Improving Self-Efficacy and Patient Activation in Cancer Survivors through Digital Health Interventions: Findings from the PERSIST Project

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Abstract

Background: Cancer survivors face various challenges but also demonstrate resilience and find ways to adapt and cope with life after cancer. Self-efficacy and patient activation are two crucial factors that significantly impact the well-being of cancer survivors. These concepts play a vital role in enabling cancer survivors to take control of their health, manage their treatment effectively, and achieve positive long-term outcomes.

Objective: The aim of this study is to assess the impact of a mobile health system (mHealthApp) to improve the self-efficacy and patient activation of breast cancer and colorectal cancer survivors.

Methods: This study presents the findings from clinical trials conducted according to the published study protocol of the PERSIST project that was funded by European Commision to support cancer survivors using digital health technologies. The acceptability and usability of the mHealthApp, as well as the perceived self-efficacy and satisfaction with care, were assessed using validated tools such as CASE-cancer, PAM, and SUS.

Results: The results indicate that the PERSIST project partially achieved its predefined objectives and hypotheses by enhancing the self-confidence and satisfaction of cancer survivors with healthcare and improving the effectiveness of cancer treatment and follow-up procedures to some extent.

Conclusions: The PERSIST project demonstrates the potential to improve clinical outcomes, empower patients, and contribute to broader social goals in cancer survivorship. However, larger studies involving a more diverse patient population and a greater number of clinicians are necessary to establish the effectiveness of digital therapies in cancer survivorship care and to provide additional data and evidence.

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Keywords: Cancer Survivorship, Self-Efficacy, Satisfaction, Patient Activation, Digital Health Interventions

INTRODUCTION

Cancer survivorship is a transformative experience that encompasses both physical and psychological challenges [1]. As individuals navigate the complexities of managing their health after treatment, fostering self-efficacy and patient activation becomes paramount to achieving optimal health outcomes. Digital health interventions, with their unique ability to personalize, engage, and empower patients, hold immense promise in addressing these critical aspects of cancer survivorship [2], [3].

Self-efficacy and patient activation play important roles in cancer survivorship [4]. Self-efficacy

refers to an individual's belief in their ability to perform a specific task or behavior, while patient activation refers to an individual's knowledge, skills, and confidence in managing their own health [5]. Studies have shown that higher levels of self-efficacy and patient activation are associated with better outcomes for cancer survivors, including improved quality of life, reduced symptoms, and healthier lifestyles [6]. Self-efficacy, defined as one's belief in their ability to succeed in a particular task, is a crucial factor in determining health outcomes [7]. Cancer survivors with high self-efficacy are more likely to adhere to treatment regimens, engage in healthy behaviours, and effectively manage symptoms [8]. Patient activation, on the other hand, refers to an individual's readiness and ability to actively participate in their own healthcare. Activated patients take ownership of their care, collaborate with providers, and seek out necessary information and support [9].

Traditionally, interventions to promote self-efficacy and patient activation have relied on in-person counselling and education [10]. While these approaches have value, they often lack the scalability and accessibility needed to reach the growing number of cancer survivors worldwide. Digital health intervention (DHI) offer a personalized, accessible, and continuous approach to enhancing self-efficacy and patient activation in cancer survivors [11]. These interventions have been shown to enhance adherence to treatment, increase physical activity, and reduce symptom burden. Additionally, digital health interventions can help survivors manage stress and anxiety, fostering resilience and improving overall well-being [12], [13], [14].

Several studies have investigated the impact of digital health interventions on self-efficacy and patient activation. For example [15], focused on the effect of digital health coaching on self-efficacy and lifestyle change in patients. Another study emphasized the importance of active patient engagement through eHealth to promote self-management and patient activation, as a critical component of quality of life and minimizing the consequences of disease in daily living [16]. A growing body of evidence suggests that adopting healthy lifestyle practices, such as regular exercise [17], increased fruit and vegetable consumption [18], maintaining a healthy weight and body

composition [18], quitting smoking [19], and engaging in cognitive behavioral therapy [20], can positively impact cancer prognosis. However, it is challenging for many cancer survivors to fully adhere to all these recommendations [19]. Overall, previous studies have predominantly focused on either self-efficacy [16], [21], [22] or patient activation [12], [23], and from a patient centered intervention. The objective of PERSIST project [24], however was, to evaluate if and how, self-efficacy and patient-activation can be address as a joint effort between patients and clinical professionals. To this end, a mobile health system (mHealthApp), supported by data-driven Clinical Decision Support System (CDSS) were integrate into clinical routine according to trial protocol [25]. The recommendations and data collected from patients during their everyday lives (i.e. real-world data), were analyzed by oncologists and actively used in discussions and joint patient clinical decision making, during follow-ups. To measure self-efficacy and patient-activation, Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer) [26], System Usability Scale (SUS) [27] and Patient Activation Measure (PAM) [28] were used. The secondary objective aimed to assess patient engagement and willingness to use the mHealth App and gather feedback from patients and clinicians on their experience of using the PERSIST solution as a whole. To sum up, this paper mainly reflects the findings of clinical trial registered under study protocol ISRCTN97617326 [25].

METHODS

PERSIST Platform

The overview of PERSIST platform is sketched in Figure 1. After collection of real-world data from patients through mobile apps and smart bracelet, some technologies were applied on data to extract multimodal features (Multimodal Risk Assessment and Symptom Tracking (MRAST) framework) in addition to physical markers and questionnaires. All objective markers (vital signs) and subjective markers (PREMs/PROMs and linguistic/vocal/face cues) were collected by the mHealth app. All

data was fused and processed via different tools (Cohort and Trajectory Analysis, Information Retrieval Tool, Alerts mechanism) to fed into the Clinical Decision Support System (CDSS) and mClinicial app.

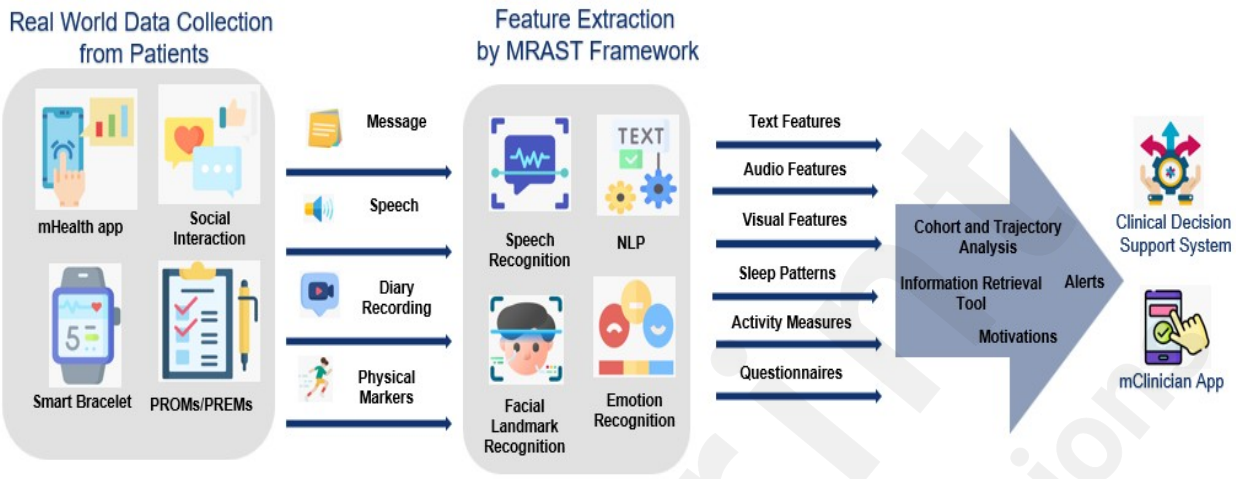
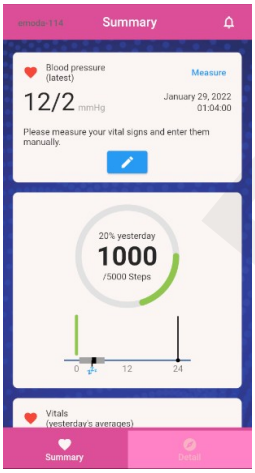


Figure 1: The main data flow through PERSIST platform.

Main Components



The mHealth app was the key component for populating the Big Data Platform with various types of patient data, enabling other services to process and analyse it. The mHealth app allows an individual to track his/her health parameters and vital values (Figure 2). The application enables data flow between users and doctors. Mobile applications were developed using the Flutter framework

with the Dart language. Interoperability of patient data was provided through FHIR standards to be shared among partners. A first version of the HL7 FHIR Healthcare Digital System was published by [29].

