

---

# JMIR Human Factors

---

Impact Factor (2022): 2.7

Volume 7 (2020), Issue 1 ISSN 2292-9495 Editor in Chief: Andre Kushniruk, BA, MSc, PhD, FACMI

---

## Contents

### Original Papers

Exploring How Professionals Within Agile Health Care Informatics Perceive Visualizations of Log File Analyses: Observational Study Followed by a Focus Group Interview ( <a href="#">e14424</a> ) Iris ten Klooster, Matthijs Noordzij, Saskia Kelders. . . . .	2
Factors Influencing Motivation and Engagement in Mobile Health Among Patients With Sickle Cell Disease in Low-Prevalence, High-Income Countries: Qualitative Exploration of Patient Requirements ( <a href="#">e14599</a> ) David-Zacharie Issom, André Henriksen, Ashenafi Woldaregay, Jessica Rochat, Christian Lovis, Gunnar Hartvigsen. . . . .	16
A Chatbot-Based Coaching Intervention for Adolescents to Promote Life Skills: Pilot Study ( <a href="#">e16762</a> ) Silvia Gabrielli, Silvia Rizzi, Sara Carbone, Valeria Donisi. . . . .	35
Engagement and Usability of a Cognitive Behavioral Therapy Mobile App Compared With Web-Based Cognitive Behavioral Therapy Among College Students: Randomized Heuristic Trial ( <a href="#">e14146</a> ) Saptarshi Purkayastha, Siva Addepally, Sherri Bucher. . . . .	42
Effectiveness of the ColorApp Mobile App for Health Education and Promotion for Colorectal Cancer: Quasi-Experimental Study ( <a href="#">e15487</a> ) Nor Yaacob, Muhamad Mohamad Marzuki, Najib Yaacob, Shahrul Ahmad, Muhammad Abu Hassan. . . . .	55
Influencing Pain Inferences Using Random Numerical Anchoring: Randomized Controlled Trial ( <a href="#">e17533</a> ) Rebecca Lewinson, Joel Katz. . . . .	64

Original Paper

# Exploring How Professionals Within Agile Health Care Informatics Perceive Visualizations of Log File Analyses: Observational Study Followed by a Focus Group Interview

Iris ten Klooster<sup>1,2</sup>, MSc; Matthijs Leendert Noordzij<sup>1</sup>, PhD; Saskia Marion Kelders<sup>1,3</sup>, PhD

<sup>1</sup>University of Twente, Faculty of Behavioral, Management, and Social Sciences, Department of Psychology, Health, and Technology, Enschede, Netherlands

<sup>2</sup>Saxion University of Applied Sciences, Department of Psychology and Human Resource Management, Deventer, Netherlands

<sup>3</sup>North West University, Optentia Research Focus Area, Vanderbijpark, South Africa

**Corresponding Author:**

Iris ten Klooster, MSc  
University of Twente  
Faculty of Behavioral, Management, and Social Sciences  
Department of Psychology, Health, and Technology  
De Zul 10  
Enschede, 7522 NJ  
Netherlands  
Phone: 31 620730557  
Email: [i.tenklooster@utwente.nl](mailto:i.tenklooster@utwente.nl)

## Abstract

**Background:** An increasing number of software companies work according to the agile software development method, which is difficult to integrate with user-centered design (UCD) practices. Log file analysis may provide opportunities for integrating UCD practices in the agile process. However, research within health care information technology mostly has a theoretical approach and is often focused on the researcher's interpretation of log file analyses.

**Objective:** We aimed to propose a systematic approach to log file analysis in this study and present this to developers to explore how they react and interpret this approach in the context of a real-world health care information system, in an attempt to answer the following question: How may log file analyses contribute to increasing the match between the health care system and its users, within the agile development method, according to agile team members?

**Methods:** This study comprised 2 phases to answer the research question. In the first phase, log files were collected from a health care information system and subsequently analyzed (summarizing sequential patterns, heat mapping, and clustering). In the second phase, the results of these analyses are presented to agile professionals during a focus group interview. The interpretations of the agile professionals are analyzed by open axial coding.

**Results:** Log file data of 17,924 user sessions and, in total, 176,678 activities were collected. We found that the Patient Timeline is mainly visited, with 23,707 (23,707/176,678; 13.42%) visits in total. The main unique user session occurred in 5.99% (1074/17,924) of all user sessions, and this comprised Insert Measurement Values for Patient and Patient Timeline, followed by the page Patient Settings and, finally, Patient Treatment Plan. In the heat map, we found that users often navigated to the pages Insert Measurement Values and Load Messages Collaborate. Finally, in the cluster analysis, we found 5 clusters, namely, the Information-seeking cluster, the Collaborative cluster, the Mixed cluster, the Administrative cluster, and the Patient-oriented cluster. We found that the interpretations of these results by agile professionals are related to stating hypotheses (n=34), comparing paths (n=31), benchmarking (n=22), and prioritizing (n=17).

**Conclusions:** We found that analyzing log files provides agile professionals valuable insights into users' behavior. Therefore, we argue that log file analyses should be used within agile development to inform professionals about users' behavior. In this way, further UCD research can be informed by these results, making the methods less labor intensive. Moreover, we argue that these translations to an approach for further UCD research will be carried out by UCD specialists, as they are able to infer which goals the user had when going through these paths when looking at the log data.

(*JMIR Hum Factors* 2020;7(1):e14424) doi:[10.2196/14424](https://doi.org/10.2196/14424)

**KEYWORDS**

log file analyses; user-centered design; agile; Markov Chains; health care systems

## *Introduction*

### **Background**

User-centered design (UCD) is a vital determinant of health care informatics' success, as it leads to quality improvement, resource savings, increased user satisfaction, and, ultimately, better patient care [1,2]. However, an increasing number of software companies work according to the agile software development method (agile), which is difficult to integrate with UCD practices [3]. Agile is defined in the Oxford Dictionary as "Able to move quickly and easily," and it also refers to multiple methods within software development, which act as a counterpart to the previously used waterfall method. Examples of these agile methods within software development are Scrum, Extreme Programming, and dynamic systems development method. Waterfall methods follow predefined steps in a fixed order, whereas agile is characterized by its small software releases, with rapid iterations of 2 to 4 weeks. Every iteration can be seen as a small project in itself, and after every iteration, the product is shown and tested, and the product and process are evaluated [4]. Two explanatory factors are regularly mentioned in the literature as a cause of the difficult integration of agile and UCD.

The first one is that agile focuses on customer input instead of user involvement [3,5,6]. In the study by Gulliksen et al [6], it is explained that while working with agile, hardly any distinction is made between the customer and end user, raising the question whether the variation in user groups is overlooked. Moreover, the question may be asked as to how the needs of the customer, the one who pays for the health information technology, must be prioritized, given the presumable differences with users' needs.

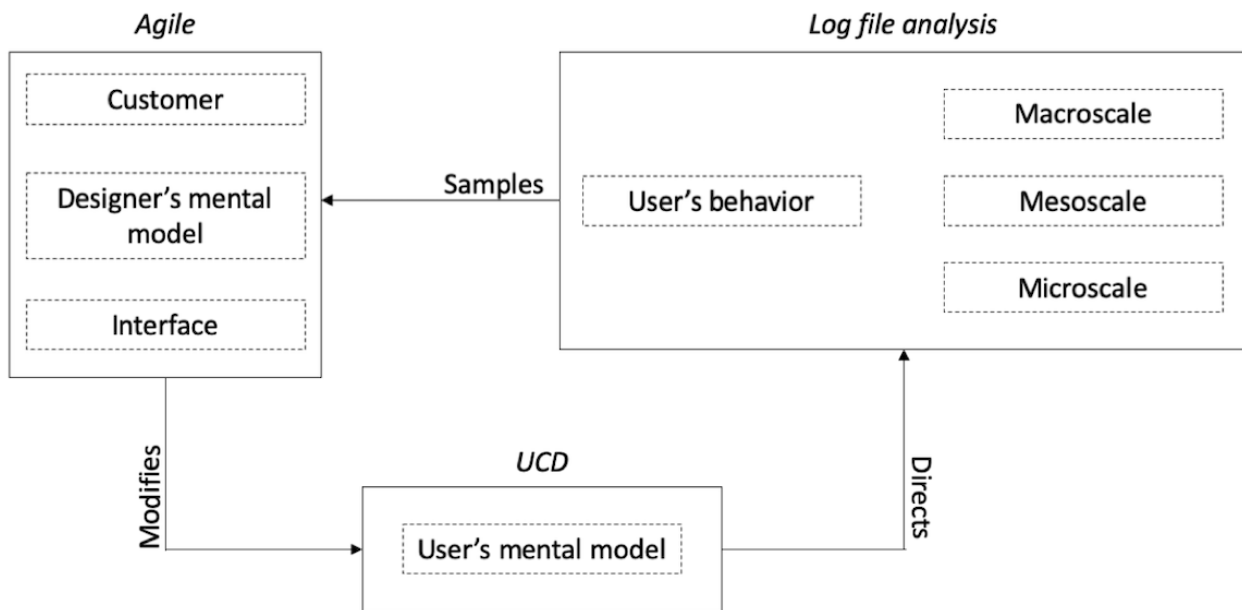
The second explanatory factor is that, although a resemblance between agile and UCD is the incorporation of iterations, there are large differences in the interpretation of these distinct iterations [7]. To begin with, agile focuses on testing code effectiveness during very short iterations, adding small pieces of very high-fidelity pieces to the health information technology. In UCD practices, we see that a Big Design Upfront approach is often used, using low-fidelity prototypes to communicate

large pieces of the health information technology. When these UCD practices are fitted into agile, the costs for developing health care information technology strongly increase; therefore, the integration of UCD within agile is problematic and mostly lacking.

Log file analysis may provide opportunities for integrating UCD practices in the agile process. Log files give an objective view of users' behavior in software systems and provide valuable insights in how health care information technology is used [8]. Gaining insight into users' behavior may give indirect clues that are relevant to the objective of UCD, without actually having to involve the user in all the phases of development. Thus, the user perspective is added within the agile process, without the need to apply labor-intensive test methods. However, to our knowledge, no studies have been reported on if and how log file analyses can be used in practice within this agile development process. Therefore, we propose a systematic approach to log file analysis (including preprocessing, analysis, and various visualizations) in this study and present this to developers to explore how they react and interpret this approach. An important question is whether their perception of this information has the potential to increase the focus on the intended user within an agile development process.

To further substantiate our expectations regarding the added value of log file analyses in the agile process, we will elaborate on the elements described above. In [Figure 1](#), these elements and their relations are summarized. Here, we see that UCD practices in developing software systems means that end users have an influence in the development throughout the design process. Thus, the focus is on the users' mental model of the system, comprising their expectations of how the system works. Within agile, the customer influences the development of software systems throughout the design process, which consequently influences the designer's mental model, thereby guiding his development of the software system. This system then modifies the user's mental model. In the following sections, we first introduce the reader to the relation between log file analysis and users' mental models. We then describe an approach to log file analysis, which fits with describing users' behavior on the macroscale. Finally, the aim of this study is described.

**Figure 1.** Graphical representation of the focus of the agile method (customer input and effective coding), user-centered design (mental models of the user), and log file analysis. This study focuses on the user's behavior on the macroscale. UCD: user-centered design.



### Log Files and Users' Mental Models

Log files are an automatically produced documentation of users' behavior within a particular system [9]. These files provide information about the time of the event, the URL visited, and either posting or retrieving information from the system. Log files provide insight into the users' real-life complex behavior while they are in their natural environment, and they are based on passive, unobtrusive monitoring. These characteristics are desirable in the increasingly complex world of health care informatics, and they compare favorably with laboratory testing, which is dependent on active, obtrusive monitoring and simplified, unengaging, and artificial use case scenarios [10]. Furthermore, log files can provide detailed information about individual users (intraindividual patterns), allowing for valid generalizations about patterns that might hold for groups of people (interindividual data) [11].

Users' behavior is strongly impacted by their mental model of the technical system [12]. These mental models are the internal representations of the system, on which users make inferences on how to carry out tasks [12]. These tasks are carried out within the target system, on which an interface is created, allowing the user to interact with the system. When working according to a user-centered approach, agile team members try to fit the software to the users' mental models. However, developers' mental models mainly comprise how the system works, whereas users' mental models comprise beliefs on how to use the system, leading to software that does not regularly fit with the mental models of the user [13]. A way to prevent this difference between the developers' and users' mental models is to get users in front of the interface and employ research methods to see whether this mental model is different from the developers' mental model [13].

These research methods can be divided into several dimensions to gain insight into the characteristics and added value of these

methods. In the study by Barkhuus and Rode [14], it is suggested to classify these methods as empiric or analytic and as quantitative or qualitative. A useful addition to this is the classification of methods on different time scales. On the basis of Newell's bands of behavior [15], earlier research explored how insights into users' behavior differ on the micro- (second-to-second), meso- (min-to-hours), and macroscale (week-to-month) [16]. To illustrate this, observing users' behavior on the microscale provides insights into usability issues, mostly in lab settings, thereby allowing to collect data about the participants and control variables while they interact with the system. Another approach is observing users' behavior on the mesoscale, in which data are collected on the affective responses to the system in a more natural setting. The most natural approach is collecting users' data on the macroscale, providing an objective insight into the entire range of users' behavior over long periods of time [16]. Given the advantages of analyzing users' behavior on the macroscale, and the small usage of analytical quantitative methods in previous research [14], we used an analytical quantitative approach on the macroscale in this study.

### Log File Analysis

A method that fits well with describing users' behavior on the macroscale is analyzing users' behavior as a sequence of events [17]. This way of analyzing provides insight into the order in which the user navigates the system, whereas the more classical approach to log file analysis for health care information systems only describes quantities of usage (eg, number of times pages are visited, mean duration of visiting a page). In this analysis, there are some key concepts that play a role. First, a user session is a set of page views between logging into the system and logging out of the system, for a particular user at 1 particular website. Second, page categories are the distinct URLs in the log files grouped into categories.

### **Summarizing Sequential Patterns**

Summarizing sequential patterns can be done by obtaining insight into the number of times that page categories and transitions between these page categories appear within users' sessions. Moreover, it describes how many times page categories appear at a specific step within the user session. For example, the number of times that a specific page is visited as a first step within all users' sessions. In earlier research related to health care information technology, these analyses provided insight into the efficiency of users navigating through the system [18].

### **Heat Mapping**

Heat mapping provides functionalities to predict which page category a user will navigate to when he or she is visiting a specific page category. The probabilities of navigating from a specific page category to the other page categories are calculated, and these probabilities are shown on a heat map. The probabilities are calculated by means of Markov Chain modeling, meaning that, in contrast to summarizing sequential patterns, the purpose is to predict future usage behavior. Probabilities can be calculated by using zero-, first-, and higher-order Markov Chains [17]. These orders differ in that the next page category is predicted only on the basis of the current page category that is visited by the user (first order) or on a combination of the current page category with the page categories that the user was visiting before the current page category (higher order). A comparable approach was deployed in the study by Elizabeth and Cimino [19], where the insights were used to find clinicians' information needs, which can be used to improve the design.

### **Clustering**

In complex health care systems, it can be assumed that the users are heterogeneous, meaning that there is variation in their behavior [17]. Therefore, these user sessions can be clustered on the basis of the transitions between page categories. With clustering, the user behavior can be described in a global way, meaning that the focus is not on transitions between the distinct page categories. Instead, it focuses on all transitions between page categories, and subsequently, complete user sessions can be typified by their cluster name on the basis of the similarity of these user sessions. In the study by Vest and Jaspersen [20], it was concluded that clustering provides a more thorough understanding of variation in users' behavior, thus in the individual patterns that emerge.

### **Aim of the Study**

Overall, we see that analyses of users' behavior through log files is used in several domains and that a small number of studies extended analyses related to quantities of usage with, for example, cluster analyses or analyzing sequential patterns. Moreover, research within health care information technology is focused on the researcher's interpretation of these log file analyses, or a theoretical approach is used, in which log file data are correlated with other demographic data, so that the concrete approach toward improving health information technology development is not suggested. Finally, to our knowledge, no studies have been reported on the agile professionals' interpretation of log file analyses; therefore, an

opening to a coupling of these interpretations with concrete steps in the agile process is missing.

Therefore, the aforementioned 3 log file analyses were assessed in the context of a real-world health care information system, in an attempt to answer the following question: How may log file analyses contribute to increasing the match between the health care system and its users within the agile development method, according to agile team members. First, these log files were summarized, heat mapped, and clustered, respectively, to illustrate how users' behavior can be described on the macroscale. Second, this study explored through a focus group interview whether and how agile team members can use these results within the agile software development method.

## **Methods**

### **Phase 1: Collection and Analysis of the Log Files**

Before the first phase of this study was carried out, permission was obtained from the Ethics Committee of the University of Twente, regarding collecting log files and analyzing these log files. The log files were treated as confidential and only kept on secured self-owned servers in Enschede, the Netherlands.

### **Data Collection**

The log files were collected through an internet-based support system that serves as an extension of the general practitioner information system (GPIS). For privacy reasons, this system is appointed by the fictitious name Extendia. It provides general practitioners (GPs) with a comprehensive range of conceptually distinct services. It is a closed system, meaning that users are required to purchase a subscription before they can use it. When users directly log in via the browser, he or she will start within the Declarations area. When a user logs in via another connected system, he or she does not have to log in, and he or she starts on a different page, depending on the link the user has clicked on. Through the menu, users can download TeamViewer, open manuals, and navigate to their own profile. Depending on which parts they purchased, users can use the services Collaborate, Patients, Declarations, Dashboards, and Practice Web. They can navigate to these services via a main menu at the top. Within these services, users can navigate to the related subfunctions. Below, we briefly describe these distinct services.

1. Collaborate: Within collaborate, users can consult another specialist to ask a question about a patient. Second, users can refer a patient to a mental health group, while keeping the opportunity to gain insight in the treatment of that patient.
2. Patients: The patient area is strongly connected to the collaborate area, and it offers users the opportunity to gain insight in patients' historical and current medication, as well as their measurement values. Moreover, historical care activities of the patient are clearly displayed in chronological order on the patient timeline.
3. Declarations: The declarations area includes 4 services for doing declarations between different health care providers and insurers. Within this area, users do declarations, and these subsequently appear in the declaration overview. Next to this, the attention page gives an overview of rejected

declarations. On the page Manual Invoices, users find and print (to send or provide) all patient invoices that are created in the health care systems' mutation screen. Finally, there is an option for creating passant invoices and third-party invoices.

4. Dashboards: The dashboard area offers users the opportunity for GPs to benchmark their results. They can make reports for insurance companies and reflect their results in comparison with colleagues on a financial level, as well as on practice and patient data.
5. Practice Web: This part of the system offers functionalities to the users to support daily practice. The main parts are an address book, a to-do list, and messages. In the address book, contact details of the institutions and care providers who are often approached with regard to the care surrounding the patients or the practice can be saved and be seen by all employees. Second, with the to-do list, actions can be assigned to the various employees, and users can

keep track of who carried out the tasks and when these tasks were carried out. Finally, through the message component, internal communication is digitally recorded.

Log files were collected through this system at server side from September 18, 2017, to October 17, 2017. They were chosen for a set of data, covering a period of 1-month, to fit well in agile (with a maximum duration of sprints of 4 weeks).

**Data Preparation**

There were 17,924 user sessions obtained from the health care system. These were cleaned before user sessions were analyzed, following the process described below. An example line of the log files collected at server side can be seen in Figure 2. This line of data comprises the date, the time, the method, the URL requested, the status code, and the session identification number. In this specific example, the user requests the timeline within the patient area for a specific patient on September 3, at around a quarter past 4.

Figure 2. Example of a line in the collected log data.

2017-09-03	16:19:59.5102	GET	/api/patient/xxxxxx/timeline	200	sessionID
------------	---------------	-----	------------------------------	-----	-----------

The columns date, time, URL, and session id were used. To ensure privacy of the users, data were anonymized while keeping the opportunity to distinguish between sessions. Second, the URL variables were separated to allow for editing these variables separately, in subsequent steps of cleaning the data. Background processes were removed, to ensure that log data only comprised page views initiated by the users. Moreover, when users visit a page for a specific patient, a unique page identifier is inserted. To analyze these pages for all users together, these identifiers were removed. At last, date and time were combined into 1 variable to use these data in detail.

As a subsequent step, each URL was pre-categorized into 62 page categories (eg, Upload Patient File, Patient Timeline, and Address Book) and grouped by session numbers ordered by the variables date and time. This way, data of user sessions are formed. This is a set of views in a user session for a particular website [21], between logging into the system and logging out of the system. The server session ends when there is user inactivity for at least 30 min. The cleaned data comprise comma-separated strings representing user sessions. An example can be seen in Figure 3.

Figure 3. Cleaned data comprising comma-separated strings representing user sessions.

2017-09-18 11:24:05	SessionID	'Insert Measurement Values for Patient', 'Patient Timeline', 'Patient Settings', 'Patient Treatment Plan'
---------------------	-----------	---

**Data Analysis**

Descriptive statistics were calculated, and a process map was obtained in Disco version 2.2.0 (Fluxicon) [22]. Subsequently, the log files were analyzed using the statistical software R (R Core Team) [23], within RStudio, version 1.0.143 (RStudio, Inc). Descriptive statistics were plotted using the ggplot2 package version 3.0.0, developed by Wickham [24]; a heat map was made, and log files were clustered using the Clickstream package version 1.3.0, developed by Scholz [17]. The number of clusters was chosen on the basis of an "elbow test." These clusters were then typified on the basis of the pages that mainly occur within user sessions that fall within the distinct clusters.

**Phase 2: Focus Group and Qualitative Analysis**

To explore how agile team members can use a description of users' behavior on the macroscale obtained through log file analyses, a focus group interview was carried out. A focus group interview lends itself to questioning people in a more natural

conversation pattern, so that it closely resembles a setting, as it occurs daily within agile.

**Participants**

The participants were obtained through purposive sampling. An invitation was sent via a digital calendar to all agile team members who worked at the collaboration department. In total, 10 Dutch-speaking employees worked at this department, of whom 7 participated in this study. Their mean age was 31.14 years (SD 4.88 years, range: 5-39 years). A total of 6 participants were male and 1 participant was female. Moreover, 3 participants were developers, 2 were designers, and 2 were information analysts.

**Materials and Procedure**

The focus group interview was carried out in an office within the software company. At the beginning of the focus group interview, the participants were asked whether they agreed with recording the interview, and they were told that these data would be processed anonymously. All the participants agreed with

this; thereafter, the recording of the focus group interview was started. Notes were made during the interview, which served as a backup in case the recording was not usable.

Subsequently, the researcher introduced the focus group interview, and results of the log file analyses were shown. In the introduction, the participants were told that the results of the log file analyses were going to be presented and that the focus was on increasing the match between the system and its users and not on the performance of the system. A number of examples were given, and they were told in which period the data were collected. To increase their input, they were told that they could respond to the analyses that they were going to see and that there were no right or wrong responses. After this introduction, the results were presented on a beamer in the following order: frequency overview of pages developed by the collaboration department, heat maps (only pages of the collaboration department included), and the process map of all pages. The clusters were not used during the interview, as this would make it necessary to include results related to parts developed by other departments. The focus group interview continued until there was no more input from the participants. This way, it was decided that sufficient data had been collected.

### Analysis

Before the analysis, the focus group interview was literally typed out using the F5 program. These transcriptions were imported into Atlas.ti version 8.1.3 to analyze the qualitative data. The data analysis took place by means of the coding method described in the study by Onwuegbuzie et al [25]: constant comparison analysis. The statements made by participants were evaluated by interpreting the meaning and assigning it a value code (open coding). A code was assigned

to relevant information per fragment. (Parts of) Fragments received a maximum of 1 code. These codes were then grouped into overarching codes. Thereafter, links were sought among the concepts, associations, and combinations. This resulted in main groups and subgroups (axial coding). A total of 10% of the data was double coded: once by the researcher and once by a colleague of the researcher. The interrater reliability was calculated by means of Cohen kappa in SPSS version 23, and it was found to be acceptable at 0.81.

## Results

### Phase 1: Collection and Analysis of the Log Files

To illustrate analyses that were shown to the agile team members, we describe the results of the first phase of this study. In this phase of the study, log files that were collected on server side were analyzed.

#### General Results

In total, 176,678 activities were conducted within 17,924 user sessions, an average of 9.86 activities per user session. In [Multimedia Appendix 1](#), an overview of the distribution of these user sessions over the days is given. On weekdays, the number of user sessions is higher (mean 776.14) than during weekend days (mean 96.38).

The page Patient timeline was the most visited page within these user sessions (n=23,707), on which historical care activities of the patient are displayed in chronological order. In addition, the page Insert Measurement Values was then the most visited page (n=21,215). [Table 1](#) shows the frequency and percentage of visits of the 6 pages that were visited most.

**Table 1.** Most visited pages within the health care system between September 18, 2017, and October 17, 2017 (N=176,678).

Page	Times visited, n (%)
Patient Timeline	23,707 (13.42)
Insert Measurement Values for Patient	21,215 (12.01)
Patient Settings	20,306 (11.49)
Load Messages Collaborate	17,284 (9.78)
View Report	15,472 (8.76)
Patient Treatment Plan	14,814 (8.38)

The least visited page was Change conversation topic (n=3). This page within Collaborate is used for conversations among several health care providers. Here, the various care providers can consult each other about the care they give to a patient.

Changing the subject of these conversations was done least within the health care system. [Table 2](#) shows the frequency and percentage of visits of the 5 pages that were least visited.

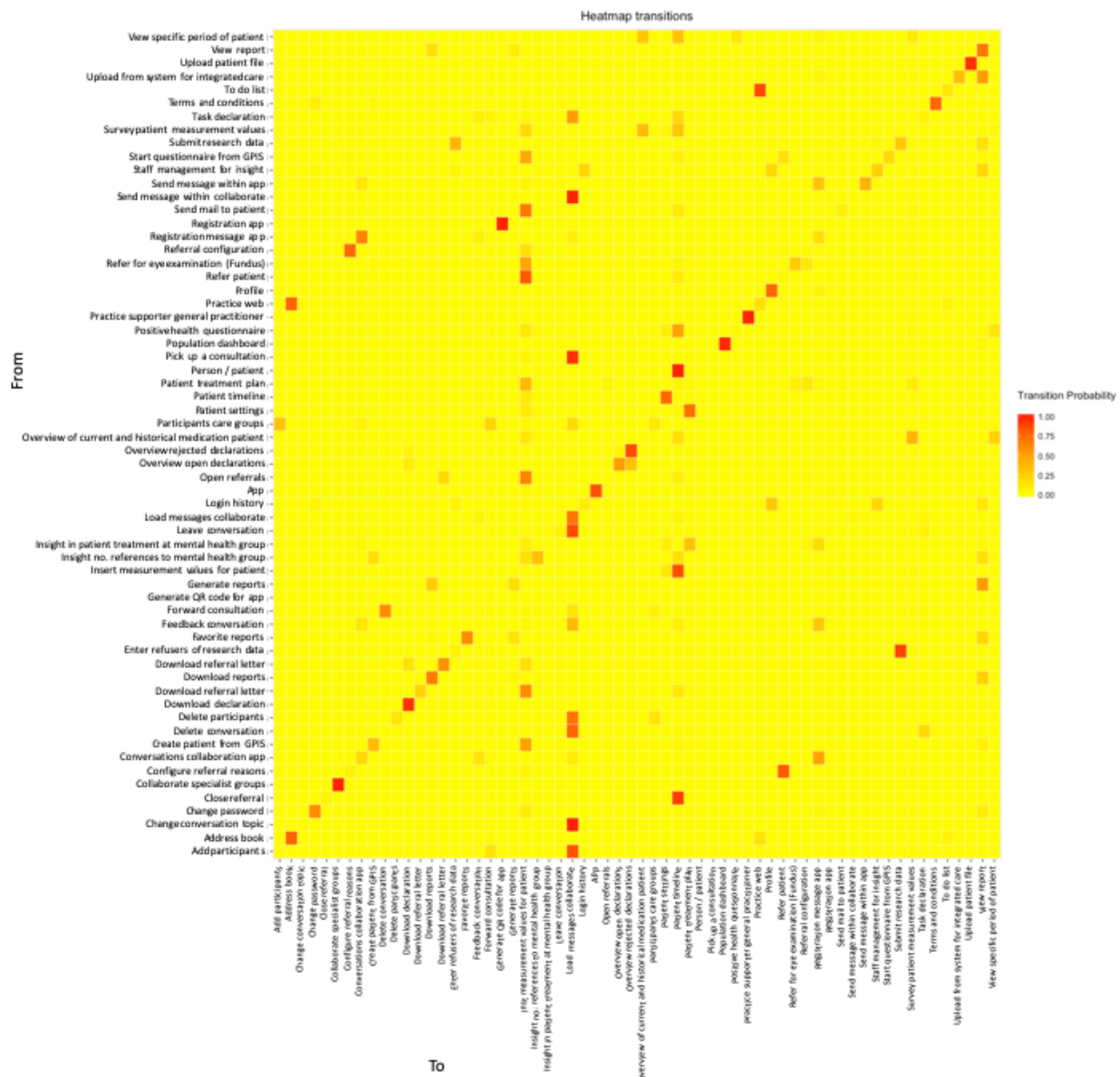
**Table 2.** Least visited pages within the health care system between September 18, 2017, and October 17, 2017 (N=176,678).

Page	Times visited, n (%)
Add Participants	20 (0.01)
Insight Number References to Mental Health Group	17 (0.01)
To-Do List	10 (0.01)
Delete Participants	7 (0.00)
Change Conversation Topic	3 (0.00)





**Figure 5.** Heat map of log files. The pages on the vertical line show from which page the user navigates, and the horizontal line shows the pages toward which page a user navigates, where yellow squares stand for low transition probabilities, red squares stand for high transition probabilities, and orange squares stand for intermediate transition probabilities. GPIS: general practitioner information system.



