a clinician.

Notifications. This theme serves as a umbrella term for the ways SYMPRO tries to communicate with AYAs. Similarly, there seems to be a need for improvement regarding the directness of certain notifications to ease the use of SYMPRO and signify the urgency of certain noticeable occurrences. Because of the lack of clarity or directness in the alerts provided by SYMPRO, there seemed to be a lacking sense of urgency. Consequently, the responses to the question "Would you, in case of alert due to high scores, contact your clinician when you feel healthy?" were balanced. Some AYAs noted that they would take it seriously, to not take the warning for granted. AYA 7, for example, found the alerts beneficial because there comes a point while AYAs are undergoing treatment where "AYAs sometimes do not know when to call". AYA 7 added: "I had the need to call almost every day, so after a while you are so done with it". Conversely, other AYAs were convinced that they would not contact their clinician, with AYA 6 thinking that "it differs per person, but I would think of the symptom as temporary so if it is gone then it should be fine”. Though AYA 7 was quite positive about the feature, there was a suggestion for a more subtle form of communication. Namely, AYA 7 suggested “to send an email because people find that more accessible than calling”. This AYA further stated that in case of alerts, AYAs would want “to call for immediate response, but if they do not know for sure, they would want to send an email”, because the answer could “come at any time, though not now”. There are some AYAs who were sure to not contact clinicians but would still bring up the alerts during consultation sessions, because “if it [the symptom] is done, then I do not need to contact [my clinician]”.

Efficiency

Efficiency was defined as the effort it took to achieve a goal. This variable was measured by the task completion time and time to learn a task. The most time was spent on filling in the weekly (symptom) survey which took AYAs an average of 07:12 minutes. The following codes based on AYA’s input show the contributions and shortcomings of certain characteristics of SYMPRO that caused AYAs to take longer when trying to achieve a specific goal. For example, some AYAs explained that treatments had impacted their ability to read normally. Some needed to take more time or read it multiple times. Many found this to be more effortful when expected to effortlessly finish their task.

Information Variety. Not only could the information provided by SYMPRO be presented in a more transparent and clearer way, the way in which it is presented could also use more variation. The AYA interviews provided brief insights into how they felt and what they thought while undergoing treatment. One of the main themes that was brought to attention was the motivation or lack thereof to do anything while under such conditions, let alone use the application. Another point of emphasis was the inability to properly read or remember information without repeating it a few times due to treatment. Hence, why a few AYAs provided suggestions for how this could be remedied and could potentially move AYAs to consider using the app. The likes of AYAs 2 and 4 made it quite adamant that the use of visual support could be a step in the right direction. Other suggestions came from the likes of AYA 3 and 7. While critiquing the weekly survey and asked about its terminology, AYA 3 suggested a feature where “you hover over a word and it could give you a brief explanation”.

Additionally, AYA 7 had remarks about the weekly survey. This instruction will always be available to AYAs at the start of the weekly survey, instructing AYAs with what they can expect from the weekly survey. Especially for AYAs who plan on filling in the survey more frequently, this could feel a bit redundant. So, AYA 7 said that on top of the survey "you could place [a button that when clicked, provides an introduction] that one could look at in his or her own time, at any time, even when the survey has been filled in three times already". This trait could possibly be attributed to exhaustion felt by AYAs while undergoing treatment, in that they feel that it would be demotivating if they would have to read and undergo more steps than necessary. Another suggestion was made by AYA 8, who suggested the inclusion of brief video clips of "1 or 2 minutes to keep the focus because reading can be difficult". Also, this suggestion can potentially cause the 'information overload' to be reduced significantly.

Information Overload. As previously mentioned, AYAs who undergo treatment can experience hinderances such as exhaustion or inability to read or store information. Hence, AYAs were adamant that the information generated within the SYMPRO app should be, as AYA 3 put it, "short and sweet". The previous suggestion made by AYA 8 about the inclusion of brief clips could then potentially be a solution, especially for "people who cannot read, but also due to exhaustion, the inability to store information, because AYAs will need to read something three or four times before they feel they can continue". AYAs 2 and 7 also felt that information should be more direct, often remarking that, as AYA 2 put it, "I can remove half of the sentences here and still understand what I should do". This could positively contribute to the overall effort AYAs need to accomplish their goals.

Direct feedback from SYMPRO. This code had an impact on multiple features of SYMPRO. AYAs were quite critical of these aspects and found that these could have been more time efficient. SYMPRO records the symptom scores in the weekly survey. When AYAs score particularly high on one (or more) symptom(s), they receive a notification that signals the high score and the advice to contact their clinician. Moreover, AYA 5 said that it would "make more sense" if the results (of the weekly survey) would be shown immediately after with the advice "maybe you need to contact your clinician" (in case of high scores), instead of "that extra step of clicking on the report to see your results". Additionally, AYA 2 critiqued the way SYMPRO communicates certain notifications (specifically the alerts) and said that if "I were to compare this to actually getting a phone call from my clinician then I would give this a 3 and that phone call a 9". AYAs 4 and 8 were also adamant that a more direct line of communication could make SYMPRO clearer. AYA 4 remarked that "you should do both, so a pop-up in the app and an additional e-mail", while AYA 8 thought that "once I am in it, I would like to see my end result to see if it is going okay or I need to tread carefully moving forward". Consequently, AYA 2 remarked how this would be needed at the end of the weekly survey, so "at the end you could see a graph of everything you have done which I personally would fine clearer".

Potential Boost. Additionally, more directness of information, specifically, the results of a weekly survey could potentially cause AYAs to be more motivated to use SYMPRO more frequently. This is in line with what AYA 2 said, namely that seeing, for instance, positive scores could "motivate [an AYA] because he or she then sees their situation improve". Though many AYAs provided strong support for the needed improvement of information, only AYA 2 explicitly stated how direct feedback could potentially cause AYAs to become more motivated to use SYMPRO. This could be a potential starting block for future research regarding AYA motivation to engage with support tools as such.

Personalization Possibilities. AYAs have provided significant suggestions for how the SYMPRO experience could be made my personal. Especially, since not all AYA situations are the same. Firstly, there were a few AYAs that brought up an interesting point, namely about including the type of treatment they are undergoing at the moment. This could be beneficial in that it could "show a clinician (with whom I share information) that for instance this week I had chemotherapy". This could cause more transparency and could cause questions to be more adapted to one's own predicament. Similarly, AYA 3 mentioned that certain questions are not always relevant to an AYA's situation and that "it can be bothersome to be constantly reminded of any symptoms that I could have had". AYA 6 reciprocated this again by referring to the input question to have SYMPRO take that input and ask AYAs "Last time you scored this as very high, how is that now?". Additionally, AYA 4 had an interesting feature to enhance personalization within SYMPRO. Namely, AYA 4 suggested a question about which treatment an AYA had and subsequently show an overview of the human body to which an AYA could then highlight where he or she experienced symptoms. AYA 7 had a similar statement, namely "if I want to quickly fill in the survey, I only want questions regarding symptoms that I am actually experiencing”. Features like the ‘Report’ change based on frequent use of SYMPRO. However, some features remain the same throughout. One such example is the introduction on pages such as the main page and of the weekly survey. AYA 7 also had a suggestion for this, namely to give AYAs the option to enable or disable whatever pieces of information they would and would not like to see. This AYA suggested “for instance, a checkmark with ‘do not show’ or to remove it and place it in the [general] introduction”.

Quick Interaction. Besides the need for improvements to the way SYMPRO communicates information, AYAs also expressed the need for a less taxing way to use the app. Especially, when undergoing treatment and being low on energy. For those who would want to use the app to track their progress, SYMPRO should adhere to their situations and not become a burden. AYA 2 expressed a need for an immediate showcase of key features in SYMPRO without too many clicks, because “if you could make it [the interaction that quickly] then it would be ideal”. AYA 3 had an interesting approach for quicker interaction with regards to the weekly (symptom) survey. Specifically, AYA 3 suggested that it could create a template of survey answers from a prior moment and “provide an overview with the question whether [an AYA] would want to change anything”. Thus, not asking AYAs to go through all the survey questions again. A step further in allowing AYAs to input their own symptoms and then rate them is to keep it stored. Particularly, AYA 4 and 6 stressed this point. AYA 4 stated that the open question was good but that “which you input should come back next time, so the registration of this input from patients by SYMPRO”. AYA 6’s answer incorporated why this could be a neat addition, namely because that contributes to a more personalized experience. Moreover, AYA 6 expressed that if “I mentioned that I had a headache, which is not a part of the general questions, SYMPRO could ask me about this next time around without having to input it again”. So, what this could do, is take into account symptoms that AYAs inserted into the weekly survey as a hinderance. SYMPRO could then ask AYAs if they were still hindered by it to ensure that AYAs are not just asked the general questions but also more personal questions, adjusted to their own predicament.

Own input into sympro. Normally, AYAs can conduct the weekly survey to log their symptoms. At the end of this survey, there is a question in which AYAs can input symptoms that have not been included in any questions to that point. Fortunately, the response to this question was overall quite positive. There were however quite a few points, specifically with regards to how this question can be refined and what happens to the input from AYAs.