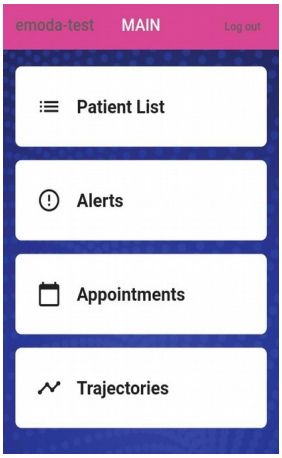


Figure 3: mClinican app

mClinician Application: The mClinican app is another data ingestion tool in PERSIST (Figure 3). It was developed mainly for the usage of clinicians to help them gather patients' data and enable them to have an overview of the acquired data. mClinician has also a simple web interface for clinicians to enter and modify patients' data. This user interface displays concepts from Symptoma's API [30] to create structured data for patients in FHIR format. mClinician gathered data from the electronic health records or they were entered by hand and displayed data collected from each patient's mHealth. The most relevant data needed to be gathered from patients' electronic health records was decided together with the clinicians from each hospital.

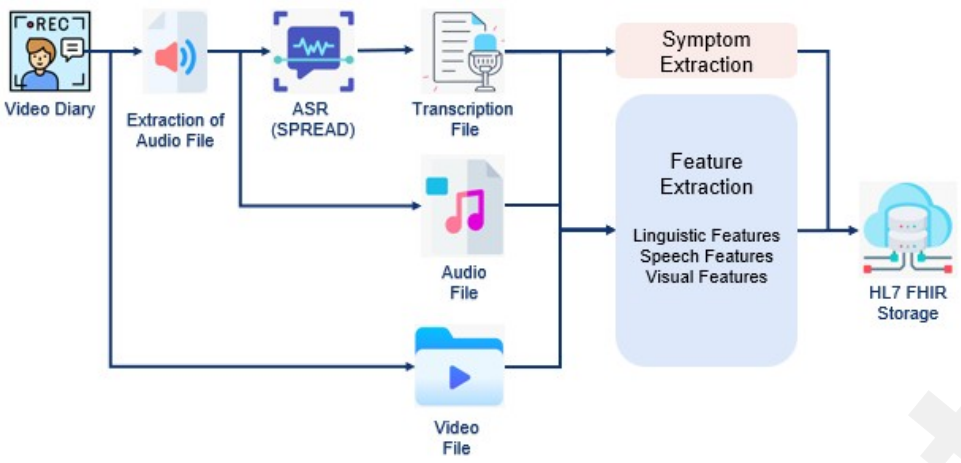


Figure 1: Feature Extraction at MRAST framework

Multimodal Risk Assessment and Symptom Tracking (MRAST): MRAST platform includes the multi-modal analysis of the patient video recordings [31] (Figure 4). It mainly consists of automatic speech recognition (SPREAD automatic speech recognition (ASR) [32]), natural language processing and facial landmark detection for the extraction of linguistic, speech and visual features. MRAST also includes disease centric discourse through the extraction of symptoms from the free text which has been carried out using information retrieval tool [33], which is developed based upon Symptoma's core technology.

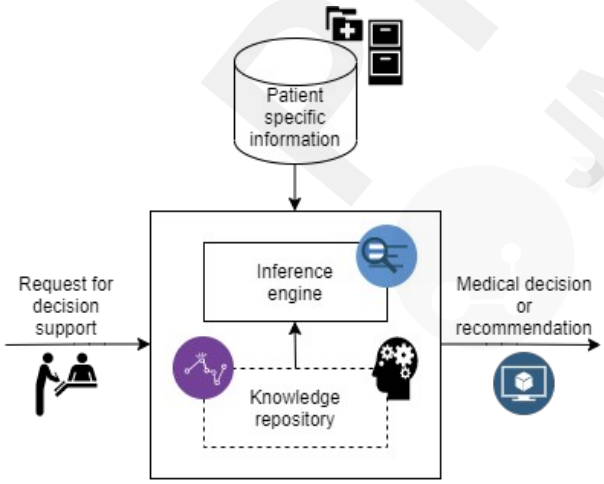


Figure 5: Overview of CDSS Structure

Clinical Decision Support System: The CDSS in PERSIST was designed as a medical software constructed with a collection of services that uses artificial intelligence technologies, algorithms, and

advanced software services to help healthcare professionals make more efficient treatment plans for their cancer-survivor patients. PERSIST CDSS has the following components (Figure 5): (1) Knowledge base (2) A user interface (3) An inference engine (4) A knowledge representation system. Additionally, cohort and trajectory analysis in multi-agent support systems [34] and breast cancer survival analysis with high-risk marker detection [35] were included into CDSS. Finally, it is worth mentioning that within the CDSS algorithms, two models related to predicting possible recurrences were also included: an AI service that predicts the likelihood of relapse recurrence in the next five years for breast and colorectal cancer survivors; and a model to automatically detect Circulating Tumor Cells (CTCs) in liquid biopsy samples.

Clinical Trials

Study Design: The PERSIST clinical trial was designed as a single-case experimental prospective study as a validation of the PERSIST platform [25]. This pilot study involved 4 clinical centres - Centre Hospitalier Universitaire De Liege (CHU) in Belgium, University Medical Centre Maribor (UKCM) in Slovenia, Complejo Hospitalario Universitario de Ourense (SERGAS) in Spain and Riga East Clinical University Hospital (REUH) in Latvia in collaboration with University of Latvia (UL).

Participants: The study involved 166 patients (85 survivors of Breast Cancer and 81 survivors of Colorectal Cancer). Among the recruited patients, 85 have had breast cancer (C50) and 81 colorectal cancer (C18/C19). The average age of the patients was 55 years old. In total, 37 male and 129 female were included in the study (for inclusion and exclusion criteria, see Mlakar et al., 2021).

Hypothesis: "A comparison of self-efficacy levels at the beginning and end of the intervention demonstrated a significant increase in self-efficacy among participants who received the personalized intervention supported by the mHealthApp."

Data Collection: Participants in the study were given both the mHealth app and a smart band, which collected various types of data including sociodemographic, clinical, lifestyle, and biomarkers. The app also provided personalized follow-up based on patterns learned from big data. Additionally,

patients were able to input additional data through questionnaires, which were prompted by notifications from the app. Specific questionnaires (CASE-cancer, SUS and PAM-13) were collected automatically during phone calls or medical follow-ups as a validation tool, while others required patients to record video diaries discussing their daily lives. The text also mentions data collected from the mClinician tool, which allows clinicians to access information about patients including their demographics, cancer diagnosis, treatment history, and diagnostic performance. The output of the Clinical Decision Support System (CDSS) used in the study includes results, scores, and accuracy, with a history of CDSS outputs shown to the clinician.

RESULTS

Perceived self-efficacy of patients (CASE cancer questionnaire)

A total of 75 questionnaires were analysed, and descriptive statistics were calculated for each score factor. No statistically significant differences in scores between the recruitment and last follow-up were found in any of the three factors using the Wilcoxon test (Table 1). The result shows that the patients participating in PERSIST are capable of understanding, managing, and obtaining information about their illness.

Table 1. CASE-Cancer Results: Comparison of the median scores of the three factors at recruitment vs at the last follow up.

	Factor 1: Understand & Participate in care		Factor 2: Maintain positive attitude		Factor 3: Seek & obtain information	
	Score at recruitment	Score at last follow-up	Score at recruitment	Score at last follow-up	Score at recruitment	Score at last follow-up
N	75	75	75	75	75	75
Mean	13.73	13.75	13.28	13.17	13.81	13.55
Median	14	14	14	14	15	14
Std. Deviation	1,905	2,014	2,299	2,435	2,312	2,207
Minimum	9	9	6	4	7	8

Maximum	16	16	16	16	16	16
Percentiles 25	12	12	12	12	12	12
50	14	14	14	14	15	14
70	16	15	15	15	16	16

Activation levels of patients (PAM questionnaire)

PERSIST participants were expected to improve self-management effectiveness, which requires a high level of health knowledge, skills, and self-confidence measured by the PAM-13 questionnaire. PAM levels 1 and 2 indicate lower patient activation, while PAM levels 3 and 4 indicate higher patient activation. As shown in Table 2, most patients reported having level 3 or 4 of activation at both recruitment and last follow-up (42,3% and 32,1% respectively), with a small increase in the number of patients reporting level 4 activation at the follow-up (from 32,1% to 35,9%). No statistically significant difference was found in the percentage of patients at each level between recruitment and last follow-up (Table 2).

Table 2. PAM Results: Comparison of the percentage of patients in each level at the recruitment vs at the last follow-up. P values have been calculated with McNemar Test

Level	Recruitment (N=75)	Last follow-up (N=75)	P value
Level 1 n (%)	5 (6,4)	6 (7,7)	1,000
Level 2 n (%)	15 (19,2)	16 (20,5)	1,000
Level 3 n (%)	33 (42,3)	28 (35,9)	0,486
Level 4 n (%)	25 (32,1)	28 (35,9)	0,648

User acceptance of mHealth App (SUS)

During the development of the mHealth App, we engaged in a co-creation phase that included user testing, where end users provided direct feedback and recommendations for improving usability. For each patient (total 27 patients), the SUS score was calculated (Lewis, 2018). Figure 6 shows the sum score of the 10 questions. At the beginning of 2022, most of the patients (n=10) thought that the

system was "experiencing usability issues" (level 50-70) and "acceptable to good" (level 70-85). This could be related to the patients' previous experience with technology in general, including the use of various types of applications and the possibility to adapt to the mHealth App, which was in the development process. During the study, the percentage of participants who rated the system as having "excellent usability (level >85)" increased from 14% to 33% (n=4 to n=9). This could be attributed to the ongoing upgrades made to the mHealth app in collaboration with technical partners. At the end of the study, the most popular score group for the system was "Experiencing usability issues (level 50-70)", which could be explained by negative feedback from patients because of getting higher complexity of the system.