This page was visited for a total of 133 times in a 1-month period. A page visited for a small number of times such as this, relatively, would not appear quickly in a process map that gives an overview of the main visited pages.

**Clustering User Sessions**

Finally, the user sessions were divided into clusters with similar browsing patterns (see Table 3). First, 1 randomly chosen day in the log files was picked for the cluster analysis because of limited computational power. These data were then divided into 5 clusters, on the basis of the “elbow test.” The clusters were typified on the basis of the pages that appear in these clusters. The 5 clusters are named as the Information-seeking cluster (sum of squares [SS]=96.16), the Collaborative cluster (SS=99.27), the Mixed cluster (SS=193.40), the Administrative cluster (177.57), and the Patient-Oriented cluster (SS=378.02). The total SS within groups was 944.42 and the between SS was 561.49.

Cluster 1, the Mixed cluster (n=311), shows a clear variance of events from event categories View Report, Registration Message Application, and Conversations Application Collaborate. As most user sessions belong to this cluster, these can be interpreted to be the most typical sessions. This shows that the most typical user session involves a variety of tasks that can be performed within the system, meaning that users value the wide range of tasks offered by the system.

Cluster 2, the Patient-oriented cluster (n=277), is also a very dominant cluster, as it is the second most common among the user sessions. User sessions that fall within this cluster are oriented around the patient. Users are actively searching for a patient’s timeline, changing the settings of the patient, and entering measurements for that patient. This cluster seems to coincide with the layout of the system, of which a part is divided into searching and inserting patient data.

**Table 3.** Clusters with similar browsing patterns, along with the number of user sessions that were grouped into these clusters and the 3 most visited pages within the clusters.

Cluster	User sessions within cluster, n	Most visited page	Second most visited page	Third most visited page
Mixed	311	View Report	Registration Message Application	Conversations Application Collaborate
Patient-oriented	277	Patient Timeline	Patient Settings	Insert Measurement Values for Patient
Information-seeking	64	Download Reports	View Report	Population Dashboard
Collaborative	54	Load Messages Collaborate	Registration Message Application	Conversations Application Collaborate
Administrative	15	Download Declaration	Overview Rejected Declarations	Download Referral Letter

Cluster 3 is the Information-seeking cluster (n=64). This cluster shows a dominance of page categories Download reports, View Report, and Population Dashboard. It is the most information behavior-related cluster, as it reveals the users searching for which patients have visited the GP and what they have done there through reports.

The Collaborative cluster (n=54) shows a dominance of sessions involving collaboration with other care providers. The pattern of loading messages within Collaborate, followed by doing registrations for the message app and visiting this message app, shapes a picture of users looking at their notifications from other care providers and being actively involved in contacting these other providers.

**Table 4.** Main categories and subcategories found in the qualitative data.

Main category and subcategory	Count (n)
<b>Hypotheses</b>	34
Usability problems	19
User requirements	6
Other systems	10
<b>Path comparison</b>	31
Logical paths	13
Illogical paths	12
Incomplete paths	4
<b>Benchmarking</b>	22
Page visits	19
Users	3
<b>Prioritize</b>	17
Redesign	4
Making improvements	13

### Hypotheses

The code Hypotheses was found 34 times in the data obtained through the focus group interview. On the basis of the results of the quantitative phase of this study, participants mainly communicated ideas about the cause of these results. These hypotheses of the participants were related to usability problems, user requirements, or the way of working in combination with

Finally, the Administrative cluster (n=15) is the pattern that is least dominant in the user sessions. This cluster is typified by the administrative purposes that are performed within the sessions. The page categories are related to downloading declarations, looking at an overview of rejected declarations, and downloading referral letters.

### Phase 2: Focus Group and Qualitative Analysis

A total of 4 main codes were found in the qualitative data, namely, Hypotheses, Path comparison, Benchmarking, and Prioritize. The number of times codes were found in the data can be found in Table 4. In this section, these codes will be defined, and the variance will be described using prime examples.

other systems. Usability problems were often mentioned while discussing the heat maps. Participants focused mainly on the diagonal line of the heat maps to think of usability problems. On this line, participants could see how often a specific page is followed by loading the same page again. Examples of usability problems that were mentioned are lack of feedback, lack of clarity as the system is often adjusted, or entering incorrect

passwords. An example of a usability problem related to the lack of feedback was mentioned by participant 1:

*Yes, we have just made a disable for that. Because Teledia received double or triple registrations. You had to press "sign up" there and then you had to wait. But there was nothing to indicate that it was logging in at that time. That's why they clicked again: they thought "nothing happens."* [Participant 1, information analyst]

Participants also formulated hypotheses that were related to user requirements related to functions that are unavailable within the system, on the basis of the heat maps and frequencies of page visits. For example, respondents mentioned that deleting messages occurred much more often than leaving the conversation. Moreover, the heat map revealed that after opening a conversation, users are inclined to directly delete the message. When a message is deleted, users cannot obtain the information about these messages anymore, whereas when leaving a conversation, this possibility is retained. Thus, according to the participants, there is no need for an archive function. An example of a participant mentioning this is the following:

*Well, if you leave the conversation then you say: "Ok, I have nothing to do with this conversation, but I want to be able to read it later."* [Participant 1, information analyst]

Finally, participants formulated hypotheses related to the way the system is used along with other systems, as well as reasons for this way of working with the other systems. Usability problems are also formulated on the basis of these hypotheses. Participants are focused on the page from which users go to another system or the other way around. The movement toward another system indicates missing parts in the system. Moreover, when users move toward the system from another system, this is an indication for functions that users find valuable. They inferred this because of the fact that users have to take extra steps from another system to use these functions. Moreover, based on the heat map, participants form hypotheses on the basis of the diagonal line. When there is a lot of repetition, users see another system as the starting point for carrying out their tasks. An example is the repetition of navigating to Extendia page categories from a GPIS. On the basis of this, the participants also formulate usability problems, for example, there is not a possibility to search on the basis of maiden name. Participant 6 mentioned this (this quotation is related to a loop that occurred in the process map):

*The user is working from GPIS, and goes to Extendia via health portal with a button navigating to Extendia. When you do this a new tab opens with that patient information. And when you're done, you close that tab again and then you go to your GPIS again, where the user searches the next patient. From there the user goes back to the Extendia button and then Extendia opens again.* [Participant 1, information analyst]

### **Path Comparison**

The code Path comparison was found 31 times in the data obtained through the semistructured interview. On the basis of the results of the quantitative phase of this study, participants compared the paths that occurred in the log data with their expectations of how users navigate through the system. Paths are defined here as a sequence of requests to the server in time (as shown in the heat map and process map). The comparison of paths in the results with their expectations was logical, illogical, or incomplete. Participants mentioned logical paths through the system, by which they mention that users carry out the steps in the right order to fulfill their tasks. This gives reason to state that certain parts of the system must be maintained in the same way. An example of a participant mentioning this is the following:

*But that is to be expected right. You start a conversation with someone. You get an answer, and then you're done.* [Participant 3, developer]

Contrary to mentioning paths that match their expectations, participants also mentioned paths through the system, which did not match their expectations (process map and heat map). Moreover, they mentioned results indicating that users carry out certain steps toward fulfilling a certain task, but users do not complete these tasks (do not go through the final steps). An example of such an incomplete path was described as follows:

*But now it becomes very complicated because the user does not close the referral. At a given moment this patient still appears to be in the overview. Then that user calls us to ask how this referral can be closed, and then we have to search for a long time, and then we finally come to the conclusion that the user has not closed the referral at the end.* [Participant 3, developer]

### **Benchmarking**

Third, participants formulated thoughts related to the frequencies that were displayed, regarding the use of the system. They wanted to compare these frequencies with other frequencies to obtain valuable clues about possible navigation problems within the system. These comments were coded as Benchmarking, and these appeared 22 times in the qualitative data. First, the participants compared the number of page visits with another number of page visits to get an idea of the use relative to another function. For example, they compared the number of times the conversation topics were changed with the total number of messages that were opened. This gave indications for whether users find these functions valuable. Second, it seemed useful to the participants to compare frequencies of the use in the past with the current frequencies of use. For example, they could see whether recent developments concerning new users led to a logical increase in the number of page visits. An example of a participant mentioning this is the following:

*So, if you analyze the frequencies, there is an opportunity to see whether the usage increases enough when a new care group is added to the system. If not, this gives reason to think something is not*

*going well with the implementation of the system for the new users.* [Participant 1, information analyst]

### **Prioritize**

Finally, participants indicated opportunities for the results to be used for prioritizing within the agile development process. This code, Prioritizing, occurred 17 times in the data. First, they mentioned some cues in the results for prioritizing a redesign of the system. To illustrate, if users had to navigate to a frequently visited page via a drop-down menu, this would give priority to redesigning this page. Navigating to this page should then be possible via a main menu. This was also the opposite for less visited pages. Second, they mentioned that the frequency of page visits provides clues for increasing or decreasing priority for making improvements to the system. An example of this is a participant mentioning the following:

*Well, I think this is a very interesting result, because my colleague is doing a lot to improve that page. That is adjusted every time, and uhhhh, that kind of things, but this page is almost never used.* [Participant 1, information analyst]

## **Discussion**

### **Principal Findings**

The goal of this study was to explore the usefulness of log file analyses within the agile development method to increase the match between the health care system and its users. We have found that analyzing log files seems to provide agile professionals valuable insights into users' behavior. This is in line with previous research related to health information technology, in which it was shown that researchers interpreted log file analyses into valuable insights into users' behavior [8,18,26]. The important innovation of this study is that researchers looked at what you can do with these log file analyses and professional agile team members were also asked about how they can use these in practice. This is obviously very valuable, as health care information technology is mostly developed in software companies working according to agile. Below, we will elaborate on the contribution of our study.

First, we illustrated the results of summarizing sequential patterns, which provided insight into the prominent order that occurs within user sessions. In our view, the prominent order was related to the effectiveness with which users navigate through the system, which is in line with the research carried out in the study by Sieverink et al [18]. For example, the loop between View Report and Download Reports indicated that users repeatedly download reports after having viewed them. If the system would have offered an option to download several reports at once, these navigation paths could be more efficient. Agile team members were mainly interested in comparing expected paths with the actual paths in which users navigate through the system, while looking at summaries of sequential patterns.

Second, we described how, in our view, heat mapping log files provided insight into the transitions between lesser visited pages within the system. Thus, this was a more detailed overview of the simplified representation of summarizing sequential patterns.

The addition of the heat map gave valuable prompts for possible bottlenecks in key functions within the system. It may be that a page is not visited often, but it also may be that it does have an important function. For example, the link between GPIS and the health care system only needs to be made once, but if this does not work, the health care system will be virtually unusable. The agile team members focused mainly on the diagonal line for stating hypotheses concerning usability problems. On this diagonal line, agile team members saw repetitions in page visits by the users. This approach is different from the one used in the study by Elizabeth and Cimino [19]. In that study, they tried to find out information needs on the basis of this sort of analyses, where we found that it mainly provides insight into possible usability problems. The reason for this is probably the different form of log data (search query logs), which was used in that study [19], as Web logs of search queries are only related to a specific part of the system. Moreover, analyzing search queries is not necessarily related to existing components within the system.

Third, the clusters provided insight into groups of user sessions led by similar mental models of the system, which is in line with the study by Huerta and McAlearney [26]. The variation that exists between user sessions could be summarized in 5 clusters, creating an understanding of differences in user behavior. In this way, the user behavior can also be looked at in a more personalized way. We also saw a clear example of how mental models can change during the use of a system. For example, the Administrative cluster was the least dominant cluster, whereas in the first instance, the system only offered tasks related to administration. The current approach of log file analysis differs from, for example, clustering user groups on the basis of survey and medical record data [27], as well as on the basis of interview data [28]. Although these approaches all aim for a description of user groups, the approach used in this study has the advantage of not requiring labor-intensive data collection that is often unfeasible within the agile process. However, the current approach can only be realized once (a part of) the system is already developed and available to its users. Therefore, one of the approaches, as described in the studies by Holden et al [27,28], is recommended when one is at the start of the health care informatics development process. When this initial stage of the development process has passed, the current approach might be used as a solution to the lacking distinction that is made between the customer and the user within agile [3,5,6]. By creating insight into the variation in user behavior, agile professionals are forced to see whether the input from customers and users within agile provides enough insight into users' behavior, by comparing this with the full range of user behavior observed in the cluster analysis.

These findings give rise to recommending several ways in which log files analyses can be fitted into the agile process. To begin with, in the study by Russell [16], investigating user behavior at all 3 levels (micro, meso, and macroscale) was suggested so that a more complete picture is obtained to improve or evaluate the system. For example, usability problems can be found on the microscale, and this can be supplemented with affective responses found on the mesoscale to obtain a more complete view. However, in this study, it was found that on the basis of

analyzing user behavior on the macroscale, hypotheses can be drawn about users' behavior on the other scales. Therefore, we argue that not all scales should be described at the same time but that insight in macroscale users' behavior should be used to adjust the methods for collecting data about users' behavior on the other scales. To illustrate this, a hypothesis concerning usability problems related to the main menu, on the basis of log file analyses (macroscale), will then result in an interview with users about their response to this specific main menu (mesoscale). In the study by Gulliksen et al [6], it was claimed that the iterations of the agile process are too fast for adopting UCD methods properly, and by giving directions to these UCD methods with log file analyses, the time to collect data on specific parts can be largely shortened by only focusing on specific parts. We argue that these translations to an approach for further UCD research will be carried out by UCD specialists, as they are able to infer which goals the user had when going through these paths, while looking at the log data [29]. At the same time, analyses of macroscale users' behavior enable the UCD specialists to be heard more in agile software development [6], as we found that agile professionals received the log file analyses positively during the interview.

### Limitations

The qualitative part of this study was based on an elaborate focus interview with relevant stakeholders. However, no follow-up or additional interviews were done to establish saturation with respect to the themes suggested here. It is important to note that the focus interview continued until all stakeholders felt they had contributed all they could, and in this way, it was established that enough data had been collected.

Nevertheless, now that we have put forward a method to integrate the log files in the agile process, it would be of value to replicate our qualitative themes in a similar environment.

A further limitation is the generalizability of this study. The data of this study were collected at a large-scale software company developing health care software. However, no data were collected of small-scale (1 team) or very large-scale (more than 10 teams) software companies. Agile team members of small-scale and very large-scale software companies might have different views on ways in which insights into users' behavior might be used because of the differences in coordination approaches during software development [30]. However, the goal of this study was to explore how a description of users' behavior within a complex health care system can be of added value within the agile development method. Complex health care software systems are defined as systems that comprise several components, which must also be able to function independently. On the one hand, it can be assumed that the more complex health care systems are developed within larger software companies. On the other hand, the cluster analysis could be useful in small software companies, as they work with less separate departments on the software, allowing agile team members to understand the meaning of the clusters. Importantly, this study provides a framework on how to examine the usefulness of and provides a starting point for integrating log file information in agile development in a variety of contexts. To overcome the previously mentioned limitations, this framework can be used in follow-up research investigating the added value in small-scale and very large-scale software companies.

---

### Conflicts of Interest

None declared.

---

### Multimedia Appendix 1

Number of user sessions over the days between September 18, 2017, and October 17, 2017.

[PNG File, 16 KB - [humanfactors\\_v7i1e14424\\_app1.png](#)]

---

### References

1. Tippet KG, Weinger MB. User-centered design means better patient care. *Biomed Instrum Technol* 2017;51(3):220-222. [doi: [10.2345/0899-8205-51.3.220](#)] [Medline: [28530864](#)]
2. Bano M, Zowghi D. A systematic review on the relationship between user involvement and system success. *Inf Softw Technol* 2015 Feb;58:148-169. [doi: [10.1016/j.infsof.2014.06.011](#)]
3. Sohaib O, Khan K. Integrating Usability Engineering and Agile Software Development: A Literature Review. In: *Proceedings of the 2010 International Conference On Computer Design and Applications.*: IEEE; 2010 Presented at: ICCDA'10; June 25-27, 2010; Qinquangdao, China. [doi: [10.1109/icdda.2010.5540916](#)]
4. Dybå T, Dingsøyr T. Empirical studies of agile software development: a systematic review. *Inf Softw Technol* 2008;50(9-10):833-859. [doi: [10.1016/j.infsof.2008.01.006](#)]
5. Martikainen S, Korpela M, Tiihonen T. User participation in healthcare IT development: a developers' viewpoint in Finland. *Int J Med Inform* 2014 Mar;83(3):189-200. [doi: [10.1016/j.ijmedinf.2013.12.003](#)] [Medline: [24382475](#)]
6. Gulliksen J, Göransson B, Boivie I, Blomkvist S, Persson J, Cajander Å. Key principles for user-centred systems design. *Behaviour & Information Technology* 2003 Nov;22(6):397-409. [doi: [10.1080/01449290310001624329](#)]
7. Blomkvist S. Department of Information Technology. Uppsala, Sweden: Uppsala University; 2006. *User-Centred Design and Agile Development of IT Systems* URL: <https://www.it.uu.se/research/publications/lic/2006-012/2006-012.pdf> [accessed 2019-11-26]

8. Sieverink F, Kelders S, Poel M, van Gemert-Pijnen L. Opening the black box of electronic health: collecting, analyzing, and interpreting log data. *JMIR Res Protoc* 2017 Aug 7;6(8):e156 [FREE Full text] [doi: [10.2196/resprot.6452](https://doi.org/10.2196/resprot.6452)] [Medline: [28784592](https://pubmed.ncbi.nlm.nih.gov/28784592/)]
9. Dumais S, Jeffries R, Russell DM, Tang D, Teevan J. Understanding user behavior through log data and analysis. In: Olson JS, Kellogg WA, editors. *Ways Of Knowing In HCI*. Second Edition. New York, NY: Springer; 2014:349-372.
10. Kushniruk A. Evaluation in the design of health information systems: application of approaches emerging from usability engineering. *Comput Biol Med* 2002 May;32(3):141-149. [doi: [10.1016/s0010-4825\(02\)00011-2](https://doi.org/10.1016/s0010-4825(02)00011-2)] [Medline: [11922931](https://pubmed.ncbi.nlm.nih.gov/11922931/)]
11. Fisher AJ, Medaglia JD, Jeronimus BF. Lack of group-to-individual generalizability is a threat to human subjects research. *Proc Natl Acad Sci USA* 2018 Jul 3;115(27):E6106-E6115 [FREE Full text] [doi: [10.1073/pnas.1711978115](https://doi.org/10.1073/pnas.1711978115)] [Medline: [29915059](https://pubmed.ncbi.nlm.nih.gov/29915059/)]
12. Norman DA. Some observations on mental models. In: Gentner D, Stevens AL, editors. *Mental Models*. New York, NY: Psychology Press; 2013:15-22.
13. Nielsen J. Nielsen Norman Group: UX Training, Consulting, & Research. 2010. Mental Models URL: <https://www.nngroup.com/articles/mental-models/> [accessed 2018-10-22] [WebCite Cache ID 73MtGaSD9]
14. Barkhuus L, Rode JA. From Mice to Men - 24 Years of Evaluation in CHI. In: *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2007 Presented at: CHI'07; April 28 - May 3, 2007; San Jose, CA. [doi: [10.1145/1240624.2180963](https://doi.org/10.1145/1240624.2180963)]
15. Newell A. Putting it all together. In: Klahr D, Kotovsky K, editors. *Complex information processing: the impact of Herbert A. Simon*. Hillsdale, NJ: Psychology Press; 1989:399-440.
16. Russell DM. Understanding user behavior at three scales: the AGoogleADay story. In: Cooper KM, Scacchi W, editors. *Computer Games and Software Engineering*. Boca Raton, FL: CRC Press; 2014:199-213.
17. Scholz M. R package Clickstream: analyzing clickstream data with markov chains. *J Stat Soft* 2016 Oct;74(4):1-17. [doi: [10.18637/jss.v074.i04](https://doi.org/10.18637/jss.v074.i04)]
18. Sieverink F, Kelders SM, Braakman-Jansen LM, van Gemert-Pijnen JE. The added value of log file analyses of the use of a personal health record for patients with type 2 diabetes mellitus: preliminary results. *J Diabetes Sci Technol* 2014 Mar;8(2):247-255 [FREE Full text] [doi: [10.1177/1932296814525696](https://doi.org/10.1177/1932296814525696)] [Medline: [24876574](https://pubmed.ncbi.nlm.nih.gov/24876574/)]
19. Chen ES, Cimino JJ. Automated discovery of patient-specific clinician information needs using clinical information system log files. *AMIA Annu Symp Proc* 2003;2003:145-149 [FREE Full text] [Medline: [14728151](https://pubmed.ncbi.nlm.nih.gov/14728151/)]
20. Vest JR, Jaspersen S. How are health professionals using health information exchange systems? Measuring usage for evaluation and system improvement. *J Med Syst* 2012 Oct;36(5):3195-3204 [FREE Full text] [doi: [10.1007/s10916-011-9810-2](https://doi.org/10.1007/s10916-011-9810-2)] [Medline: [22127521](https://pubmed.ncbi.nlm.nih.gov/22127521/)]
21. Srivastava J, Cooley R, Deshpande M, Tan P. Web usage mining: discovery and applications of usage patterns from web data. *SIGKDD Explor News* 2000 Jan;1(2):12-23. [doi: [10.1145/846183.846188](https://doi.org/10.1145/846183.846188)]
22. Günther CW, Rozinat A. Disco: Discover Your Processes. In: *10th International Conference on Business Process Management*. 2012 Presented at: BPM'12; September 3-6, 2012; Tallinn, Estonia p. 40-49.
23. The R Project for Statistical Computing. 2013. URL: <https://www.R-project.org/> [accessed 2019-11-26] [WebCite Cache ID 73hsjHim3]
24. Wickham H. *Ggplot2: Elegant Graphics For Data Analysis*. New York, NY: Springer; 2016.
25. Onwuegbuzie AJ, Dickinson WB, Leech NL, Zoran AG. A qualitative framework for collecting and analyzing data in focus group research. *Int J Qual Methods* 2009;8(3):1-21. [doi: [10.1177/160940690900800301](https://doi.org/10.1177/160940690900800301)]
26. Fareed N, Walker D, Sieck CJ, Taylor R, Scarborough S, Huerta TR, et al. Inpatient portal clusters: identifying user groups based on portal features. *J Am Med Inform Assoc* 2019 Jan 1;26(1):28-36. [doi: [10.1093/jamia/ocy147](https://doi.org/10.1093/jamia/ocy147)] [Medline: [30476122](https://pubmed.ncbi.nlm.nih.gov/30476122/)]
27. Holden RJ, Joshi P, Rao K, Varrier A, Daley CN, Bolchini D, et al. Modeling personas for older adults with heart failure. *Proc Hum Factors Ergon Soc Annu Meet* 2018 Sep;62(1):1072-1076. [doi: [10.1177/1541931218621246](https://doi.org/10.1177/1541931218621246)]
28. Holden RJ, Kulanthaivel A, Purkayastha S, Goggins KM, Kripalani S. Know thy eHealth user: development of biopsychosocial personas from a study of older adults with heart failure. *Int J Med Inform* 2017 Dec;108:158-167 [FREE Full text] [doi: [10.1016/j.ijmedinf.2017.10.006](https://doi.org/10.1016/j.ijmedinf.2017.10.006)] [Medline: [29132622](https://pubmed.ncbi.nlm.nih.gov/29132622/)]
29. Menezes TC, Nonnecke B. UX-Log: Understanding Website Usability through Recreating Users' Experiences in Logfiles. *Int J Virtual World Hum-Comput Interact* 2014;2:47-56. [doi: [10.11159/vwhci.2014.006](https://doi.org/10.11159/vwhci.2014.006)]
30. Dingsøyr T, Fægri T, Itkonen J. What is large in large-scale? A taxonomy of scale for agile software development. In: Jedlitschka A, Kuvaja P, Kuhmann M, Männistö T, Münch J, Raatikainen M, editors. *Product-Focused Software Process Improvement*. Cham: Springer International Publishing; 2014:273-276.

## Abbreviations

**GP:** general practitioner

**GPIS:** general practitioner information system

**SS:** sum of squares

**UCD:** user-centered design

*Edited by G Eysenbach; submitted 25.04.19; peer-reviewed by B Chaudhry, J Aarts; comments to author 13.07.19; revised version received 04.09.19; accepted 04.09.19; published 21.01.20.*

*Please cite as:*

*ten Klooster I, Noordzij ML, Kelders SM*

*Exploring How Professionals Within Agile Health Care Informatics Perceive Visualizations of Log File Analyses: Observational Study Followed by a Focus Group Interview*

*JMIR Hum Factors 2020;7(1):e14424*

URL: <https://humanfactors.jmir.org/2020/1/e14424>

doi: [10.2196/14424](https://doi.org/10.2196/14424)

PMID: [31961325](https://pubmed.ncbi.nlm.nih.gov/31961325/)

©Iris ten Klooster, Matthijs Leendert Noordzij, Saskia Marion Kelders. Originally published in JMIR Human Factors (<http://humanfactors.jmir.org>), 21.01.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Human Factors, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# Factors Influencing Motivation and Engagement in Mobile Health Among Patients With Sickle Cell Disease in Low-Prevalence, High-Income Countries: Qualitative Exploration of Patient Requirements

David-Zacharie Issom<sup>1,2</sup>, BSc, MSc; André Henriksen<sup>3</sup>, BSc, MSc; Ashenafi Zebene Woldaregay<sup>4</sup>, BSc, MSc; Jessica Rochat<sup>1,2</sup>, BSc, MSc; Christian Lovis<sup>1,2</sup>, MD, MPH; Gunnar Hartvigsen<sup>4</sup>, BSc, MSc, PhD

<sup>1</sup>Division of Medical Information Sciences, Geneva University Hospitals, Geneva, Switzerland

<sup>2</sup>Faculty of Medicine, University of Geneva, Geneva, Switzerland

<sup>3</sup>Department of Community Medicine, UiT – The Arctic University of Norway, Tromsø, Norway

<sup>4</sup>Department of Computer Science, UiT – The Arctic University of Norway, Tromsø, Norway

**Corresponding Author:**

David-Zacharie Issom, BSc, MSc

Faculty of Medicine

University of Geneva

Rue Michel-Servet 1

Geneva, 1206

Switzerland

Phone: 41 223722601

Email: [david.issom@unige.ch](mailto:david.issom@unige.ch)

## Abstract

**Background:** Sickle cell disease (SCD) is a hematological genetic disease affecting over 25 million people worldwide. The main clinical manifestations of SCD, hemolytic anemia and vaso-occlusion, lead to chronic pain and organ damages. With recent advances in childhood care, high-income countries have seen SCD drift from a disease of early childhood mortality to a neglected chronic disease of adulthood. In particular, coordinated, preventive, and comprehensive care for adults with SCD is largely underresourced. Consequently, patients are left to self-manage. Mobile health (mHealth) apps for chronic disease self-management are now flooding app stores. However, evidence remains unclear about their effectiveness, and the literature indicates low user engagement and poor adoption rates. Finally, few apps have been developed for people with SCD and none encompasses their numerous and complex self-care management needs.

**Objective:** This study aimed to identify factors that may influence the long-term engagement and user adoption of mHealth among the particularly isolated community of adult patients with SCD living in low-prevalence, high-income countries.

**Methods:** Semistructured interviews were conducted. Interviews were audiotaped, transcribed verbatim, and analyzed using thematic analysis. Analysis was informed by the Braun and Clarke framework and mapped to the COM-B model (capability, opportunity, motivation, and behavior). Results were classified into high-level functional requirements (FRs) and nonfunctional requirements (NFRs) to guide the development of future mHealth interventions.

**Results:** Overall, 6 males and 4 females were interviewed (aged between 21 and 55 years). Thirty FRs and 31 NFRs were extracted from the analysis. Most participants (8/10) were concerned about increasing their physical capabilities being able to stop pain symptoms quickly. Regarding the psychological capability aspects, all interviewees desired to receive trustworthy feedback on their self-care management practices. About their physical opportunities, most (7/10) expressed a strong desire to receive alerts when they would reach their own physiological limitations (ie, during physical activity). Concerning social opportunity, most (9/10) reported wanting to learn about the self-care practices of other patients. Relating to motivational aspects, many interviewees (6/10) stressed their need to learn how to avoid the symptoms and live as normal a life as possible. Finally, NFRs included inconspicuousness and customizability of user experience, automatic data collection, data shareability, and data privacy.

**Conclusions:** Our findings suggest that motivation and engagement with mHealth technologies among the studied population could be increased by providing features that clearly benefit them. Self-management support and self-care decision aid are patients'



major demands. As the complexity of SCD self-management requires a high cognitive load, pervasive health technologies such as wearable sensors, implantable devices, or inconspicuous conversational user interfaces should be explored to ease it. Some of the required technologies already exist but must be integrated, bundled, adapted, or improved to meet the specific needs of people with SCD.

(*JMIR Hum Factors* 2020;7(1):e14599) doi:[10.2196/14599](https://doi.org/10.2196/14599)

## KEYWORDS

mHealth; wearable devices; self-management; sickle cell disease; patient engagement; adoption; motivation; user computer interfaces; health behavior; persuasion

## Introduction

### A Tsunami of Mobile Health Apps for Chronic Disease Self-Management

Mobile health (mHealth) apps are flooding the app stores, with 200 new apps each day [1]. Many apps can significantly improve health outcomes [2,3] by supporting people with diverse medical conditions [4]. However, little is known about the app usage frequency and long-term engagement among chronic patients [5,6]. Indeed, Robbins et al [7] underlined that people who would most benefit from such apps underuse them. To promote mHealth usage, app developers need to comprehend what could motivate patients to engage in mHealth [8]. The theory of reasoned action [9,10] demonstrates that the likelihood to engage in a specific behavior is a function of the motivation to perform it. Authors, such as Coa et al [11], confirmed that calculating baseline motivation levels could predict retention rates for apps. To influence people's motivation through persuasion rather than coercion, the field of persuasive technology offers novel user-centered approaches (ie, cocreation) [12-18].