SYMPRO accessibility. To grant AYAs access to SYMPRO, the researchers needed their personal information. It was entirely expected to assume that AYAs were going to be split on this idea. Surprisingly, the majority of AYAs that were interviewed had no problem with it, with the exception of some. With questions directed at the level of accessibility to SYMPRO (e.g., login to and/or find SYMPRO), AYAs were able to provide some insight that could make SYMPRO easier to find and to access. Currently, the way SYMPRO operates, is that AYAs will be admitted to the app (by a handler) and sent preliminary login data by email. Though referred to as an app, in actuality SYMPRO is a web application. As previously mentioned, to do this AYAs need to share personal information (e.g., email address, age, phone number). AYAs are then bound to that email and the specific link that comes with it to login to SYMPRO, which had a divisive response. For instance, AYA 3 mentioned that “when trying to access SYMPRO itself [through the main website]” using the login data “resulted in an error”. AYA 6 found it “annoying that you have to look for the mail to click on the link to access the [web]app”. Most AYAs expected that SYMPRO will eventually be converted into a full-on (mobile) application, which in turn would enhance its accessibility. AYA 6 and 7 in particular reciprocated this, with AYA 6 saying that it “would make things easier”. As previously mentioned, AYAs were asked to disclose personal information to gain access to SYMPRO. Once in possession of login credentials, AYAs have to insert the number that was assigned to them, a password and an additional verification code for extra safety. This is referred to as two-factor authentication. With regards to sharing personal information for access, not all AYAs were completely on board with this. AYA 4 in particular found this to be “annoying” in that “you ask for my date of birth, my phone number and those are the things that I do not voluntarily want to share”. However, most AYAs were on board with it due to their trust in SYMPRO and trust in the people behind SYMPRO. With regards to the two-factor authentication, the response was quite split on its necessity. In reference to a previous expectation that SYMPRO will be translated into a mobile app, AYA 7 suggested that the extra safety measure could instead be a pin number, because “every app uses a pin number nowadays. This is so much faster than this [verification] code”.

Satisfaction

Satisfaction was defined as the degree of comfortability and positivity a user experiences while using a system. The SUS was used to measure to which extent AYAs agreed or disagreed with certain statements regarding their SYMPRO experience. Overall, AYAs were quite positive when shown the statements with the positive tone. For instance, AYAs mostly did not notice inconsistencies and were fairly certain that it was easy to use and to learn. Hence, AYAs were satisfied with the foundation for the most part but felt that there is a definite room for improvement. The following input from AYAs denoted points of emphasis that either contributed or negatively influenced whether AYAs were satisfied with SYMPRO. For instance, a few AYAs did not have a problem with the way SYMPRO addressed them. They did feel however that there was room for more character. This could possibly make AYAs more comfortable when using SYMPRO moving forward.

Tone used by SYMPRO. Though not a huge point of critique by AYAs, it became apparent rather quickly that AYAs preferred to be called ‘je’ (which is more informal) instead of ‘u’ (which is formal). AYA 7 expressed how the use of ‘je’ instead of ‘u’ and first names instead of just the first letter could “enhance the feeling of it”. AYA 4 took it a step further by expressing that “I am annoyed when it calls me ‘u’, especially because I chose to do this and it makes me want to stop reading”. This applied to the interviews and the way SYMPRO refers to these AYAs. This is especially understandable when taking into account that the age group is still 15 to 39 years old. Furthermore, some AYAs even found that first name use would be a better way to go. Though not immensely detrimental to the overall experience, AYAs did find that the use of a first name when referring to them would be, according to AYA 5 “regarded as friendlier”. AYA 7 even suggested how the welcoming message on the start screen could be changed to “Welcome back, (…)”.

Clinician contact. A main topic of discussion with AYAs was their willingness to not only use SYMPRO but also share information and symptom results with their clinicians. For the most part, AYAs were in agreement with this, but there were some AYAs who felt that it depends on the relationship and level of trust between them and their clinicians. Still, there were some interesting points that AYAs made with regards to high symptom scores, to not just make AYAs responsible but also have more active participation from the side of clinicians or hospitals. AYA 2 provided an example of a system that allowed engineers to monitor the state of certain machines. In case of defects, the engineers took the initiative to visit "unannounced to fix problems". With regards to SYMPRO, AYA 2 expected the same procedure "from the clinician side". Other AYAs felt the same, though obviously were understanding to the fact that clinicians do not have time to monitor their health related quality of life 24/7. For instance, AYA 7 expressed that need to "not only fill it [the weekly survey] in for yourself but for someone else as well". Moreover, AYA 5 reciprocated this notion by stating that it would be "fine if your clinician would call you, asking you how you are doing in case they received an alert". However, this does not mean that AYAs expect clinicians to have full responsibility. AYA 4 said that if "in case of an alert, there is a clinician that I can send a mail to, I would choose this" with the question "I feel okay, I do not know what the alert means, do you agree with it?". This is congruent with an earlier statement made by AYA 7 who also suggested contact by mail because it is less direct, more accessible than a phone call. So, AYAs do not expect clinicians to monitor them 24/7 but do hope for contact from their side when the situation calls for it. Especially, because the app already provides AYAs who are not sure when to contact clinicians a push in the right direction. AYA 4 said that "if you have been worrying all this time about something and the clinician constantly ignores it, then you will start doing the same".

Discussion

To answer the research question "*How do AYAs evaluate the usability of the SYMPRO app in monitoring their health on a regular basis?*", a total of eight interviews were conducted. The purpose of this study was to generate a deeper understanding usability in patient health monitoring tools while using SYMPRO as a case. To support the research question, three sub-research questions that incorporated the most frequent usability traits were generated: 1) "How effective do AYAs find the SYMPRO app?", 2) "To what extent do AYAs find the SYMPRO app efficient?" and 3) "To what extent are AYAs satisfied with the SYMPRO app?".

Main Findings

In general, AYAs were quite positive about the way SYMPRO currently looks and feels. The overall response was that the current version had a strong foundation. However, AYAs did notice a few aspects that need to be improved to make SYMPRO more usable.

Effectiveness. During the interview/think-aloud study, AYAs were monitored on task completion. As previously mentioned, all AYAs finished the task. However, that does not make SYMPRO overly effective. There were a few traits that caused AYAs to be hindered in their quest to accurately and completely finish their objectives. In particular, the way SYMPRO generally provided information caused AYAs to be uncertain. They found information to be rather clear but felt that there was room for improvement, specifically with regards to its clarity. Moreover, AYAs felt that the way SYMPRO generally notified them, was less urgent than expected, especially with SYMPRO being a health intervention application.

Efficiency. As previously mentioned, the average time AYAs needed to accomplish tasks was relatively quick. However, this did not tell the full story. Most time was spent on filling in the weekly survey and that did not take more than 7 minutes on average. Nonetheless, the comments as a result of the think aloud and the questions during the interviews showed that total task time did not cover all areas. AYAs found ways in which SYMPRO could be made much more efficient. For example, information could be made clearer and notifications could be made more urgent.

Satisfaction. AYAs were quite satisfied while filling in the SUS. In general, they agreed with the positive statements and disagreed or were unsure about the negative statements. However, though AYAs were content with the way SYMPRO currently looks and feels, there still were a lot of input for further development. Mainly, AYAs found that the way SYMPRO addressed them could have been more personable to contribute to comfortability. Furthermore, AYAs did not mind the overall independence but did express the need for contact with caregivers in case of high symptom scores as a way to minimize health risks or stress due to unawareness.

Implications for Practice

To adhere more to the design guidelines set by Rodriguez-Ascaso et al. (2007) for a better UX, improvements and more importantly to provide AYAs with better SYMPRO experiences, a few improvements can be made. Firstly, taking under consideration the way AYAs can feel while undergoing treatments, the way information is provided can be improved. For instance, information provision can be expanded from just textual to multimodal (e.g., visual support, clips). This could allow AYAs to process information is different ways and process it whenever they want. Additionally, this could enhance the sense of motivation to fill in the symptom survey and keep up one's progression while undergoing treatment. Though AYA response has been quite positive, the amount of feedback begs to question how SYMPRO would have looked if AYAs were included into the design process from the start. To include AYAs during concept phase to iterate as soon as possible to put together an end product that adheres more to the needs of AYAs. Furthermore, this adheres to sentiments by Walsh et al. (2020), who stated that AYAs should be included in the developments of mHealth health intervention apps.

There were a few feedback points given by AYAs that were relevant o potentially enhance UX. This feedback can put in perspective with the help of the design guidelines that what SYMPRO is missing or that which needs further improvement. For starters, many AYAs hoped that SYMPRO will eventually be turned into a full-on mobile application, instead of a web-application. Multiple reasons were given for this expectation. For instance, to make SYMPRO more accessible, or to make notifications more direct. Though it can be expected that SYMPRO in its current version is available whenever, in the end it remains a web-app which means that it requires on internet connection. No internet connection could result in a decrease in availability of SYMPRO, whenever AYAs need it. Thus, this feedback point could be taken into consideration to keep SYMPRO available and not be reliant on internet connectivity. This would adhere to the 'availability and privacy' guideline, namely that a patient health monitoring tool should be made available whenever patients need it and provide a proper UX. Interestingly, this does not adhere to the results of Jobe's (2013) study in which he compared native and mobile web apps and found that mobile web apps were beneficial for regular content consumption.