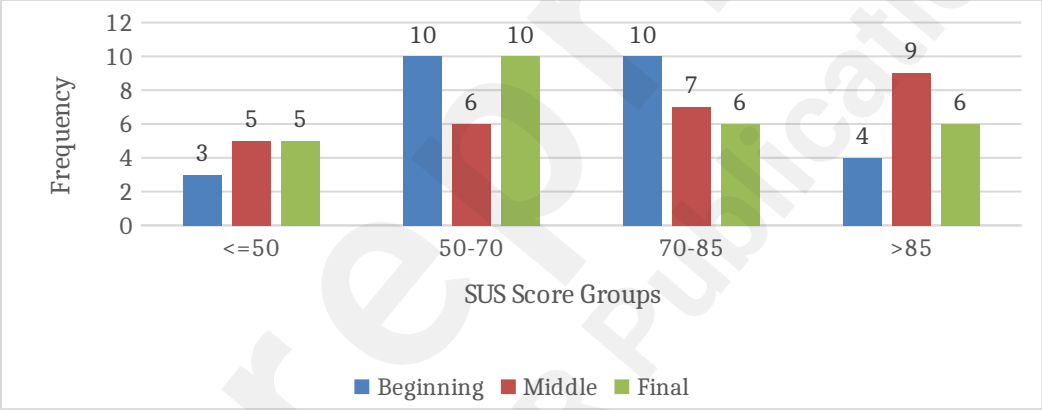


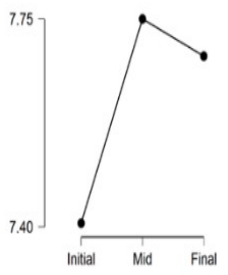
Figure 6. SUS Results: The sum score of the points acquired in all 10 questions.

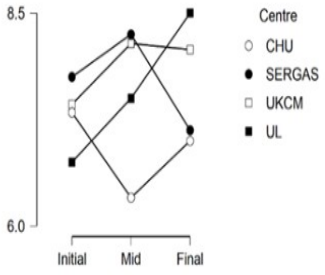
General feedback from patients

Part A: feedback about the project

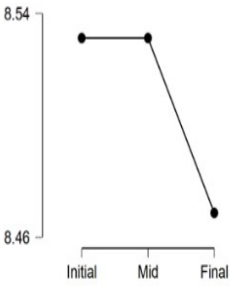
To gather general feedback from patients, patient surveys were conducted at three different time points using an app-based questionnaire (Appendix 1). The aim was to understand patients' experience of participating in the study and to identify and share their most important insights. In total, 32 participants from different healthcare institutions (6 from CHU, 8 from SERGAS, 14 from UKCM, and 4 from UL) were included in the analysis. There were no statistically significant

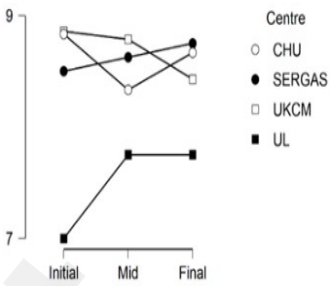
differences between any two time points for any questions (Figure 7).



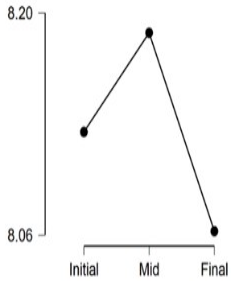


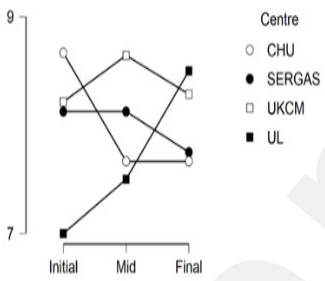
(a) 1st question (Friedman's ANOVA p=0,585; Conover's test: initial and middle time points (p=0,391), initial and final time points (p=0,346), middle and final time points (p=0,931).)





(b) 2nd question (Friedman's ANOVA p=0,833; Conover's test: initial and middle time points (p=0,866), initial and final time points (p=0,672), middle and final time points (p=0,554).)



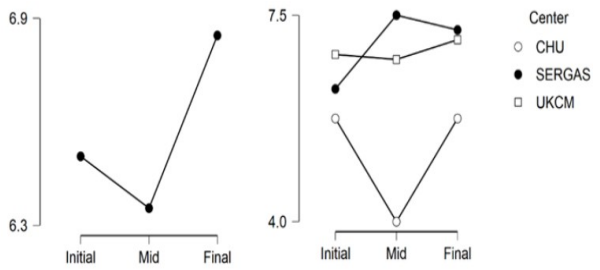


(c) 3rd question (Friedman's ANOVA p=0,502; Conover's test: initial and middle time points (p=0,554), initial and final time points (p=0,238), middle and final time points (p=0,554).)

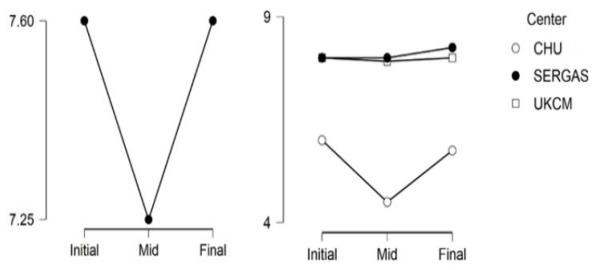
Figure 7. The results of general feedback from patients (Left: Means of al centres; Right: Means of individual centres)

Part B: feedback about mHealth

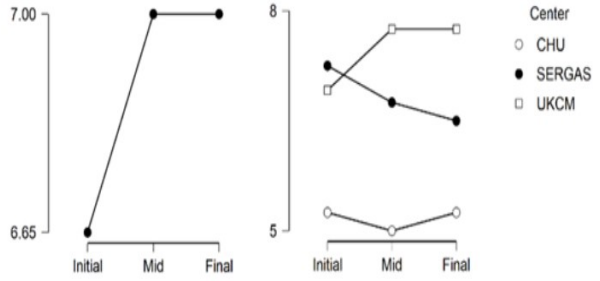
Twenty participants responded to the survey at three different time points, with 4 participants from CHU, 4 from SERGAS, and 12 from UKCM (Appendix 1). However, none of the participants were from UL as none of them replied in 3 time points to this questionnaire (Figure 8).



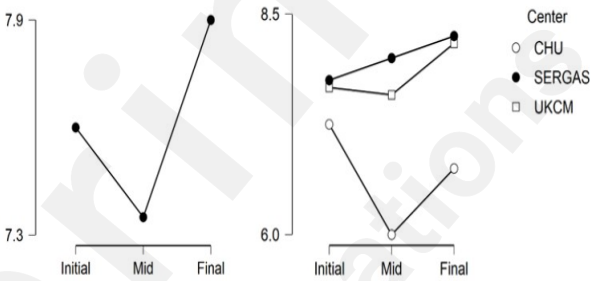
(a) 1st question (Friedman's ANOVA p=0,109; Conover's test: initial and middle time points (p>0,999), initial and final time points (p=0,235), middle and final time points (p=0,235).)



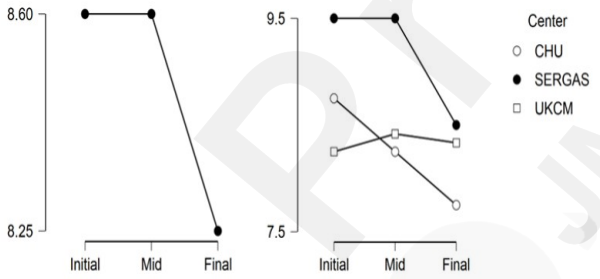
(b) 2nd question (Friedman's ANOVA p=0,779; Conover's test: initial and middle time points (p=0,490), initial and final time points (p=0,843), middle and final time points (p=0,622).)



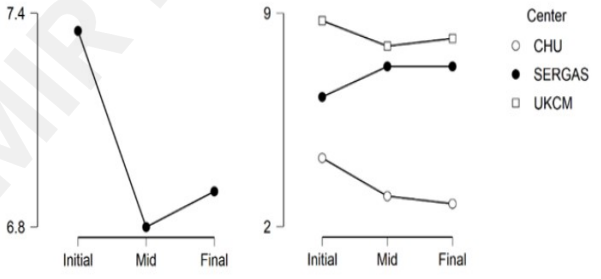
(c) 3rd question (Friedman's ANOVA p=0,581; Conover's test: initial and middle time points (p=0,304), initial and final time points (p=0,512), middle and final time points (p=0,707).)