### The Case of Sickle Cell Disease: One of the World's Most Neglected Chronic Diseases

In this paper, we focus on sickle cell disease (SCD). SCD is the most common monogenic blood disorder in the world. Studies approximate 400,000 neonates per year [19,20] and between 25 and 100 million patients worldwide living with the disease [21,22]. In this study, we specifically target populations from low-prevalence areas of high-income countries. In these settings, the disease is underresourced, research-derived evidence is lacking, and patients are particularly isolated [23].

SCD is still a serious illness. Hemolytic anemia and vaso-occlusive pain crises (VOCs) are the hallmarks of the disease [24]. Patients may suffer severe and potentially lethal complications [25]. Hydroxyurea, the preferred disease-modifying treatment, is underutilized and not effective for every patient [26]. Furthermore, the only curative option, bone marrow transplant, is largely inaccessible [27].

However, public health interventions such as regional screening programs, preventive care, coordinated care and comprehensive care plans have been introduced in the major regions of high-prevalence, high-income countries [28]. These interventions drastically reduced early childhood mortality and made SCD shift to a chronic disease of adulthood [29].

Nevertheless, such programs have not been implemented widely and remain virtually absent in most low-prevalence, high-income

countries [20,30]. In addition, there are few trained physicians and access to specialized health care is suboptimal [31-33]. Indeed, patients with SCD are particularly prone to confront stigmatization, to suffer unequal treatment, and to experience health care injustice (ie, perception as drug seekers) [33-35]. This often leads to mistrust between patients and health care providers [36,37]. As several studies demonstrated [38-44], when patients arrive in emergency departments, the lack of objective hematological findings and little awareness of those findings make health care providers suspicious of the veracity of a VOC. This distrust makes the SCD community infamously difficult to recruit in research initiatives and hard to engage in interactions with medical providers, and the distrust also lowers adherence to medical recommendations [36,45-48].

Consequently, most patients are left to self-manage and rely on poor-quality health care, and they report low levels of quality of life [49,50].

### Persuasive Mobile Health Interventions to Support an Undersupported Population

To make matters worse, as several studies demonstrated [51,52], self-care management is challenging for people with SCD. Indeed, managing the numerous potential precipitating factors of VOCs requires high levels of self-efficacy [52-55]. Well-known triggers [56] include inadequate diet, stress (ie, exertional, oxidative, and psychological), infections, inflammations, acidosis, dehydration, fatigue, chronic hemolysis, hypoxia, smoke inhalation, alcohol intoxication, pregnancy, and environmental factors (ie, altitude, pollution, extremes of temperature, climate, and wind speed). As a consequence, SCD self-care management practices require patients to pay special attention to everything. In a usual day, extreme temperature changes, bad weather, and high altitudes should be avoided; eating behaviors should be optimized with regular hydration; exercise should be moderate and not exhausting; rest should be sufficient; prescribed drugs should be taken; and stress should be managed and avoided as much as possible [50,57-59]. Finally, as in all diseases, socioeconomic factors such as education levels, occupation, or income play an important role in empowering patients [60,61].

mHealth apps, because of their relatively low cost and wide reach, could offer a potential route to support patients' numerous self-management tasks [62]. Little work has been done to design tailored mHealth interventions for the comprehensive self-management needs of patients with SCD [63,64]. Today, most existing apps and research focuses on medication adherence [65]. Consequently, solutions encompassing the

multiple components of SCD self-management are absent. Shah et al [66] suggested that patients with SCD could be interested in such tools. However, as with other chronic diseases, little is known about those patients' mHealth app adoption and long-term engagement.

This paper is the last component of a study from which preliminary results have already been published [67]. This prior publication was the first to elaborate on mHealth long-term engagement among patients with SCD. The authors explored common motivational patterns for mHealth use between patients with SCD, patients with diabetes, and *healthy* people.

This paper focuses on adults with SCD living in low-prevalence areas of high-income countries. It was aimed to assess patients' requirements in terms of value-adding digital health tools and to guide the development of future mHealth interventions that people with SCD would want to use.

## Methods

### Inclusion Criteria

To be part of the study, applicants had to be diagnosed with SCD or be the caregiver of a person with SCD. Participants had to be at least 18 years old and able to understand French or English. People who had been cured (ie, bone marrow transplantation) were excluded.

### Recruitment

The sample for this study was a convenience sample from Switzerland and Norway, two very low-prevalence, high-income

countries. Indeed, compared with an average in the European Union of 2.5 cases in 10,000 people [68], these two countries have less than approximately 1 to 4 cases per 100,000 people [69-71] and a total of approximately 100 adult patients with SCD. We recruited participants through the national patient associations' online support groups. In all, 64 individuals with SCD were invited to participate. One week after the initial invitation, nonresponders were sent a reminder.

### Instrument

The first author (DI), an expert patient, conducted most of the semistructured interviews using the guide presented in Table 1. The choice of an *insider* interviewer was made to build a trusted, warm, and open rapport with the interviewees and to maximize the reception of honest and open responses. In addition, the interviewer was already familiar with some participants. JR conducted the test interviews. Both interviewers have many years of interview experiences. Interviews were conducted in locations convenient and comfortable for the participants (ie, university and private address).

The interview guide was developed previously as a joint effort by all coauthors [67]. It was divided into five themes: (1) preliminary questions, (2) goals, expectations, and attitudes, (3) electronic health literacy and data integration, (4) wearables and sensors, and (5) data sharing. Data saturation was reached and determined by no new information emerging after conducting interviews with all participants. Interviews were audiotaped and lasted approximately 60 min. Questions were open ended, and discussions were conducted flexibly. Questions were ignored or adapted relative to the context.

**Table 1.** Overview of the questions asked during the interviews.

Themes	Questions
Preliminary questions	<ul style="list-style-type: none"> <li>• What is most important for you in your life?</li> <li>• If you had access to a new health technology, which purpose or features should it have?</li> </ul>
Goals, expectations, and attitudes	<ul style="list-style-type: none"> <li>• What motivates and demotivates you to access Web-based health information?</li> <li>• What are the most difficult things about your self-care?</li> <li>• What could help you become more autonomous with your self-care?</li> </ul>
Electronic health literacy and data integration	<ul style="list-style-type: none"> <li>• Have you ever used an app that collects health data?</li> <li>• What factors would discourage you from using such an app?</li> </ul>
Wearables and sensors	<ul style="list-style-type: none"> <li>• What indication would you expect from wearable sensors for health self-monitoring?</li> <li>• What is the most valuable indication you would want from devices collecting your data?</li> </ul>
Data sharing	<ul style="list-style-type: none"> <li>• What would you share with other patients, caregivers, and doctors and why?</li> <li>• What feedback should be provided by the system?</li> </ul>

### Data Analysis

First, transcriptions of the resulting interviews were deidentified. Second, an inductive thematic analysis was conducted using the guidelines and checklist from Braun et al [72]. Codes were extracted by reading the interviews recursively. Third, emerging patterns were clustered together and checked for variability and consistency. Themes were interpreted by reading the codes back and forth. Once saturation was reached, themes were mapped across the capability, opportunity, motivation, and behavior

model (COM-B), hub of the behavior change wheel (BCW) framework [73]. The BCW is a fairly recent, theory-driven approach that helps to design health interventions for preventive care [73]. With the specific reading grid it provides, it allows us to identify barriers and enablers of engagement in any intervention and in our particular case, to identify factors that, if implemented together, may elicit the long-term engagement and user adoption of mHealth apps [74-76]. Transcripts were organized and coded using ATLAS.ti version 8.3.20.0

(ATLAS.ti Scientific Software Development GmbH, Berlin, Germany).

Finally, to make it easier for software developers to comprehend, themes were categorized into functional requirements (FRs) and nonfunctional requirements (NFRs) [77]. In software engineering, FRs are descriptions of the specific behaviors and functions of an information system. They make explicit the features a software should offer to the end user. In other words, it describes what the system should do [78]. NFRs are descriptions of how the system should operate, which is not linked to the functionalities. To put simply, NFRs define how the system should be (eg, responsive, intuitive, fast, and secure).

### Ethics and Study Approvals

The Norwegian Regional Committees for Medical and Health Research Ethics and the Swiss Regional Research Ethics

Committee approved the study protocol and interview questions. As required by committees, all participants gave informed consent before the interview, and responses were anonymized.

## Results

### Participant Characteristics

A total of 11 participants (7 males and 4 females) agreed to join the study. In all, 8 patients and 3 caregivers took part in the study, but 1 patient withdrew because of a VOC. This led to a total of 7 patients and 3 caregivers participating in the study. Patients were aged between 21 and 55 years. A total of 7 participants were residing in Switzerland, 3 in Norway, and 1 was partly residing in the Democratic Republic of the Congo and in Switzerland. [Table 2](#) presents the demographics of the population studied.

**Table 2.** Distribution of characteristics of the studied sample (N=10).

Characteristics of respondents	Value
Gender, male, n (%)	5 (50)
<b>Age (years)</b>	
Mean (SD)	35.6 (9.41)
Median	37
<b>Country of residence, n (%)</b>	
Switzerland <sup>a</sup>	7 (70) <sup>a</sup>
Norway	3 (30)
Democratic Republic of the Congo <sup>a</sup>	1 (10) <sup>a</sup>

<sup>a</sup>One respondent was partly residing in the Democratic Republic of the Congo and in Switzerland.

### Interview Results

This section shows extracted themes from the interview data. The themes were classified into 31 FRs and 30 NFRs. We organized them with the COM-B framework and illustrated them with quotations from interviewees. [Table 3](#) presents some

of the most frequent themes that appeared during interviews. Each theme is an FR or an NFR and belongs to a COM-B system category. In the table, themes are sorted by COM-B system attribute, type of requirement, and then by the number of quotes. The complete list is available in [Multimedia Appendix 1](#).

**Table 3.** Overview of potential influencers of adoption through the capability, opportunity, motivation, and behavior (COM-B) lens.

Requirement	Quotes	COM-B system	Type
Prevent crises by avoiding symptoms	12	Automatic motivation	Functional
Family and social community support (shareability)	15	Automatic motivation	Nonfunctional
Gain more control on disease through daily self-care support	28	Physical capability	Functional
Limit management	9	Physical capability	Functional
Importance of information trustworthiness	17	Physical opportunity	Nonfunctional
Invisibility or inconspicuousness	9	Physical opportunity	Nonfunctional
Similarity with messaging apps	8	Physical opportunity	Nonfunctional
Automatic reminders and automatability	5	Physical opportunity	Nonfunctional
Simplicity	3	Physical opportunity	Nonfunctional
Learn trigger factors	14	Psychological capability	Functional
Predict health outcomes	11	Psychological capability	Functional
Receive threshold alerts	10	Psychological capability	Functional
Feedback on self-care practices	17	Psychological capability	Nonfunctional
Customizable	8	Reflective motivation	Nonfunctional
Privacy	4	Reflective motivation	Nonfunctional
Learn what other patients do	14	Social opportunity	Functional

### Physical Capability

All participants were concerned about not being able to better predict the onset of VOCs or avoid chronic complications. Another point to consider is that many differentiated general daily self-management skills (ie, pain management) from preventive care (ie, symptoms prevention). As one patient said:

*It's difficult when the situation changes in a short time and prevents you from being active, without warning. When suddenly you cannot do anything.* [Patient 5, 49 years]

In addition, a couple of interviewees said they would want novel technologies that automatically regulate their hematologic parameters (ie, hemoglobin concentration, leucocyte adherence to vascular endothelium) [79]. Accordingly, a participant proposed a very innovative solution:

*I would like nanorobots that help my blood stay normal, self-regulate.* [Patient 9, 30 years]

### Psychological Capability

The majority of participants desired to receive feedback about SCD self-care tasks. Most emphasized the difficulty of managing their own limits. Some wished to be warned before exceeding their physical limitations. Namely, an interviewee proposed:

*A sensor that informs me if I can go into the water or...when I play sport, a sensor that allows me to know what I have to limit, if there is a threshold not to exceed.* [Patient 1, 21 years]

Importantly, most of participants suggested that such warnings should be detected with wearable sensors, releasing their cognitive load. This can be illustrated by the following quote:

*Something that shows my limitations. For example, I would not want something that tells me 'if you go on like this, you're going to have a crisis'. But something configurable. Because, I like pushing my limits. For example, when I'm walking, well... first it must realize that I'm walking, but it could ask me how I feel, learn my limits.* [Patient 9, 30 years]

### Social Opportunity

For most participants, learning about other patients' self-care practices was a very important concern. A majority of the participants said they would like to share their own experiences on digital platforms. For example, one participant said:

*An indication of good health. And see what influences what in whom. Compare what people do to feel good.* [Caregiver 1, 37 years]

Many participants stressed the importance of social support. Some stated that mHealth could help them communicate their needs. As one participant suggested:

*Help family members to better understand the problem, but also for crisis prevention, teach people how to manage the disease.* [Caregiver 3, 49 years]

A majority of participants reported using social media for information sharing, communication, or entertainment. Only a minority of them used social media to get health information. Many participants deplored the absence of mechanisms to easily access and control the quality of information. As one participant said:

*How to check the veracity of information sources and information. How to demonstrate that it is validated information. We can already see that fake news may*

*surpass the traditional media. So it's a sensitive topic.*  
[Patient 2, 37 years]

### Physical Opportunity

For several interviewees, it was crucial to receive trustworthy information. Many suggested that wearable sensors could support this. As one participant highlighted:

*Indications that support my decisions, based on sensor data or collected data. An alert, a barometer that allows me to refocus and would say: "be careful, be careful, your temperature is high, your hemoglobin is low, your CRP is high, your oxygen is low, you should rather be at this level."* [Patient 9, 30 years]

Several participants stated that information overload would demotivate them for long-term engagement, specifying that mHealth apps should be as discreet as possible. Furthermore, most participants recognized the potential usefulness of notifications, but only if discreet and not disturbing. As one participant stressed:

*Yes, but not frequently, not something that screaming "you're sick! you're sick!"* [Patient 7, 55 years]

Notwithstanding, the majority of participants preferred user interfaces that are simple to use and do not require a high learning curve. Some participants believed messaging software was the best inspiration because of its intuitive interface. As one caregiver said:

*A technology that is easy to use, user-friendly for the digital illiterate. A system using widespread technologies. A system, an application that has a long life cycle. Proven technology like messaging, a simple thing that everyone can understand.* [Caregiver 2, 37 years]

### Motivation

#### Reflective Motivation

Importantly, a majority of the participants were not using mHealth apps. One of the 10 participants reported using Apple Health for menstruation management, hydration, and physical activity management. Two participants reported using Samsung Health for blood oxygen recording and physical activity management. Another point to consider is that all participants expressed a lack of specificity and adaptability to SCD particularities in the usual health apps (ie, normal values for people with SCD are the values indicating a disease in healthy people). As one participant stressed:

*Things should be adapted, for instance since oxygen or arrhythmia are usual for SCD. It should be adapted. It's difficult to compare to normal people.* [Patient 6, 35 years]

Privacy issues were also a fundamental concern for most interviewees. Many feared to lose control on their data. As one participant said:

*I am not against connected devices, Cloud... I just do not want to be found and get problems.* [Patient 2, 37 years]

Finally, most participants preferred customizable information systems. As one interviewee said:

*I want to be the decision maker of what I share. I want to control what I receive.* [Patient 9, 28 years]

#### Automatic Motivation

The three main motivators identified were (1) *strengthen social support*, (2) *prevent VOC*, and (3) *reduce the limitations to functioning and independent living*. Regarding the first motivator, participants wished to be able to enjoy with their families and give back to their communities. As one participant said:

*My daughter is the most important thing in my life, because of that, I must not forget my health. If I'm not happy she's not happy.* [Patient 7, 55 years.]

Regarding the second motivator, all participants stated their desire to prevent the excruciating pain crises. As one participant said:

*I want to be able to regulate, to avoid health problems before they appear, to prevent rather than to cure.* [Patient 4, 29 years]

More importantly, most participants stressed the importance of living as normal a life as possible and stay in good health. This can be illustrated by the following quote:

*I am particularly motivated by the desire to live well, to be like everyone else. For my self-esteem, to show that I am able to do the same things as a normal person, and even better.* [Patient 9, 28 years]

## Discussion

### Principal Findings

To the best of our knowledge, this is the first study to explore factors that could influence the long-term engagement with mHealth interventions of adults with SCD living in low-prevalence, high-income countries. As a result, interviewees described how mHealth could benefit their life and detailed what could increase their long-term engagement and motivation toward the mHealth app usage.

### Functional Requirements in the Prism of the Capability, Opportunity, Motivation, and Behavior Framework

To maximize the chances of eliciting behavior change and engagement, as many patient requirements as possible should be implemented. In other words, providing patients with information or alerts is not sufficient to lead to behavior change. However, through simultaneously implementing other features such as therapeutic education (eg lessons and accompaniment), specifically designed wearable devices could maximize engagement. In the following sections, we propose potential solutions and summarize what needs to be done before being able to develop specifically designed wearable devices.

### ***Increasing Physical Capability: Regulate Hematological Parameters***

Patients suggested how pioneering technologies such as blood-regulating nanorobots could inspire future pharmaceutical research or stimulate patient-led research initiatives [80]. By altering hematological parameters, some innovative pharmaceutical compounds are already aligned with patients' suggestions [56,81]. For instance, recent clinical trials of crizanlizumab, an antibody acting against endothelial adhesion, have shown a significant reduction in the frequency of VOCs [82]. However, this substance requires frequent intravenous injections. Therefore, knowing the current underutilization of orally administered therapies such as hydroxyurea, intravenous therapies bring a supplementary barrier.

In the meantime, although nonpharmaceutical strategies based on information technologies could inform patients on how to adapt their behaviors (ie, dietary change) to alter blood parameters (ie hemoglobin levels, oxygen levels, and inflammation) [83-86], novel devices, inspired from other clinical populations, could be created. This can be illustrated by what is happening in the Diabetes Do It Yourself (DIY) community [87] (ie, #WeAreNotWaiting and #DIYPS). Here, impatient patients self-organized to hack blood glucose-monitoring system and insulin pump. They proceeded to create a system that can, after clever calculation, automatically inject the needed dose of insulin. In comparison, one could foresee similar initiatives of DIY solutions supporting SCD self-care practices. In particular, as a reminder, anemia and oxygen desaturation are common complications among people with SCD. As oxygen delivery by hemoglobin increases when the number of red blood cells and the hemoglobin level increases, one could imagine creating a closed-loop system using a wearable hemoglobin meter or a blood oxygen meter. This could subsequently be combined with an autoinjector filled with ultrashort-term anemia-reducing treatments [88] (eg, erythropoietin alpha, vitamin B<sub>12</sub>, oral folic acid, and voxelotor [89]).

Nonetheless, it is important to consider that a significant amount of work is required before such a system could be created and made accurate or safe. Even if bypassing any approval from a health authority (eg, Federal Drugs Administration), implantable autoinjectors and specific biomonitoring devices would have to be engineered. Then appropriate software would have to be created to be able to analyze significant quantity of patient-generated data. Indeed, to be accurate and effective, such algorithm should be trained on a high quantity of data. Afterward, the data-driven algorithm should be able to actuate the injection of individualized doses of the adequate substances. All of this requires a tremendous amount of skilled bioengineering work. Another point to consider is the lower socioeconomic status of members of the SCD community [90] and the low awareness of SCD among the general population, especially in high-income, low-prevalence countries. This mechanically leads to a limited number of patient innovators and interested independent researchers. In consequence, few people would be skilled to build such a specialized system.

Therefore, the SCD community could start with less invasive, less complex, but also less cognitively unloading solutions. A simpler system could be proposed to prompt patients to ingest relevant drugs or dietary supplements (eg, anti-inflammatory drugs and antioxidants), after a biosensor [91] (eg, blood oxygen and inflammation) detects a threshold. In addition, an mHealth app could send an alert. On the one hand, medication adherence would then become an issue to overcome, on the other, if the medication is taken, the effect of the substance would be delayed compared with a direct subcutaneous injection.

To summarize, the most effective solution using today's technology would be a closed-loop system with an autoinjector and smart algorithm, functioning without any patient intervention, but there is still a long and challenging way to go before such a system could be built.

### ***Increasing Physical Capability: Stop Pain Fast***

Quick pain relief was a very important concern for most interviewees. In the current VOC self-management, pain crises are treated at home with oral painkillers [92,93]. When oral drugs are no longer sufficient or when complications surge, patients need to visit emergency departments to receive acute care [38]. However, despite being aware of the several challenges they would face in emergency departments (ie, long waiting times, recurrent stigma, unrelieved pain, and prolonged hospitalizations), many patients choose to postpone the admission until pain becomes totally unbearable [94,95].

These challenges could partly explain why interviewees were highly motivated by mHealth interventions that could help them relieve their pain as fast as possible. To this end, novel sensors and software measuring pain levels through physiological signs or electrical signals [96] could be combined with implantable pumps for intrathecal opioid therapy or subcutaneous injections [97]. However, to decrease cognitive load and avoid patients to calculate themselves how much they should inject, smart, accurate, safe, and individualized algorithms would have to be developed.

In the United States, one mHealth app helps children and adolescents with SCD to inform family, physicians, or friends about their health status [98]. Recently, innovative digital health interventions have been deployed to facilitate emergency care process [99]. We could also imagine apps that allow sufferers to support and motivate each other or to come together to share their experience of treatment efficacies [100,101]. Existing mHealth apps for pain management could be adapted to SCD [102]. Finally, virtual reality could be used as a new option for pain relief through patient distraction [103].

### ***Increasing Psychological Capability: Quality Feedback on Self-Care Practices***

The complexity of SCD self-care tasks demands various skills (eg, high cognitive capabilities and good disease-specific knowledge) [59]. The literature has shown that only 1% of SCD patients were able to master them [104]. Therefore, it is easy to understand why most interviewees desired to receive feedback on their self-care practices.

For instance, a release of the cognitive load could be partially decreased by using a natural user interface (eg, text, voice, mixed reality, and augmented reality), gamification items [105], and simple data visualization [106-109] when providing patients with targeted information. The technology exists but needs to be integrated, adapted, bundled, and improved [110-112]. Inspiration could be taken from already existing systems for people with diabetes [113,114].

Furthermore, studies have shown that behavior change techniques for self-management such as health coaching could improve the outcomes important for patients, such as self-efficacy, self-management, or medication adherence, by 80% [115-118]. For instance, collecting physiological and behavioral data, such as eating behaviors and oxygen levels, and then automatically reporting them to an SCD expert could allow the latter to provide advice directly in the mHealth app. This would not require overcoming many barriers as data could already be collected through fitness and wellness apps and smartwatches. However, the biggest challenge lies in the development of smart algorithms and methods to allow the automated interpretation of such individualized and heterogeneous data [119]. In the meantime, coaching and high-quality electronic patient decision aids could be created to structure information and help patients make informed decisions [120-122].

Regarding disease-specific knowledge, studies have reported that many patients did not follow medical recommendations [45] but may still search for health information on the Web. When the quality of information is poor, disparities in health information accessibility are created [123,124]. Frost et al [125] have already discussed the promises of Web-based health information for people with SCD, and Breakey et al [126] argued that information was not always adequate and of good quality.

Consequently, the use of artificial intelligence [127] with evaluation criteria, such as Health On the Net code [128] or the DISCERN [129] framework, could facilitate the provision of quality material to patients. Finally, content constructed with the help of patients with SCD and using consumer health vocabulary, simple patient language, and thesauri could improve the communication of health information and adequacy [130,131].

### ***Increasing Physical Opportunity: Receive Alerts When Reaching Own Physical Limits***

Already struggling with normal life challenges, several interviewees strongly desired help to manage the potential triggers of VOC. However, objective laboratory, clinical, hematological, biochemical, and rheological data are not easy to self-monitor [41-43,132-134]. Existing noninvasive sport-related wearable device technologies could help monitor some markers of hematological parameters [96]. For instance, sport watches with pulse oximeters [135], connected bottles, oxidative stress monitor, and pH meters [136,137] could be used. To this end, smart algorithms could be developed to provide patients with individualized feedback.

Studies have shown that poor physical functioning was frequent among people with SCD, making their participation in sports

difficult [138,139]. mHealth interventions specifically tailored for physical activity support could be developed to assist people with SCD. Accurate sensors could be integrated during physical activity (ie, exhaustion) or after exercise (ie, recovery) [140,141].

### ***Increasing Social Opportunity: Learn What Other Patients Do***

One of the most reported motivational factors was the desire to learn from other patients. This consideration is coherent with the stigma and isolation faced by patients with SCD living in low endemic areas [142]. This concern is also consistent with the general lack of educational interventions [143] and the limited availability of specialized health care providers [144]. It is well known that patients with a chronic disease hold nonnegligible experiential knowledge (eg, effective dietary supplements and where to find them, tips) and often share it on social networks [145-147]. However, the knowledge available on these platforms is difficult to extract, the quality is difficult to guarantee, and the information is often unstructured, hence difficult to mine [148].

Well-funded and organized social networks such as Patients Like Me or Diabetes online support groups (eg, TuDiabetes, glu, and Diabetes Daily) could serve as inspiration to structure patients' experiential knowledge [149]. However, in comparison to the total SCD population, few patients with SCD use online support groups. A study by Ragnedda et al [150] has demonstrated that socially disadvantaged groups (eg, gender, ethnicity, and disability) tended to use the internet less than more advantaged groups. Conversely, a study by Issom et al [151] suggests that patients with SCD would be willing to use such online support groups if the quality of information is ensured and if it is specifically tailored for people with SCD.

Consequently, SCD-specific online support groups such as OneSCDVoice [152] could be turned into persuasive social networks with questions and answers, ensuring the medical accuracy of patients' shared experiences [153]. In addition, artificial intelligence techniques could be used to help detect low-quality information [154]. Another issue is the multitude of SCD online support groups (eg, hundreds of Facebook groups and various websites). This spreads the information, fragments messages, and complicates access to experiential knowledge. In addition, as people with SCD and their caregivers have low educational levels [61], their organizational skills and digital literacy are reduced, subsequently hindering their access to online health information.

### ***Main Motivations: Live a Normal Life and Learn to Avoid Symptoms***

A majority of participants stated that their highest motivation would be to be asymptomatic. When bone marrow transplant is not possible, or when hydroxyurea does not significantly reduce symptom frequency, alternative treatment options such as self-management interventions, chronic transfusions, or red blood cells exchange could be proposed [155]. Transfusions have shown to significantly reduce the frequency of VOCs but require high quantities of rare phenotype blood. In addition, phenotype matching is difficult in high-income, low-prevalence

areas. Self-management interventions require a high level of self-efficacy. Electronic patient decision aids (ePtDAs) could be helpful. Indeed, ePtDAs have proven effective in engaging patients in self-care processes and helping patients choose alternative treatment options [156]. To date, there are no such tools for SCD. However, a study by Kulandaivelu et al [157] showed that people with SCD asked for such help.

To push for the development of such systems, patients would require to be more aware of novel treatment options, innovative solutions, or self-management support possibilities. As a result, they could better organize to create awareness among potential payers (eg, philanthropists and pharmaceutical companies) who could help finance the development of such advanced solutions. However, this remains a challenge for the socioeconomically disadvantaged majority of people with SCD [61].

### Nonfunctional Requirements

This section discusses the most frequently reported NFRs by the interviewees. NFRs important for the patients are crucial when developing software [158]. A mismatch between them and the final product could lead to low adoption rates and discourage app usage.

#### Automatability

Participants clearly preferred automatic health data acquisition rather than manual data entry. To date, there is no SCD-specific mHealth intervention using automated data capture. However, data from electronic health records, smartphone sensors, or wearable devices [159] could be automatically collected in future mHealth interventions for people with SCD [160].

#### Invisibility

Invisibility or inconspicuousness is the ability of a system not to attract attention. As many interviewees reported and consistent with existing literature [161], mHealth interventions are more likely to be adopted if they clearly reduce the inconvenience and burden of self-management tasks, while being discreet. Indeed, bulky and inelegant wearable devices could indicate to other people that wearer has a disease. Implantable devices, discreet patches, and wearables with subtle design or integrable into daily life objects (eg, contact lenses, implants, and bottles) could be preferred [162-165].

#### Similarity With Messaging Apps

More than half of the respondents called for an mHealth intervention that provides a user experience similar to that provided by the apps they are using the most (ie, messaging apps). Only few studies have explored conversational designs for mHealth interventions. However, some conversational user interfaces have been successfully used to reduce obesity or as support for mental health interventions [166,167]. Such systems have been already shown to encourage behavior changes and have high levels of acceptability. This could encourage similar designs in future studies for patients with SCD.

#### Shareability

In the context of Web-based health information, shareability [168] is the capacity of patient-generated health data to be shared with third parties. By allowing patients to share their knowledge,

mHealth apps could highlight valuable information that clinicians cannot offer [169] and ease social support [170]. As for people with rare diseases, question and answer social networks [171] could be leveraged [172].