Furthermore, there was a lot of criticism with regards to SYMPRO's information provision. Namely, AYAs were of the opinion that there should be an increase in information clarity, more variety and directness, and a decrease in information overload. The reasons for these arguments could be attributed to a decrease in attention and storage ability, and an increase in amount of time need for text comprehension, caused by treatments. Conversely, Rodriguez-Ascaso et al. (2007) proposed guidelines under the ‘user interaction’ group with the advice that patients should be able to observe information and that it should be multimodal. Moreover, patients should be able to use the app without discomfort and should be able to understand the app. Coincidentally, AYA’s responses showed that SYMPRO does need improvements to adhere to these guidelines. For example, they provided the perspective of a patient that already has a lot of stress, a lot of information to process and is very exhausted due to treatment. AYAs found that some aspects of SYMPRO’s information provision (e.g., the way SYMPRO instructs AYAs) would potentially cause discomfort due to information overload. Furthermore, the understandability of SYMPRO was at times slightly decreased due to lack of information clarity and directness as experienced by AYAs. Also, the aforementioned AYA discomfort shows that SYMPRO needs improvement for a guideline under the ‘ethics’ group which states that TS should make sure that the well-being (e.g., physical, mental or social interaction) of patients should remain intact.

Finally, a guideline under the group ‘localizations and customization’ states that the development of TSs should consider different markets, languages and cultures. Instead of taking that guideline too literal, it can be adjusted to patients diagnosed with cancer and the inclusion of multiple types of cancer in SYMPRO. Most AYAs noticed how SYMPRO’s current version was geared towards patients diagnosed with lung cancer. Hence, to adhere to this adjusted guideline, different types of cancer should be included into SYMPRO and surveyed.

Limitations and Suggestions for Further Research

Eight participants were interviewed in total. The expectation beforehand was that ten participants would cause saturation. However, considering variables such as the age range (which falls between 15 and 39), gender and types of cancer, it could have been more beneficial if the interviewees were more diverse. More specifically, to have an interviewee amount that spanned across the entire AYA age range, that was more balanced with regards to gender and was more diverse regarding types of cancer as to record more diverse experiences. For instance, the youngest age (in years) recorded among AYAs that were interviewed was 27. Moreover, of the ten AYAs who were interviewed, two were male and eight were female. Though there were thirteen possible types of cancer to select (in the recruitment survey), the most recorded types of cancer were thyroid (*N* = 2), breast (*N* = 3), bone (*N* = 2), and testicular (*N* = 2) cancer. The article of Stoneham (2020) in which became apparent that medical care for AYAs had to be personalized, drew interest. Mainly, because of their unique age range and the occurrences of, for instance, risky behavior and eating disorders. It would have been interesting to have a more diverse group because of factors like these, to record more different experiences and to see how they would respond to SYMPRO. However, due to constant messages to the AYA panel and kanker.nl, while recruiting AYAs for this study, it remains a question what could be done differently when considering further research. Perhaps, attempt to contact hospitals but that would bring along a lot of ethical discussion.

Based on the aforementioned statements made by AYAs who experienced SYMPRO, considerable changes could be made to the app to accommodate AYAs. Naturally when those changes have been implemented, AYAs will once again have to be consulted on whether the functionalities that the application provides can genuinely accommodate them. Furthermore, it could possibly be more beneficial if this evaluation would be done face-to-face, instead of online. Possible reasons could be to eliminate of connectivity issues, timidness. Additionally, face-to-face sessions could provide researchers with more control over an experiment.

Conclusion

This study was conducted with the intent to generate further knowledge about the usability necessary in patient health monitoring tools. However, the usual metrics that were used for usability variables such as effectiveness, efficiency and satisfaction did not tell a full story. In general, AYAs were positive about SYMPRO and liked the foundation of it, but noticed some traits that could warrant some improvements. Specifically, with regards to SYMPRO’s information provision, directness of notifications in general, communication and accessibility. Future research could take later iterations of SYMPRO and test these with AYA’s to gauge whether later SYMPRO versions adhere to the UX design guidelines and more importantly, to the expectations of AYAs. It has become clear that there is still some work to be done to make SYMPRO adhere to the needs of AYAs and to make the overall use more convenient. All of the aforementioned arguments can be summarized as features to improve upon to ease the treatment process, provide transparency with regards to symptoms and make using SYMPRO less time and energy consuming.

Main Research Question

"*How do AYAs evaluate the usability of an health monitoring app with the intent to monitor their health-related quality of life on a regular basis?*". They approved the foundation, but felt that certain features could have been executed more thoroughly. It did hinder AYAs to a point where a tool meant to make their lives easier and more transparent certainly attempted. However, it could have had more certainty if some features were thoroughly evaluated through the perspective of AYAs.

References

Adinda, P. P. & Suzianti, A. (2018). Redesign of user interface for e-government application using usability testing method. In *ICCIP 2018 - Proceedings of 2018 4th International Conference on Communication and Information Processing*, 145–149. Association for Computing Machinery. https://doi.org/10.1145/3290420.3290433

Almahdi, E. M., Zaidan, A. A., Zaidan, B. B. Alsalem, M. A., Albahri1, O. S., & Albahri, A. S. (2019). Mobile patient monitoring systems from a benchmarking aspect: Challenges, open issues and recommended solutions. *Journal of Medical Systems, 43*(7), 1-23. https://doi.org/10.1007/s10916-019-1336-z

Andrade, E., Quinlan, L. R., Harte, R., Byrne, D., Fallon, E., Kelly, M., O'Connor, P., O'Hora, D., Scully, M., Laffey, J., Pladys, P., Beuchée, A., & ÓLaighin, G. (2019). State of the art and future trends in the usability of patient monitors. In T. Ahram., W. Karwowski & R. Taiar (eds), *Human Systems Engineering and Design*, 338-344. Springer, Cham.. https://doi.org/10.1007/978-3-030-02053-8_52

Baggott, C., Gibson. F., Coll, B., Kletter, R., Zelter, P., & Miaskowski, C. (2012). Initial evaluation of an electronic symptom diary for adolescents with cancer. *JMIR Res Protoc, 1*(2). https://doi.org/10.2196/resprot.2175

Basch, E., Deal, A. M., Kris, M. G., Scher, H. I., Hudis, C. A., Sabbatini, P., Rogak, L., Bennett, A. V., Dueck, A. C., Atkinson, T. M., Chou, J. F., Dulko, D., Sit, L., Barz, A., Novotny, P., Fruscione, M., Sloan, J. A., & Schrag, D. (2016). Symptom monitoring with patient-reported outcomes during routine cancer treatment: A randomized controlled trial. *Journal of Clinical Oncology, 34* (6), 557-565. https://doi.org/10.1200/JCO.2015.63.0830

Bevan, N., Carter, J., Earthy, J., Geis, T., & Harker, S. (2016). New ISO Standards for Usability, Usability Reports and Usability Measures. In M. Kurosu (Ed.): *HCI 2016, Part I, LNCS 9731*, 268–278. https://doi.org/10.1007/978-3-319-39510-4_25

Broekhuis, M., Van Velsen, L., & Hermens, H. (2019). Assessing usability of eHealth technology: A comparison of usability benchmarking instruments. *International Journal of Medical Informatics, 128*, 24–31. https://doi.org/10.1016/j.ijmedinf.2019.05.001

Cox, A., Illsley, M., Knibb, W., Lucas, C., O'Driscoll, M., Potter, C., Flowerday, A., & Faithfull, S. (2011). The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer. *Palliative Medicine, 25*(7), 675-681. https://doi.org/10.1177/0269216311399489

Duman-Lubberding, S., Van Uden-Kraan, C. F., Jansen, F., Witte, B. I., Eerenstein, S. E. J., Van Weert, S., De Bree, R., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2017). Durable usage of patient-reported outcome measures in clinical practice to monitor health-related quality of life in head and neck cancer patients. *Support Care Cancer, 25*(12), 3775-3783. https://doi.org/10.1007/s00520-017-3808-3

Erickson, J. M., Ameringer, S., Linder, L., Macpherson, C. F., Elswick, R. K., Luebke, J. M., & Stegenga, K. (2018). Using a heuristic app to improve symptom self-management in adolescents and young adults with cancer. *Journal of Adolescent and Young Adult Oncology 8*(2). https://doi.org/10.1089/jayao.2018.0103

Ferrari, A., Stark, D., Peccatori, F. A., Fern, L., Laurence, V., Gaspar, N., Bozovic-Spasojevic, I., Smith, O., De Munter, J., Derwich, K., Hjorth, L., Van der Graaf, W. T. A., Soanes, K., Jezdic, S., Blondeel, A., Bielack, S., Douillard, J. -Y., Mountzios, G., & Saloustros, E. (2021). Adolescents and young adults (AYA) with cancer: A position paper from the AYA working group of the European society for medical oncology (ESMO) and the European society for paediatric oncology (SIOPE). *ESMO Open, 6*(2). https://doi.org/10.1016/j.esmoop.2021.100096