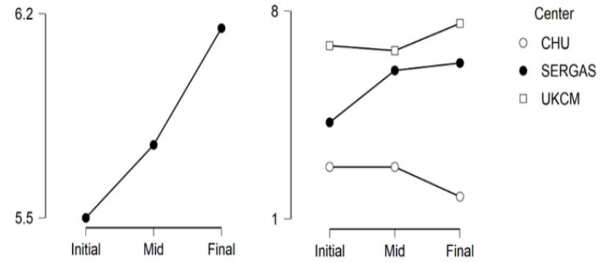
(d) 4th question (Friedman's ANOVA p=0,279; Conover's test: initial and middle time points (p=0,891), initial and final time points (p=0,138), middle and final time points (p=0,176).)



(e) 5th question (Friedman's ANOVA p=0,109; Conover's test: initial and middle time points (p=0,910), initial and final time points (p=0,078), middle and final time points (p=0,062).)



(f) 6th question (Friedman's ANOVA p=0,395; Conover's test: initial and middle time points (p=0,704), initial and final time points (p=0,189), middle and final time points (p=0,345).)

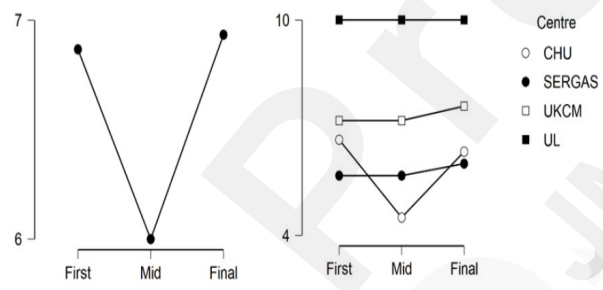


(g) 7th question (Friedman's ANOVA p=0,755; Conover's test: initial and middle time points (p=0,707), initial and final time points (p=0,454), middle and final time points (p=0,707).)

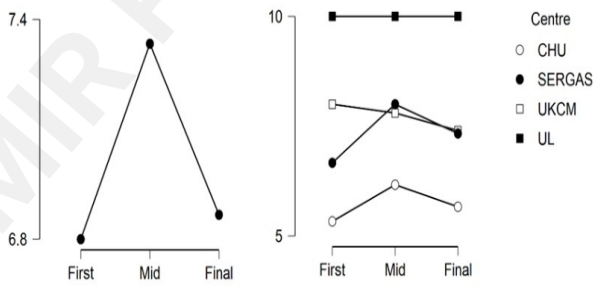
Figure 8. The results of general feedback about mHealth app (Left: Means of al centres; Right: Means of individual centres)

Part C: feedback about devices

Altogether 15 questionnaires were filled in three time points (6 from CHU, 3 from SERGAS, 1 from UL and 5 from UKCM) (Appendix 1). The results are shown in Figure 9.



(a) 1st question (Friedman's ANOVA p=0,041; Conover's test: initial and middle time points (p=0,035), initial and final time points (p>0,999), middle and final time points (p=0,035).)



(b) 2nd question (Friedman's ANOVA p=0,227; Conover's test: initial and middle time points (p=0,087), initial and final time points (p=0,500), middle and final time points (p=0,284).)

Figure 9. The results of general feedback about devices (Left: Means of al centres; Right: Means of individual centres)

User acceptance (SUS) for mClinician

User acceptance questionnaires were also distributed to clinicians working with mClinician web and

App in the 4 participating hospitals. The sum score of the points of 10 questions in each round can be seen in Figure 10. According to the classification of SUS, most of the clinicians (81,55%) who replied thought that system was ‘not easy to use’ (level <=50) (n=7 for both rounds) and had some usability issues (level 50-70) (increasing from n=6 to 7).

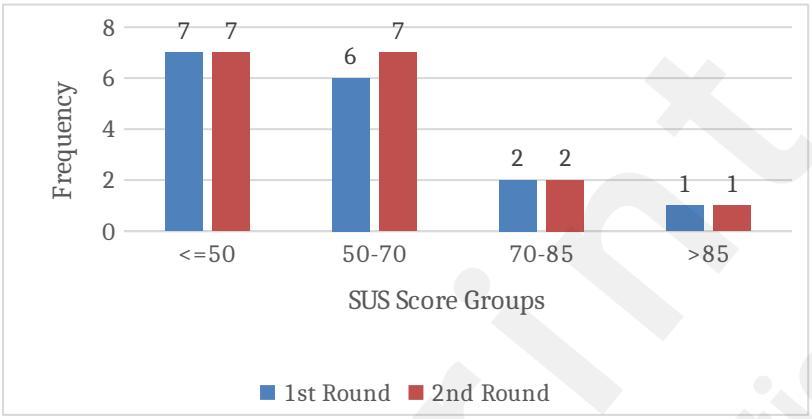


Figure 10.SUS Results: mClinician score group

Clinicians’ Questionnaire

A generic questionnaire was developed to standardise the feedback from clinicians of the 4 hospitals (Appendix 1). Altogether 11 clinicians involved in PERSIT research replied (4 from UL, 2 from SERGAS, 2 from CHU and 3 from UKCM). The results were given in Appendix 1.

DISCUSSION

The results support the initial hypothesis, demonstrating that the use of an mHealth application can contribute to self-efficacy, patient activation, and satisfaction with care among colorectal and breast cancer survivors. Overall, 44,44% of patients evaluated the usability of the app as good or excellent. Clinician’s, however, rated that the system was ‘not easy to use’ or had some usability issues.

Patient Participation: Altogether, 41 patients left the clinical study before its end. A comprehensive analysis of the reasons (total=65) of this withdrawal were related to personal circumstances (n=11)

and technical issues (n=10), including smart-bracelet malfunctions and other technical problems. It is also important to note that "participation takes too much time" (n=9) was among the common reasons for leaving the study. However, despite those problems, most of the patients remained engaged in the study and the patients from UKCM and UL who attended the last PERSIST workshop in February 2023 expressed their enthusiasm and willingness to continue participating in future projects based on results gained in the project.

Patients' Perspective

CASE-Cancer: Although there is no statistically significance between different phases of the study, patients showed a high level of understanding and participation in their care at the recruitment, with no score below 9 in *Factor 1: Understand & Participate in care*. This suggests that recruited patients had a good understanding of their treatment regimens and options and a high level of ability to participate in healthcare decisions. The scores for *Factor 2: Maintain positive attitude* ranged from 4 to 16, indicating some difficulty in maintaining a positive attitude for some patients. However, all patients seemed willing to stay informed about their disease to some extent, according to the scores obtained for *Factor 3: Seek & obtain information.*

PAM: The results of the PAM-13 questionnaire in the study suggest that the participating cancer patients had a good level of self-management skills at baseline, which was maintained throughout the study. Most patients reported having level 3 or 4 of activation at both recruitment and last follow-up, indicating that they were acting and gaining control over their condition. Although no statistically significant differences were found in the activation levels of the participants throughout the project, the results suggest that the mHealth app has potential to support patients in improving their self-management skills, which is an encouraging finding for the PERSIST system.

SUS: The use of user testing and the SUS questionnaire proved to be an effective tool for identifying usability issues with the mHealth app and making improvements that benefit end users. As the study progressed, there was a notable increase in the number of participants who perceived the system as having excellent usability, which could be attributed to the constant upgrades made to the app in collaboration with technical partners. Despite some negative feedback through the end of the study, 44,44% of patients still evaluated the usability of the app as good or excellent. These findings highlight the importance of user testing and continuous improvement to enhance the usability and user acceptance of mHealth apps.

General feedback from patients: According to patient feedback - Part A, the PERSIST study was well-received and valuable. Patients rated their participation positively, and their ratings improved slightly over time. They found the instructions and explanations to be understandable and rated their overall participation as great. These findings suggest that the project successfully engaged patients and provided them with clear instructions and explanations throughout the study period. Patients consistently rated their participation and the quality of personnel explanations highly, indicating that the project was effective in providing clear guidance. The absence of statistically significant differences between different time points suggests that the results are reliable and consistent.

According to patient feedback - Part B, participants generally had a positive experience with an mHealth app, with high ratings (mean 6.57) for the emotion wheel/detection feature, instructions, and questionnaires. The app's instructions and explanations were found to be clear (mean 8,48) and understandable throughout the study period, and participants' ratings slightly increased over time. While there were no statistically significant differences in ratings between any two time points, the consistently high ratings suggest that the app was well-received and useful to patients across different locations. The app's performance was positive overall, but further research may be needed

to fully evaluate its effectiveness and user-friendliness.

According to patient feedback - Part C, participants generally had a positive experience with smart bracelets, with high ratings that tended to improve over time. However, no statistically significant differences were found, and further research is required to confirm these observations. Participants also rated their experience with mobile phones as satisfactory to good on average, indicating their contentment with the phones' functionality and usability. The fact that participants' opinions did not decrease over time is a positive indication that the mobile phone experience did not deteriorate over time. The differences in ratings between centres may be influenced by various factors such as cultural and social differences, access to technology and healthcare, and personal preferences.

Clinicians' Perspective

User acceptance (SUS) for mClinician: The results of the user acceptance questionnaire distributed to clinicians using the mClinician web and app versions show that there were some usability issues identified by most of the clinicians (81,55% in the first round and 87,5% in the second round). The results show that the scores did not significantly differ between the two rounds, indicating that the app version did not introduce new usability issues. Additionally, one clinician rated the usability as excellent in the first round, which is a positive indication. Further investigation and improvement of the identified usability issues could potentially lead to increased acceptance and adoption of the mClinician system among clinicians.