#### Privacy

In the mHealth context, privacy is the ability of a patient to protect information about their medical condition [173]. Being aware of the rarity of SCD in their countries, interviewees were particularly attentive to this issue. Participants emphasized that control should be given on what they share and to whom. Studies for other chronic diseases showed that privacy is a very important aspect [174]. Answering this concern by taking into account regulations (ie, General Data Protection Regulation and Health Insurance Portability and Accountability Act) when designing mHealth interventions would be key to reduce poor adoption [175]. Here, existing compliant data management platforms with dynamic consent management [176] or personal data cooperatives [177] could be used. Furthermore, novel deidentification approaches could help implement this NFR important for the patients [178].

#### Customizability

To maximize acceptability and inconspicuousness, most participants proposed the customization of the timing of delivery of push notifications. This finding is aligned with a study by Morrison et al [179] suggesting that notifications with tailored timing could enhance exposure to mHealth interventions. However, several patients stressed their dislike of recurrent notifications (ie, water intake), saying it would remind them of their disease. This is aligned with a study by Bidargaddi et al [180] suggesting that notifications should be sent at midday or on weekends. The truth probably lies in between, where a system could allow patients to choose from a range of predefined settings.

Finally, as the interviews demonstrated, patients did not think that existing health apps were adapted to their needs. As a result, any new digital health solution for people with SCD should include patients in every phase of the development and focus on SCD particularities. Finally, the developed system should be strongly marketed as a patient-centered solution.

#### Lessons Learned

Our findings highlighted the participants' very clear expectations toward mHealth apps. Respondents seemed undeniably motivated to use *an invisible technology* that would accompany their self-care practices (ie, personalized feedback). Participants were very critical toward privacy issues and information quality. Given the numerous and complex day-to-day self-care management tasks that patients with SCD face and taking into account the isolation of living in low-prevalence, high-income countries, it appears that, in order to get long-term engagement and adoption, mHealth apps must add clear value and be particularly tailored to patients' needs.

#### From Requirements to Successful Implementation

For such an mHealth solution to have an impact once implemented, quality and perceived value must be distinguished. However, the digital health world still lacks a standardized



mechanism for health app quality evaluation and certification [181]. There is no consensus for guidelines, nor clear criteria to help recognize what a quality mHealth app is. For instance, people with diabetes, with more than 300 apps on the Google Play Store, can easily struggle to find what apps they should download. Some app curation websites [182] help end users to find health apps ranked by quality. However, the analytic methods vary for each website. For instance, in the United Kingdom, the National Health Service Digital and National Institute for Health and Care Excellence has chosen clinical effectiveness, regulatory approval, clinical safety, privacy and confidentiality, security, usability and accessibility, interoperability, technical stability, and change management as criteria. Other websites could use other criteria, for instance apps for which there is published medical evidence.

As a result, app developers should make an effort to meet requirements important for the patients and thrive to meet as many quality indicators as possible. This can be summarized with the following steps:

- Take a patient-centered approach: make sure the app improves patient outcomes; and the app is validated in terms of clinical outcomes.
- Offer a real solution to self-management problems faced by patients: the app should meet patients' requirements and do better than any alternative and should be cheaper.
- Be compatible with the existing health care information system infrastructure: implement interoperability standards by design; and answer privacy and safety requirements.

### Key Points

Nevertheless, it is clear that there is no *invisible technology* yet to support the self-care practices of patients with SCD. However, the various technological pieces needed to build such a ubiquitous system are largely available today. Nonetheless, they are scattered, not bundled nor adapted to the specificity of SCD. The following steps summarize what needs to be done before implementing the key requirements:

- Disease-modifying functionalities (ie, pain relief and regulation of hematological variables) to reduce poor adoption rates by providing patients with continuous blood oxygen meters, specific autoinjectors, and smart software that includes algorithms that are able to manage and make sense of the big datasets generated.
- Targeted information (eg, alerts when approaching limits and access to other patients' self-care practices) could influence the long-term engagement by providing patients with knowledge adapted to their health literacy levels, user interface matching their digital literacy levels, and information adapted to their disease-specific knowledge, and if necessary, offer assistance to interpret the information.
- Controlling data flows (eg, shareability, privacy, and quality information) could influence patients' motivation to start using apps by storing data on personal data cooperatives, implementing existing interoperable standards, using algorithms, and hiring content moderators (eg, physicians and expert patients) to monitor content creation and the quality of information.

### Future Plans

Given the complexity of SCD self-management, supporting self-care needs important for the patients using mHealth interventions will be challenging. However, such systems will be key to fill the gaps in health care delivery service. Further work is needed to implement patient requirements. Prioritization could be done using participatory approaches. Tools such as the APEASE (Affordability, Practicability, Effectiveness/cost-effectiveness, Acceptability, Side-effects/safety, Equity) criteria, a set of benchmarks from the BCW framework, can be helpful to decide what content should be included and what intervention delivery strategies should be used. In addition to proven added value with the effective implementation of requirements important for the patients, other NFRs include affordability, practicability, effectiveness and cost-effectiveness, acceptability, side effects, safety, and equity.

In addition, Delphi surveys [183], a technique consisting of seeking experts' views to obtain a level of agreement by transforming opinion into group consensus, could be sent to expert patients [121,184].

Finally, motivational factors will have to be assessed in the long run to maintain high user engagement levels. This could be done using tailored frameworks for mHealth engagement analysis such as the Analyzing and Measuring Usage and Engagement Data framework [185].

### Strengths and Limitations

The study has a number of strengths and limitations. Using the COM-B model to identify motivational factors is a relatively recent approach in the field of mHealth. However, in this example, the lens offered by the model was helpful to gain a full picture of patients' motivations. In addition, this model allowed us to classify patient requirements into explicit categories and helped us to discuss potentially useful technologies to meet patients' unmet needs.

The age range of the sample was large; consequently, younger patients may feel more comfortable using digital health interventions than older ones. In addition, our sample size approximates 10% of the adults with SCD living in the selected low-prevalence, high-income countries. Also, because of the notorious difficulty in enrolling patients with SCD in studies, we were surprised by this relatively high response rate. The fact that the main interviewer was an expert patient may have eased enrollment and facilitated trust building but also added a bias.

Finally, the study results could be affected by the recruitment criteria. As participants were selected inside an active SCD community, it is possible that those who volunteered to be interviewed were more in search of new coping solutions and had more positive views about the disease than those who declined or did not replied.

### Conclusions

As interviewees were particularly explicit in what could benefit them, this study provides initial insights on how to build mHealth apps that could engage particularly isolated SCD populations. The use of qualitative methods enabled in-depth

exploration of interviewees' responses. Furthermore, the BCW and, its hub, the COM-B model could be used as a robust framework to inform the development of future persuasive technologies for people with SCD. As patients highlighted,

future research should focus on supporting their self-care decisions. Exploring the integration, adaption, or improvement of highly adopted mHealth interventions for other chronic diseases could be helpful.

---

## Acknowledgments

This study would not have been possible without the support of the Swiss Sickle Cell Association and the Norwegian Sickle Cell Association. The authors thank Henna Martilla, Gerit Pfühl, Martin Mikalsen, and Keiichi Sato for their input in the earlier phases.

---

## Authors' Contributions

DI, AH, AZW, CL, and GH conceived the qualitative study. DI conducted the interviews with the support from JR. DI wrote the manuscript and subsequent revisions were undertaken with the support and input from all authors. DI, AH, and AZW created the interview guide with the support from all authors. DI coded the data and coanalyzed them with the support from AZW and AH. All authors approved the final manuscript.

---

## Conflicts of Interest

None declared.

---

## Multimedia Appendix 1

Themes extracted from interviews.

[[XLSX File \(Microsoft Excel File\), 14 KB - humanfactors\\_v7i1e14599\\_app1.xlsx](#) ]

---

## References

1. Pohl M. Research2Guidance. 325,000 Mobile Health Apps Available in 2017 – Android Now the Leading mHealth Platform URL: <https://research2guidance.com/325000-mobile-health-apps-available-in-2017/> [accessed 2018-07-06] [[WebCite Cache ID 76VKcYo9e](#)]
2. Wu Y, Yao X, Vespasiani G, Nicolucci A, Dong Y, Kwong J, et al. Mobile app-based interventions to support diabetes self-management: a systematic review of randomized controlled trials to identify functions associated with glycemic efficacy. *JMIR Mhealth Uhealth* 2017 Mar 14;5(3):e35 [[FREE Full text](#)] [doi: [10.2196/mhealth.6522](https://doi.org/10.2196/mhealth.6522)] [Medline: [28292740](https://pubmed.ncbi.nlm.nih.gov/28292740/)]
3. Kitsiou S, Paré G, Jaana M, Gerber B. Effectiveness of mHealth interventions for patients with diabetes: an overview of systematic reviews. *PLoS One* 2017;12(3):e0173160 [[FREE Full text](#)] [doi: [10.1371/journal.pone.0173160](https://doi.org/10.1371/journal.pone.0173160)] [Medline: [28249025](https://pubmed.ncbi.nlm.nih.gov/28249025/)]
4. Free C, Phillips G, Galli L, Watson L, Felix L, Edwards P, et al. The effectiveness of mobile-health technology-based health behaviour change or disease management interventions for health care consumers: a systematic review. *PLoS Med* 2013;10(1):e1001362 [[FREE Full text](#)] [doi: [10.1371/journal.pmed.1001362](https://doi.org/10.1371/journal.pmed.1001362)] [Medline: [23349621](https://pubmed.ncbi.nlm.nih.gov/23349621/)]
5. Asimakopoulos S, Asimakopoulos G, Spillers F. Motivation and user engagement in fitness tracking: heuristics for mobile healthcare wearables. *Inform* 2017;4(1):5. [doi: [10.3390/informatics4010005](https://doi.org/10.3390/informatics4010005)]
6. Thies K, Anderson D, Cramer B. Lack of adoption of a mobile app to support patient self-management of diabetes and hypertension in a federally qualified health center: interview analysis of staff and patients in a failed randomized trial. *JMIR Hum Factors* 2017 Oct 3;4(4):e24 [[FREE Full text](#)] [doi: [10.2196/humanfactors.7709](https://doi.org/10.2196/humanfactors.7709)] [Medline: [28974481](https://pubmed.ncbi.nlm.nih.gov/28974481/)]
7. Robbins R, Krebs P, Jagannathan R, Jean-Louis G, Duncan DT. Health app use among US mobile phone users: analysis of trends by chronic disease status. *JMIR Mhealth Uhealth* 2017 Dec 19;5(12):e197 [[FREE Full text](#)] [doi: [10.2196/mhealth.7832](https://doi.org/10.2196/mhealth.7832)] [Medline: [29258981](https://pubmed.ncbi.nlm.nih.gov/29258981/)]
8. Lewis C. *Irresistible Apps: Motivational Design Patterns for Apps, Games, and Web-based Communities*. New York: Apress; 2014.
9. Madden TJ, Ellen PS, Ajzen I. A comparison of the theory of planned behavior and the theory of reasoned action. *Pers Soc Psychol Bull* 1992;18(1):3-9. [doi: [10.1177/0146167292181001](https://doi.org/10.1177/0146167292181001)]
10. Glanz K, Rimer BK, Viswanath K. *Health Behavior and Health Education: Theory, Research, and Practice*. San Francisco, CA: John Wiley & Sons; 2008.
11. Coa K, Patrick H. Baseline motivation type as a predictor of dropout in a healthy eating text messaging program. *JMIR Mhealth Uhealth* 2016 Sep 29;4(3):e114 [[FREE Full text](#)] [doi: [10.2196/mhealth.5992](https://doi.org/10.2196/mhealth.5992)] [Medline: [27688034](https://pubmed.ncbi.nlm.nih.gov/27688034/)]
12. Fogg BJ. *Persuasive Technology: Using Computers to Change What We Think and Do*. London: Ubiquity; 2002.
13. Hamari J, Koivisto J, Pakkanen T. Do persuasive technologies persuade? - a review of empirical studies. In: Spagnoli A, Chittaro L, Gamberini L, editors. *Persuasive Technology*. Switzerland: Springer International Publishing; 2014:118-136.
14. Orji R, Moffatt K. Persuasive technology for health and wellness: state-of-the-art and emerging trends. *Health Informatics J* 2018 Mar;24(1):66-91. [doi: [10.1177/1460458216650979](https://doi.org/10.1177/1460458216650979)] [Medline: [27245673](https://pubmed.ncbi.nlm.nih.gov/27245673/)]

15. Eyles H, Jull A, Dobson R, Firestone R, Whittaker R, Te Morenga L, et al. Co-design of mHealth delivered interventions: a systematic review to assess key methods and processes. *Curr Nutr Rep* 2016;5(3):160-167. [doi: [10.1007/s13668-016-0165-7](https://doi.org/10.1007/s13668-016-0165-7)]
16. Sanders EB, Stappers PJ. Co-creation and the new landscapes of design. *CoDesign* 2008 Mar;4(1):5-18. [doi: [10.1080/15710880701875068](https://doi.org/10.1080/15710880701875068)]
17. Schnall R, Bakken S, Rojas M, Travers J, Carballo-Diequez A. mHealth technology as a persuasive tool for treatment, care and management of persons living with HIV. *AIDS Behav* 2015 Jun;19(Suppl 2):81-89 [FREE Full text] [doi: [10.1007/s10461-014-0984-8](https://doi.org/10.1007/s10461-014-0984-8)] [Medline: [25572830](https://pubmed.ncbi.nlm.nih.gov/25572830/)]
18. Schnall R, Rojas M, Bakken S, Brown W, Carballo-Diequez A, Carry M, et al. A user-centered model for designing consumer mobile health (mHealth) applications (apps). *J Biomed Inform* 2016 Apr;60:243-251 [FREE Full text] [doi: [10.1016/j.jbi.2016.02.002](https://doi.org/10.1016/j.jbi.2016.02.002)] [Medline: [26903153](https://pubmed.ncbi.nlm.nih.gov/26903153/)]
19. Aygun B, Odame I. A global perspective on sickle cell disease. *Pediatr Blood Cancer* 2012 Aug;59(2):386-390. [doi: [10.1002/pbc.24175](https://doi.org/10.1002/pbc.24175)] [Medline: [22535620](https://pubmed.ncbi.nlm.nih.gov/22535620/)]
20. Lobitz S, Telfer P, Cela E, Allaf B, Angastiniotis M, Johansson CB, with the endorsement of EuroBloodNet, the European Reference Network in Rare Haematological Diseases. Newborn screening for sickle cell disease in Europe: recommendations from a Pan-European Consensus Conference. *Br J Haematol* 2018 Nov;183(4):648-660. [doi: [10.1111/bjh.15600](https://doi.org/10.1111/bjh.15600)] [Medline: [30334577](https://pubmed.ncbi.nlm.nih.gov/30334577/)]
21. Saraf SL, Molokie RE, Nouriae M, Sable CA, Luchtman-Jones L, Ensing GJ, et al. Differences in the clinical and genotypic presentation of sickle cell disease around the world. *Paediatr Respir Rev* 2014 Mar;15(1):4-12 [FREE Full text] [doi: [10.1016/j.prrv.2013.11.003](https://doi.org/10.1016/j.prrv.2013.11.003)] [Medline: [24361300](https://pubmed.ncbi.nlm.nih.gov/24361300/)]
22. United Nations. 2008. Adopting Consensus Text, General Assembly Urges Member States, United Nations System to Raise Awareness of Sickle-cell Anaemia on 19 June Each Year URL: <https://www.un.org/press/en/2008/ga10803.doc.htm> [accessed 2019-02-26] [WebCite Cache ID [76VKrj7nL](https://www.webcitation.org/76VKrj7nL)]
23. Brousse V, Makani J, Rees DC. Management of sickle cell disease in the community. *Br Med J* 2014 Mar 10;348:g1765 [FREE Full text] [doi: [10.1136/bmj.g1765](https://doi.org/10.1136/bmj.g1765)] [Medline: [24613806](https://pubmed.ncbi.nlm.nih.gov/24613806/)]
24. Vichinsky EP, DeBaun MR. UpToDate. Acute Vaso-Occlusive Pain Management in Sickle Cell Disease URL: <https://www.uptodate.com/contents/vaso-occlusive-pain-management-in-sickle-cell-disease> [accessed 2019-02-19] [WebCite Cache ID [76lqk3Tpt](https://www.webcitation.org/76lqk3Tpt)]
25. Rice L, Teruya M. Sickle cell patients face death in the ICU\*. *Crit Care Med* 2014 Jul;42(7):1730-1731. [doi: [10.1097/CCM.0000000000000387](https://doi.org/10.1097/CCM.0000000000000387)] [Medline: [24933050](https://pubmed.ncbi.nlm.nih.gov/24933050/)]
26. Kanter J, Kruse-Jarres R. Management of sickle cell disease from childhood through adulthood. *Blood Rev* 2013 Nov;27(6):279-287 [FREE Full text] [doi: [10.1016/j.blre.2013.09.001](https://doi.org/10.1016/j.blre.2013.09.001)] [Medline: [24094945](https://pubmed.ncbi.nlm.nih.gov/24094945/)]
27. Meier ER, Johnson T, Pinkney K, Velez MC, Kamani N, Odame I. Access to hematopoietic stem cell transplant for patients with sickle cell anemia. *Pediatr Blood Cancer* 2018 Sep;65(9):e27105. [doi: [10.1002/pbc.27105](https://doi.org/10.1002/pbc.27105)] [Medline: [29693782](https://pubmed.ncbi.nlm.nih.gov/29693782/)]
28. Lanzkron S, Carroll CP, Haywood C. Mortality rates and age at death from sickle cell disease: US, 1979-2005. *Public Health Rep* 2013;128(2):110-116 [FREE Full text] [doi: [10.1177/003335491312800206](https://doi.org/10.1177/003335491312800206)] [Medline: [23450875](https://pubmed.ncbi.nlm.nih.gov/23450875/)]
29. Rahimy MC, Gangbo A, Ahouignan G, Adjou R, Deguenon C, Goussanou S, et al. Effect of a comprehensive clinical care program on disease course in severely ill children with sickle cell anemia in a sub-Saharan African setting. *Blood* 2003 Aug 1;102(3):834-838. [doi: [10.1182/blood-2002-05-1453](https://doi.org/10.1182/blood-2002-05-1453)] [Medline: [12702514](https://pubmed.ncbi.nlm.nih.gov/12702514/)]
30. Kuznik A, Habib AG, Munube D, Lamorde M. Newborn screening and prophylactic interventions for sickle cell disease in 47 countries in sub-Saharan Africa: a cost-effectiveness analysis. *BMC Health Serv Res* 2016 Jul 26;16:304 [FREE Full text] [doi: [10.1186/s12913-016-1572-6](https://doi.org/10.1186/s12913-016-1572-6)] [Medline: [27461265](https://pubmed.ncbi.nlm.nih.gov/27461265/)]
31. Ware RE. Is sickle cell anemia a neglected tropical disease? *PLoS Negl Trop Dis* 2013;7(5):e2120 [FREE Full text] [doi: [10.1371/journal.pntd.0002120](https://doi.org/10.1371/journal.pntd.0002120)] [Medline: [23750287](https://pubmed.ncbi.nlm.nih.gov/23750287/)]
32. Scott RB. Health care priority and sickle cell anemia. *J Am Med Assoc* 1970 Oct 26;214(4):731-734. [doi: [10.1001/jama.1970.03180040039008](https://doi.org/10.1001/jama.1970.03180040039008)] [Medline: [5536114](https://pubmed.ncbi.nlm.nih.gov/5536114/)]
33. Evensen CT, Treadwell MJ, Keller S, Levine R, Hassell KL, Werner EM, et al. Quality of care in sickle cell disease: Cross-sectional study and development of a measure for adults reporting on ambulatory and emergency department care. *Medicine (Baltimore)* 2016 Aug;95(35):e4528 [FREE Full text] [doi: [10.1097/MD.0000000000004528](https://doi.org/10.1097/MD.0000000000004528)] [Medline: [27583862](https://pubmed.ncbi.nlm.nih.gov/27583862/)]
34. Keane B, Defoe L. Supported or stigmatised? The impact of sickle cell disease on families. *Community Pract* 2016 Jun;89(6):44-47. [Medline: [27443031](https://pubmed.ncbi.nlm.nih.gov/27443031/)]
35. Smith LA, Oyeku SO, Homer C, Zuckerman B. Sickle cell disease: a question of equity and quality. *Pediatrics* 2006 May;117(5):1763-1770. [doi: [10.1542/peds.2005-1611](https://doi.org/10.1542/peds.2005-1611)] [Medline: [16651336](https://pubmed.ncbi.nlm.nih.gov/16651336/)]
36. Stevens EM, Patterson CA, Li YB, Smith-Whitley K, Barakat LP. Mistrust of pediatric sickle cell disease clinical trials research. *Am J Prev Med* 2016 Jul;51(1 Suppl 1):S78-S86 [FREE Full text] [doi: [10.1016/j.amepre.2016.01.024](https://doi.org/10.1016/j.amepre.2016.01.024)] [Medline: [27320470](https://pubmed.ncbi.nlm.nih.gov/27320470/)]
37. Tsyvkin E, Riessman C, Mathew P. Distrust and conflict in sickle cell disease: intersecting narratives of patients and physicians. *Blood* 2015;126(23):4472 [FREE Full text] [doi: [10.1182/blood.V126.23.4472.4472](https://doi.org/10.1182/blood.V126.23.4472.4472)]

38. Campos J, Lobo C, Queiroz AM, do Nascimento EM, Lima CB, Cardoso G, et al. Treatment of the acute sickle cell vaso-occlusive crisis in the Emergency Department: a Brazilian method of switching from intravenous to oral morphine. *Eur J Haematol* 2014 Jul;93(1):34-40. [doi: [10.1111/ejh.12293](https://doi.org/10.1111/ejh.12293)] [Medline: [24571671](https://pubmed.ncbi.nlm.nih.gov/24571671/)]
39. Almuqamam M, Diaz – Frias J, Malik M, Mohamed A, Sedrak A. Emergency management of SCD pain crises: current practices and playing variables. *Pediatr Hematol Oncol J* 2018;3(2):37-41. [doi: [10.1016/j.phoj.2018.06.002](https://doi.org/10.1016/j.phoj.2018.06.002)]
40. Matthie N, Jenerette C. Sickle cell disease in adults: developing an appropriate care plan. *Clin J Oncol Nurs* 2015 Oct;19(5):562-567 [FREE Full text] [doi: [10.1188/15.CJON.562-567](https://doi.org/10.1188/15.CJON.562-567)] [Medline: [26688919](https://pubmed.ncbi.nlm.nih.gov/26688919/)]
41. Ballas SK. The sickle cell painful crisis in adults: phases and objective signs. *Hemoglobin* 1995;19(6):323-333. [doi: [10.3109/03630269509005824](https://doi.org/10.3109/03630269509005824)] [Medline: [8718691](https://pubmed.ncbi.nlm.nih.gov/8718691/)]
42. Ballas SK, Kesen MR, Goldberg MF, Luttly GA, Dampier C, Osunkwo I, et al. Beyond the definitions of the phenotypic complications of sickle cell disease: an update on management. *ScientificWorldJournal* 2012;2012:949535 [FREE Full text] [doi: [10.1100/2012/949535](https://doi.org/10.1100/2012/949535)] [Medline: [22924029](https://pubmed.ncbi.nlm.nih.gov/22924029/)]
43. Ballas SK. More definitions in sickle cell disease: steady state v base line data. *Am J Hematol* 2012 Mar;87(3):338 [FREE Full text] [doi: [10.1002/ajh.22259](https://doi.org/10.1002/ajh.22259)] [Medline: [22190068](https://pubmed.ncbi.nlm.nih.gov/22190068/)]
44. Sant'Ana PG, Araujo AM, Pimenta CT, Bezerra ML, Junior SP, Neto VM, et al. Clinical and laboratory profile of patients with sickle cell anemia. *Rev Bras Hematol Hemoter* 2017;39(1):40-45 [FREE Full text] [doi: [10.1016/j.bjhh.2016.09.007](https://doi.org/10.1016/j.bjhh.2016.09.007)] [Medline: [28270345](https://pubmed.ncbi.nlm.nih.gov/28270345/)]
45. Haywood C, Lanzkron S, Bediako S, Strouse JJ, Haythornthwaite J, Carroll CP, IMPORT Investigators. Perceived discrimination, patient trust, and adherence to medical recommendations among persons with sickle cell disease. *J Gen Intern Med* 2014 Dec;29(12):1657-1662 [FREE Full text] [doi: [10.1007/s11606-014-2986-7](https://doi.org/10.1007/s11606-014-2986-7)] [Medline: [25205621](https://pubmed.ncbi.nlm.nih.gov/25205621/)]
46. Haywood C, Lanzkron S, Diener-West M, Haythornthwaite J, Strouse JJ, Bediako S, IMPORT Investigators. Attitudes toward clinical trials among patients with sickle cell disease. *Clin Trials* 2014 Jun;11(3):275-283 [FREE Full text] [doi: [10.1177/1740774513519876](https://doi.org/10.1177/1740774513519876)] [Medline: [24532686](https://pubmed.ncbi.nlm.nih.gov/24532686/)]
47. Inoue S, Kodjebacheva G, Scherrer T, Rice G, Grigorian M, Blankenship J, et al. Adherence to hydroxyurea medication by children with sickle cell disease (SCD) using an electronic device: a feasibility study. *Int J Hematol* 2016 Aug;104(2):200-207. [doi: [10.1007/s12185-016-2027-x](https://doi.org/10.1007/s12185-016-2027-x)] [Medline: [27225236](https://pubmed.ncbi.nlm.nih.gov/27225236/)]
48. Haywood C, Bediako S, Lanzkron S, Diener-West M, Strouse J, Haythornthwaite J, IMPORT Investigators. An unequal burden: poor patient-provider communication and sickle cell disease. *Patient Educ Couns* 2014 Aug;96(2):159-164 [FREE Full text] [doi: [10.1016/j.pec.2014.05.013](https://doi.org/10.1016/j.pec.2014.05.013)] [Medline: [24935607](https://pubmed.ncbi.nlm.nih.gov/24935607/)]
49. Adeyemo TA, Ojewunmi OO, Diaku-Akinwumi IN, Ayinde OC, Akanmu AS. Health related quality of life and perception of stigmatisation in adolescents living with sickle cell disease in Nigeria: a cross sectional study. *Pediatr Blood Cancer* 2015 Jul;62(7):1245-1251. [doi: [10.1002/pbc.25503](https://doi.org/10.1002/pbc.25503)] [Medline: [25810358](https://pubmed.ncbi.nlm.nih.gov/25810358/)]
50. Ahmadi M, Jahani S, Poormansouri S, Shariati A, Tabesh H. The Effectiveness of self management program on quality of life in patients with sickle cell disease. *Iran J Ped Hematol Oncol* 2015;5(1):18-26 [FREE Full text] [Medline: [25914799](https://pubmed.ncbi.nlm.nih.gov/25914799/)]
51. Blakemore S. Self-care is key in sickle-cell disease. *Emerg Nurse* 2016 May;24(2):9. [doi: [10.7748/en.24.2.9.s9](https://doi.org/10.7748/en.24.2.9.s9)] [Medline: [27165379](https://pubmed.ncbi.nlm.nih.gov/27165379/)]
52. Ahmadi M, Shariati A, Jahani S, Tabesh H, Keikhaei B. The effectiveness of self-management programs on self-efficacy in patients with sickle cell disease. *Jundishapur J Chronic Dis Care* 2014;3(3). [doi: [10.17795/jjcdc-21702](https://doi.org/10.17795/jjcdc-21702)]
53. Adegbola M. Spirituality, self-efficacy, and quality of life among adults with sickle cell disease. *South Online J Nurs Res* 2011 Apr;11(1) [FREE Full text] [Medline: [21769284](https://pubmed.ncbi.nlm.nih.gov/21769284/)]
54. Molter BL, Abrahamson K. Self-efficacy, transition, and patient outcomes in the sickle cell disease population. *Pain Manag Nurs* 2015 Jun;16(3):418-424. [doi: [10.1016/j.pmn.2014.06.001](https://doi.org/10.1016/j.pmn.2014.06.001)] [Medline: [25047808](https://pubmed.ncbi.nlm.nih.gov/25047808/)]
55. Treadwell M, Johnson S, Sisler I, Bitsko M, Gildengorin G, Medina R, et al. Self-efficacy and readiness for transition from pediatric to adult care in sickle cell disease. *Int J Adolesc Med Health* 2016 Nov 1;28(4):381-388. [doi: [10.1515/ijamh-2015-0014](https://doi.org/10.1515/ijamh-2015-0014)] [Medline: [26226116](https://pubmed.ncbi.nlm.nih.gov/26226116/)]
56. Khan SA, Damanhoury G, Ali A, Khan SA, Khan A, Bakillah A, et al. Precipitating factors and targeted therapies in combating the perils of sickle cell disease--- A special nutritional consideration. *Nutr Metab (Lond)* 2016;13:50 [FREE Full text] [doi: [10.1186/s12986-016-0109-7](https://doi.org/10.1186/s12986-016-0109-7)] [Medline: [27508000](https://pubmed.ncbi.nlm.nih.gov/27508000/)]
57. Norris SL, Engelgau MM, Narayan KM. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. *Diabetes Care* 2001 Mar;24(3):561-587. [doi: [10.2337/diacare.24.3.561](https://doi.org/10.2337/diacare.24.3.561)] [Medline: [11289485](https://pubmed.ncbi.nlm.nih.gov/11289485/)]
58. Jenerette CM, Leak AN, Sandelowski M. Life stories of older adults with sickle cell disease. *Assoc Black Nurs Fac J* 2011;22(3):58-63. [Medline: [21901994](https://pubmed.ncbi.nlm.nih.gov/21901994/)]
59. Jenerette CM, Lauderdale G. Successful aging with sickle cell disease: using qualitative methods to inform theory. *J Theory Constr Test* 2008 Apr 1;12(1):16-24 [FREE Full text] [Medline: [19838320](https://pubmed.ncbi.nlm.nih.gov/19838320/)]
60. Schroeder SA. Shattuck Lecture. We can do better--improving the health of the American people. *N Engl J Med* 2007 Sep 20;357(12):1221-1228. [doi: [10.1056/NEJMsa073350](https://doi.org/10.1056/NEJMsa073350)] [Medline: [17881753](https://pubmed.ncbi.nlm.nih.gov/17881753/)]
61. Jesus AC, Konstantyner T, Lôbo IK, Braga JA. Socioeconomic and nutritional characteristics of children and adolescents with sickle cell anemia: a systematic review. *Rev Paul Pediatr* 2018;36(4):491-499 [FREE Full text] [doi: [10.1590/1984-0462/2018;36;4;00010](https://doi.org/10.1590/1984-0462/2018;36;4;00010)] [Medline: [30540112](https://pubmed.ncbi.nlm.nih.gov/30540112/)]