Ferreira, J. M., Acuña, S. T., Dieste, O., Vegas, S., Santos, A., Rodríguez, F., & Juristo, N. (2020). Impact of usability mechanisms: An experiment on efficiency, effectiveness and user satisfaction. *Information and Software Technology, 117*. https://doi.org/10.1016/j.infsof.2019.106195

Fridriksdottir, N., Gunnarsdottir, S., Zoëga, S., Ingadottir, B., & Hafsteinsdottir, E. J. G. (2017). Effects of web-based interventions on cancer patients' symptoms: review of randomized trials. *Support Care Cancer, 26*, 337–351. https://doi.org/10.1007/s00520-017-3882-6

Frøkjær, E., Hertzum, M., & Hornbæk, K. (2000). Measuring usability: Are effectiveness, efficiency, and satisfaction really correlated? *CHI '00: Proceedings of the SIGCHI conference on Human Factors in Computing Systems*, 345–352. https://doi.org/10.1145/332040.332455

Georgsson, M. & Staggers, N. (2015). Quantifying usability: an evaluation of a diabetes mHealth system on effectiveness, efficiency, and satisfaction metrics with associated user characteristics. *Journal of the American Medical Informatics Association, 23*(1), 5–11. https://doi.org/10.1093/jamia/ocv099

Hanghøj, S., Boisen, K. A., Hjerming, M., Elsbernd, A., & Pappot, H.. (2020). Usability of a mobile phone app aimed at adolescents and young adults during and after cancer treatment: Qualitative study. *JMIR Cancer, 6*(1). https://doi.org/10.2196/15008

Harrati, N., Bouchrika, I., Tari, A., Ladjaillia, A. (2016). Exploring user satisfaction for e-learning systems via usage-based metrics and system usability scale analysis. *Computers in Human Behavior 61*, 463-471. http://dx.doi.org/10.1016/j.chb.2016.03.051

Henshall, C., Davey, Z., Jacelon C., & Martin C. (2019). A usability study to test the effectiveness, efficiency and simplicity of a newly developed Internet-based Exercise-focused Health App for Lung cancer survivors (iEXHALE): Protocol paper. *Health Informatics Journal, 26*(2) 1431–1442. https://doi.org/10.1177/1460458219882268

Holland, L. R., Walker, R., Henney, R., Cashion, C. E., & Bradford, N. K. (2021). Adolescents and young adults with cancer: Barriers in access to psychosocial support. *Journal of Adolescent and Young Adult Oncology, 10*(1). https://doi.org/10.1089/jayao.2020.0027

Jobe, W. (2013). Native apps vs. mobile web apps. *iJIM, 7*(4). https://doi.org/10.3991/IJIM.V7I4.3226

Joo, S., Lin, S., & Lu, K. (2011). A usability evaluation model for academic library websites: efficiency, effectiveness and learnability. *Journal of Library and Information Studies, 9*(2), 11-26. Retrieved from https://www.semanticscholar.org/paper/A-Usability-Evaluation-Model-for-Academic-Library-Joo-Lin/f0466fda1939a7a6bb87f3426ce1e3b8cecf3381

Kallio, H. K., Pietilä, A.- M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing, 72*(12), 2949-3217. https://doi.org/10.1111/jan.13031

Kluge, E. -H. W. (2020). Chapter 5 – Framework considerations. *The Electronic Health Record*:

Ethical Considerations, 105-133, Academic Press. https://doi.org/10.1016/B978-0-12-822045-0.00005-8

Lawrence, J. & Tar, U. (2013). The use of grounded theory technique as a practical tool for qualitative data collection and analysis. *Electronic Journal of Business Research Methods, 11*(1), 29-40. Retrieved from https://www.semanticscholar.org/paper/The-Use-of-Grounded-Theory-Technique-as-a-Practical-Lawrence-Tar/0ff165c393b17e429a13d3789d72db36f8ab6829#references

Lettieri, E., Fumagalli, L. P., Radaelli, G., Bertele, P., Vogt, J., Hammerschmidt, R., Lara, J. L., Carriazo, A., & Masella, C. (2015). Empowering patients through eHealth: a case report of a pan-European project. *BMC Health Services Research, 15*(309).

https://doi.org/10.1186/s12913-015-0983-0

Low, J. K. & Manias, E. (2019). Use of technology-based tools to support adolescents and young adults with chronic disease: systematic review and meta-analysis. *JMIR Mhealth Uhealth, 7*(7). https://doi.org/10.2196/12042

McGregor, B. A., Vidal, G. A., Shah, S. A., Mitchell, J. D., & Hendifar, A. E. (2020). Remote oncology care: Review of current technology and future directions. *Cureus 12*(8). https://doi.org/10.7759/cureus.10156

Mirkovic, J., Kaufman, D. R., Ruland, C. M. (2014). Supporting cancer patients in illness management: Usability evaluation of a mobile app. *JMIR Mhealth Uhealth, 2*(3). https://doi.org/10.2196/mhealth.3359

Nathan, P. C., Hayes-Lattin, B., Sisler, J. J., & Hudson, M. M. (2011). Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer 117*(10), 2335–2341. https://doi.org/10.1002/cncr.26042

Oldenmenger, W. H., Baan, M. A. G., & Van der Rijt, C. C. D. (2017). Development and feasibility of a web application to monitor patients' cancer-related pain. *Support Care Cancer, 26*(2), 635-642. https://doi.org/10.1007/s00520-017-3877-3

O'Malley, D. M., Davis, S. N., Devine, K., Sullivan, B., Bator, A., Clemow, L., Ferrante, J. M., Findley, P., Miller, S. M., & Hudson, S. V. (2020). Development and usability testing of the e-excels tool to guide cancer survivorship follow-up care. *Psycho-oncology, 29*(1), 123–131. https://doi.org/10.1002/pon.5222

Pal, D. & Vanijja, V. (2020). Perceived usability evaluation of Microsoft Teams as an online learning platform during COVID-19 using system usability scale and technology acceptance model in India. *Children and Youth Services Review, 119*. https://doi.org/10.1016/j.childyouth.2020.105535

Psihogios, A. M., Schwartz, L. A., Deatrick, J. A., Ver Hoeve, E. S., Anderson, L. M., Wartman, E. C., & Szalda, D. (2019). Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents. *Journal of Cancer Survivorship, 13*, 620–631. https://doi.org/10.1007/s11764-019-00781-x

Pugh, G. & McCann, L. (2017). Assessing the quality, feasibility, and efficacy of electronic patient platforms designed to support adolescents and young adults with cancer: A systematic review protocol. *JMIR Res Protoc, 6*(1). https://doi.org/10.2196/resprot.6597

Ramkumar, P. N., Haeberle, H. S., Ramanathan, D., Cantrell, W. A., Navarro, S. M., Mont, M. A., Bloomfield, M., & Patterson, B. M. (2019). Remote patient monitoring using mobile health for total knee arthroplasty: validation of a wearable and machine learning-based surveillance platform. *The Journal of Arthroplasty, 34*(10), 2253-2259. https://doi.org/10.1016/j.arth.2019.05.021

Ries L., Trama A., Nakata K., Gatta G., Botta L., Bleyer A. (2017). Cancer incidence, survival, and mortality among adolescents and young adults. In A. Bleyer, R. Barr, L. Ries, J. Whelan, A. Ferrari (eds), *Cancer in Adolescents and Young Adults. Pediatric Oncology*. Springer, Cham. https://doi.org/10.1007/978-3-319-33679-4_2

Rodriguez-Ascaso, A., Von Niman, B., Brown, S., & Sund, T. (2007). User experience design guidelines for telecare (E-health) services. *Interactions 14*(5), 36-40. https://doi.org/10.1145/1288515.1288537

Saeed, N., Manzoor, M., & Khosravi, P. (2019). An exploration of usability issues in telecare monitoring systems and possible solutions: A systematic literature review. *Disability and Rehabilitation: Assistive Technology, 15*(3), 271-281. https://doi.org/10.1080/17483107.2019.1578998

Sauro, J. & Lewis, J. R. (2016). *Quantifying the user experience: practical statistics for user research*. (2nd ed.), Cambridge, MA: Morgan Kaufmann. https://doi.org/10.1016/C2010-0-65192-3

Smith, A. B., Bamgboje-Ayodele, A., Butow, P., Klein, B., Turner, J., Sharpe, L., Fardell, J., Beatty, L., Pearce, A., Thewes, B., Beith, J., iConquerFear Community Advisory Group, & Girgis, A. (2019). Development and usability evaluation of an online self-management intervention for fear of cancer recurrence (iConquerFear). *Psycho-oncology, 29*(1), 98-106. https://doi.org/10.1002/pon.5218

Sneha, S. & Varshney, U. (2008). Enabling ubiquitous patient monitoring: Model, decision protocols, opportunities and challenges. *Decision Support Systems, 46*(3), 606-619. https://doi.org/10.1016/j.dss.2008.11.014

Stoneham, S. J. (2020). AYA survivorship: The next challenge. *Cancer, 126*(10), 2116-2119. https://doi.org/10.1002/cncr.32774

Szydlo, T. & Konieczny, M. (2015). Mobile devices in the open and universal system for remote patient monitoring. *IFAC-PapersOnLine, 48*(4), 296-301. https://doi.org/10.1016/j.ifacol.2015.07.050