Generic questionnaire for clinicians: PERSIST system received an average rating of 6.27 out of 10, indicating that clinicians generally found it to be useful. Most clinicians (9 out of 11) would like to use some part of the PERSIST system in their clinical practice. The most useful aspects of the PERSIST system for clinicians include feedback from patients, alerts, data on vital parameters, and risk factors. Clinicians believe that the PERSIST system could be used in various medical fields,

such as general practice, psychology, infections, and inflammatory diseases. Physical activity was identified as the most important potentially modifiable lifestyle factor for cancer survivors that the PERSIST system detects. The usability of the PERSIST system was rated as average to good by clinicians.

Principal Results

The PERSIST project effectively engaged cancer survivors and provided a positive experience. Participants demonstrated patient activation and self-efficacy and the project enhanced self-management among cancer patients (Textbox 1). Participants were satisfied with the mobile app and its usage. On the other hand, clinical trial attendance was high (75.3%) which was one of the most important expectations of the study protocol. The PERSIST system can be beneficial in other fields of medicine, particularly for general practitioners who attend to many patients with different health conditions daily. The PERSIST project used mHealth apps and smart bracelets to study the physical activity levels, heart rate, and emotional well-being of cancer survivors. The findings suggest that patients were moderately active and had a positive outlook on life after cancer treatment. Patients' engagement with the mHealth app was measured through their willingness to follow up and monitor their gathered data. The mean score for engagement was around 7 out of 10, indicating that patients were actively using the app. Furthermore, there was a slight increase in mean score over time, suggesting increasing engagement. The study also identified potential reasons for differences in physical activity levels among hospitals, such as environmental factors and weather conditions. The use of mHealth apps and smart bracelets led to a decrease in signs of depression and anxiety among

patients, indicating a positive impact on their psychological well-being. The PERSIST tool provides personalized cancer survivor care plans, alert systems, and parameter overviews for clinicians. Clinicians provided positive feedback indicating that the PERSIST system and mClinician app have the potential to be useful tools in clinical practice. They highlighted their usefulness in monitoring patient parameters and providing personalized care plans. The PERSIST project has the potential to improve clinical outcomes, patient empowerment, and contribute to broader social goals in cancer survivorship. However, further investigation and improvement of usability issues are needed for greater acceptance and adoption among clinicians. Larger-scale studies are required to demonstrate the effectiveness of digital therapies in cancer survivor care and expanding the Although this study met most of the expectations of the study protocol, the PERSIST project to involve a wider patient population and more clinicians would provide more data and evidence for its benefits.

Textbox 1: Narrative feedback from patients

‘‘It is interesting to record and monitor measurements. It’s good because it diverts your thoughts’ (44-year-old female survivor of breast cancer)’
‘I would like to know more about the development itself and how this technology works’(68-year old female survivor from a colorectal cancer)
‘The patient enjoys the opportunity to monitor his features and he thinks this may help other patients’ (68-year-old male survivor from a colorectal cancer)
‘The project has encouraged some positive emotions. It helps me to follow my state of health in general, the opportunity to view the data stimulates the consciousness of the need to get moving’ (75-year-old female survivor of breast cancer)
‘The appreciation to the people who treated me motivated me to participate in a clinical study. Technology can help cancer patients and survivors, however, the constant thinking about onself may prevent them to move on.’ (53-year-old female survivor from a colorectal cancer)

CONCLUSIONS

The PERSIST tool offers a significant advancement in cancer survivorship care by delivering personalized and dynamic care plans based on individual survivor needs. This personalized approach has the potential to improve patient outcomes and overall quality of life while reducing healthcare costs. The system is user-friendly and easy to use, with participants expressing a neutral to slightly positive attitude towards using it frequently. The high rate of adherence in almost all hospitals suggests that patients found the app easy to use and manage daily. The PERSIST tool aligns with the goals of the Precision Medicine Initiative (PMI), which aims to tailor medical treatments and preventive strategies to an individual's unique genetic and environmental profile. It has the potential to be a key driver in the transition towards personalized survivorship care, adapting to the changing needs of each individual survivor and delivering personalized care plans. This can lead to better health outcomes, increased patient satisfaction, and significant cost savings for healthcare providers and insurers. The tool can also improve the coordination and continuity of care among healthcare providers, reduce healthcare costs associated with cancer survivorship care, and potentially prevent chronic disease. The use of mHealth apps and smart bracelets can provide valuable data that can inform strategies to promote healthy behavior and prevent chronic disease, potentially leading to long-term cost savings for healthcare systems and society. Overall, the PERSIST approach represents an exciting opportunity to improve survivorship care for cancer patients and transition towards more personalized medicine strategies.

DATA AVAILABILITY

The deidentified data are available from the corresponding author upon reasonable request.

ACKNOWLEDGEMENTS

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AUTHOR CONTRIBUTIONS

All authors conceived of the idea for the intervention for cancer survivors and led the application for funding for the project. DB, IP, KA, AML, MM, SN, SM, AMM, BCC, JAA, MC, PD, VB, CL led the patient recruitment, data collection and the execution of clinical trials in four different clinical centers. UA, IM, US, VS developed the MRAST framework. TC, KU developed the mHealth application. UA, IM, US, VS, SL, JN, TC, KU, GM, JPC, SCA contributed to the development of CDSS. Data analysis and results of the questionnaires were prepared by all authors.

COMPETING INTERESTS

The author declares no competing interests.

ABBREVIATIONS

ANOVA: Analysis of variance

ASR: Automatic Speech Recognition

CASE-cancer: Communication and Attitudinal Self-Efficacy scale for cancer

CDSS: Clinical Decision Support System

CHU: Centre Hospitalier Universitaire De Liege

CTCs: Circulating Tumor Cells

DHI: Digital health intervention

HL7 FHIR: Health Level 7 Fast Healthcare Interoperability Resources

MRAST: Multimodal Risk Assessment and Symptom Tracking

PAM: Patient Activation Measure

PERSIST: Acronym of project ‘Patients-centered SurvivorShIp care plan after Cancer treatments based on Big Data and Artificial Intelligence technologies’

PMI: Precision Medicine Initiative

PREMs: Patient Reported Experience Measures

PROMs: Patient-reported outcome measures

REUH: Riga East Clinical University Hospital

SERGAS: Complejo Hospitalario Universitario de Ourense

SUS: System Usability Scale

UKCM: University Medical Centre Maribor

UL: University of Latvia

ETHICS

This study has been approved by relevant ethical committees in Belgium (Institutional Ethics Committee of CHU de Liege, approval ref. no: 2020/248), Latvia (Riga Eastern Clinical University Hospital Support Foundation Medical and Biomedical Research Ethics Committee, approval ref. no: 8-A/20), Slovenia (National Ethics Committee, approval ref. no. 0120–352/2020/5) and Spain (Regional Institutional Review Board, approval ref. no. 2020/394). A written informed consent was obtained from each participant.

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Appendix 1 - Questions

Questions of Part A: feedback about the project

1. How do you rate your experience with participation in the PERSIST project (in general)?
2. Are the instructions and explanations about the project from personnel understandable?
3. How does the participation in the PERSIST project make you feel?

Questions of Part B: feedback about mHealth

1. How do you rate the emotion wheel/detection in the app? From 1 (bad, confusing) to 10

(super, interesting): Figure 8 (a) shows there were no statistically significant differences between any two time points. Only there were slight differences between the initial-final and mid-final time points (p=0,235).

2. How do you rate your experience with questionnaires in the app? From 1 (bad) to 10 (excellent): Figure 8 (b) shows there were no statistically significant differences between any two time points.
3. How do you rate your experience with diary recording? From 1 (bad, confusing) to 10 (super, interesting): Figure 8 (c) indicates that there were no statistically significant differences observed between any two time points.
4. How do you rate your experience with the mHealth app? From 1 (really bad) to 10 (excellent): The data in Figure 8 (d) shows that there were no statistically significant differences between any two time points in terms of participants' ratings of the app's ease of use. The results of the Friedman ANOVA suggest that the p-value was not significant at 0,279, indicating that any observed differences in the ratings were likely due to chance. Furthermore, there were significant differences between the initial and final time points (p=0,138) and the mid and final time points (p=0,176).
5. Are the instructions and explanations about mHealth app usage understandable? From 1 (completely confusing) to 10 (completely clear): Figure 8 (e) indicates that there were no statistically significant differences between any two time points.
6. Do you follow up your gathered data in the mHealth app? From 1 (no at all) to 10 (all the time): As can be seen in Figure 8 (f) there are no statistically significant differences between any two time points.
7. Does the mHealth app affect your behaviour? From 1 (no at all) to 10 (I modify my behaviour after looking at the data): As can be seen in Figure 8 (g) there are no statistically significant differences between any two time points.

Questions of Part C: feedback about devices

1. How do you rate your experience with smart bracelets: There is a statistically significant difference between any two time points (Figure 9 (a)).
2. How do you rate your experience with mobile phone: There are no statistically significant differences between any two time points (Figure 9 (b)).