62. Anderson K, Burford O, Emmerton L. Mobile health apps to facilitate self-care: a qualitative study of user experiences. *PLoS One* 2016;11(5):e0156164 [FREE Full text] [doi: [10.1371/journal.pone.0156164](https://doi.org/10.1371/journal.pone.0156164)] [Medline: [27214203](https://pubmed.ncbi.nlm.nih.gov/27214203/)]
63. Crosby LE, Ware RE, Goldstein A, Walton A, Joffe NE, Vogel C, et al. Development and evaluation of iManage: a self-management app co-designed by adolescents with sickle cell disease. *Pediatr Blood Cancer* 2017 Jan;64(1):139-145. [doi: [10.1002/pbc.26177](https://doi.org/10.1002/pbc.26177)] [Medline: [27574031](https://pubmed.ncbi.nlm.nih.gov/27574031/)]
64. Issom DZ, Zosso A, Wipfli R, Ehrler F, Lovis C, Hartvigsen G, et al. Meeting Sickle Cell Patients' Unmet Needs with eHealth Tools: A Preliminary Study. In: *Proceedings from The 13th Scandinavian Conference on Health Informatics*. Linköping: Linköping University Electronic Press; 2015 Presented at: SHI'15; June 15-17, 2015; Tromsø, Norway p. 66-77 URL: <http://www.ep.liu.se/ecp/article.asp?issue=115&article=011#>
65. Badawy SM, Cronin RM, Hankins J, Crosby L, DeBaun M, Thompson AA, et al. Patient-centered eHealth interventions for children, adolescents, and adults with sickle cell disease: systematic review. *J Med Internet Res* 2018 Jul 19;20(7):e10940 [FREE Full text] [doi: [10.2196/10940](https://doi.org/10.2196/10940)] [Medline: [30026178](https://pubmed.ncbi.nlm.nih.gov/30026178/)]
66. Shah N, Jonassaint J, de Castro L. Patients welcome the Sickle Cell Disease Mobile Application to Record Symptoms via Technology (SMART). *Hemoglobin* 2014;38(2):99-103. [doi: [10.3109/03630269.2014.880716](https://doi.org/10.3109/03630269.2014.880716)] [Medline: [24512633](https://pubmed.ncbi.nlm.nih.gov/24512633/)]
67. Woldaregay AZ, Issom D, Henriksen A, Marttila H, Mikalsen M, Pfuhl G, et al. Motivational factors for user engagement with mHealth apps. *Stud Health Technol Inform* 2018;249:151-157. [Medline: [29866972](https://pubmed.ncbi.nlm.nih.gov/29866972/)]
68. European Medicines Agency. Perma. EU/3/10/832 URL: <https://perma.cc/F9DE-WL8Q> [accessed 2019-11-05]
69. Graesdal JS, Gundersen K, Holm B, Waage A. [Thalassemia and sickle-cell disease in Norway]. *Tidsskr Nor Laegeforen* 2001 Feb 28;121(6):678-680 [FREE Full text] [Medline: [11293347](https://pubmed.ncbi.nlm.nih.gov/11293347/)]
70. Schmugge M, Speer O, Ozsahin A, Martin G. La drépanocytose en Suisse. 2e partie: Mesures thérapeutiques et prophylactiques. *Forum Med Suisse* 2008;8(34):606-608. [doi: [10.4414/fms.2008.06563](https://doi.org/10.4414/fms.2008.06563)]
71. Schmugge M, Speer O, Hulya Ozsahin A, Martin G. La drépanocytose en Suisse. Ire partie: Physiopathologie, Clinique. *Forum Med Suisse* 2008;8(33):582-586. [doi: [10.4414/fms.2008.06560](https://doi.org/10.4414/fms.2008.06560)]
72. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006 Jan;3(2):77-101. [doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)]
73. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci* 2011 Apr 23;6:42 [FREE Full text] [doi: [10.1186/1748-5908-6-42](https://doi.org/10.1186/1748-5908-6-42)] [Medline: [21513547](https://pubmed.ncbi.nlm.nih.gov/21513547/)]
74. Curtis KE, Lahiri S, Brown KE. Targeting parents for childhood weight management: development of a theory-driven and user-centered healthy eating app. *JMIR Mhealth Uhealth* 2015 Jun 18;3(2):e69 [FREE Full text] [doi: [10.2196/mhealth.3857](https://doi.org/10.2196/mhealth.3857)] [Medline: [26088692](https://pubmed.ncbi.nlm.nih.gov/26088692/)]
75. Litterbach EK, Russell CG, Taki S, Denney-Wilson E, Campbell KJ, Laws RA. Factors influencing engagement and behavioral determinants of infant feeding in an mHealth program: qualitative evaluation of the growing healthy program. *JMIR Mhealth Uhealth* 2017 Dec 18;5(12):e196 [FREE Full text] [doi: [10.2196/mhealth.8515](https://doi.org/10.2196/mhealth.8515)] [Medline: [29254908](https://pubmed.ncbi.nlm.nih.gov/29254908/)]
76. Korpershoek YJ, Vervoort SC, Trappenburg JC, Schuurmans MJ. Perceptions of patients with chronic obstructive pulmonary disease and their health care providers towards using mHealth for self-management of exacerbations: a qualitative study. *BMC Health Serv Res* 2018 Oct 4;18(1):757 [FREE Full text] [doi: [10.1186/s12913-018-3545-4](https://doi.org/10.1186/s12913-018-3545-4)] [Medline: [30286761](https://pubmed.ncbi.nlm.nih.gov/30286761/)]
77. Robertson J, Robertson S. Research Gate. Volere Requirements Specification Template URL: [https://www.researchgate.net/publication/243771804\\_Volere\\_Requirements\\_Specification\\_Template](https://www.researchgate.net/publication/243771804_Volere_Requirements_Specification_Template) [accessed 2019-02-27] [WebCite Cache ID [76VLGpcyD](https://www.webcitation.org/76VLGpcyD)]
78. Chen L, Ali Babar M, Nuseibeh B. Characterizing architecturally significant requirements. *IEEE Softw* 2013 Mar;30(2):38-45. [doi: [10.1109/ms.2012.174](https://doi.org/10.1109/ms.2012.174)]
79. Akinbami A, Dosunmu A, Adediran A, Oshinaike O, Adebola P, Arogundade O. Haematological values in homozygous sickle cell disease in steady state and haemoglobin phenotypes AA controls in Lagos, Nigeria. *BMC Res Notes* 2012 Aug 1;5:396 [FREE Full text] [doi: [10.1186/1756-0500-5-396](https://doi.org/10.1186/1756-0500-5-396)] [Medline: [22849350](https://pubmed.ncbi.nlm.nih.gov/22849350/)]
80. Mader LB, Harris T, Kläger S, Wilkinson IB, Hiemstra TF. Inverting the patient involvement paradigm: defining patient led research. *Res Involv Engagem* 2018;4:21 [FREE Full text] [doi: [10.1186/s40900-018-0104-4](https://doi.org/10.1186/s40900-018-0104-4)] [Medline: [30002875](https://pubmed.ncbi.nlm.nih.gov/30002875/)]
81. Manwani D, Frenette PS. Vaso-occlusion in sickle cell disease: pathophysiology and novel targeted therapies. *Blood* 2013 Dec 5;122(24):3892-3898 [FREE Full text] [doi: [10.1182/blood-2013-05-498311](https://doi.org/10.1182/blood-2013-05-498311)] [Medline: [24052549](https://pubmed.ncbi.nlm.nih.gov/24052549/)]
82. Ataga KI, Kutlar A, Kanter J, Liles D, Cancado R, Friedrisch J, et al. Crizanlizumab for the prevention of pain crises in sickle cell disease. *N Engl J Med* 2017 Feb 2;376(5):429-439 [FREE Full text] [doi: [10.1056/NEJMoa1611770](https://doi.org/10.1056/NEJMoa1611770)] [Medline: [27959701](https://pubmed.ncbi.nlm.nih.gov/27959701/)]
83. Skrøvseth SO, Årsand E, Godtliebsen F, Joakimsen RM. Data-driven personalized feedback to patients with type 1 diabetes: a randomized trial. *Diabetes Technol Ther* 2015 Jul;17(7):482-489 [FREE Full text] [doi: [10.1089/dia.2014.0276](https://doi.org/10.1089/dia.2014.0276)] [Medline: [25751133](https://pubmed.ncbi.nlm.nih.gov/25751133/)]
84. Fontana JM, Farooq M, Sazonov E. Automatic ingestion monitor: a novel wearable device for monitoring of ingestive behavior. *IEEE Trans Biomed Eng* 2014 Jun;61(6):1772-1779 [FREE Full text] [doi: [10.1109/TBME.2014.2306773](https://doi.org/10.1109/TBME.2014.2306773)] [Medline: [24845288](https://pubmed.ncbi.nlm.nih.gov/24845288/)]
85. Andreu-Perez J, Leff DR, Ip HM, Yang G. From wearable sensors to smart implants--toward pervasive and personalized healthcare. *IEEE Trans Biomed Eng* 2015 Dec;62(12):2750-2762. [doi: [10.1109/TBME.2015.2422751](https://doi.org/10.1109/TBME.2015.2422751)] [Medline: [25879838](https://pubmed.ncbi.nlm.nih.gov/25879838/)]

86. Kim J, Kim M, Lee M, Kim K, Ji S, Kim Y, et al. Wearable smart sensor systems integrated on soft contact lenses for wireless ocular diagnostics. *Nat Commun* 2017 Apr 27;8:14997 [FREE Full text] [doi: [10.1038/ncomms14997](https://doi.org/10.1038/ncomms14997)] [Medline: [28447604](https://pubmed.ncbi.nlm.nih.gov/28447604/)]
87. Perma. DIYPS.org URL: <https://perma.cc/CUD4-9H2F> [accessed 2019-12-26]
88. Dimković N. [Erythropoietin-beta in the treatment of anemia in patients with chronic renal insufficiency]. *Med Pregl* 2001;54(5-6):235-240. [Medline: [11759218](https://pubmed.ncbi.nlm.nih.gov/11759218/)]
89. Vichinsky E, Hoppe CC, Ataga KI, Ware RE, Nduba V, El-Beshlawy A, HOPE Trial Investigators. A phase 3 randomized trial of Voxelotor in sickle cell disease. *N Engl J Med* 2019 Aug 8;381(6):509-519. [doi: [10.1056/NEJMoa1903212](https://doi.org/10.1056/NEJMoa1903212)] [Medline: [31199090](https://pubmed.ncbi.nlm.nih.gov/31199090/)]
90. Bird Y, Lemstra M, Rogers M, Moraros J. The relationship between socioeconomic status/income and prevalence of diabetes and associated conditions: A cross-sectional population-based study in Saskatchewan, Canada. *Int J Equity Health* 2015 Oct 12;14:93 [FREE Full text] [doi: [10.1186/s12939-015-0237-0](https://doi.org/10.1186/s12939-015-0237-0)] [Medline: [26458543](https://pubmed.ncbi.nlm.nih.gov/26458543/)]
91. Salvo P, Dini V, Kirchhain A, Janowska A, Oranges T, Chiricozzi A, et al. Sensors and biosensors for c-reactive protein, temperature and pH, and their applications for monitoring wound healing: a review. *Sensors (Basel)* 2017 Dec 19;17(12) [FREE Full text] [doi: [10.3390/s17122952](https://doi.org/10.3390/s17122952)] [Medline: [29257113](https://pubmed.ncbi.nlm.nih.gov/29257113/)]
92. Adams-Graves P, Bronte-Jordan L. Recent treatment guidelines for managing adult patients with sickle cell disease: challenges in access to care, social issues, and adherence. *Expert Rev Hematol* 2016 Jun;9(6):541-552. [doi: [10.1080/17474086.2016.1180242](https://doi.org/10.1080/17474086.2016.1180242)] [Medline: [27098013](https://pubmed.ncbi.nlm.nih.gov/27098013/)]
93. Amid A, Odame I. Improving outcomes in children with sickle cell disease: treatment considerations and strategies. *Paediatr Drugs* 2014 Aug;16(4):255-266. [doi: [10.1007/s40272-014-0074-4](https://doi.org/10.1007/s40272-014-0074-4)] [Medline: [24797542](https://pubmed.ncbi.nlm.nih.gov/24797542/)]
94. Benjamin LJ, Swinson GI, Nagel RL. Sickle cell anemia day hospital: an approach for the management of uncomplicated painful crises. *Blood* 2000 Feb 15;95(4):1130-1136. [Medline: [10666181](https://pubmed.ncbi.nlm.nih.gov/10666181/)]
95. Haywood C, Naik R, Beach M, Lanzkron S. Do sickle cell patients wait longer to see physicians in the emergency department? *Blood* 2011;118(21):2070 [FREE Full text] [doi: [10.1182/blood.v118.21.2070.2070](https://doi.org/10.1182/blood.v118.21.2070.2070)]
96. Chu Y, Zhao X, Han J, Su Y. Physiological signal-based method for measurement of pain intensity. *Front Neurosci* 2017;11:279 [FREE Full text] [doi: [10.3389/fnins.2017.00279](https://doi.org/10.3389/fnins.2017.00279)] [Medline: [28603478](https://pubmed.ncbi.nlm.nih.gov/28603478/)]
97. Paiz JA, Rosa CP, Risso R, Monaco B, Duarte KP, Lopez WO, et al. Intrathecal morphine therapy for chronic non-malignant pain using a constant flow infusion system. *J Pain Relief* 2015;4(1):168. [doi: [10.4172/2167-0846.1000168](https://doi.org/10.4172/2167-0846.1000168)]
98. Apple App Store. Voice Crisis Alert V2 URL: <https://itunes.apple.com/us/app/voice-crisis-alert-v2/id1271708147?mt=8> [accessed 2019-02-18] [WebCite Cache ID 76HKd49mM]
99. Ehrler F, Lovis C, Rochat J, Schneider F, Gervais A, Galetto-Lacour A, et al. [InfoKids: changing the patients' journey paradigm in an Emergency Department]. *Rev Med Suisse* 2018 Sep 5;14(617):1538-1542. [Medline: [30226668](https://pubmed.ncbi.nlm.nih.gov/30226668/)]
100. Markotic F, Vrdoljak D, Puljiz M, Puljak L. Risk perception about medication sharing among patients: a focus group qualitative study on borrowing and lending of prescription analgesics. *J Pain Res* 2017;10:365-374 [FREE Full text] [doi: [10.2147/JPR.S123554](https://doi.org/10.2147/JPR.S123554)] [Medline: [28243140](https://pubmed.ncbi.nlm.nih.gov/28243140/)]
101. Beyene KA, Sheridan J, Aspden T. Prescription medication sharing: a systematic review of the literature. *Am J Public Health* 2014 Apr;104(4):e15-e26. [doi: [10.2105/AJPH.2013.301823](https://doi.org/10.2105/AJPH.2013.301823)] [Medline: [24524496](https://pubmed.ncbi.nlm.nih.gov/24524496/)]
102. Thurnheer SE, Gravestock I, Pichierri G, Steurer J, Burgstaller JM. Benefits of mobile apps in pain management: systematic review. *JMIR Mhealth Uhealth* 2018 Oct 22;6(10):e11231 [FREE Full text] [doi: [10.2196/11231](https://doi.org/10.2196/11231)] [Medline: [30348633](https://pubmed.ncbi.nlm.nih.gov/30348633/)]
103. Pourmand A, Davis S, Marchak A, Whiteside T, Sikka N. Virtual reality as a clinical tool for pain management. *Curr Pain Headache Rep* 2018 Jun 15;22(8):53. [doi: [10.1007/s11916-018-0708-2](https://doi.org/10.1007/s11916-018-0708-2)] [Medline: [29904806](https://pubmed.ncbi.nlm.nih.gov/29904806/)]
104. Ballas SK. Self-management of sickle cell disease: a new frontier. *J Natl Med Assoc* 2010 Nov;102(11):1042-1043. [doi: [10.1016/s0027-9684\(15\)30722-7](https://doi.org/10.1016/s0027-9684(15)30722-7)] [Medline: [21141292](https://pubmed.ncbi.nlm.nih.gov/21141292/)]
105. Miller AS, Cafazzo JA, Seto E. A game plan: gamification design principles in mHealth applications for chronic disease management. *Health Informatics J* 2016 Jun;22(2):184-193. [doi: [10.1177/1460458214537511](https://doi.org/10.1177/1460458214537511)] [Medline: [24986104](https://pubmed.ncbi.nlm.nih.gov/24986104/)]
106. Medhi I, Patnaik S, Brunskill E, Gautama SN, Thies W, Toyama K. Designing mobile interfaces for novice and low-literacy users. *ACM Trans Comput-Hum Interact* 2011;18(1):1-28. [doi: [10.1145/1959022.1959024](https://doi.org/10.1145/1959022.1959024)]
107. Fu LP, Landay J, Nebeling M, Xu Y, Zhao C. Redefining Natural User Interface. In: Proceedings of the Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems. USA: ACM; 2018 Presented at: CHI EA'18; April 21 - 26, 2018; Montréal, Canada p. 1-3. [doi: [10.1145/3170427.3190649](https://doi.org/10.1145/3170427.3190649)]
108. McLaughlin AC, Matalenas LA, Coleman MG. Design of human centered augmented reality for managing chronic health conditions. In: Pak R, McLaughlin AC, editors. *Aging, Technology And Health*. San Diego: Elsevier Academic Press; 2018:261-296.
109. Gutiérrez F, Verbert K, Htun N. PHARA: An Augmented Reality Grocery Store Assistant. In: Proceedings of the 20th International Conference on Human-Computer Interaction with Mobile Devices and Services Adjunct. USA: ACM; 2018 Presented at: MobileHCI'18; September 3 - 6, 2018; Barcelona, Spain p. 339-345. [doi: [10.1145/3236112.3236161](https://doi.org/10.1145/3236112.3236161)]
110. Talbot TB. Virtual reality and interactive gaming technology for obese and diabetic children: is military medical technology applicable? *J Diabetes Sci Technol* 2011 Mar 1;5(2):234-238 [FREE Full text] [doi: [10.1177/193229681100500205](https://doi.org/10.1177/193229681100500205)] [Medline: [21527087](https://pubmed.ncbi.nlm.nih.gov/21527087/)]

111. Elswailer D, Hors-Fraile S, Ludwig B, Said A, Schäfer H, Trattner C, et al. Second Workshop on Health Recommender Systems: (HealthRecSys 2017). In: Proceedings of the Eleventh ACM Conference on Recommender Systems. New York: ACM; 2017 Presented at: RecSys'17; August 27 - 31, 2017; Como, Italy p. 374-375. [doi: [10.1145/3109859.3109955](https://doi.org/10.1145/3109859.3109955)]
112. Oing T, Prescott J. Implementations of virtual reality for anxiety-related disorders: systematic review. *JMIR Serious Games* 2018 Nov 7;6(4):e10965 [FREE Full text] [doi: [10.2196/10965](https://doi.org/10.2196/10965)] [Medline: [30404770](https://pubmed.ncbi.nlm.nih.gov/30404770/)]
113. Izahar S, Lean QY, Hameed MA, Murugiah MK, Patel RP, Al-Worafi YM, et al. Content analysis of mobile health applications on diabetes mellitus. *Front Endocrinol (Lausanne)* 2017;8:318 [FREE Full text] [doi: [10.3389/fendo.2017.00318](https://doi.org/10.3389/fendo.2017.00318)] [Medline: [29230195](https://pubmed.ncbi.nlm.nih.gov/29230195/)]
114. Rossi MG, Bigi S. mHealth for diabetes support: a systematic review of apps available on the Italian market. *Mhealth* 2017;3:16 [FREE Full text] [doi: [10.21037/mhealth.2017.04.06](https://doi.org/10.21037/mhealth.2017.04.06)] [Medline: [28567412](https://pubmed.ncbi.nlm.nih.gov/28567412/)]
115. Lager G, Pataky Z, Golay A. Efficacy of therapeutic patient education in chronic diseases and obesity. *Patient Educ Couns* 2010 Jun;79(3):283-286. [doi: [10.1016/j.pec.2010.03.015](https://doi.org/10.1016/j.pec.2010.03.015)] [Medline: [20413242](https://pubmed.ncbi.nlm.nih.gov/20413242/)]
116. Assal J, Golay A. Patient education in Switzerland: from diabetes to chronic diseases. *Patient Educ Couns* 2001 Jul;44(1):65-69. [doi: [10.1016/s0738-3991\(01\)00105-7](https://doi.org/10.1016/s0738-3991(01)00105-7)] [Medline: [11390160](https://pubmed.ncbi.nlm.nih.gov/11390160/)]
117. Boehmer KR, Barakat S, Ahn S, Prokop LJ, Erwin PJ, Murad MH. Health coaching interventions for persons with chronic conditions: a systematic review and meta-analysis protocol. *Syst Rev* 2016 Sep 1;5(1):146 [FREE Full text] [doi: [10.1186/s13643-016-0316-3](https://doi.org/10.1186/s13643-016-0316-3)] [Medline: [27585627](https://pubmed.ncbi.nlm.nih.gov/27585627/)]
118. Ghorob A. Health coaching: teaching patients how to fish. *Fam Pract Manag* 2013;20(3):40-42 [FREE Full text] [Medline: [23939739](https://pubmed.ncbi.nlm.nih.gov/23939739/)]
119. Davenport T, Kalakota R. The potential for artificial intelligence in healthcare. *Future Healthc J* 2019 Jun;6(2):94-98 [FREE Full text] [doi: [10.7861/futurehosp.6-2-94](https://doi.org/10.7861/futurehosp.6-2-94)] [Medline: [31363513](https://pubmed.ncbi.nlm.nih.gov/31363513/)]
120. Gheondea-Eladi A. Patient decision aids: a content analysis based on a decision tree structure. *BMC Med Inform Decis Mak* 2019 Jul 19;19(1):137 [FREE Full text] [doi: [10.1186/s12911-019-0840-x](https://doi.org/10.1186/s12911-019-0840-x)] [Medline: [31324237](https://pubmed.ncbi.nlm.nih.gov/31324237/)]
121. Elwyn G, O'Connor A, Stacey D, Volk R, Edwards A, Coulter A, International Patient Decision Aids Standards (IPDAS) Collaboration. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *Br Med J* 2006 Aug 26;333(7565):417 [FREE Full text] [doi: [10.1136/bmj.38926.629329.AE](https://doi.org/10.1136/bmj.38926.629329.AE)] [Medline: [16908462](https://pubmed.ncbi.nlm.nih.gov/16908462/)]
122. Stacey D, Kryworuchko J, Belkora J, Davison BJ, Durand M, Eden KB, et al. Coaching and guidance with patient decision aids: A review of theoretical and empirical evidence. *BMC Med Inform Decis Mak* 2013;13(Suppl 2):S11 [FREE Full text] [doi: [10.1186/1472-6947-13-S2-S11](https://doi.org/10.1186/1472-6947-13-S2-S11)] [Medline: [24624995](https://pubmed.ncbi.nlm.nih.gov/24624995/)]
123. Jacobs W, Amuta AO, Jeon KC. Health information seeking in the digital age: an analysis of health information seeking behavior among US adults. *Cogent Soc Sci* 2017;3(1):1302785. [doi: [10.1080/23311886.2017.1302785](https://doi.org/10.1080/23311886.2017.1302785)]
124. Tan SS, Goonawardene N. Internet health information seeking and the patient-physician relationship: a systematic review. *J Med Internet Res* 2017 Jan 19;19(1):e9 [FREE Full text] [doi: [10.2196/jmir.5729](https://doi.org/10.2196/jmir.5729)] [Medline: [28104579](https://pubmed.ncbi.nlm.nih.gov/28104579/)]
125. Frost JR, Cherry RK, Oyeku SO, Faro EZ, Crosby LE, Britto M, et al. Improving sickle cell transitions of care through health information technology. *Am J Prev Med* 2016 Jul;51(1 Suppl 1):S17-S23 [FREE Full text] [doi: [10.1016/j.amepre.2016.02.004](https://doi.org/10.1016/j.amepre.2016.02.004)] [Medline: [27320460](https://pubmed.ncbi.nlm.nih.gov/27320460/)]
126. Breakey VR, Harris L, Davis O, Agarwal A, Ouellette C, Akinnawo E, et al. The quality of information about sickle cell disease on the Internet for youth. *Pediatr Blood Cancer* 2017 Apr;64(4). [doi: [10.1002/pbc.26309](https://doi.org/10.1002/pbc.26309)] [Medline: [27786409](https://pubmed.ncbi.nlm.nih.gov/27786409/)]
127. Zhang Y, Cui H, Burkell J, Mercer RE. A Machine Learning Approach for Rating the Quality of Depression Treatment Web Pages. In: *iConference 2014 Proceedings*. 2014 Presented at: iConference 2014; March 4-7, 2014; Berlin, Germany p. 192-212 URL: <https://doi.org/10.9776/14065> [doi: [10.9776/14065](https://doi.org/10.9776/14065)]
128. Boyer C, Dolamic L. Automated detection of HONcode website conformity compared to manual detection: an evaluation. *J Med Internet Res* 2015 Jun 2;17(6):e135 [FREE Full text] [doi: [10.2196/jmir.3831](https://doi.org/10.2196/jmir.3831)] [Medline: [26036669](https://pubmed.ncbi.nlm.nih.gov/26036669/)]
129. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *J Epidemiol Community Health* 1999 Feb;53(2):105-111 [FREE Full text] [doi: [10.1136/jech.53.2.105](https://doi.org/10.1136/jech.53.2.105)] [Medline: [10396471](https://pubmed.ncbi.nlm.nih.gov/10396471/)]
130. Qenam B, Kim TY, Carroll MJ, Hogarth M. Text simplification using consumer health vocabulary to generate patient-centered radiology reporting: translation and evaluation. *J Med Internet Res* 2017 Dec 18;19(12):e417. [doi: [10.2196/jmir.8536](https://doi.org/10.2196/jmir.8536)] [Medline: [29254915](https://pubmed.ncbi.nlm.nih.gov/29254915/)]
131. Smith CA. Consumer language, patient language, and thesauri: a review of the literature. *J Med Libr Assoc* 2011 Apr;99(2):135-144 [FREE Full text] [doi: [10.3163/1536-5050.99.2.005](https://doi.org/10.3163/1536-5050.99.2.005)] [Medline: [21464851](https://pubmed.ncbi.nlm.nih.gov/21464851/)]
132. Hosseinzadeh VA, Brugnara C, Holt RG. Shape oscillations of single blood drops: applications to human blood and sickle cell disease. *Sci Rep* 2018 Nov 14;8(1):16794 [FREE Full text] [doi: [10.1038/s41598-018-34600-7](https://doi.org/10.1038/s41598-018-34600-7)] [Medline: [30429489](https://pubmed.ncbi.nlm.nih.gov/30429489/)]
133. Li X, Du E, Lei H, Tang Y, Dao M, Suresh S, et al. Patient-specific blood rheology in sickle-cell anaemia. *Interface Focus* 2016 Feb 6;6(1):20150065 [FREE Full text] [doi: [10.1098/rsfs.2015.0065](https://doi.org/10.1098/rsfs.2015.0065)] [Medline: [26855752](https://pubmed.ncbi.nlm.nih.gov/26855752/)]
134. Jacob E, Beyer JE, Miaskowski C, Savedra M, Treadwell M, Styles L. Are there phases to the vaso-occlusive painful episode in sickle cell disease? *J Pain Symptom Manage* 2005 Apr;29(4):392-400 [FREE Full text] [doi: [10.1016/j.jpainsymman.2004.07.006](https://doi.org/10.1016/j.jpainsymman.2004.07.006)] [Medline: [15857743](https://pubmed.ncbi.nlm.nih.gov/15857743/)]