Telles, C. M. (2021). A scoping review of literature: What has been studied about adolescents and young adults (AYAs) with cancer? *Cancer Treatment and Research Communications, 27*(4). https://doi.org/10.1016/j.ctarc.2021.100316

Thompson, K., Palmer, S., & Dyson, G. (2009). Adolescents & young adults: Issues in transition from active therapy into follow-up care. *European Journal of Oncology Nursing, 13*, 207–212. https://doi.org/10.1016/j.ejon.2009.05.001

Van der Meer, D. J., Karim-Kos, H. E., Van der Mark, M., Aben, K. K. H., Bijlsma, R. M., Rijneveld, A. W., Van der Graaf, W. T. A., & Husson, O. (2020). Incidence, survival, and mortality trends of cancers diagnosed in adolescents and young adults (15-39 Years): A populationbased study in The Netherlands 1990-2016. *Cancers, 12*(11)*,* 3421. https://doi.org/10.3390/cancers12113421

Van der Cingel, M., Bulle-Smid, L., Holterman, S., Prins, H., Keuning, W., & Hettinga, M. (2015). From clinical reasoning to ehealth interventions; a study on how nurses asses care and ehealth in home care. *Nurse Education in Practice, 50*. https://doi.org/10.1016/j.nepr.2020.102925

Vandevelde, S., Van Keer, H., Schellings, G., Van Hout-Wolters, B. (2015). Using think-aloud protocol analysis to gain in-depth insights into upper primary school children's self-regulated learning. *Learning and Individual Differences, 43*, 11–30. http://dx.doi.org/10.1016/j.lindif.2015.08.027

Van Eenbergen, M. C., Van den Hurk, C., Mols, F., & Van de Polls-Franse, L. V. (2019). Usability of an online application for reporting the burden of side effects in cancer patients. *Supportive Care in Cancer, 27*(9), 3411-3419. https://doi.org/10.1007/s00520-019-4639-1

Van der Weegen, S., Verwey, R., Tange, H. J., Spreeuwenberg, M. D., & De Witte, L. P. (2014). Usability testing of a monitoring and feedback tool to stimulate physical activity. *Patient Preference and Adherence, 8*, 311–322. http://dx.doi.org/10.2147/PPA.S57961

Walsh, C. A., Rosenberg, A. R., Lau, N., Syrjala, K. L. (2020). Key considerations for advancing the development and testing of mhealth interventions in adolescent and young adult oncology. Psycho-oncology, 29(1), 220–223. https://doi.org/10.1002/pon.5216

Wetzlinger W., Auinger A., & Dörflinger M. (2014). Comparing effectiveness, efficiency, ease of use, usability and user experience when using tablets and laptops. In A. Marcus (eds), *Design, User Experience, and Usability. Theories, Methods, and Tools for Designing the User Experience*. Springer, Cham. https://doi.org/10.1007/978-3-319-07668-3_39

Wilson, C. M. & Mooney, K. (2020). Advancing oncology nursing practice through adoption of patient monitoring digital tools. *Seminars in Oncology Nursing, 36*(6). https://doi.org/10.1016/j.soncn.2020.151087

Wolcott, M. D. & Lobczowski, N. G. (2021). Using cognitive interviews and think-aloud protocols to understand thought processes. *Currents in Pharmacy Teaching and Learning, 13*(2), 181-188. https://doi.org/10.1016/j.cptl.2020.09.005

Wong, C. A., Madanay, F., Ozer, E. M., Harris, S. K., Moore, M., Master, S. O., Moreno, M., & Weitzman, E. R. (2020). Digital health technology to enhance adolescent and young adult clinical preventive services: affordances and challenges. *Journal of Adolescent Health, 67*, 24-33. https://doi.org/10.1016/j.jadohealth.2019.10.018

Appendices

A. Design guidelines to boost UX in telecare systems (Rodríguez-Ascaso and Sund, 2007)

Theme	**Group**	**Guidelines**
Trust	*Confidentiality and privacy*	Associates should be aware that patients should be provided with access to own health information.
		Associates should be aware that it has a duty to uphold confidentiality of the patients if they grant permission for their health information to be revealed.
	Ethics	Telecare applications should make sure that the well-being (e.g., mental, physical health and social interaction) of patients remain intact.
		Telecare applications should respect the patients ability to make their own decisions.
	Legal aspects	Associates should take the European and national laws regarding the advancement and supply of telecare systems and additional equipment into account.
		Associates should comprehend the responsibilities of developing such systems and have measures ready to protect themselves and the patients.
		Associates should make sure that there are contracts at every telecare stage that clearly state the agreements.
	Availability and privacy	Telecare applications should be made available whenever patients need it and provide a proper UX.
		Telecare applications should be made reliable and provide a proper UX.
	Integrity	Telecare applications should be made in a way that data and information is preserved during transfer.
		Telecare applications should be made in a way that data and information is preserved during storage.
		Telecare applications should be made in a way that data and information is preserved during retrieval.
	Safety	Telecare applications should be made in a way that minimizes negative consequences in case patients make a mistake.
		Telecare applications should be made in a way that minimizes unfavorable effects in case patients make a mistake.
Usability	*Installation, setup, configuration and maintenance*	To access telecare applications, patients should not have to be exposed to any sort of installation or setup. That should be for service providers.
	User interaction	Patients should be able to observe the information within the apps and it should be multimodal (i.e., different ways to present information).
		Patients should be able to use the apps and its functionalities without discomfort and it should be multimodal.
		Patients should be able to understand the telecare applications.
		Patients should be able to use telecare applications directly or through assistive technologies.

	Localizations and customization	While developing telecare applications, different markets, language and cultures should be considered.
	Service and system aspects	Telecare applications should be maintained throughout its different stages.
	Organizational aspects	Addressing measures to supply care service.
	User education	Patients should be able to understand and learn how to efficiently use the telecare applications.
	Interoperability	Connecting telecare applications with the internet to possibly improve its quality, if affordable for all patients.
	Development process and testing	Guidelines to be implemented into usability testing of telecare applications.

B. Interview tasks setup (in Dutch)

Belscript Kevin Netteb

Taken

Ik zal jou na deze uitleg vragen om **de BijKanker applicatie erbij te pakken en jouw scherm te delen** tijdens het gebruik. Vervolgens zal ik jou vragen om **4 taken** uit te voeren. **Per taak** heb ik een aantal **vervolgvragen die dieper ingaan op de taak** die je zojuist heeft uitgevoerd. Iedere taak laat jou een functionaliteit van BijKanker zien en de verwachting is dat alle taken bijeen jou een compleet beeld moet geven van hoe BijKanker werkt en wat het allemaal te bieden heeft. Dit is belangrijk om jou in staat te stellen de vragen zo optimaal mogelijk te beantwoorden.

Think-aloud

Wel wil ik jou twee dingen vragen, namelijk om tijdens uw gebruik van BijKanker en het uitvoeren van de taken jouw scherm te delen en om hardop na te denken. Wat ik hiermee bedoel, is dat ik jou vraag om **hardop uit te leggen** wat jouw mening is over datgene wat je ervaart terwijl je de taken uitvoert (bijv., "*de navigatie is duidelijk*", "*ik begrijp de onderscheid tussen de twee vragenlijsten op het hoofdscherm niet helemaal*", et cetera). Dit zal mij wat **meer inzicht geven van jouw mening** en hoe je BijKanker ervaart. **Jouw input** tijdens het hardop nadenken en als antwoord op de vervolgvragen kunnen **mogelijk bijdragen aan de verbetering van de BijKanker applicatie**.

Ik wil jou er nogmaals op duiden dat er **geen goede of foute antwoorden zijn**. Je zal niet worden beoordeeld op datgene wat je invult, het gaat hier om jouw ervaring met de BijKanker applicatie.

Taak 1 - Inloggen

> Je heeft een bericht ontvangen met inloggegevens en een link voor de BijKanker applicatie. **Log in op BijKanker** en **doorloop het proces** totdat je een **"Welkom terug" bericht** krijgt te zien.
>
> [Probeer **hardop na te denken** tijdens het uitvoeren van de opdrachten]

Hoe lang duurde het uitvoeren van de taak? 00:00

Is de taak afgerond? ja / nee

1) Wat is jouw mening over de stappen die je moet doorlopen om in te loggen?

   - Om toegang te krijgen tot de BijKanker applicatie.

   - Het inloggen met veiligheidscode als extra stap.

2) Hoe sta je tegenover het telkens opnieuw inloggen met veiligheidscode?

   - In hoeverre heb je hier behoefte aan?

   - In hoeverre voel je je hierdoor veiliger?

3) Wat is jouw mening over het ontwerp van het beginscherm van BijKanker?

- Bijvoorbeeld, de indeling.

- Minimalistisch

- Vindt je dat er iets ontbreekt?

- In hoeverre vindt je het beginscherm persoonlijk?

4) Hoe ervaar je BijKanker qua duidelijkheid?

- Hoe beoordeel je BijKanker op duidelijkheid?

- Geeft de introductie een beeld van wat de app te bieden heeft?