Questions of Clinicians' Questionnaire

1. How would you rate the PERSIST system in general (from 1 bad to 10 excellent)? Average points given were 6,27. Clinicians from all hospitals had similar average points.

2. Would you like to use the PERSIST system as it is in general in your clinical practice? The 2 clinicians who disagree to use the system reported that the system is running too slowly and is not aligned with use in oncology practice.

3. What is the most useful thing the PERSIST system would help you with in your practice? (Free text answer) Feedback from patients, data on vital parameters, patients' subjective feelings, patient's statistics, risk factors etc. were marked.

4. What kind of other medicine field uses a PERSIST system? (Free text answer) "General practice" was mentioned most of the times (5), followed by "psychology", "infections" and "inflammatory diseases".

5. What, in your opinion, are the most important potentially modifiable lifestyle factors for cancer survivors that PERSIST detects? "Physical activity" was the most chosen response (9); followed by "Blood Pressure" (6) and "Heart Rate" (6) and "depression signals" (3).

6. What do you see as PERSIST overall added value? (Free text answer) In general the "option of monitoring the patients" was considered as the best value.

7. How would you rate PERSIST usability? (from 1 bad to 10 excellent) Average points –

7.

8. How would you rate the precision of PERSIST system to identify risks in advance for cancer survivors? (from 1 bad to 10 excellent) Average values – 6,9

9. Is PERSIST helping to personalise care plans/treatments for cancer survivors (yes, no, hard to say,)? 5 clinicians chose part of it, 4 marked yes, but 1 – hard to say.

10. What would be the best way to implement preventive strategies considering the individual patient's trajectories? (1)Automatization of the App, (2)checking once a week or every six months, (3)the involvement of trained assistants.

11. How would you rate mClinician web in general (from 1 bad to 10 excellent). On average 6,1

12. Would you like to use the mClinician web version as it is in your clinical practice? 5 - hard to say, 4 – no, 1-yes.

13. Which parts of the mClinician web version seems most useful for clinical practice to you?

mHealth data (8); Tests (6); General and medical history (5), Diagnosis and symptoms (5), Cancer treatment (4)

14. What parts of mClinician web should be changed or removed? (1)Tests, (2)diagnostic and (3)therapeutic parts.

15. How would you rate the mClinician app in general (from 1 bad to 10 excellent)? Average points - 6.

16. Would you like to use the mClinician app version as it is in your clinical practice? 9, yes -1, no - n1.

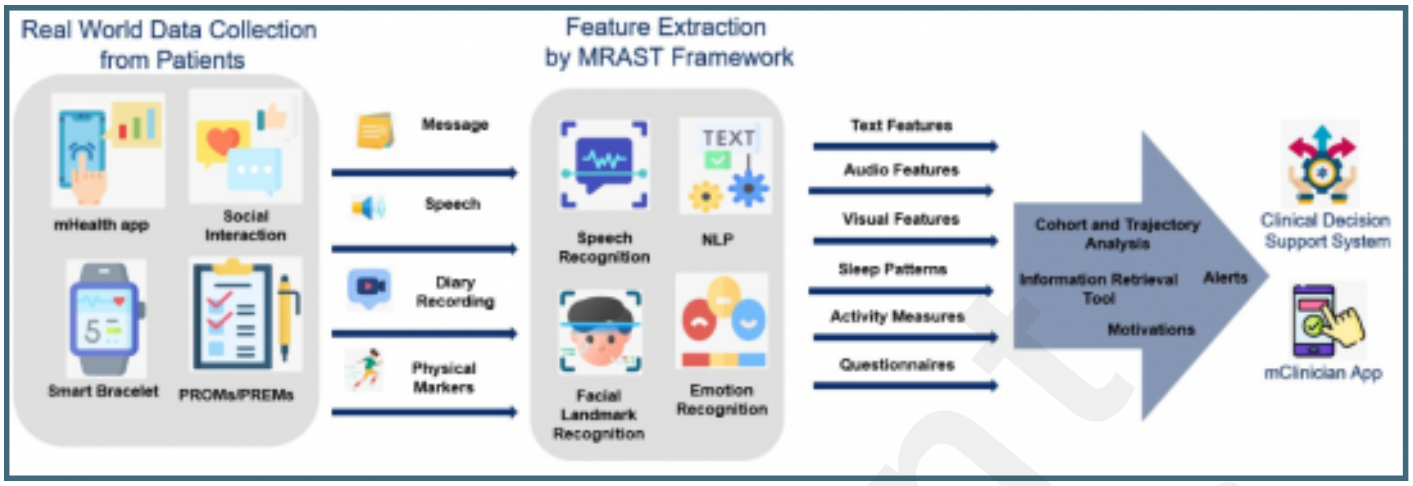
17. Which parts of the mClinician app version seems most useful for clinical practice to you? Alerts 7, Patient overview 6, Appointments 5, Recurrence prediction 3, Cardiovascular Disease Risk 2, Usage stats 1, Trajectories 1

18. What parts of the mClinician app should be changed or removed? Trajectories and duplication of EHR.

Supplementary Files

Figures

The main data flow through PERSIST platform.

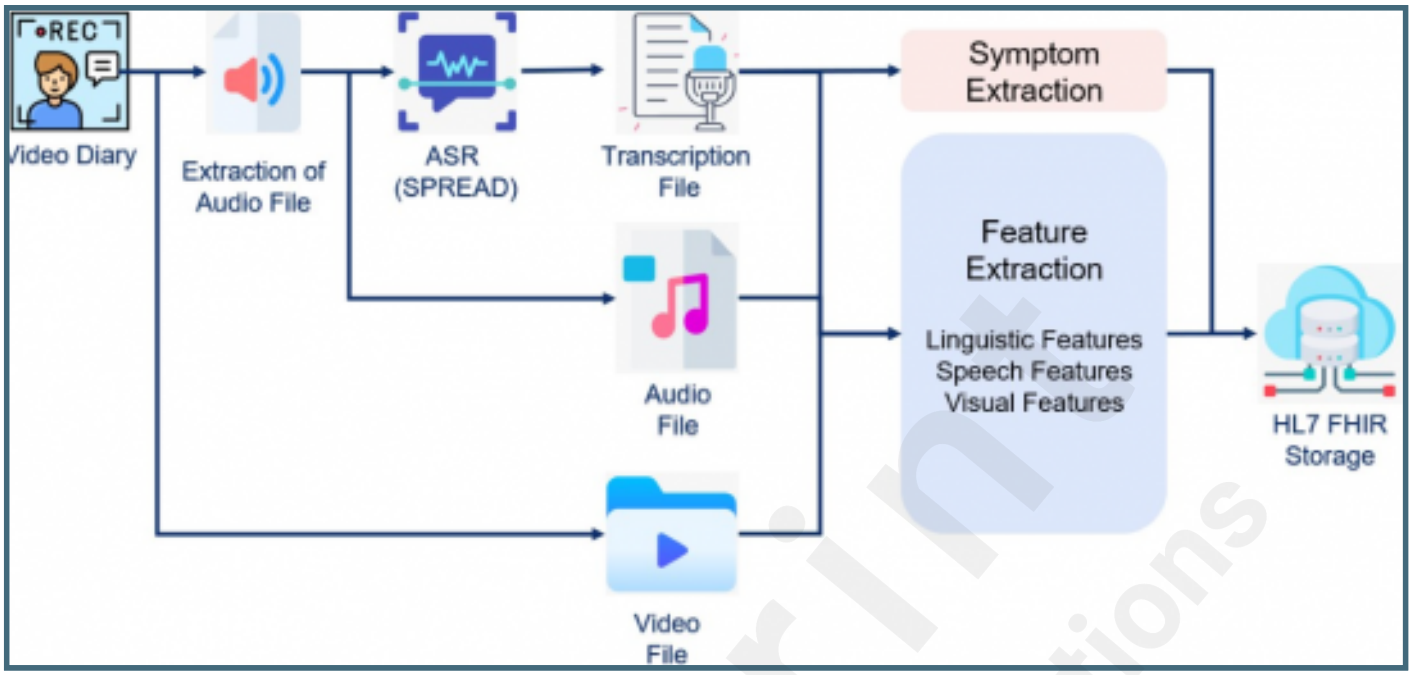


mHealth App.