135. Wang G, Zhang S, Dong S, Lou D, Ma L, Pei X, et al. Stretchable optical sensing patch system integrated heart rate, pulse oxygen saturation, and sweat pH detection. *IEEE Trans Biomed Eng* 2019 Apr;66(4):1000-1005. [doi: [10.1109/TBME.2018.2866151](https://doi.org/10.1109/TBME.2018.2866151)] [Medline: [30130170](https://pubmed.ncbi.nlm.nih.gov/30130170/)]
136. Jin W, Wu L, Song Y, Jiang J, Zhu X, Yang D, et al. Continuous intra-arterial blood pH monitoring by a fiber-optic fluorosensor. *IEEE Trans Biomed Eng* 2011;58(5):1232-1238. [doi: [10.1109/tbme.2011.2107514](https://doi.org/10.1109/tbme.2011.2107514)]
137. Anastasova S, Crewther B, Bembnowicz P, Curto V, Ip HM, Rosa B, et al. A wearable multisensing patch for continuous sweat monitoring. *Biosens Bioelectron* 2017 Jul 15;93:139-145 [FREE Full text] [doi: [10.1016/j.bios.2016.09.038](https://doi.org/10.1016/j.bios.2016.09.038)] [Medline: [27743863](https://pubmed.ncbi.nlm.nih.gov/27743863/)]
138. Diaw M, samb A, Diop S, Sall ND, Ba A, Cissé F, et al. Effects of hydration and water deprivation on blood viscosity during a soccer game in sickle cell trait carriers. *Br J Sports Med* 2014 Feb;48(4):326-331. [doi: [10.1136/bjsports-2012-091038](https://doi.org/10.1136/bjsports-2012-091038)] [Medline: [22685122](https://pubmed.ncbi.nlm.nih.gov/22685122/)]
139. Omwanghe OA, Muntz DS, Kwon S, Montgomery S, Kemiki O, Hsu LL, et al. Self-reported physical activity and exercise patterns in children with sickle cell disease. *Pediatr Exerc Sci* 2017 Aug;29(3):388-395. [doi: [10.1123/pes.2016-0276](https://doi.org/10.1123/pes.2016-0276)] [Medline: [28530510](https://pubmed.ncbi.nlm.nih.gov/28530510/)]
140. Morita AA, Silva LK, Bisca GW, Oliveira JM, Hernandez NA, Pitta F, et al. Heart rate recovery, physical activity level, and functional status in subjects with COPD. *Respir Care* 2018 Aug;63(8):1002-1008 [FREE Full text] [doi: [10.4187/respcare.05918](https://doi.org/10.4187/respcare.05918)] [Medline: [29765005](https://pubmed.ncbi.nlm.nih.gov/29765005/)]
141. Thompson D, Batterham AM, Peacock OJ, Western MJ, Booso R. Feedback from physical activity monitors is not compatible with current recommendations: A recalibration study. *Prev Med* 2016 Oct;91:389-394 [FREE Full text] [doi: [10.1016/j.ypmed.2016.06.017](https://doi.org/10.1016/j.ypmed.2016.06.017)] [Medline: [27330025](https://pubmed.ncbi.nlm.nih.gov/27330025/)]
142. Zempsky WT, Loiselle KA, McKay K, Lee BH, Hagstrom JN, Schechter NL. Do children with sickle cell disease receive disparate care for pain in the emergency department? *J Emerg Med* 2010 Nov;39(5):691-695. [doi: [10.1016/j.jemermed.2009.06.003](https://doi.org/10.1016/j.jemermed.2009.06.003)] [Medline: [19703740](https://pubmed.ncbi.nlm.nih.gov/19703740/)]
143. Ballas SK. Current issues in sickle cell pain and its management. *Hematology Am Soc Hematol Educ Program* 2007;2007:97-105. [doi: [10.1182/asheducation-2007.1.97](https://doi.org/10.1182/asheducation-2007.1.97)] [Medline: [18024616](https://pubmed.ncbi.nlm.nih.gov/18024616/)]
144. Ogu UO, Billett HH. Comorbidities in sickle cell disease: Adult providers needed!. *Indian J Med Res* 2018 Jun;147(6):527-529 [FREE Full text] [doi: [10.4103/ijmr.IJMR\\_1019\\_18](https://doi.org/10.4103/ijmr.IJMR_1019_18)] [Medline: [30168482](https://pubmed.ncbi.nlm.nih.gov/30168482/)]
145. Bender JL, Jimenez-Marroquin M, Jadad AR. Seeking support on Facebook: a content analysis of breast cancer groups. *J Med Internet Res* 2011 Feb 4;13(1):e16 [FREE Full text] [doi: [10.2196/jmir.1560](https://doi.org/10.2196/jmir.1560)] [Medline: [21371990](https://pubmed.ncbi.nlm.nih.gov/21371990/)]
146. Rosa SD, Sen F. Health topics on Facebook groups: content analysis of posts in multiple sclerosis communities. *Interact J Med Res* 2019 Feb 11;8(1):e10146 [FREE Full text] [doi: [10.2196/10146](https://doi.org/10.2196/10146)] [Medline: [30741640](https://pubmed.ncbi.nlm.nih.gov/30741640/)]
147. Harpel T. Pregnant women sharing pregnancy-related information on Facebook: web-based survey study. *J Med Internet Res* 2018 Mar 22;20(3):e115 [FREE Full text] [doi: [10.2196/jmir.7753](https://doi.org/10.2196/jmir.7753)] [Medline: [29567636](https://pubmed.ncbi.nlm.nih.gov/29567636/)]
148. Troncone A, Cascella C, Chianese A, Iafusco D. Using computerized text analysis to assess communication within an Italian type 1 diabetes Facebook group. *Health Psychol Open* 2015 Jul;2(2):2055102915615338 [FREE Full text] [doi: [10.1177/2055102915615338](https://doi.org/10.1177/2055102915615338)] [Medline: [28070379](https://pubmed.ncbi.nlm.nih.gov/28070379/)]
149. Okun S, Goodwin K. Building a learning health community: By the people, for the people. *Learn Health Syst* 2017 Jul;1(3):e10028 [FREE Full text] [doi: [10.1002/lrh2.10028](https://doi.org/10.1002/lrh2.10028)] [Medline: [31245561](https://pubmed.ncbi.nlm.nih.gov/31245561/)]
150. Ragnedda M. *The Digital Divide*. New York: Routledge; 2015.
151. Issom DZ, Hartvigsen G, Bonacina S, Koch S, Lovis C. User-centric eHealth tool to address the psychosocial effects of sickle cell disease. *Stud Health Technol Inform* 2016;225:627-628. [Medline: [27332283](https://pubmed.ncbi.nlm.nih.gov/27332283/)]
152. oneSCDvoice. URL: <https://www.onescdvoice.com/> [accessed 2019-02-27] [WebCite Cache ID 76VMO9bsi]
153. Adaji I, Vassileva J. Persuasive Patterns in Q&A Social Networks. In: *Proceedings of the 11th International Conference on Persuasive Technology*. Cham: Springer; 2016 Presented at: PERSUASIVE'16; April 5-7, 2016; Salzburg, Austria p. 189-196. [doi: [10.1007/978-3-319-31510-2\\_16](https://doi.org/10.1007/978-3-319-31510-2_16)]
154. Hu Z, Zhang Z, Yang H, Chen Q, Zuo D. A deep learning approach for predicting the quality of online health expert question-answering services. *J Biomed Inform* 2017 Jul;71:241-253 [FREE Full text] [doi: [10.1016/j.jbi.2017.06.012](https://doi.org/10.1016/j.jbi.2017.06.012)] [Medline: [28606870](https://pubmed.ncbi.nlm.nih.gov/28606870/)]
155. Mize L, Burgett S, Xu J, Rothman J, Shah N. The use of chronic transfusions in sickle cell disease for non-stroke related indications. *Blood* 2014;124(21):4934 [FREE Full text] [doi: [10.1182/blood.v124.21.4934.4934](https://doi.org/10.1182/blood.v124.21.4934.4934)]
156. Scalia P, Durand MA, Kremer J, Faber M, Elwyn G. Online, interactive option grid patient decision aids and their effect on user preferences. *Med Decis Making* 2018 Jan;38(1):56-68. [doi: [10.1177/0272989X17734538](https://doi.org/10.1177/0272989X17734538)] [Medline: [29078054](https://pubmed.ncbi.nlm.nih.gov/29078054/)]
157. Kulandaivelu Y, Lalloo C, Ward R, Zempsky WT, Kirby-Allen M, Breakey VR, et al. Exploring the needs of adolescents with sickle cell disease to inform a digital self-management and transitional care program: qualitative study. *JMIR Pediatr Parent* 2018 Sep 25;1(2):e11058 [FREE Full text] [doi: [10.2196/11058](https://doi.org/10.2196/11058)] [Medline: [31518307](https://pubmed.ncbi.nlm.nih.gov/31518307/)]
158. Yusop N, Zowghi D, Lowe D. The impacts of non-functional requirements in web system projects. *Int J Value Chain Manag* 2008;2(1):18. [doi: [10.1504/ijvcm.2008.016116](https://doi.org/10.1504/ijvcm.2008.016116)]
159. Hamilton JJ, Hopkins RS. Perma.: Center for Disease Control and Prevention Using Technologies for Data Collection and Management URL: <https://perma.cc/8J62-RPGE> [accessed 2019-02-19]



160. Li X, Dunn J, Salins D, Zhou G, Zhou W, Rose SM, et al. Digital Health: tracking physiomes and activity using wearable biosensors reveals useful health-related information. *PLoS Biol* 2017 Jan;15(1):e2001402 [FREE Full text] [doi: [10.1371/journal.pbio.2001402](https://doi.org/10.1371/journal.pbio.2001402)] [Medline: [28081144](https://pubmed.ncbi.nlm.nih.gov/28081144/)]
161. Ancker JS, Witteman HO, Hafeez B, Provencher T, van de Graaf M, Wei E. 'You Get Reminded You're a Sick Person': personal data tracking and patients with multiple chronic conditions. *J Med Internet Res* 2015 Aug 19;17(8):e202 [FREE Full text] [doi: [10.2196/jmir.4209](https://doi.org/10.2196/jmir.4209)] [Medline: [26290186](https://pubmed.ncbi.nlm.nih.gov/26290186/)]
162. Halko S, Kientz JA. Personality and persuasive technology: an exploratory study on health-promoting mobile applications. In: Ploug T, Hasle P, Oinas-Kukkonen H, editors. *Persuasive Technology*. Berlin, Heidelberg: Springer; 2010:150-161.
163. Chiu MC, Chang SP, Chang YC, Chu HH, Chen CH, Hsiao FH, et al. Playful Bottle: A Mobile Social Persuasion System to Motivate Healthy Water Intake. In: *Proceedings of the 11th international conference on Ubiquitous computing. USA: ACM; 2009 Presented at: Ubicomp'09; September 30 - October 3, 2009; Orlando, Florida p. 185-194.* [doi: [10.1145/1620545.1620574](https://doi.org/10.1145/1620545.1620574)]
164. Elsherif M, Hassan MU, Yetisen AK, Butt H. Wearable contact lens biosensors for continuous glucose monitoring using smartphones. *ACS Nano* 2018 Jun 26;12(6):5452-5462 [FREE Full text] [doi: [10.1021/acsnano.8b00829](https://doi.org/10.1021/acsnano.8b00829)] [Medline: [29750502](https://pubmed.ncbi.nlm.nih.gov/29750502/)]
165. Motiv Ring. URL: <https://mymotiv.com/> [accessed 2019-02-20]
166. Stein N, Brooks K. A fully automated conversational artificial intelligence for weight loss: longitudinal observational study among overweight and obese adults. *JMIR Diabetes* 2017 Nov 1;2(2):e28 [FREE Full text] [doi: [10.2196/diabetes.8590](https://doi.org/10.2196/diabetes.8590)] [Medline: [30291087](https://pubmed.ncbi.nlm.nih.gov/30291087/)]
167. Fulmer R, Joerin A, Gentile B, Lakerink L, Rauws M. Using psychological artificial intelligence (Tess) to relieve symptoms of depression and anxiety: randomized controlled trial. *JMIR Ment Health* 2018 Dec 13;5(4):e64 [FREE Full text] [doi: [10.2196/mental.9782](https://doi.org/10.2196/mental.9782)] [Medline: [30545815](https://pubmed.ncbi.nlm.nih.gov/30545815/)]
168. Macmillan Dictionary. Shareable (adjective): Definition and Synonyms URL: <https://www.macmillandictionary.com/dictionary/british/shareable> [accessed 2019-02-27] [WebCite Cache ID 76VLwj70x]
169. Hartzler A, Pratt W. Managing the personal side of health: how patient expertise differs from the expertise of clinicians. *J Med Internet Res* 2011 Aug 16;13(3):e62 [FREE Full text] [doi: [10.2196/jmir.1728](https://doi.org/10.2196/jmir.1728)] [Medline: [21846635](https://pubmed.ncbi.nlm.nih.gov/21846635/)]
170. Elaheebocus SM, Weal M, Morrison L, Yardley L. Peer-based social media features in behavior change interventions: systematic review. *J Med Internet Res* 2018 Feb 22;20(2):e20 [FREE Full text] [doi: [10.2196/jmir.8342](https://doi.org/10.2196/jmir.8342)] [Medline: [29472174](https://pubmed.ncbi.nlm.nih.gov/29472174/)]
171. Lochmüller H, Badowska DM, Thompson R, Knoers NV, Aartsma-Rus A, Gut I, RD-Connect consortium, NeurOmics consortium, EUREnOmics consortium. RD-Connect, NeurOmics and EUREnOmics: collaborative European initiative for rare diseases. *Eur J Hum Genet* 2018 Jun;26(6):778-785 [FREE Full text] [doi: [10.1038/s41431-018-0115-5](https://doi.org/10.1038/s41431-018-0115-5)] [Medline: [29487416](https://pubmed.ncbi.nlm.nih.gov/29487416/)]
172. Vasilescu B, Serebrenik A, Devanbu P, Filkov V. How Social Q&A Sites Are Changing Knowledge Sharing in Open Source Software Communities. In: *Proceedings of the 17th ACM Conference on Computer Supported Cooperative Work & Social Computing*. New York, NY: ACM; 2014 Presented at: CSCW'14; February 15 - 19, 2014; Baltimore, Maryland, USA p. 342-354 URL: <https://doi.org/10.1145/2531602.2531659> [doi: [10.1145/2531602.2531659](https://doi.org/10.1145/2531602.2531659)]
173. Arora S, Yttri J, Nilse W. Privacy and Security in Mobile Health (mHealth) Research. *Alcohol Res* 2014;36(1):143-151 [FREE Full text] [Medline: [26259009](https://pubmed.ncbi.nlm.nih.gov/26259009/)]
174. Zhao J, Freeman B, Li M. Can mobile phone apps influence people's health behavior change? An evidence review. *J Med Internet Res* 2016 Oct 31;18(11):e287 [FREE Full text] [doi: [10.2196/jmir.5692](https://doi.org/10.2196/jmir.5692)] [Medline: [27806926](https://pubmed.ncbi.nlm.nih.gov/27806926/)]
175. Cohen IG, Mello MM. HIPAA and Protecting Health Information in the 21st Century. *J Am Med Assoc* 2018 Jul 17;320(3):231-232. [doi: [10.1001/jama.2018.5630](https://doi.org/10.1001/jama.2018.5630)] [Medline: [29800120](https://pubmed.ncbi.nlm.nih.gov/29800120/)]
176. Pryv. Pryv Enables Businesses to Manage Privacy & Personal Data. URL: <https://pryv.com/> [accessed 2019-12-26]
177. Hafen E. Personal data cooperatives – a new data governance framework for data donations and precision health. In: Krutzinna J, Floridi L, editors. *The Ethics of Medical Data Donation*. Cham: Springer International Publishing; 2019:141-149.
178. Gaudet-Blavignac C, Foufi V, Wehrli E, Lovis C. De-identification of French medical narratives. *Swiss Med Informatics* 2018;34:00417. [doi: [10.4414/smi.34.00417](https://doi.org/10.4414/smi.34.00417)]
179. Morrison LG, Hargood C, Pejovic V, Geraghty AW, Lloyd S, Goodman N, et al. The effect of timing and frequency of push notifications on usage of a smartphone-based stress management intervention: an exploratory trial. *PLoS One* 2017;12(1):e0169162 [FREE Full text] [doi: [10.1371/journal.pone.0169162](https://doi.org/10.1371/journal.pone.0169162)] [Medline: [28046034](https://pubmed.ncbi.nlm.nih.gov/28046034/)]
180. Bidargaddi N, Almirall D, Murphy S, Nahum-Shani I, Kovalcik M, Pituch T, et al. To Prompt or Not to Prompt? A microrandomized trial of time-varying push notifications to increase proximal engagement with a mobile health app. *JMIR Mhealth Uhealth* 2018 Nov 29;6(11):e10123 [FREE Full text] [doi: [10.2196/10123](https://doi.org/10.2196/10123)] [Medline: [30497999](https://pubmed.ncbi.nlm.nih.gov/30497999/)]
181. Mathews SC, McShea MJ, Hanley CL, Ravitz A, Labrique AB, Cohen AB. Digital health: a path to validation. *NPJ Digit Med* 2019;2:38 [FREE Full text] [doi: [10.1038/s41746-019-0111-3](https://doi.org/10.1038/s41746-019-0111-3)] [Medline: [31304384](https://pubmed.ncbi.nlm.nih.gov/31304384/)]
182. Boudreaux ED, Waring ME, Hayes RB, Sadasivam RS, Mullen S, Pagoto S. Evaluating and selecting mobile health apps: strategies for healthcare providers and healthcare organizations. *Transl Behav Med* 2014 Dec;4(4):363-371 [FREE Full text] [doi: [10.1007/s13142-014-0293-9](https://doi.org/10.1007/s13142-014-0293-9)] [Medline: [25584085](https://pubmed.ncbi.nlm.nih.gov/25584085/)]

183. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. *J Adv Nurs* 2000 Oct;32(4):1008-1015. [Medline: [11095242](#)]
184. Garvelink MM, Ter Kuile MM, Louwé LA, Hilders CG, Stiggelbout AM. A Delphi consensus study among patients and clinicians in the Netherlands on the procedure of informing young breast cancer patients about Fertility Preservation. *Acta Oncol* 2012 Nov;51(8):1062-1069. [doi: [10.3109/0284186X.2012.702927](#)] [Medline: [23050612](#)]
185. Miller S, Ainsworth B, Yardley L, Milton A, Weal M, Smith P, et al. A Framework for Analyzing and Measuring Usage and Engagement Data (AMUsED) in Digital Interventions: Viewpoint. *J Med Internet Res* 2019 Feb 15;21(2):e10966 [[FREE Full text](#)] [doi: [10.2196/10966](#)] [Medline: [30767905](#)]

## Abbreviations

**BCW:** behavior change wheel  
**COM-B:** capability, opportunity, motivation, and behavior  
**DIY:** Do It Yourself  
**ePtDA:** electronic patient decision aid  
**FR:** functional requirement  
**mHealth:** mobile health  
**NFR:** nonfunctional requirement  
**SCD:** sickle cell disease  
**VOC:** vaso-occlusive pain crisis

*Edited by G Eysenbach; submitted 04.05.19; peer-reviewed by N Shah, C Fincham, C Duignan; comments to author 28.05.19; revised version received 29.12.19; accepted 24.01.20; published 24.03.20.*

*Please cite as:*

Issom DZ, Henriksen A, Woldaregay AZ, Rochat J, Lovis C, Hartvigsen G  
*Factors Influencing Motivation and Engagement in Mobile Health Among Patients With Sickle Cell Disease in Low-Prevalence, High-Income Countries: Qualitative Exploration of Patient Requirements*  
*JMIR Hum Factors* 2020;7(1):e14599  
URL: <http://humanfactors.jmir.org/2020/1/e14599/>  
doi: [10.2196/14599](#)  
PMID: [32207692](#)

©David-Zacharie Issom, André Henriksen, Ashenafi Zebene Woldaregay, Jessica Rochat, Christian Lovis, Gunnar Hartvigsen. Originally published in *JMIR Human Factors* (<http://humanfactors.jmir.org>), 24.03.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Human Factors*, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# A Chatbot-Based Coaching Intervention for Adolescents to Promote Life Skills: Pilot Study

Silvia Gabrielli<sup>1\*</sup>, PhD; Silvia Rizzi<sup>1\*</sup>, MSc; Sara Carbone<sup>1\*</sup>, MSc; Valeria Donisi<sup>1\*</sup>, PhD

eHealth Unit, Fondazione Bruno Kessler, Trento, Italy

\*all authors contributed equally

**Corresponding Author:**

Silvia Gabrielli, PhD

eHealth Unit

Fondazione Bruno Kessler

Via Sommarive 18

Trento, 38123

Italy

Phone: 39 0461312477

Email: [sgabrielli@fbk.eu](mailto:sgabrielli@fbk.eu)

## Abstract

**Background:** Adolescence is a challenging period, where youth face rapid changes as well as increasing socioemotional demands and threats, such as bullying and cyberbullying. Adolescent mental health and well-being can be best supported by providing effective coaching on life skills, such as coping strategies and protective factors. Interventions that take advantage of online coaching by means of chatbots, deployed on Web or mobile technology, may be a novel and more appealing way to support positive mental health for adolescents.

**Objective:** In this pilot study, we co-designed and conducted a formative evaluation of an online, life skills coaching, chatbot intervention, inspired by the positive technology approach, to promote mental well-being in adolescence.

**Methods:** We co-designed the first life skills coaching session of the CRI (for girls) and CRIS (for boys) chatbot with 20 secondary school students in a participatory design workshop. We then conducted a formative evaluation of the entire intervention—eight sessions—with a convenience sample of 21 adolescents of both genders (mean age 14.52 years). Participants engaged with the chatbot sessions over 4 weeks and filled in an anonymous user experience questionnaire at the end of each session; responses were based on a 5-point Likert scale.

**Results:** A majority of the adolescents found the intervention useful (16/21, 76%), easy to use (19/21, 90%), and innovative (17/21, 81%). Most of the participants (15/21, 71%) liked, in particular, the video cartoons provided by the chatbot in the coaching sessions. They also thought that a session should last only 5-10 minutes (14/21, 66%) and said they would recommend the intervention to a friend (20/21, 95%).

**Conclusions:** We have presented a novel and scalable self-help intervention to deliver life skills coaching to adolescents online that is appealing to this population. This intervention can support the promotion of coping skills and mental well-being among youth.

(*JMIR Hum Factors* 2020;7(1):e16762) doi:[10.2196/16762](https://doi.org/10.2196/16762)

**KEYWORDS**

life skills; chatbots; conversational agents; mental health; participatory design; adolescence; bullying; cyberbullying; well-being intervention

## Introduction

**Background**

Adolescence is a challenging period characterized by rapid changes [1] and increasing emotional and social demands. Interventions that foster life skills, coping, and well-being are

particularly important during adolescence; virtual coaching solutions could greatly enhance delivery of these interventions in both school and out-of-school settings. The aim of this study was to co-design a life skills coaching intervention with adolescents to be delivered by a chatbot; this would be done by conducting an initial participatory design workshop followed by testing the feasibility of the whole intervention with another

convenience sample of adolescents. The life skills virtual coaching intervention was meant to be used either in out-of-school settings for individual training on life skills or in combination with school interventions on life skills provided by a human coach (ie, teacher or domain expert).

## Literature Review

Several challenges and emotional demands characterize adolescence, often affecting the mental well-being of youths. Among these, bullying and cyberbullying is recognized nowadays as a major social problem, affecting 37% of adolescents [2,3], with extensive negative consequences for the victims involved. Research has shown that adolescent bully victimization is associated with poorer school achievement [4]; lower self-esteem; and increased loneliness, depression, and anxiety [5], whose consequences persist into adulthood [6]. Interventions that foster life skills [7], coping, and well-being are particularly important during adolescence as protective and preventive strategies against the consequences of bullying and cyberbullying. Life skills include the ability to exhibit adaptive and positive behaviors that enable individuals to deal effectively with the demands, challenges, and stress of daily life [8]. Childhood and adolescence are the developmental stages during which one acquires these skills through various methods and people [9]; a positive technology approach [10,11] can support the design of such experiences in a digital format. These solutions have the potential to be highly scalable, since almost three-quarters of adolescents (73%) have a mobile phone or have access to one [12]; as well, digital interventions have been proven to be effective at changing a range of health behaviors [13]. Digital assistants or chatbots are conversational agents that can be easily used to support the delivery of educational interventions for mental health and well-being [14]. A chatbot conducts an interaction through conversation with its users by simulating humans' dialogue patterns and behaviors. However, there is still a paucity of research showing the design and effective usage of chatbot interventions for supporting mental well-being of adolescents [15].

## Methods

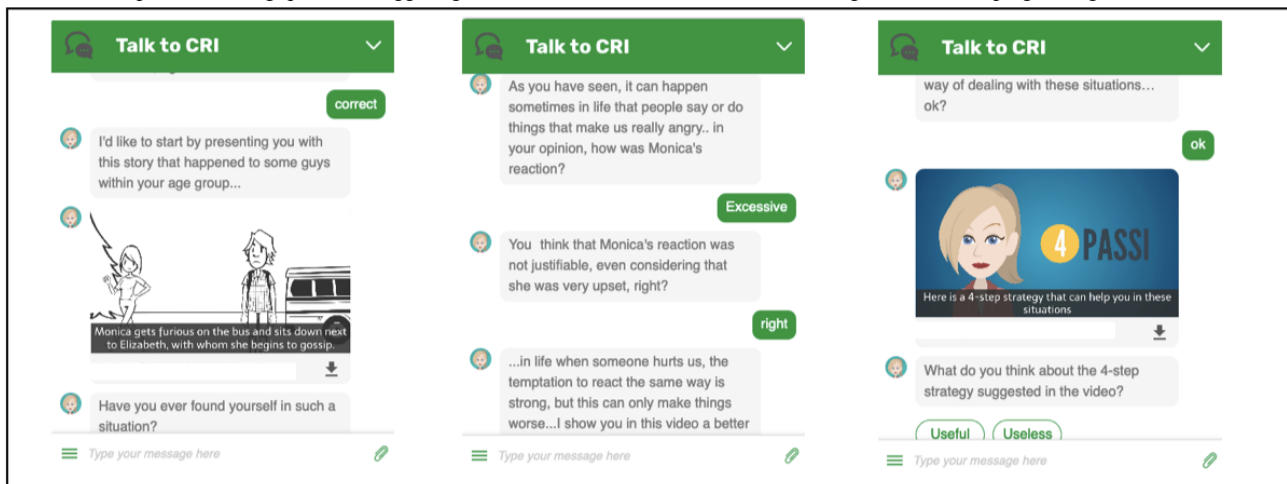
### Phase 1: Co-Design Workshop and Participants

The co-design phase of the study involved a sample of 20 adolescents (age range 14-15 years) attending a first-year class of a secondary school in Northeast Italy. A participatory design

workshop was organized and led by a research staff of four psychologists. The staff involved the students in using and commenting upon a prototyped session of the chatbot intervention to collect their needs and preferences on the following: the chatbot's look and feel, the type of content and duration of the session, their unmet expectations regarding the prototype, and suggested improvements. Participants provided signed parental consent. Discussions held during the initial co-design workshop were audio-recorded and transcribed. Qualitative data collected were analyzed using a modified version of Braun and Clarke's guidelines [16] for thematic analysis. Specifically, two members of the research team read the transcripts and independently developed categories of responses. Agreement on the proposed categories was reached through discussion.

Based on the co-design results, the research staff developed the entire life skills coaching intervention, including eight online sessions, delivered by means of a series of coaching dialogues, exercises, and video cartoons presented by the CRI (for girls) and CRIS (for boys) chatbot—the chatbot was named CRI and CRIS as abbreviated forms of the Italian names Cristina (female) and Cristiano (male), respectively. As shown in [Figure 1](#), each session starts by chatting with the CRI or CRIS chatbot, which looks like an older peer—boy or girl—of the user. The chatbot asks the user to watch a 1-2-minute video cartoon about a bullying or cyberbullying situation involving adolescents, which is relevant to the skill addressed, embedded within the conversation system. The chatbot then continues the conversation by asking questions and proposing exercises to trigger user self-reflection on how to cope and behave in such a situation. By the end of the session, the chatbot asks the user to watch another video cartoon where the CRI or CRIS coach provides advice on constructive strategies for coping well with the challenges and emotions triggered by the situation (see [Multimedia Appendix 1](#) for an example of the coaching session). Each session was designed to stimulate self-reflection on life skills and coping strategies relevant to bullying or cyberbullying situations [9], including emotional self-awareness, social awareness, interpersonal relationships, conflict resolution, assertive communication, sadness and loneliness, leadership, and positive emotions. Each session lasted between 5 and 15 minutes. To facilitate engagement, the coaching sessions were personalized according to gender; the chatbot represented a peer of the same gender—girl or boy—as the participant (see [Table 1](#)).

**Figure 1.** Screenshots of the chatbot conversation with a female user during the coaching session on conflict resolution: (a) initial video on challenging situation, (b) example of coaching questions triggering self-reflection, and (c) final video coaching the user on coping strategies.