Taak 2 – Jouw gegevens

Dit is een hypothetische scenario. Stel je voor, om het voor jezelf makkelijker te maken, wilt je een **ander e-mailadres** gebruiken om **berichten te ontvangen** met betrekking tot de BijKanker applicatie. **Verander jouw huidige e-mailadres** die in BijKanker staat geregistreerd.

[Probeer **hardop na te denken** tijdens het uitvoeren van de opdrachten]

Hoe lang duurde het uitvoeren van de taak? 00:00

Is de taak afgerond? ja / nee

5) Wat vind je van de manier waarop de navigatie van BijKanker is ingedeeld?

- Vragenlijst, Rapport, Uw gegevens, Wachtwoord wijzigen, Uitloggen

- Zijkant positie, altijd beschikbaar

- Geven de termen die zijn gebruikt in de navigatie een indicatie wat erachter zit?

6) Wat is jouw mening over de twee-factor authenticatie?

- Veiligheidscode ontvangen via SMS, i.p.v. e-mail

- In hoeverre vindt je dit betrouwbaar?

- Andere (veiligere) mogelijkheden om in te loggen in gedachten?

Taak 3 – Wekelijkse vragenlijst

Je hebt een herinnering ontvangen van BijKanker om de wekelijkse vragenlijst in te vullen. Hierin kunt je aangeven welke symptomen je ervaart en in hoeverre je hierdoor verhinderd wordt. **Vul** de **wekelijkse vragenlijst** in. [Je kunt de vragenlijst vrij invullen, er zijn geen goede of foute antwoorden]

[Probeer **hardop na te denken** tijdens het uitvoeren van de opdrachten]

Hoe lang duurde het uitvoeren van de taak? 00:00

Is de taak afgerond? ja / nee

Tijdens instructie

7) In hoeverre geeft de instructie jou een duidelijk beeld wat er van je verwacht wordt in de wekelijkse vragenlijst?

- Is het duidelijk waar het om gaat?

8) In hoeverre geeft de instructie jou een duidelijk beeld waar de wekelijkse vragenlijst over gaat?

- Geeft de naam een indicatie waar het over gaat?

Tijdens vragenlijst

9) Hoe ervaar je de termen in de wekelijkse vragenlijst?

- Te medisch?

- Hoe beoordeel je de begrijpelijkheid?

- Is er nog iets toe te voegen?

10) Wat vindt u van de optie om zelf klachten aan te geven?

- In hoeverre geeft dat meer vrijheid?

- Qua handigheid?

11) Heeft u liever een andere aanpak gehad in plaats van het zelf invullen van klachten?

- Selectie maken uit een lijst?

- Wat persoonlijker, dus aangepast op uw eigen situatie?

Taak 4 – Rapport

Het door jou ingevulde informatie is ten alle tijden terug te zien. Je wilt bijvoorbeeld weten hoe jouw **gewicht** in de afgelopen paar dagen **is veranderd**. **Zoek deze informatie op**.

[Probeer **hardop na te denken** tijdens het uitvoeren van de opdrachten]

Hoe lang duurde het uitvoeren van de taak? 00:00

Is de taak afgerond? ja / nee

12) Wat is jouw mening over de opzet van het rapport?

- Duidelijkheid in de uitleg?

13) Wat is jouw mening over de manier waarop jouw informatie is gevisualiseerd?

- Grafieken

- Per meetpunt

- Qua duidelijkheid?

- Heeft het een bepaalde betekenis?

14) Op basis van hoge scores geeft BijKanker een melding, ben je in geval van hoge scores geneigd om contact op te nemen met jouw zorgverlener?

- In geval van stabiele gezondheid?

- Alert opvallend genoeg?

- Alert significant genoeg?

- Wat vindt je van het idee van de BijKanker applicatie? Vindt je het nuttig? Zou je het gebruiken?

- Ten slotte, heb je eventueel nog iets toe te voegen?

Nr.	**Item**	**Sterk mee oneens**	**Oneens**	**Neutraal**	**Eens**	**Sterk mee eens**
1	Ik denk dat ik deze applicatie **vaker** zal gebruiken.					
2	Ik vond dat de applicatie **onnodig complex** was.					
3	Ik vond de applicatie **makkelijk** te gebruiken.					
4	Ik denk dat ik een **technisch persoon nodig** heb om deze applicatie te gebruiken.					
5	Ik vond de **verschillende functionaliteiten goed geïntegreerd** in de applicatie.					
6	Ik vond dat er **veel inconsistentie** was in de applicatie.					
7	Ik stel me voor dat de meeste mensen **heel snel kunnen leren** om de applicatie te gebruiken.					
8	Ik vond de applicatie **heel erg onhandig** om te gebruiken.					
9	Ik **voelde me zelfverzekerd** toen ik de applicatie gebruikte.					

10	Ik **moest veel leren** voordat ik de applicatie kon gebruiken.					

Debrief form Interviews

Voordat wij het interview afsluiten, willen we vragen wat u vond van het interview. Heeft u enige tips voor ons? Wij willen u bedanken voor uw medewerking aan dit onderzoek. Zoals u weet, is de BijKanker applicatie nog in ontwikkeling en is het heel belangrijk dat ook AYAs in dit proces worden betrokken. De input die we van u hebben gekregen tijdens dit interview zal dan ook mee worden genomen in de verdere ontwikkeling van de BijKanker applicatie.

U zult nog een vragenlijst ontvangen via de e-mail van Mies van Eenbergen, onderzoeker van Integraal Kankercentrum Nederland. Wij zullen deze vragenlijst via de e-mail toesturen. Mocht u nog vragen hebben over het onderzoek, of willen praten over de onderwerpen die in de interviews zijn besproken, mag u altijd contact met een van de onderzoekers opnemen:

Merel van Dorst - 0650401229 - m.vandorst@tilburguniversity.edu

Kevin Netteb - 0611756885 - k.n.netteb@tilburguniversity.edu

C. Curved Grading Scale (CGS) for interpreting SUS

Range of SUS Score	Grading	Percentile Range
84.1–100	A+	96–100
80.8–84.0	A	90–95
78.9–80.7	A-	85–89
77.2–78.8	B+	80–84
74.1–77.1	B	70–79
72.6–74.0	B-	65–69
71.1–72.5	C+	60–64
65.0–71.0	C	41–59
62.7–64.9	C-	35–40
51.7–62.6	D	15–34
0.0–51.6	F	0–14

D. Codebook

Main theme	Sub theme	Quote	#
Information in SYMPRO	*Clarity of information*	Hier staat zelfs, ik zit nu toevallig bij een vraag “Hoe erg was je verstopping op het slechtste moment?” en **er staat onder heel netjes** “Verstopping is darmverstopping”.	1
		Wellicht zou er **een disclaimer** bij kunnen dat er geen foute antwoorden zijn, dat het gaat om de gezondheid zo goed mogelijk in kaart te brengen.	3
		Misschien **wel communiceren** dat indien je de klachten die worden gevraagd niet ondervindt, dat je **klachten die wel van toepassing zijn, later zelf kan invullen**, zodat je op zo een manier alvast de **indicatie geeft** dat het er aan zit te komen.	3
		Nou, de eerste keer toen ik op de website kwam, dacht ik “**En nu?** Wekelijkse klachtenlijst, ik dacht dat ik het dagelijks bij moest houden”. Ik heb nu in een week tijd drie keer de klachtenlijst ingevuld. **Wat is nou de bedoeling**, is het dat ik mijn bijwerkingen bij hou op het moment dat ik ze heb/merk of is het de bedoeling dat ik ze op een vaste dag in de week ga noteren	7
		Ik denk dat als van tevoren **de toegevoegde waarde duidelijk wordt gemaakt**, dat je dat eerder zal gebruiken.	8
	Information variety	**Korter, bondiger**. Soms kan het ook prettig zijn om korte animatiefilmpjes erin te hebben. Ik bedoel dan 1 of 2 minuten, **want die focus houden en het lezen is moeilijk**.	8
		Ja, **meer plaatjes, minder tekst**.	2
		Wat je bijvoorbeeld zou kunnen doen, is dat je **over een woord kan hoveren** zodat je een **korte uitleg** erbij krijgt van “oke, dit is de definitie van dit woord” of dit is een medische term maar hier heb je wel **aanvullende informatie**.	3
		Ik denk dat als je **bovenaan de klachtenlijst** zet van “klik hier voor introductie”, dan kun je daar **in je eigen tijd naar kijken** en ook al heb je die vragenlijst drie keer ingevuld, kun je dan toch **nog die introductie bekijken**. Uiteindelijk zou ik dat wel doen denk ik, om te kijken **of ik toch iets gemist heb**.	7
		Ik weet niet in hoeverre het handig is dat je elke keer een antwoord moet geven en **verder moet klikken**. **Kan ook een scrollijst zijn van een vraag of 5 met een kopje** voeding, kopje pijn maar het zijn maar klikje.	7
		Het is door een talig iemand ontworpen, wat zonde is want het is een app dus **beeld zou goed gebruikt kunnen worden**.	4
	Information overload	Ik kan dit hele lijstje wat hier staat, kan ik zo **de helft van de zinnen er al uit halen en dan weet ik nog wat ik moet doen**.	2
		Als je met [SYMPRO] ook **nog veel moet lezen, dan demotiveert dat**. Probeer daarom kort en krachtig te blijven.	3
		Het is sowieso **voor mensen die niet kunnen lezen prettig** maar ook voor de **vermoeidheid**, het **opslaan**, want soms moet je het **drie, vier keer lezen** voor je denk “oké, ik kan verder”.	8
		Meestal is het wel duidelijk dan denk ik dat ik het niet nodig heb. **Als ik dit doorlees**, waar ik moeite voor moet doen, dan **zie ik er geen dingen in** staan van “**die had ik echt moeten lezen**”.	7