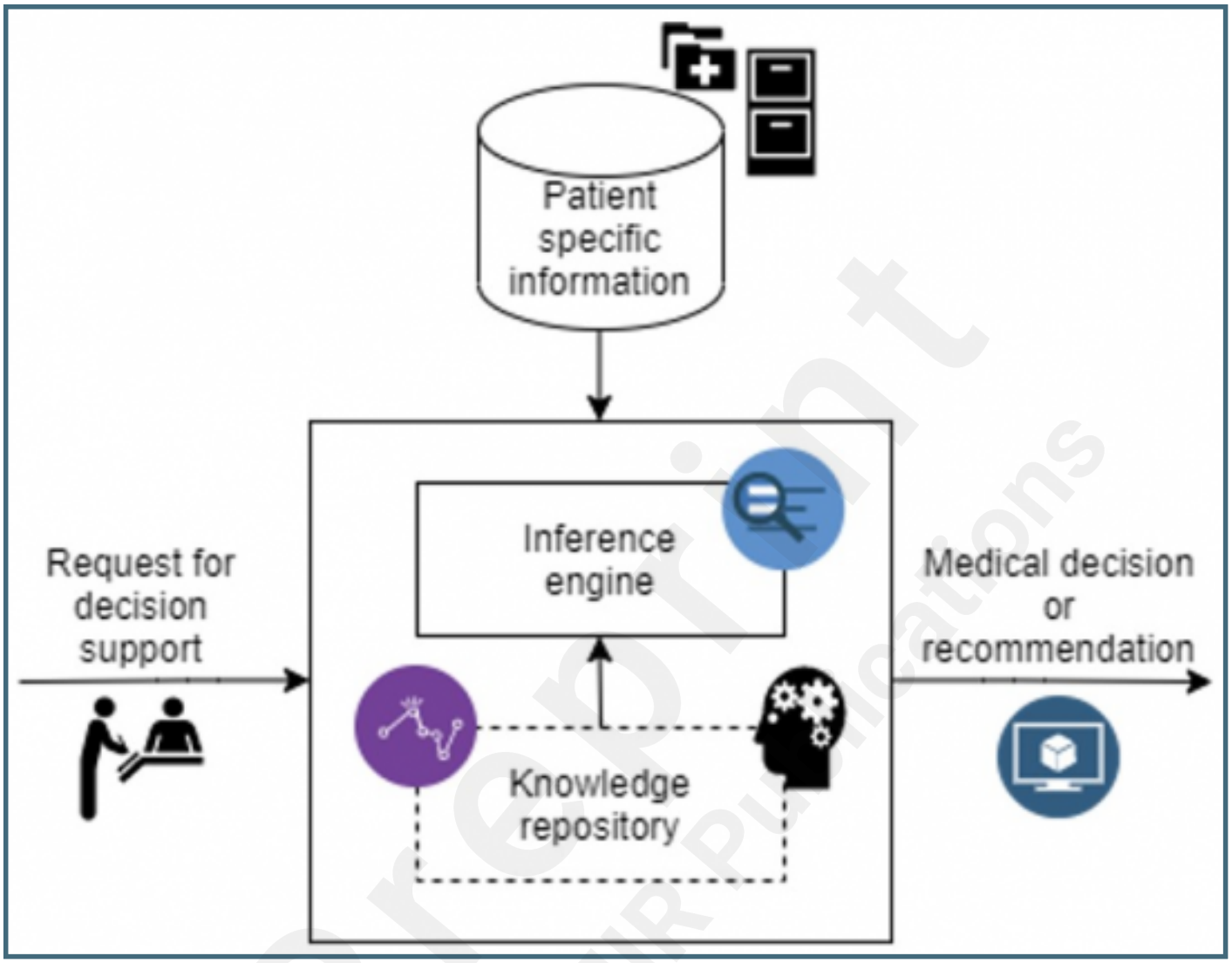

emoda-114
Summary
Blood pressure
(latest)
Measure
12/2 mmHg
January 29, 2022
01:04:00
Please measure your vital signs and enter them manually.
20% yesterday
1000
/5000 Steps
0
12
24
Vitals
(yesterday's averages)
Summary
Detail

mClinican app.

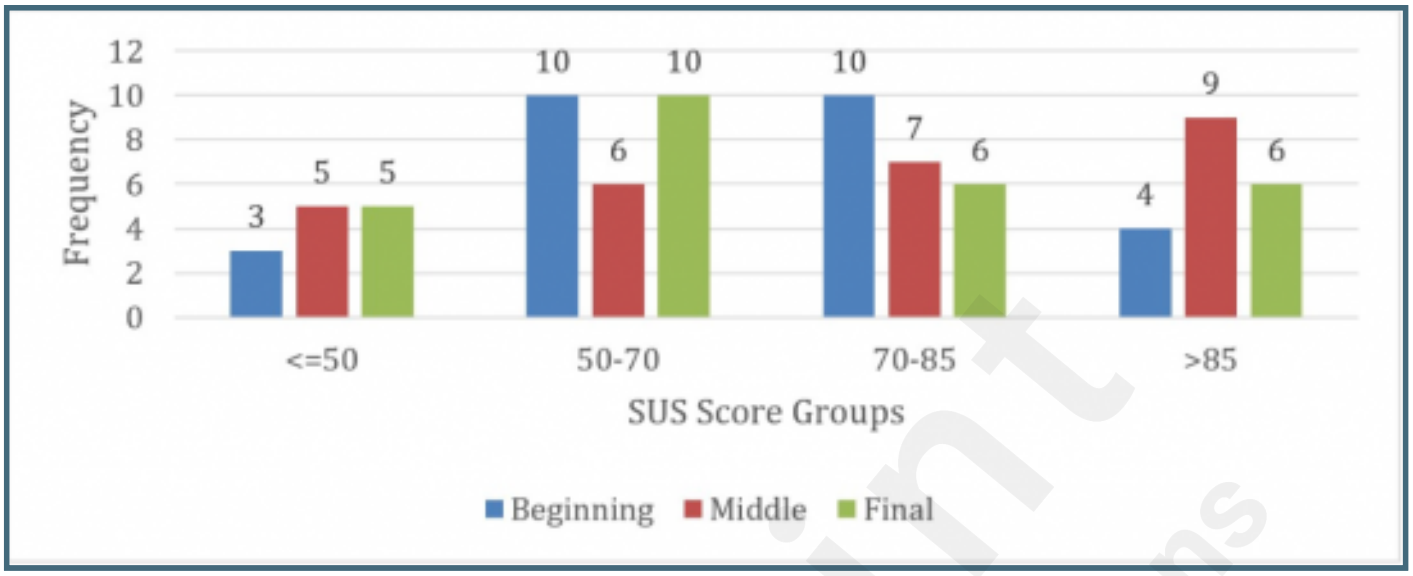
Feature Extraction at MRAST framework.



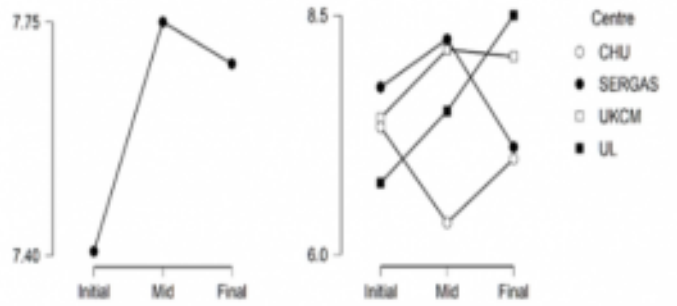
Overview of CDSS Structure.



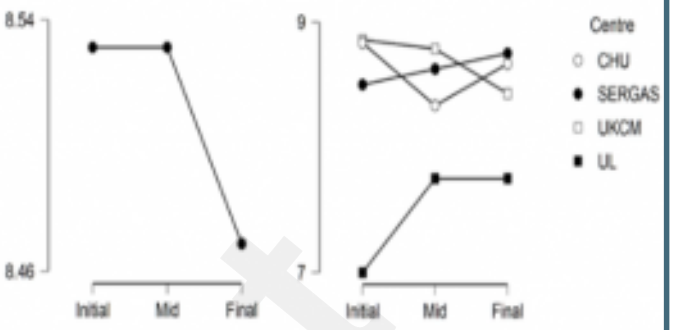
SUS Results: The sum score of the points acquired in all 10 questions.



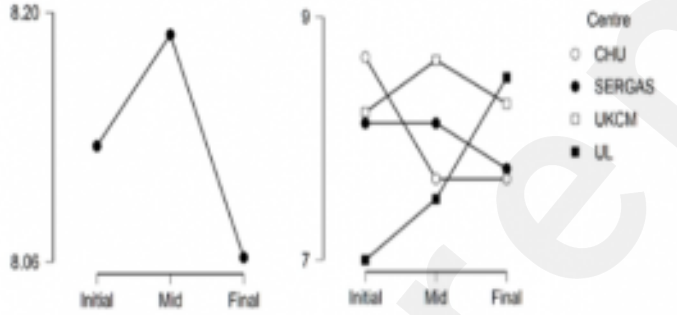
The results of general feedback from patients (Left: Means of al centres; Right: Means of individual centres).



(a) 1st question (Friedman's ANOVA p=0,585; Conover's test: initial and middle time points (p=0,391), initial and final time points (p=0,346), middle and final time points (p=0,931).)

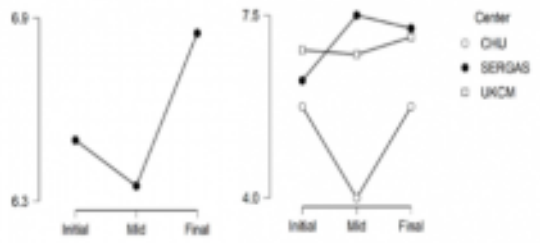


(b) 2nd question (Friedman's ANOVA p=0,833; Conover' test: initial and middle time points (p=0,866), initial and fina time points (p=0,672), middle and final time point (p=0,554).)