(a)

(b)

(c)

**Table 1.** Sample content of the coaching sessions.

Life skill session	Sample of dialogue messages
Emotional self-awareness	<p>... understanding how our feelings and emotions work is the first step to feel better equipped for life and more self-confident ... have you ever thought about this?</p> <p>... we can learn how to give room to anger, to knowing it, watching it with calm and curiosity as we may watch new things. My hint is to use breathing as a means ...</p>
Social awareness	<p>Take a look at your mobile phone and your messages: which are the emoji you use the most? Which are the ones you receive most often?</p> <p>Let's exercise by playing a game! I'll show you an emotion, you guess which one it is by choosing one of three options.</p>
Interpersonal relationships	<p>Our relationships depend very much on the way we give meaning to the characteristics of people we meet. We are generally attracted to people who are similar to us, or to those we would like to be like.</p> <p>Learning to recognize and accept these traits in ourselves or others may help us to overcome prejudice and improve our relationships with others.</p>
Conflict resolution	<p>... in life when someone hurts you, you are tempted to react in the same way, but this can only make things worse ... in this video, I show you a better way of dealing with these situations ... OK?</p> <p>Often interpreting a situation is easier than just observing it in terms of facts ... but this can really help us to not be overwhelmed by negative emotions, like anger and jealousy ... do you agree?</p>
Assertive communication	<p>When you communicate in an assertive manner, your feelings are closely related to the situation you are experiencing at that time and you act constructively.</p> <p>I issue you a challenge: next time you speak with someone, pay attention to the words you are using, to the feelings you experience, to your body language ...</p>
Sadness and loneliness	<p>Sadness and loneliness are basic feelings, but very often we find it hard to express them, because in our society, especially on social networks, most people tend to be happy and smiling ... in short, it looks cooler to be happy ... right?</p> <p>Trying to change our thoughts or do something pleasurable is a good way to feel better ... try to do this in the next few days when you feel sad for any reason ...</p>
Leadership	<p>Although we often think about leaders as popular people, each of us can be a leader, by nurturing the right qualities. Watch this video to better understand the story of Matteo ...</p> <p>Being a good leader is not a trait we need to have from birth, but we can achieve it by being committed and doing our exercises! How? Watch this video ...</p>
Positive emotions	<p>We need to train our brains to see and value positive things. Let's see an example ... Try to write below at least one positive thing that happened to you (even small things, such as "a buddy was kind to me," "there is sunshine today," ...).</p> <p>The good news is that we can learn to be happy, by nurturing optimism, openness, and trust!</p>

## Phase 2: Feasibility Test Participants and Setting

A convenience sample of 21 adolescents (13/21, 62% male; 8/21, 38% female) in the age range of 12-17 years (mean 14.52) were invited to use the entire coaching intervention over 4 weeks, participating in two sessions per week. The aims of this formative and qualitative study were as follows: (1) to assess the perceived value of the coaching intervention for a population of adolescents having a wider age range with respect to the group involved in the co-design workshop and (2) to check the user experience with the full set of online coaching sessions in order to refine and finalize their content. Due to the focus of our study—assessing human factors of the virtual coaching experience provided—and the homogeneity of our target group, a sample size of around 20 adolescents was considered appropriate [17,18].

After providing signed parental consent, participants were instructed to access the chatbot from any preferred device by visiting a website where the coaching sessions had been published for the formative evaluation. An anonymous 10-item satisfaction questionnaire was delivered online at the end of each coaching session; a 5-point Likert scale was used to rate overall usefulness, ease of use, and the value of the program, and suggestions for improvements were provided via open-ended questions. Descriptive statistics were calculated for satisfaction items.

## Results

### Phase 1

Regarding the interaction with the prototyped session in the co-design phase, three main themes emerged. First, participants

found the educational video cartoons provided in the session to be appealing and helpful in triggering self-reflection on the challenging situation presented: “The black and white video presenting a real-life setting helped me to reflect more on myself, how I would react in that case ...” Second, participants reported that the need to type answers during the chat when replying to the chatbot’s questions helped them to reflect on their feelings and thoughts relevant to the topic, even if they knew that the chatbot was not able to understand their replies as a human being: “Even if I know that the chatbot cannot reply as a real person, since it is not able to understand everything, the fact of typing in the chat what I think about the situation helps me to reflect ...” Third, participants said that the chatbot looked like a nice, smart old friend, someone you can trust and talk with when you want to address important issues: “I like this chatbot, he looks like a boy, just a bit older than me, but not an adult; he is sensitive and very smart.”

With respect to potential improvements, participants found that some parts of the dialogue with the chatbot were a bit unclear or were missing empathy from the chatbot side: “I got confused; after a video, I don’t know what I should say to go on with the session” and “It would be great if the chatbot would reply with something more relevant and empathic to my comment.” Second, some participants reported that parts of the session were too redundant or the chatbot provided too much text that required scrolling up the chat window: “... at some points, the bot gets a bit repetitive, it repeats the same thing many times” and “When the bot sends too much text in a turn, I need to scroll up not to miss the first lines and this is a bit annoying.” Supporting quotes are displayed in [Table 2](#).

**Table 2.** Examples of participant quotes supporting the themes.

Theme	Frequency of quotes	Examples of supporting quotes
Videos support self-reflection	5	I think the video contents were more useful than written sentences. The black and white video presenting a real-life setting helped me to reflect more on myself, how I would react in that case.
Typing answers to reply to the chatbot supports self-reflection	6	I understand that the chatbot doesn’t read what I am typing for real, but this is not a problem because typing makes me think about something and this is important per se. ... even if I know that the chatbot cannot reply as a real person, since it is not able to understand everything, the fact of typing in the chat what I think about the situation helps me to reflect ...
The chatbot looks like a nice, smart, trustworthy old friend	4	I like this chatbot, he looks like a boy, just a bit older than me, but not an adult; he is sensitive and very smart. ... this chatbot is serious, since the things he talks about are important, it makes me think about something I normally do not reflect upon.
Unclear dialogue and chatbot not empathic	5	It’s not nice to write something personal ... and then the chatbot goes on without considering it ... it would be nice if he could react in a more empathic way to what I type. I got confused; after a video, I don’t know what I should say to go on with the session. It would be great if the chatbot would reply with something more relevant and empathic to my comment.
Redundancy in some sessions and the chatbot provided too much text that required scrolling up	6	At some points, the bot gets a bit repetitive, it repeats the same thing many times. When the bot sends too much text in a turn, I need to scroll up not to miss the first lines and this is a bit annoying.

## Phase 2

All 21 participants involved in the feasibility test completed the eight coaching sessions and the relevant questionnaires. For all eight sessions, on a scale of 1 (very little) to 5 (very much), the majority of participants (16/21, 76%) gave a rating of 4 or 5 in response to the question “How useful was this session for you?” Ratings were also 4 or 5 for *ease of use* (19/21, 90%) and *innovativeness* (17/21, 81%) of sessions. Participants' ratings on *usefulness* and *ease of use* for each specific session are reported in Table 3. Note that all sessions have a mean rating above 3, corresponding to the positive side of the scale, for both *usefulness* and *ease of use*.

**Table 3.** Ratings for *usefulness* and *ease of use* for the eight coaching sessions.

Coaching session	Usefulness, mean (SD) <sup>a</sup>	Ease of use, mean (SD) <sup>a</sup>
Emotional self-awareness	3.60 (0.60)	4.15 (0.45)
Social awareness	3.70 (0.66)	3.92 (0.54)
Interpersonal relationships	4.06 (0.60)	4.53 (0.64)
Conflict resolution	4.33 (0.69)	4.56 (0.71)
Assertive communication	4.14 (0.71)	4.50 (0.75)
Sadness and loneliness	3.89 (0.65)	3.98 (0.66)
Leadership	4.00 (0.66)	4.44 (0.70)
Positive emotions	3.09 (0.53)	4.58 (0.61)

<sup>a</sup>Rating scores range from 1 (very little) to 5 (very much).

## Discussion

### Principal Findings

To our knowledge, today there is still a paucity of chatbot-based interventions for life skills training and well-being promotion among adolescents, as well as a lack of data and guidelines on how to effectively design the user experience with educational chatbots for this intervention domain. However, use of Internet and digital solutions by youth is increasing worldwide, providing cost-effective opportunities for reaching this population with the delivery of self-help educational programs. Also, recent studies support our findings, showing that digital interventions based on chatbots or videogames can be highly engaging, improve well-being, and reduce stress for this population and for nonclinical populations [19-21].

The chatbot intervention that was co-designed and evaluated in this study was rather easy and fast to implement and was well-received by adolescents. The two phases of our participatory design process took into account the feedback and suggestions of an overall sample of 41 adolescents; the results reported can guide the future development of virtual coaching solutions for adolescents' training, solutions that have been found to be acceptable and appealing to use for this target user group. The deployment of educational video cartoons and dialogue-based interaction with the chatbot turned out to be very engaging and useful for self-reflecting on the challenging situations presented, making the virtual coaching sessions a very promising digital environment for experiential forms of

learning in youth. The virtual coaching experience that was designed could easily be integrated into existing school programs and interventions for bullying and cyberbullying prevention; this coaching experience could also be considered a practical way of providing out-of-school interventions for life skills training.

Regarding the design of the contents provided in the sessions, 71% (15/21) of participants reported a preference for the coaching videos and 66% (14/21) expressed a preference for having each session last between 5 and 10 minutes. Among the possible *improvements*, participants mentioned a wider range of answer options to some of the chatbot questions and suggested removing redundancy in the dialogue of the longer sessions. Regarding perceived *value*, 95% (20/21) of the participants indicated they would recommend the CRI or CRIS chatbot to a friend.

This study is limited by the participant sample size and by having been conducted only in Northeast Italy, which impacts the generalizability of our results to other countries and settings. However, mental health promotion programs for adolescents provided by a variety of delivery platforms, including digital media, are strongly recommended by public health policies in many countries and by the World Health Organization [22]. These recommendations support the international relevance of our study.

These recommendations support the international relevance of our study.

### Conclusions

In summary, this study presented the co-design and formative evaluation of a chatbot-based coaching intervention for adolescents' life skills training, which was grounded in a positive technology approach and was well-received by adolescents. Further research is needed for a more in-depth evaluation of the efficacy of this intervention in strengthening coping strategies and resilience.

A future step of this study consists of integrating our chatbot intervention on life skills into the Cyberbullying Effects Prevention (CREEP) platform for cyberbullying prevention, which will be tested for efficacy by involving approximately 200 secondary school students in Italy and France.

## Acknowledgments

The authors want to thank Anna Lavezzari for assisting in the design of the digital intervention and in data collection, as well as the students who participated in this study. This work was supported by the European Institute of Innovation and Technology (EIT) Digital project CREEP 2019 (project number: 19256).

## Authors' Contributions

SG developed the concept of the chatbot life skills intervention, designed the study, contributed to the co-design phase, conceived two life skills sessions, wrote the manuscript, prototyped the intervention, and provided guidance with the analysis of the formative study. SR contributed to the co-design phase, conceived two life skills sessions, prototyped the intervention, supported the coordination of the formative study, and proofread the manuscript. SC contributed to the co-design phase, conceived two life skills sessions, supported the formative study design, and proofread the manuscript. VD contributed to the co-design phase, conceived two life skills sessions, supported the formative study design, and proofread the manuscript.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Video of the chatbot-user interaction for the coaching session on conflict resolution.

[[MOV File , 31868 KB - humanfactors\\_v7i1e16762\\_app1.mov](#) ]

## References

1. Giedd JN. The teen brain: Insights from neuroimaging. *J Adolesc Health* 2008 Apr;42(4):335-343. [doi: [10.1016/j.jadohealth.2008.01.007](https://doi.org/10.1016/j.jadohealth.2008.01.007)] [Medline: [18346658](https://pubmed.ncbi.nlm.nih.gov/18346658/)]
2. Patchin JW. Cyberbullying Research Center. 2019 Jul 09. 2019 Cyberbullying data URL: <https://cyberbullying.org/2019-cyberbullying-data> [accessed 2020-01-06]
3. Craig W, Harel-Fisch Y, Fogel-Grinvald H, Dostaler S, Hetland J, Simons-Morton B, HBSC Violence & Injuries Prevention Focus Group, HBSC Bullying Writing Group. A cross-national profile of bullying and victimization among adolescents in 40 countries. *Int J Public Health* 2009 Sep;54 Suppl 2:216-224 [FREE Full text] [doi: [10.1007/s00038-009-5413-9](https://doi.org/10.1007/s00038-009-5413-9)] [Medline: [19623475](https://pubmed.ncbi.nlm.nih.gov/19623475/)]
4. Nakamoto J, Schwartz D. Is peer victimization associated with academic achievement? A meta-analytic review. *Soc Dev* 2010 Mar 15;19(2):221-242. [doi: [10.1111/j.1467-9507.2009.00539.x](https://doi.org/10.1111/j.1467-9507.2009.00539.x)]
5. Hawker DS, Boulton MJ. Twenty years' research on peer victimization and psychosocial maladjustment: A meta-analytic review of cross-sectional studies. *J Child Psychol Psychiatry* 2000 May;41(4):441-455. [Medline: [10836674](https://pubmed.ncbi.nlm.nih.gov/10836674/)]
6. Copeland WE, Wolke D, Angold A, Costello EJ. Adult psychiatric outcomes of bullying and being bullied by peers in childhood and adolescence. *JAMA Psychiatry* 2013 Apr;70(4):419-426 [FREE Full text] [doi: [10.1001/jamapsychiatry.2013.504](https://doi.org/10.1001/jamapsychiatry.2013.504)] [Medline: [23426798](https://pubmed.ncbi.nlm.nih.gov/23426798/)]
7. Botvin G. J. In: *Life Skills Training*. Princeton, NJ:: Princeton Health Press; 2000.
8. Birrell Weisen R, Orley J, Evans V, Lee J, Sprunger B, Pellaux D, World Health Organization. Division of Mental Health. *Life Skills Education for Children and Adolescents in Schools*. Pt. 1, Introduction to Life Skills for Psychosocial Competence. Pt. 2, Guidelines to Facilitate the Development and Implementation of Life Skills Programmes, 2nd revision. Geneva, Switzerland: World Health Organization; 1997. URL: [https://apps.who.int/iris/bitstream/handle/10665/63552/WHO\\_MNH\\_PSF\\_93.7A\\_Rev.2.pdf?sequence=1&isAllowed=y](https://apps.who.int/iris/bitstream/handle/10665/63552/WHO_MNH_PSF_93.7A_Rev.2.pdf?sequence=1&isAllowed=y) [accessed 2020-01-06]
9. Srikala B, Kishore KK. Empowering adolescents with life skills education in schools - School mental health program: Does it work? *Indian J Psychiatry* 2010 Oct;52(4):344-349 [FREE Full text] [doi: [10.4103/0019-5545.74310](https://doi.org/10.4103/0019-5545.74310)] [Medline: [21267369](https://pubmed.ncbi.nlm.nih.gov/21267369/)]
10. Botella C, Riva G, Gaggioli A, Wiederhold BK, Alcaniz M, Banos RM. The present and future of positive technologies. *Cyberpsychol Behav Soc Netw* 2012;15(2):78-84. [doi: [10.1089/cyber.2011.0140](https://doi.org/10.1089/cyber.2011.0140)]
11. Riva G, Baños RM, Botella C, Wiederhold BK, Gaggioli A. Positive technology: Using interactive technologies to promote positive functioning. *Cyberpsychol Behav Soc Netw* 2012 Feb;15(2):69-77. [doi: [10.1089/cyber.2011.0139](https://doi.org/10.1089/cyber.2011.0139)] [Medline: [22149077](https://pubmed.ncbi.nlm.nih.gov/22149077/)]
12. Lenhart A. Pew Research Center. Washington, DC: Pew Internet & American Life Project; 2015 Apr 09. Teens, social media & technology: Overview 2015 URL: <https://www.pewresearch.org/internet/2015/04/09/teens-social-media-technology-2015/> [accessed 2020-01-06]
13. Free C, Phillips G, Watson L, Galli L, Felix L, Edwards P, et al. The effectiveness of mobile-health technologies to improve health care service delivery processes: A systematic review and meta-analysis. *PLoS Med* 2013;10(1):e1001363 [FREE Full text] [doi: [10.1371/journal.pmed.1001363](https://doi.org/10.1371/journal.pmed.1001363)] [Medline: [23458994](https://pubmed.ncbi.nlm.nih.gov/23458994/)]



14. Fitzpatrick KK, Darcy A, Vierhile M. Delivering cognitive behavior therapy to young adults with symptoms of depression and anxiety using a fully automated conversational agent (Woebot): A randomized controlled trial. *JMIR Ment Health* 2017 Jun 06;4(2):e19 [FREE Full text] [doi: [10.2196/mental.7785](https://doi.org/10.2196/mental.7785)] [Medline: [28588005](https://pubmed.ncbi.nlm.nih.gov/28588005/)]
15. Pereira J, Díaz Ó. Using health chatbots for behavior change: A mapping study. *J Med Syst* 2019 Apr 04;43(5):135. [doi: [10.1007/s10916-019-1237-1](https://doi.org/10.1007/s10916-019-1237-1)] [Medline: [30949846](https://pubmed.ncbi.nlm.nih.gov/30949846/)]
16. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006 Jan;3(2):77-101. [doi: [10.1191/1478088706qp063oa](https://doi.org/10.1191/1478088706qp063oa)]
17. Faulkner L. Beyond the five-user assumption: Benefits of increased sample sizes in usability testing. *Behav Res Methods Instrum Comput* 2003 Aug;35(3):379-383. [doi: [10.3758/bf03195514](https://doi.org/10.3758/bf03195514)] [Medline: [14587545](https://pubmed.ncbi.nlm.nih.gov/14587545/)]
18. Boddy CR. Sample size for qualitative research. *Qual Mark Res* 2016 Sep 12;19(4):426-432. [doi: [10.1108/qmr-06-2016-0053](https://doi.org/10.1108/qmr-06-2016-0053)]
19. Ly KH, Ly A, Andersson G. A fully automated conversational agent for promoting mental well-being: A pilot RCT using mixed methods. *Internet Interv* 2017 Dec;10:39-46 [FREE Full text] [doi: [10.1016/j.invent.2017.10.002](https://doi.org/10.1016/j.invent.2017.10.002)] [Medline: [30135751](https://pubmed.ncbi.nlm.nih.gov/30135751/)]
20. Carissoli C, Villani D. Can videogames be used to promote emotional intelligence in teenagers? Results from EmotivaMente, a school program. *Games Health J* 2019 Dec;8(6):407-413. [doi: [10.1089/g4h.2018.0148](https://doi.org/10.1089/g4h.2018.0148)] [Medline: [31241356](https://pubmed.ncbi.nlm.nih.gov/31241356/)]
21. Young Oh E, Song D, Hong H. Interactive computing technology in anti-bullying education: The effects of conversation-bot's role on K-12 students' attitude change toward bullying problems. *J Educ Comput Res* 2019 Apr 10;073563311983917. [doi: [10.1177/0735633119839177](https://doi.org/10.1177/0735633119839177)]
22. World Health Organization. 2019 Oct 23. Adolescent mental health URL: <https://www.who.int/news-room/fact-sheets/detail/adolescent-mental-health> [accessed 2020-01-06]

## Abbreviations

**CREEP:** Cyberbullying Effects Prevention

**EIT:** European Institute of Innovation and Technology

*Edited by A Kushniruk; submitted 22.10.19; peer-reviewed by E Borycki, D Chrimes, JT te Gussinklo, M Mulvenna; comments to author 11.11.19; revised version received 13.11.19; accepted 17.11.19; published 14.02.20.*

*Please cite as:*

*Gabrielli S, Rizzi S, Carbone S, Donisi V*

*A Chatbot-Based Coaching Intervention for Adolescents to Promote Life Skills: Pilot Study*

*JMIR Hum Factors* 2020;7(1):e16762

URL: <http://humanfactors.jmir.org/2020/1/e16762/>

doi: [10.2196/16762](https://doi.org/10.2196/16762)

PMID: [32130128](https://pubmed.ncbi.nlm.nih.gov/32130128/)

©Silvia Gabrielli, Silvia Rizzi, Sara Carbone, Valeria Donisi. Originally published in *JMIR Human Factors* (<http://humanfactors.jmir.org>), 14.02.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Human Factors*, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# Engagement and Usability of a Cognitive Behavioral Therapy Mobile App Compared With Web-Based Cognitive Behavioral Therapy Among College Students: Randomized Heuristic Trial

Saptarshi Purkayastha<sup>1</sup>, PhD; Siva Abhishek Addepally<sup>1</sup>, PharmD, MS; Sherri Bucher<sup>2</sup>, PhD

<sup>1</sup>Indiana University - Purdue University Indianapolis, Indianapolis, IN, United States

<sup>2</sup>Indiana University School of Medicine, Indianapolis, IN, United States

**Corresponding Author:**

Saptarshi Purkayastha, PhD

Indiana University - Purdue University Indianapolis

719 Indiana Avenue

WK 119

Indianapolis, IN,

United States

Phone: 1 3172740439

Email: [saptpurk@iupui.edu](mailto:saptpurk@iupui.edu)

## Abstract

**Background:** Recent evidence in mobile health has demonstrated that, in some cases, apps are an effective way to improve health care delivery. Health care interventions delivered via mobile technology have demonstrated both practicality and affordability. Lately, cognitive behavioral therapy (CBT) interventions delivered over the internet have also shown a meaningful impact on patients with anxiety and depression.

**Objective:** Given the growing proliferation of smartphones and the trust in apps to support improved health behaviors and outcomes, we were interested in comparing a mobile app with Web-based methods for the delivery of CBT. This study aimed to compare the usability of a CBT mobile app called MoodTrainer with an evidence-based website called MoodGYM.

**Methods:** We used convenience sampling to recruit 30 students from a large Midwestern university and randomly assigned them to either the MoodGYM or MoodTrainer user group. The trial period ran for 2 weeks, after which the students completed a self-assessment survey based on Nielsen heuristics. Statistical analysis was performed to compare the survey results from the 2 groups. We also compared the number of modules attempted or completed and the time spent on CBT strategies.

**Results:** The results indicate that the MoodTrainer app received a higher usability score when compared with MoodGYM. Overall, 87% (13/15) of the participants felt that it was easy to navigate through the MoodTrainer app compared with 80% (12/15) of the MoodGYM participants. All MoodTrainer participants agreed that the app was easy to use and did not require any external assistance, whereas only 67% (10/15) had the same opinion for MoodGYM. Furthermore, 67% (10/15) of the MoodTrainer participants found that the navigation controls were easy to locate compared with 80% (12/15) of the MoodGYM participants. MoodTrainer users, on average, completed 2.5 modules compared with 1 module completed by MoodGYM users.

**Conclusions:** As among the first studies to directly compare the usability of a mobile app-based CBT with smartphone-specific features against a Web-based CBT, there is an opportunity for app-based CBT as, at least in our limited trial, it was more usable and engaging. The study was limited to evaluate usability only and not the clinical effectiveness of the app.

(*JMIR Hum Factors* 2020;7(1):e14146) doi:[10.2196/14146](https://doi.org/10.2196/14146)

**KEYWORDS**

cognitive behavioral therapy; mHealth; mental health; heuristics; usability

## Introduction

### The Need for Digital Interventions in Mental Health

According to the World Health Organization, depression is a widespread chronic mental health issue, affecting over 350 million individuals globally [1]. About 16.1 million adults over the age of 18 years in the United States had at least one depressive episode in the past year [2]. Globally, between 2011 and 2030, the impact of depression on the aggregate economic output is estimated to be around US \$5.36 trillion [1]. The reduction of costs related to diagnosis, management, and treatment of mental health issues, including depression, is a crucial target for global health system partners [3-6].

Prevalent methods for the management of depression include the use of both pharmacological (medication) and nonpharmacological (psychotherapy) interventions. The use of antidepressant medications is common and cost-effective; however, its clinical efficacy can be impacted by poor patient compliance to the medication regimens, which often have undesirable side effects (eg, weight gain) or take up to 6 weeks of use, upon initiation, to begin making a measurable impact on depressive symptoms [7-10]. Thus, current literature suggests supplementing pharmacological interventions with cognitive behavioral therapy (CBT) as the most effective combination treatment for the management of major depression in most patients [11,12]. Some studies have suggested that CBT, on its own, is as effective as antidepressant medications for depression [8].

Typically, a psychotherapist delivers CBT during in-person therapeutic encounters at regular intervals. During these interactions, the psychotherapist typically assesses the past and current psychological status of the client using validated instruments such as questionnaires. CBT can provide long-term protection against the relapse of depression [13], but at the same time, this is highly dependent on the skills of the psychotherapist delivering the CBT [14]. Training therapists to deliver effective CBT is expensive and can take 2 to 6 years of additional training [15]. The lack of resources to provide such training and the lack of availability of trained professionals are the most critical limiting factors restricting the widespread uptake of this type of therapy [16,17]. Thus, there is much interest in Web-based CBT as it may remove the above-mentioned barriers [18-21].

### Mobile Apps for Delivering Mental Health Interventions

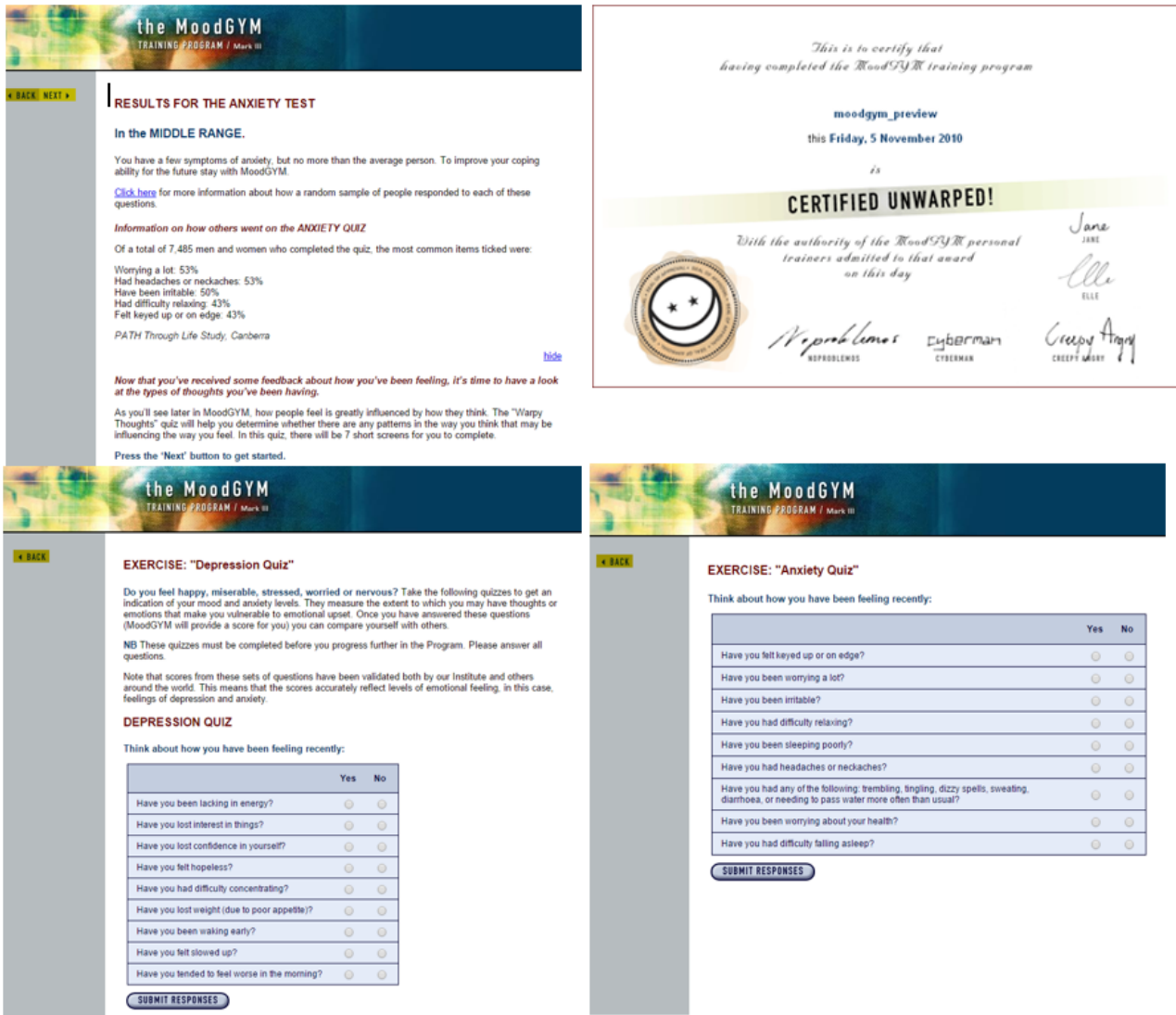
Globally, health systems need effective and scalable methods that are cost-effective for delivering CBT to patients suffering from depression. Mobile health (mHealth) is rapidly gaining importance and acceptance and thus presents an exciting opportunity for delivering mental health care [22]. Recent research has found that we can attribute a user's personality to the way they use their mobile phones [23]. This makes us wonder whether monitoring the user's real-time data and activity [24,25] in a self-directed CBT can be a supplement to the clinical interventions as depressive adults might show unique traits in mobile phone usage. Few researchers have claimed that CBT delivered via an mHealth app is equally valid and also convenient [26,27]. By tracking the patient's behavior using mHealth apps, health care providers can gain great insights regarding the patient's condition and their response to psychotherapy [28]. More recently, CBT for patients with incurable cancers showed anxiety and mood improvements [29]. A systematic review by Rathbone et al on the efficacy of mHealth apps for CBT suggested collaboration, which is our starting point with the use of existing validated evidence [30]. As part of our research in this study, we developed a mobile app that included real-time user location, motion, and voice pitch tracking. However, because of the lack of accuracy of sensors across different smartphones, we had to disable those features as we have reported elsewhere [31].

## Methods

### MoodGYM—An Interactive Cognitive Behavioral Therapy Website

MoodGYM [32] is a popular, evidence-based interactive CBT website designed for the prevention, treatment, and management of depression in young people with internet access. When we conducted the study, MoodGYM was a free website, and we had access to it until March 2018. Currently, it requires an annual subscription fee for access. This website can be accessed using a computer with a standard Web browser, and it utilizes interactive and multimedia features to deliver CBT. MoodGYM requires user registration and collects basic demographics such as age group, gender, locality of residence, and the highest level of education. MoodGYM provides depression assessment scales for evaluating the progress of the user. Figure 1 contains screenshots of the version of MoodGYM used in this study.

Figure 1. Screenshot of the MoodGYM user interface.



**MoodTrainer—A Smartphone Cognitive Behavioral Therapy App**

We developed a smartphone app called MoodTrainer, inspired by MoodGYM, and incorporated all the modules that were available in the earlier version of MoodGYM. The current version of MoodGYM in its terms of use describes intellectual property rights, similar to the version we used, which allow for noncommercial use. Our adaptation of the questionnaire is from published material, with appropriate references to the original authors. Before beginning the development of our app, we requested permission from the MoodGYM team to develop a mobile app for usability research purposes. We believe that the MoodGYM content was already relevant to young adults in the US context and did not need any contextual adaptation. We developed certain smartphone-specific features such as location tracking, offline storage, reminders and notifications, voice pitch and motion tracking. The voice pitch and motion tracking were not accurate as a measure of anxiety, based on the research team’s tests (see User Interface Development). So, we eventually removed these features.