		Stukken van de tekst, moest ik heel **veel lezen om het op te slaan.**	8
	Direct feedback	Hier moet je op **die resultaten klikken**, dat is weer **een extra stap**. Dan moet je ergens klikken om te controleren of er ergens een alarmbelletje gaat rinkelen. Het zou **logischer** zijn **aan het einde van die vragenlijst**, "Dank je wel voor het invullen, misschien is het handig dat je even contact opneemt met je arts".	5
		Ja, ik zou zelf zeggen **hoe simpeler, hoe beter**. Ik zou zelf zeggen van "Je weet vooraf dat je elke dag iets in moet vullen. **Begin daar meteen mee** en als je het hebt ingevuld**, zie je je grafiek of je resultaat**, **waar je dan staat** op dat moment en klaar".	2
Alerts given by SYMPRO	*Clarity of alert*	Ja, je moet opnemen erin **wat die alert is** en als dat vanwege privacy niet kan, dat je dan krijgt van je hebt iets ingevoerd in die applicatie waardoor wij **ons zorgen maken**, **kijk in die applicatie** waarom dat is.	4
		Het zou mooi zijn om hierin te zetten: "**Wij adviseren u om te bellen", dat je nogmaals die bevestiging krijgt**. Desnoods, "Bel tijdens werkuren hiernaartoe, bel tijdens weekend/avond hiernaartoe. Dit en dit zijn de alerts die ons zijn opgevallen, bespreek dit met je dokter".	7
		Het had wel iets kunnen zijn van "Mevrouw, je hebt net een vragenlijst ingevuld, **hier is jouw bevestiging**.	5
	Urgency	Nee, dan zou ik het **later wel bespreken**, maar als het is afgelopen dan hoef ik geen contact meer op te nemen.	8
		Ik denk wel dat dat verschilt per persoon, maar ik zou dan denken van "oh, **dat was een tijdelijk** iets dus als het **nu weg** is, dan is het **wel goed**".	6
		Misschien is het handig om te zeggen van "Bel je liever niet? Mail dan naar…", want **mailen is voor veel mensen toch laagdrempeliger** dan bellen. En ik denk ook dat bij spoed dan wil je **bellen dan wil je direct antwoord**. Als je het niet weet, dan mail je, want dan krijg je antwoord, alleen niet nu. Kan er een **paar uur overheen** gaan.	7
		Het is handig dat ie dat aangeeft. Er zijn mensen die op een gegeven moment **niet weten wanneer ze moeten bellen**, ik wist het zelf niet eens meer, omdat ik wel dagelijks kon bellen, ben je ook wel een beetje klaar mee op een gegeven moment.	7
	Directness	Als ik het **meteen zie**, dan gaat er wel een alarmbelletje en dan ga je **actie ondernemen**.	8
		Ja ik denk wel dat het **meer de noodzaak uitdrukt**.	6
Motivation to use SYMPRO	*Exhausting*	...ik weet het ook op het moment toen ik **onder behandeling** was, heb je vaak genoeg **geen zin aan dingen** en om je dan te gaan te gaan verzetten, dan moet het iets **heel korts zijn**.	2
		Als je met [SYMPRO] ook nog **veel moet lezen**, dan **demotiveert** dat. Probeer daarom **kort en krachtig** te **blijven**.	3
		Het **spreekt wel voor zich**, maar qua **tekstueel uitleggen** hoe het in elkaar zit, was het wel **verwarrend** vooral voor iemand	6

		die **onder behandeling** is en **vermoeid** is. Dat kan diegene **afschrikken** van het is **teveel** of ik kan het niet **opnemen**.	
	Boost	Dan gaat het **misschien motiverend** werken om het **in te** gaan **vullen**, omdat je ziet dat bepaalde **dingen** juist **beter gaan**.	2
Accessibility to SYMPRO	*Find SYMPRO*	**Want als ik nu naar SYMPRO zelf ga, dan kom ik bij deze site uit**. Als ik hier wil loggen met mijn gegevens en wachtwoord, dan krijg ik **een error**.	3
		Het enige vervelende of nou ja vervelend is dat je **iedere keer de mail moet opzoeken om** op de link te klikken om de app te openen. Denk dat het **makkelijker** [zou zijn als het **echt een applicatie**] is.	6
		Ik wil het heel **graag als app zien**, in plaats van webapp, want ik moest constant naar mijn mail zoeken waar die link is.	7
	Login to SYMPRO	Het enige wat ik **irritant** vond eraan, was dat ik echt **persoonsgegevens met jullie heb moeten delen** om mee te kunnen doen. Dus jullie vroegen naar mijn **geboortedatum** en mijn **telefoonnummer** en dat is het **allerlaatste wat ik** vrijwillig **heb willen geven**.	4
		Maar ik denk ook verder, als je er **een telefoon app** van maakt, **iedere app** heeft **tegenwoordig pincode**. Dat is zoveel **sneller** dan zo een code.	7
Speed of use	*Direct feedback*	Maar als je elke keer je vragen gedaan zou hebben en je zou **aan het einde** daarvan een **grafiek** zien van **alles watje hebt gedaan,** ja dan, ik zou dat persoonlijk nog **duidelijker** vinden.	2
	Quick interaction	Nee dan is het **hup, klik, klik** en dan ga ik, punt. Als je het mij vraagt, dan vind ik het **ideaal**, als je **zo een situatie kan creëren**.	2
		Dus, hoe **sneller** en hoe **makkelijker** je door **bepaalde stappen** heen kan, hoe **beter** als dat het is.	2
		Ja, je moet het zeker **niet te lang maken**.	3
		Bij wijze van, dat [het systeem] zegt dit **is het overzicht**, zo heb [jij] het nu ingevuld: “**Wil je nog hieraan aanpassen**?” en dan **doorklikken** bij wijze van.	3
Own SYMPRO input	*Symptom input*	Ik bedoel als je **klachten** hebt die **er niet tussen** staan, dan is het wel **prettig** dat je die **kan benoemen** in de app.	1
		Of het moet inderdaad een **standaard lijstje** waar onder op staat wat je wel vaker ziet natuurlijk “**Of anders**” en dat het **alsnog vrij in te vullen** is.	1
		Die **behoefte aan beheersbaarheid** kun je met die app wel ondervangen door **duidelijk** te **maken wat naar wie** moet. Maar het **uit de app weg** laten vallen om **het beheersbaar te maken,** daarmee **schoffeer** je een **patiënt**.	4
		Als je in een behandeling zit, misschien wel beter om je af te vragen van heb ik dat niet, dus dat je **eerst** de **algemene dingen** krijgt en dan **daarna specifiek** je eigen dingen kan **benoemen** dat vond ik juist **handig**.	5
	Stored input	Verder vind ik die **open vraag** wel **prettig**, maar dan wel als **wat je hebt ingevoerd** de **volgende keer terugkomt**. Dus dat het **systeem** ook **input** van patiënten **registreert**.	4

		Het zou wel fijn zijn als dat **richting geeft** voor een **persoonlijkere** ding van “hee, ik **had ingevuld** dat ik **hoofdpijn heb**, dat **is geen standaard vraag** als bijwerking”, dat je dan de **volgende keer** wordt **teruggevraagd** zonder dat je dat zelf weer moet noteren omdat je dat ook in het rapport kan zien.	6
Contact with clinicians	*High symptom scorest detected*	Ja, **onaangekondigd** komen we dan **problemen oplossen** en ja, zo zie ik dat dan werken om zo maar te zeggen bij zoiets als dit bij **de hulplijn** zelf. **Vanuit de dokters en medici die dit bekijken**.	2
		Ik zit wel te denken of het dan niet **fijner** zou zijn dat **je zorgverlener jou dan belt** van “hoe gaat het, want **we hebben een alert ontvangen**?”. Op de een of andere manier voelt het alsof je **heel veel verantwoordelijkheid bij de patiënt** legt.	5
		Als ik me **okay voel en ik krijg zo een melding en ik heb een zorgverlener die ik kan mailen**, dan zou ik voor een mailtje kiezen van “joh, ik **krijg die melding**, ik heb zelf **niet het idee** dat er **wat aan de hand** is, ben jij het **eens met die applicatie**?” dan moeten we contact hebben.	4
		Als jij ergens **hele tijd zorgen** hebt gemaakt over iets en dat wordt **iedere keer genegeerd** door een arts, dan ga jij het **zelf ook** altijd **negeren**.	4
		Je **ziet** hier wel “**score verergerd**” dus dat geeft wel **aanduiding** dat je er misschien **iets mee moet doen**.	3
		Dat je het **voor iemand invult**, niet alleen voor jezelf.	7
Personalization within SYMPRO	*Adjust to AYA situation*	Stel dat je het inderdaad **deelt met je zorgverlener**, dan is het misschien **handig** dat die ook **in een oogopslag ziet** van “oh **deze week** heeft ze **chemo** gehad”.	1
		Ja, want **sommige vragen doen er niet altijd toe** voor de sommige patiënten. Dan kan het **lastig zijn** om wel **elke keer** herinnert te worden aan **bijwerkingen** die je **zou kunnen hebben**.	3
		Ja, ik denk dat je zou moeten **beginnen** met een scherm van “**welke behandeling** heb je net gehad?”, dan daarna “**waar** heb je **last**?” dat je dan die **lichaamsdelen** waar je **last hebt** aan kunt **klikken** en dat de app daarna **per lichaamsdeel gaat kijken** wat er aan de hand is.	4
		Dus het **helpt** je als **patiënt** heel erg om het te kunnen **koppelen** aan wat er **qua behandelwijze** met je is gebeurd.	4
		Het zou het iets **persoonlijker** maken als je zou zien van “de **vorige keer** was dit heel **heftig**, **hoe is dat nu**?”…	6
		Als je **snel vragenlijst** wilt **invullen**, dan **alleen** die **dingen waar je** op dit moment **last van hebt**. Misschien is dat een idee, in plaats van dat mensen gaan denken “**moet ik nou weer over mijn stoelgang gaan praten?**”, ik wil graag deze vragenlijst invullen omdat ik misselijk ben.	7
		Dus ik denk dat het **fijn** is als ik zou **invullen welke medicatie** en **welke dosering of** het kan **er al instaan** maar dan moet het wel goed **geconnect** zijn **met je patiëntendossier** van het ziekenhuis.	6