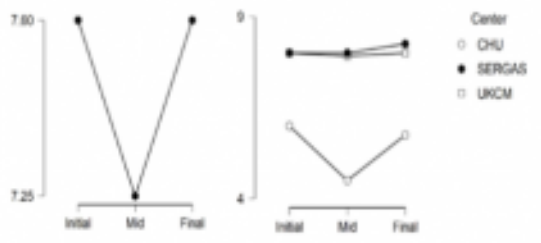


(c) 3rd question (Friedman's ANOVA p=0,502; Conover's test: initial and middle time points (p=0,554), initial and final time points (p=0,238), middle and final time points (p=0,554).)

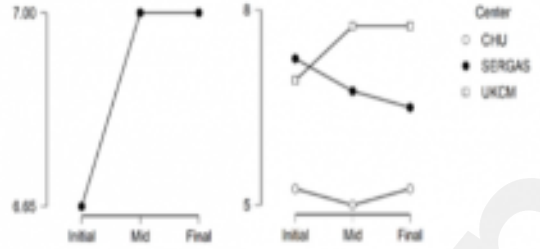
The results of general feedback about mHealth app (Left: Means of al centres; Right: Means of individual centres).



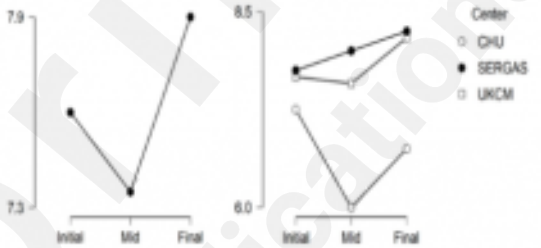
(a) 1st question (Friedman's ANOVA p=0,109; Conover's test: initial and middle time points (p>0,999), initial and final time points (p=0,235), middle and final time points (p=0,235).)



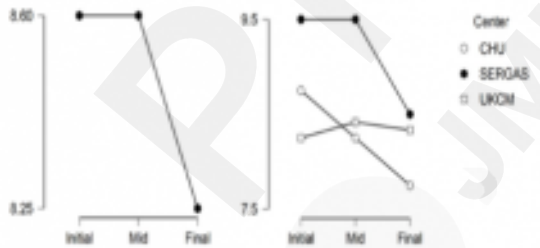
(b) 2nd question (Friedman's ANOVA p=0,779; Conover's test: initial and middle time points (p=0,490), initial and final time points (p=0,843), middle and final time points (p=0,622).)



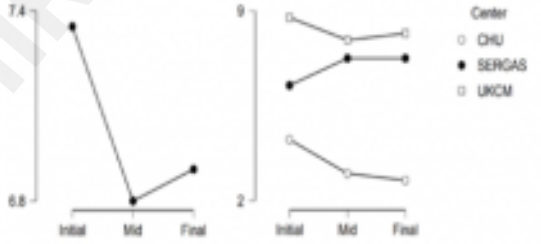
(c) 3rd question (Friedman's ANOVA p=0,581; Conover's test: initial and middle time points (p=0,304), initial and final time points (p=0,512), middle and final time points (p=0,707).)



(d) 4th question (Friedman's ANOVA p=0,279; Conover's test: initial and middle time points (p=0,891), initial and final time points (p=0,138), middle and final time points (p=0,176).)

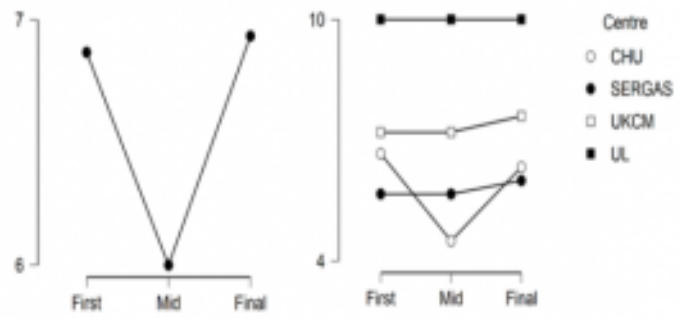


(e) 5th question (Friedman's ANOVA p=0,109; Conover's test: initial and middle time points (p=0,910), initial and final time points (p=0,078), middle and final time points (p=0,062).)

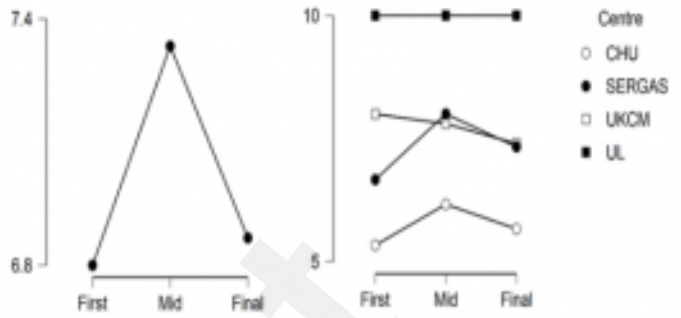


(f) 6th question (Friedman's ANOVA p=0,395; Conover's test: initial and middle time points (p=0,704), initial and final time points (p=0,189), middle and final time points (p=0,345).)

The results of general feedback about devices (Left: Means of al centres; Right: Means of individual centres) .

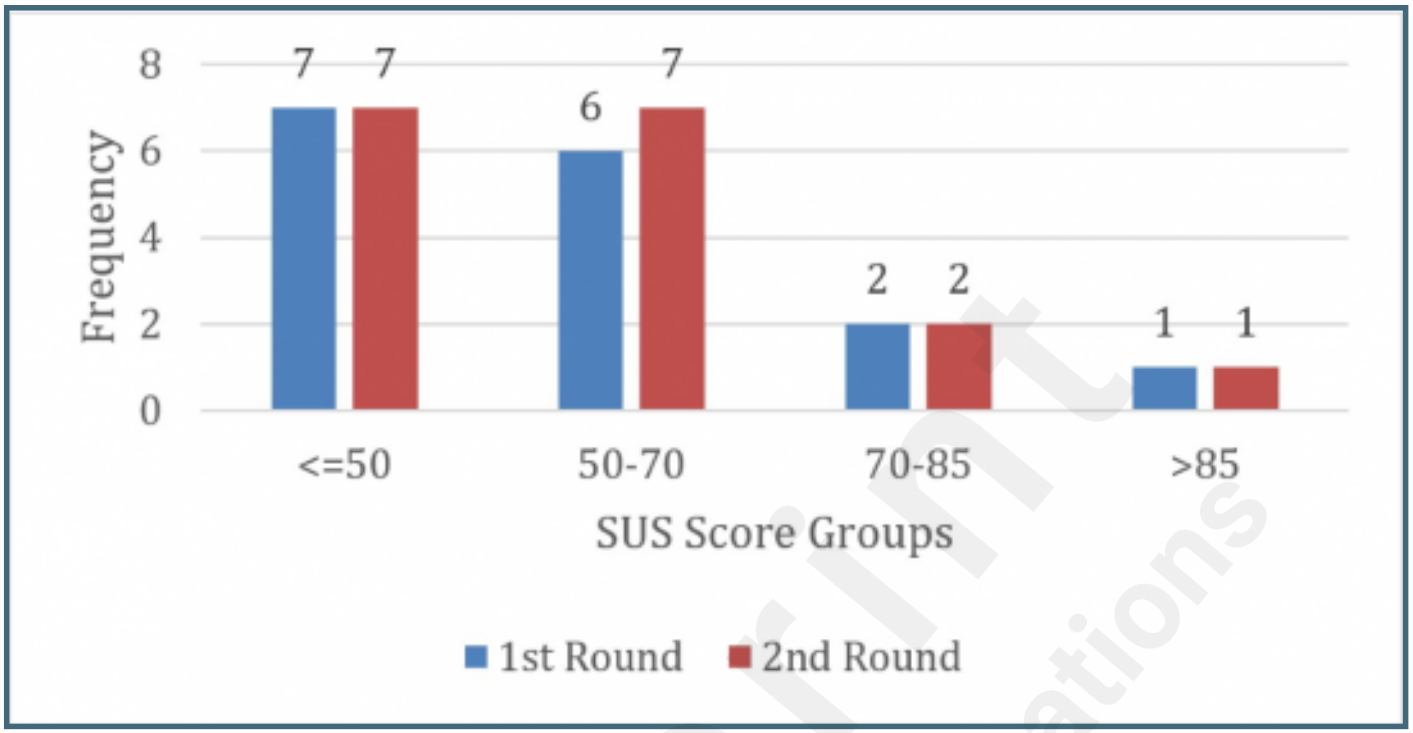


(a) 1st question (Friedman's ANOVA p=0,041; Conover's test: initial and middle time points (p=0,035), initial and final time points (p>0,999), middle and final time points (p=0,035).)



(b) 2nd question (Friedman's ANOVA p=0,227; Conover's test: initial and middle time points (p=0,087), initial and final time points (p=0,500), middle and final time points (p=0,284).)

SUS Results: mClinician score group.



Multimedia Appendixes

Questions of the questionnaires.
URL: http://asset.jmir.pub/assets/cfc08872f57f4d32c20ed8e2b4fe4d9e.doc