	Adjust experience	Ja, bijv. **een vinkje** van "**niet weergeven**" of haal het **eruit** en zet het bij de **introductie**.	7
Reports provided by SYMPRO	*Graph scales*	Ik denk wel dat de **schaalverdeling breder** kan i.p.v. 1,2, 3.	6
		Dit zou dan **ook in 5 schalen** [gevisualiseerd moeten worden].	5
	Clarity	De **eerste keer** staat er **nauwelijks informatie**. De **tweede keer** wordt het wat **duidelijker**.	3
		Nou, niet echt want hier staat **hoe erg je klachten waren**, maar **niet echt of het je heeft verhinderd** in het **dagelijks leven**.	5
		Als je het **per kwartaal terug kan zien**, dan heb je wel een beetje " oh, maar er is nu iets bijgekomen of een andere behandeling", dat je toch een beetje **voor jezelf overzichtelijk** kan houden.	8
Tone of SYMPRO	*First name use*	Misschien ook dat je je **voornaam gebruikt** van "…, hier zijn jouw uitslagen van de wekelijkse klachtenlijst", dus dat het wat **vriendelijker** overkomt.	5
		Op zich had ik het wel beter gevonden als ik mijn **voornaam terug kon zien**. Want je hebt nu mijn voorletters en mijn achternaam. Ik zag net bijvoorbeeld "welkom terug" [op het beginscherm], maar dat kan ook "**welkom terug, (…)**" zijn.	7
	Informal	Ik **irriteer me mateloos van u genoemd worden** in iets waar ik zelf voor gekozen heb. Daar **haak ik ook echt op af**, wat betekent dat ik de **rest niet meer lees**.	4
		Ik zou er "**je**" van maken. Ik zou mijn **voornaam** erin willen in plaats van voorletters. Slaat nergens op maar het is toch een **stukje gevoel**.	7
Two-factor authentication to login to SYMPRO	*Positive*	Ik krijg [mijn veiligheidscode] al **via de SMS** en dat vind ik **handig**.	1
		Ik denk trouwens dat het heel **handig** is dat je die **veiligheidscode** krijgt. Ik vind dat **extra veilig**.	6
		Vindt het ook **goed** dat er een **additionele verificatiecode** is die je dan moet gebruiken voor het inloggen zodat **niet zomaar iemand bij jou gegevens kan,** ook al laat je bijvoorbeeld je laptop achter en staan verschillende zaken al vooraf ingevuld.	3
	Tolerable	Elke **code is irritant** maar ik **snap** dat **vanwege beveiliging** zo een **veiligheidscode nodig** is.	4
		Het is wel een **gedoe**, maar ik snap wel omdat het **gaat om medische gegevens** dat er dan **extra beveiliging** op zit.	5
	Negative	Ik denk wel dat je **gebruikersnaam** en je **wachtwoord** ook **voldoende** moeten zijn.	1
		Dit vind ik al **irritant**. het is mijn **mail**, **moet dat echt dubbel beveiligd**? Ik vind het irritant.	7
Notifications	*Directness*	Als ik dit zou vergelijken **met hoe kwalijk als deze notificatie** is, vergeleken bij de notificatie die ik zou krijgen bij **een telefoontje van een behandelaar**, dan zou ik **deze rapportcijfer 3** geven en een telefoontje van mijn behandelaar **een 9.**	2
		Ik denk dat je het **allebei** moet doen, dus **in de app** in de vorm van een **pop-up** en daarnaast **nog een mail**.	4
		Omdat je **toch mee bezig** bent, zou ik het als **eindresultaat** wel prettig vinden **om te zien**, van **het is okay** of **houd het in de gaten**.	8

E. Honorable mentions (formerly part of the Results section)

Certain input from AYAs denoted additional points of emphasis for further development of SYMPRO, though not classifiable under efficiency, effectiveness and satisfaction.

Report.

Inconsistencies Regarding Scales Used In Graphs. Whenever AYAs were asked to conduct the weekly survey, they had to rate certain symptoms (e.g., exhaustion) on a scale from 1 (not at all) to 5 (very much so). AYAs had no problem with this, but they did not understand why this five point scale was not included into the graphs themselves. Particularly, AYA 6 said that for consistency and clarity sake "I think that the scales [in the graphs] should be expanded instead of just 1, 2, 3". It is a matter of keeping that consistency.

Clarity. AYAs reacted to the 'Report' page relatively positive, though there were a few details that were brought to attention. If an AYA has not yet conducted the weekly symptom survey, then the graphs will be empty. Hence, that is why AYA 3 said that "there is barely any information the first time, while the second time it starts to get clearer". Not every AYA was overly positive though. AYA 5 for instance thought that the graphs "signal how severe your symptoms were but not whether it bothered you in your daily routine". Furthermore, AYA 8 posted an interesting question. In case of more frequent use during and perhaps after treatment cycles, AYA 8 was curious as to how the graphs would visualize all those measurement points. A suggestion was made that "if you could track per quarter then you could keep an overview of your progression". This suggestion was made as a way to keep the graphs orderly and not chaotic.

Two-Factor Authentication

AYAs were questioned on the extra safety measure in the form of two-factor authentication, which was previously mentioned in the login process. There was a mixed response to this idea. AYAs for the idea understood why it could be considered "annoying", as AYA 7 put it, while AYAs against it understood why it could be considered "convenient", as described by AYA 1. AYAs 1, 6 and 3 were quite positive about the inclusion of the two-factor authentication. AYA 6 complimented the "extra level of safety" while AYA 3 said that it would prevent "just anybody from gaining access to your personal data, even if you leave your laptop somewhere". However, there were AYAs that felt positive but had an understanding as to why other AYAs could find it not at all positive. For instance, AYA 4 who said that “every code is bothersome, but I understand that for safety reasons this code is necessary”. Additionally, AYA 5 agreed that “it is a hassle but that there is an extra safety measure due to the medical information”. Not everyone was as tolerant with regards to the two-factor authentication. Though AYA 1 initially mentioned that she “already receives the code by SMS” which she found convenient, she did state that “a username and a password should be enough”. Before the first question was even asked, AYA 7 already expressed annoyance at the two-factor authentication in that “it is my mail, does that really have to be secured like that?”. All in all, there is a mixed response but general understanding (with the exception of a few) that the two-factor authentication is included in the login process. As previously mentioned, the expected step from web app to mobile app could provide for more and quicker safety measures (e.g., entering a pin number).

Information

Perceived As Exhausting. Yet again, AYAs have expressed the need to keep information “short and sweet”. AYA 3 mentioned that having to put extra effort into reading with SYMPRO, that it could be “demotivating”. Additionally, AYA 2 harped on how treatment affects an AYA’s habits to a points where “you do not feel like doing anything or to waste energy, so it [SYMPRO] should be very concise”. AYA 6 also said that fatigue plays a significant role and that too much information could “freak [an AYA] out because it is too much to take in”.

Personalization

Input own symptoms. Currently, AYAs are asked at the end of the survey to input symptoms that were not in the questions and then rate how much it hindered them. Overall, AYAs were positive about the ability to insert and rate symptoms themselves. AYA 5 liked the overall structure of the weekly survey “to first get the general questions out of the way and then start listing specific symptoms”. Consequently, when asked how this final question could be improved, AYA 1 agreed with a list of symptoms to choose from (that were not in the general questions) but to preserve “what you occasionally see [in surveys], namely the option ‘or else’ to keep the ability to input something”. Finally, AYA 5 stressed that “leaving this out of the app to keep it manageable, would hurt a patient”. More specifically, AYA 5 stated the importance in keeping the ability to input own symptoms.