**App Development**

MoodTrainer is a cross-platform, hybrid app that utilizes Web technologies, such as HTML, Cascading Style Sheets, and JavaScript, which allow us to create packages for platforms such as Android, iPhone Operating System, and Windows [33]. We used the Android package (APK) of the app for heuristic evaluation. By using the Cordova framework [34], we leveraged smartphone Application Programming Interfaces (API) such as location tracking, offline storage, reminders, and notifications, which are smartphone-specific features that are unavailable in a Web-based CBT.

**User Interface Development**

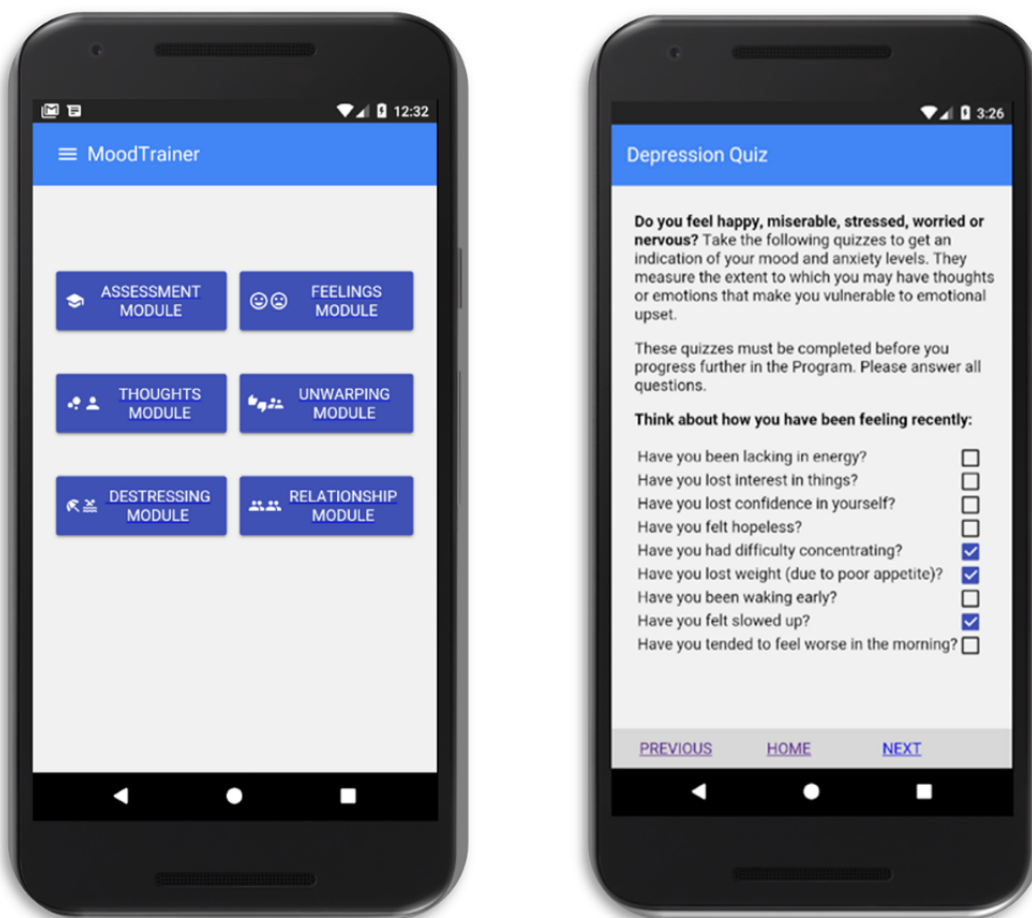
The user interface (UI) was developed in HTML5 by going through iterative cycles of prototyping, user feedback, and further development. We included a mental health expert with 8 years in practice, an informatics expert with 10 years of experience in mobile app development, and a clinically depressed student as users to provide prototyping feedback. The student was already being treated through MoodGYM and thus confirmed that it could be used in our context. Overall, we conducted 63 prototyping cycles before finalizing the version used in the heuristic evaluation. We initially used JQuery Mobile

to design the app's UI. Although the app was fast and responsive, preliminary UI testing with a small group of users made us rethink our app's usability.

On the basis of this early feedback, we reimplemented the app using Polymer components that use Material Design principles [35], as can be seen in Figure 2. Material Design is a design language developed by Google for a unified interface across platforms. Material Design utilizes grid-based layouts, responsive transitions, and animations, and it utilizes lights and shadows to showcase depth [36]. By using Polymer components, we got the native Android look and feel in the app and also a design language that was familiar to the users.

We added Google Analytics (GA) to track the time spent by the user on the app, the number of screens viewed per session, session duration, app crashes, and page exits. Our app's APK was compiled using CrossWalk [35], a Cordova plugin that bundles Chromium WebView [37] along with the app to provide the app with the up-to-date features on any device. The WebView bundled by CrossWalk facilitates the use of all device APIs and enables the utilization of all the HTML5 features on older Android phones. Despite these advantages, the plugin increases the APK size.

**Figure 2.** User interface of MoodTrainer.



### Cognitive Behavioral Therapy Delivered by MoodTrainer and MoodGYM

The CBT aspect of MoodTrainer uses 6 modules, with each module focusing on a specific type of intervention. Previously

Literature suggests that smartphone-specific features were not utilized in any of the previous apps used for the management of depression [38]. Following are the innovations that differentiate MoodTrainer from other available CBT apps:

- Tracking user location has never been implemented in a CBT app before, as far as we know. The user location is captured at 1-min intervals. The user can see the location history on a map from the user profile page. This location tracking is not shared with anyone by default but could be shared with the provider if the user allows it. Patients with depressive episodes usually spend time alone in secluded places with many risks. Our app's location tracking feature is a reminder to the user or, when shared with a clinician, is a potential data point in decision making.
- Notifications and reminders have been combined with evidence-based modules in MoodTrainer. Users can set reminders from the app if their mood scores are lower than the baseline. We also pushed notifications to users if they did not complete a module, nudging them to go through the mood training.

mentioned evidence from MoodGYM suggests that the sequential format of the modules helps to improve depressive mood [39]. The modules available in the app, in the order of appearance, are as follows:

- **Assessment module:** The primary purpose of this module is to identify the severity of depression and anxiety symptoms experienced by the users before starting the CBT program.
- **Feelings module:** This module has tasks which make the users aware of their feelings and how they respond to routine life events. Later, this module associates moods with feelings.
- **Thoughts module:** This module provides examples of different negative thoughts. Later, in a series of activities, the user is asked to identify the thoughts that they usually experience.
- **Unwarping module:** This module identifies the negative thoughts experienced by the user, and the evidence-based mental health survey instruments guide the user to counter these with positive thoughts.
- **Destressing module:** The main goal of this module is to equip the user with destressing strategies and also help the users in applying these strategies in real-life scenarios.
- **Relationship module:** The final module focuses on building relationships and suggests the user to look at the bright side in a relation. This module also analyzes the users' relation with their parents and helps them in having a better relationship with their parents.

In addition to these modules, CBT also provides scales to evaluate the user's depression and anxiety status using Goldberg Depression and Anxiety Scales [40]. These scales are designed to aid general physicians and nonpsychiatrists in detecting depression. These scales have a specificity of 91% and a sensitivity of 86% [40]. The CBT aspect also helps in identifying dysfunctional thoughts with the help of warped thoughts scale. Parslow et al developed this scale and implemented it in MoodGYM [41]. This is a 20-item scale that covers 7 different areas such as the need for approval, love, influence on others, the need to succeed, perfectionism, external requirements for happiness, and expectations of rights. Research suggests that the warped thoughts scores correlate with the levels of depression and anxiety symptoms [41]. In addition to these scales, there are other evidence-based questionnaires integrated into the CBT modules such as (1) the Life Whacks Questionnaire [42], (2) the Measure of Parenting Style [43], and (3) the Pleasant Events Schedule [44].

### Research Design

The study received ethics approval from the institutional review board of Indiana University, with protocol number 1708867512. We used a 2-arm randomized trial design, where the enrolling participants are randomized into 2 groups—the Web-based CBT group or the mobile app-based CBT group.

### Participants

The mobile app for CBT is targeted for the management of depression in adolescents and young adults. Although it might be beneficial to exactly target clinically depressed adolescents and young adults, it was not feasible for this study, as that would require Food and Drug Administration approval for 510(k), a US market approval rule, as a mobile medical app and would require the trial to be conducted under the supervision of a mental health practitioner. The student population from which we selected our participants matched the target audience age group, including the 18+ years requirement by the MoodGYM instruments. As CBT aims to improve mood and reduce anxiety, we conducted the trial during the week of final exams, which is, as shown in previous studies, usually the time when students experience anxiety for 2 to 4 weeks [45,46]. This also informed our trial study period of 2 weeks [47].

### Recruitment Strategy and Randomization

The participants in the study were recruited by convenience sampling. We approached the participants in usual congregation areas such as waiting areas, cafeterias, and designated workstations. During the initial meeting, the participants were provided with the study details and recruited if they fulfilled the inclusion criteria and consented to participate in the study. The inclusion criteria were as follows:

- The participants should be enrolled as students at Indiana University at the time of recruitment.
- The participants must be aged 18 years or above.
- The participants must own an Android smartphone.
- To mitigate risks/harm, the participants should have no history of a major depressive episode within the past 5 years.

The study participants were randomized into 2 groups, with one group receiving a link to download the app and another group receiving log-in information to the MoodGYM website. Participants were given identifiers that were used as username in MoodGYM and as GA ID in MoodTrainer. There were 15 male and 15 female subjects, with age ranging from 24 to 44 years and a median age of 32 years. All the recruited subjects were graduate students from the health informatics program and had clinical background in pharmacy, nursing, dentistry, or medicine.

### Evaluation

We collected data on the usability of MoodTrainer and MoodGYM using a heuristics survey with a 5-point Likert scale for responses based on Nielsen heuristics [48]. The heuristic characteristics which were studied are summarized in Table 1.

**Table 1.** Summary of Nielsen heuristics evaluated in the study.

Heuristics	Aspects evaluated
Visibility of system status	This category evaluates if the user can view all the modules and access the different features present in the app.
Match between the system and the real world	This heuristic evaluates if the app can perform the task which it is expected to do.
Control and freedom	This category evaluates if the user can perform different tasks on the system and if the user has performed any unwanted task was able to recover from that without any consequences.
Consistency and standards	This heuristic evaluated if all the user interface elements of the app were consistent and if the cognitive behavioral therapy aspect of the app was straightforward.
Error prevention	This heuristic evaluated if the user had experienced any of the error prevention features and whether they helped the user in preventing errors.
Recognition rather than recall	It is better to suggest what action should be performed next rather than allowing the user to think what the next action should be. This can be achieved by having all the navigation options visible to the user.
Flexibility and ease of use	This heuristic evaluated if the app's users were able to access the app with minimal or no external assistance.
Aesthetic and minimalistic design	This heuristic evaluated if the app's design is minimal and the functionality that supports the task and goals of that interface.
Help users recognize, diagnose, and recover from errors	Errors are a common phenomenon when a user navigates through an app or an interface, and this heuristic evaluated if the app helped the users in recognizing and recovering from errors.
Help and documentation	This is a very important aspect of any user interface. If the user has reached a point where he is no longer coherent with what is going on in the app, the user interface must provide enough information to put the user back in place.

## Procedures

We evaluated the feasibility and acceptability of the mobile CBT using a heuristic evaluation survey and evaluated the user engagement through GA in MoodTrainer and modules completed in MoodGYM. At the end of the 2 weeks, participants received an email with the heuristic evaluation that was developed using REDCap [49]. This survey included questions regarding the features of the mobile phone-based and the Web-based CBT and the self-reported usage of the interventions. The participants were also asked to submit the summarized scores of both the depression and anxiety scales present in the app using the settings page available in the app. These data included details about when the form was completed, and scores were reported anonymously to a research-hosted District Health Information Software v2 instance, a popular open-source health management information system.

## Results

### The MoodTrainer Mobile App

The MoodTrainer app was designed with a focus on improving user engagement. The app provides location-based feedback and visual feedback of the progress of the user's CBT module. The progress visualization of MoodTrainer was developed using Chart.js, a JavaScript library for interactive visualization. On the basis of the scores generated by the CBT scales, a chart was generated to indicate the user's progress across different modules.

Providing location feedback is one of our main innovations, a feature never implemented in a CBT app before. This feature captures the location of the user using the native device API at regular time intervals and displays it to the user on a map. Google Maps API was used to generate a map and create markers of the various locations where the user had been in the past 24 hours. On the basis of this, the user will be able to get appropriate feedback if they are spending more time in an isolated place. Initially, we planned to build a motion-sensing feature using the device's accelerometer to detect agitations or violent movements. However, integrating this feature did not work as anticipated and had to be removed from the final version of the app. MoodTrainer also provides interactive feedback to the users regarding their performance across different CBT modules. These unique features of MoodTrainer ensure that the user is constantly engaged with the app. The level of real-time feedback provided by MoodTrainer is unique and has not been implemented previously in a CBT. The literature suggests that smartphone-specific features were not utilized in any of the previous apps that were designed for the management of depression [50].

### Heuristic Evaluation of MoodTrainer and MoodGYM

The participants were given these applications for 2 weeks to use, and at the end of the 2-week period, the participants were provided with Nielsen heuristic evaluation survey. The results of the survey are as given in Table 2, which summarizes the responses of the heuristic evaluation survey respondents who responded *Yes* and Fisher exact test results for the responses.

**Table 2.** Summary of the responses and the statistics of the heuristic evaluation survey.

Heuristic and question	MoodTrainer (n=15)	MoodGYM (n=15)	P value (2-tailed)
<b>Visibility of system status</b>			
Is the app home screen clearly depicting the features and modules?	15	12	.22
Are the buttons clear and of appropriate size to select?	14	14	>.99
Were you able to access the location feedback provided by the app?	12	— <sup>a</sup>	—
<b>Match between the system and the real world</b>			
Do the actions provided by the system match the actions performed by user?	15	12	.22
Does the activity scheduling match a real-time experience in scheduling activities?	12	11	>.99
Are the activities for identifying warped thoughts effective enough?	14	15	>.99
Are the modules effective enough in identifying positive thoughts?	14	15	>.99
<b>User control and freedom</b>			
Is it easy to navigate across the various modules and features present in the app?	13	12	>.99
Are the navigation controls easy to locate?	10	12	.68
<b>Consistency and standards</b>			
Are all the screens consistent in format (font, color, and layout) across the application?	12	13	>.99
Are all the questions in the application easy to understand and straightforward?	12	10	.68
<b>Error prevention</b>			
Is navigation to the next screen prevented until the current task is completed?	9	13	.21
Can you randomly navigate across the modules?	10	9	.68
<b>Recognition rather than recall</b>			
Are all the buttons used relevant?	15	12	.22
Are the buttons and icons used consistent and similar across the application?	14	15	>.99
<b>Flexibility and efficacy of use</b>			
Are the buttons navigating you to the appropriate location?	15	15	>.99
Is the application easy to use and navigate with minimal or no external assistance?	15	10	.04 <sup>b</sup>
<b>Aesthetic and minimalist design</b>			
Does the alignment of input boxes and buttons look appropriately spaced?	12	15	.22
Are the colors (window/button) aesthetic to look?	10	13	.38
<b>Help users recognize, diagnose, and recover from errors</b>			
Is the error message understandable?	12	13	>.99
Does the error message provide feedback with instructions?	14	12	.59
<b>Help and documentation</b>			
Does the button provide enough help in completing the task?	15	15	>.99
Do the buttons provide enough information to reflect what they are intended to do?	15	15	>.99

<sup>a</sup>The location feedback is only available in MoodTrainer and not in MoodGYM.

<sup>b</sup>Statistically significant difference between MoodTrainer and MoodGYM.

### **Heuristic 1—Visibility of System Status**

Most participants agreed that both the interventions were clear and that the UI depicts all the features and modules of the application. However, some MoodGYM users commented that the website's home screen was not very intuitive and did not show all the features at the onset.

### **Heuristic 2—Match Between the System and the Real World**

All participants agreed that both the systems performed their intended actions. Some MoodGYM participants commented that the navigation buttons were not intuitive and that they had to click a button twice to get the desired action. Furthermore, 73% (11/15) of MoodGYM participants agreed that the activity



scheduling (activity in the CBT program) provided a real-time experience, whereas 86% (13/15) of the MoodTrainer users agreed that this activity matched the real-time experience. Overall, 93% (14/15) of MoodTrainer and 100% (15/15) of MoodGYM participants agreed that warped thought activities were effective. Both MoodGYM and MoodTrainer users agreed that the modules were effective in identifying positive thoughts.

### **Heuristic 3—User Control and Freedom**

Overall, 13 of the 15 participants responded that it was easy to navigate across the various modules present in MoodTrainer. However, 12 of the 15 participants responded that it was easy to navigate across MoodGYM, although some of them commented that they could not locate the navigation menu, and it was difficult to navigate to the previous page as the browser back would not produce the same action. Participants had to browse through a lot of pages to find the different CBT modules. Overall, 80% (12/15) of the participants agreed that the navigation controls were easy to locate for MoodGYM, and 66% (10/15) found that the navigation controls present on the MoodTrainer app were easy to locate.

### **Heuristic 4—Consistency and Standards**

Overall, 80% (12/15) of the users commented that all the screens of the MoodTrainer app were consistent with regard to font, color, and layout. One participant commented that these screens “could be more colorful and interesting” and another participant did not think that the screens were consistent. Although all MoodGYM participants agreed that the screens were consistent, some of them additionally commented that the layout could be improved for a better user experience. Furthermore, 80% (12/15) of the MoodTrainer participants agreed that all the questionnaires in the app were easy and straightforward, but some commented that they were too lengthy and required effort to understand. We believe that these validated psychological instruments are hard to understand for the uninitiated user but did not want to change for obvious clinical efficacy reasons.

### **Heuristic 5—Error Prevention**

Overall, 60% (9/15) of the MoodTrainer participants and 86% (13/15) of the MoodGYM participants agreed that the navigation to the next task was prevented until the current task was completed. Furthermore, 73% (11/15) of the MoodTrainer participants agreed that they were able to navigate across different modules compared with 60% (9/15) among the MoodGYM participants.

### **Heuristic 6—Recognition Rather Than Recall**

Overall, 100% (15/15) of the MoodTrainer and 80% (12/15) of the MoodGYM users agreed that the buttons were visible and understandable. Furthermore, 93% (14/15) of the MoodTrainer participants, compared with 100% (15/15) of the MoodGYM participants, agreed that the icons and other UI elements were similar across the application.

### **Heuristic 7—Flexibility and Efficacy of Use**

Both MoodTrainer and MoodGYM participants agreed that the buttons were navigating them to the appropriate location. Furthermore, 100% (15/15) of the MoodTrainer participants agreed that the application was easy to use with minimal or no

external assistance compared with 66% (10/15) of the MoodGYM participants.

### **Heuristic 8—Aesthetic and Minimalist Design**

Overall, 80% (12/15) of the MoodTrainer users and 100% (15/15) of the MoodGYM users felt that the input boxes and buttons were appropriately placed in the UI. Furthermore, 66% (10/15) of the MoodTrainer users and 86% (10/15) of the MoodGYM users agreed that the colors, windows, and buttons were aesthetic.

### **Heuristic 9—Help Users Recognize, Diagnose, and Recover From Errors**

Overall, 80% (12/15) and 86% (10/15) of MoodTrainer and MoodGYM users, respectively, felt that the error messages were understandable. Some commented that they did not encounter any errors. Furthermore, 53% (8/15) of MoodTrainer users agreed that the error messages guided them to recover from the error. A total of 2 participants mentioned that the error messages must be framed better. In addition, 73% (11/15) of the MoodGYM participants found that the error messages were helpful. Furthermore, 93% (14/15) and 80% (12/15) of the MoodTrainer and MoodGYM users, respectively, agreed that the error messages provided sufficient feedback with instructions.

### **Heuristic 10—Help and Documentation**

Overall, 100% (15/15) of the MoodTrainer and MoodGYM participants agreed that there was enough information provided throughout the CBT to understand the tasks that had to be performed in the apps.

We performed Fisher exact test on the survey responses to check for statistically significant differences between the MoodGYM and MoodTrainer survey responses. It was found that easy navigation (heuristic number 7) was the only feature with a statistically significant difference. However, application usage statistics showed a larger difference between MoodGYM and MoodTrainer, highlighting a difference in user engagement.

### **Application Usage Statistics**

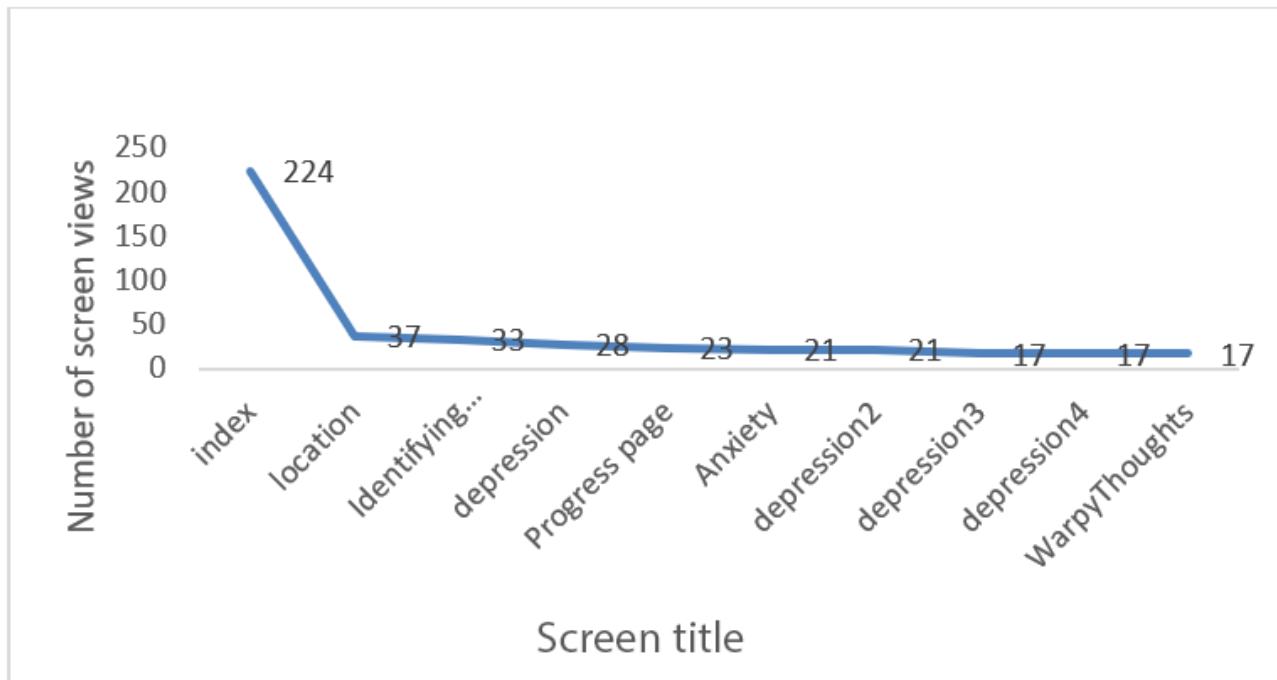
The app usage statistics were generated using GA can be seen in [Figure 3](#). GA provided detailed metrics of app usage, such as the number of sessions logged, screen views, number of screens per session, and session duration. During the study period, compared to 52 in MoodGYM, a total of 67 sessions were logged by the MoodTrainer users, and there were 608 screen views during this period. On an average, the users viewed about 9 screens per session, and the average session duration was 3 min 34 seconds. During the study, it was also observed that the location feedback screen was the second most-viewed screen, with 6.0% (37/608) of the total screen views. This indicates that the study participants were interested and often looked at the location history. The progress page was among the top 5 most viewed pages during the study period, and it had about 3.8% (23/608) of the total views.

As can be seen in [Table 3](#), 25% of the sessions lasted for about 3 min to 10 min, with an average session duration of 6 min. Furthermore, 10% of the sessions lasted between 10 min to 30 min, with an average session duration of 15 min and 24 screens

per session. During the study duration, it was found that 16% of the sessions had a screen depth of 3 screens and lasted about 1 min 30 seconds min, and 11% of the sessions had a screen depth of 20+ screens and lasted about 8 min 30 seconds min. It

was also observed that out of the 5 modules, on an average, MoodTrainer users completed about 2.5 modules and MoodGYM users completed only 1 module.

**Figure 3.** Distribution of screen views.



**Table 3.** Number of sessions by session duration for the app and web cognitive behavioral therapy.

Duration per session, seconds	MoodTrainer app sessions, n	MoodGYM web sessions, n
0-10	15	10
11-30	8	11
31-60	5	8
61-180	15	10
181-600	17	11
601-1800	7	2

## Discussion

### Differences in User Engagement Between the Two CBTs

This study is among the first to develop a mobile phone-based CBT on the basis of a Web-based CBT and compare the differences in the medium of CBT delivery. We selected MoodGYM as it is widely used in a global context. Its focus on mood disorder allowed us to apply it to the student context, where we have seen mood issues come up often. The results of our limited trial indicate that the MoodTrainer app is more usable when compared with MoodGYM. Previous studies, such as a study by Watts et al [51] in 2013, demonstrated the efficacy of delivering CBT over mobile phones. Our study affirms the computer-based versus the mobile phone-based CBT comparison for the same CBT content, with additional smartphone-specific features. More recent reviews [52] and studies [53] also show that app-based CBT is more usable and

engaging. However, it is important to highlight that as more users get comfortable with smartphone interfaces and more accustomed to spending time on devices, this might simply be a reflection of user familiarization. The time spent on the app and the number of sessions logged indicate that MoodTrainer is more accepted by the users compared with MoodGYM. The usability evaluation of the app reveals that it has a user-friendly design. The app can be monotonous after a while and needs to be designed with more colors and better imagery. As we took most of the graphics and content without much change from the Web-based CBT, there is an opportunity to customize the content for delivery through mobile phones in the future. The users of the MoodTrainer app were able to access the location feedback feature. This page was also the most-viewed page during the study period. This might indicate that location tracking was useful and might improve user engagement. The statistical analysis of the survey responses showed that there were no differences in the responses between the MoodGYM and MoodTrainer users, except for a statistically significant

difference in the navigation of the application. The mobile app was easier to navigate than the Web application. The session durations which were logged by the users showed that most sessions were between 3 min to 10 min. In terms of self-monitored CBT or note-taking, this may be considered usual time of daily activity. The median age of the subjects was 32 years, with the youngest at 24 years and the oldest at 44 years. So, even though our study was conducted among student population, the sample was not millennials. We also reflected that even though our subject population were not identified as depressed or having mood disorders, referring to them as mentally healthy was also not accurate. Mood disorders are fairly prevalent among college students, and many do not seek help as these are fairly temporary. Thus, we avoid the claim that our subjects are healthy, as we deliberately did not compare their clinical scales as this was only a usability study.

### Limitations

This study was restricted as a usability study and did not evaluate the clinical efficacy of the application because of cost and time constraints. The study included healthy young adults, although including young adults with depression would have given an appropriate understanding of the clinical efficacy. Depressed adults might also have cognitive issues, but there is

no clear evidence on this yet. The apps were provided to users only for a brief period of 2 weeks.

### Future Work

We have attempted to make modifications based on user feedback and released the app to Google Play Store. Evaluating the app for clinical efficacy in a depressed population is the next step.

### Conclusions

We presented the first evaluation of a mobile phone-based CBT delivery, where we implemented smartphone-specific features. The study also revealed that CBT delivered by this method was more intuitive and user-friendly than Web-based CBT. This method of CBT delivery might thus be more accessible and cost-effective, with improved user engagement. Such apps being more accessible have great potential in limited-resource settings, where access to face-to-face CBT is a challenge. The MoodTrainer app does not aim to replace a clinical care provider but can supplement it as a self-supporting tool. This app might be utilized by clinical psychologists as a continuum of care to prevent the relapse of multiple episodes. It can also be used as a monitoring aid to track a patient's progress after the therapy or during the therapy.

### Conflicts of Interest

None declared.

### References

1. Bloom DE, Cafiero ET, Jané-Llopis E, Abrahams-Gessel S, Bloom LR, Fathima S, et al. Weforum - World Economic Forum. Geneva: World Economic Forum; 2011. The Global Economic Burden of Non-communicable Diseases URL: [http://www3.weforum.org/docs/WEF\\_Harvard\\_HE\\_GlobalEconomicBurdenNonCommunicableDiseases\\_2011.pdf](http://www3.weforum.org/docs/WEF_Harvard_HE_GlobalEconomicBurdenNonCommunicableDiseases_2011.pdf) [accessed 2019-12-13]
2. WHO. World Health Organization. Depression Factsheet URL: <http://www.who.int/mediacentre/factsheets/fs369/en/> [accessed 2019-12-13]
3. Boydell KM, Hodgins M, Pignatiello A, Teshima J, Edwards H, Willis D. Using technology to deliver mental health services to children and youth: a scoping review. *J Can Acad Child Adolesc Psychiatry* 2014 May;23(2):87-99 [FREE Full text] [Medline: 24872824]
4. Torio CM, Encinosa W, Berdahl T, McCormick MC, Simpson LA. Annual report on health care for children and youth in the United States: national estimates of cost, utilization and expenditures for children with mental health conditions. *Acad Pediatr* 2015;15(1):19-35. [doi: 10.1016/j.acap.2014.07.007] [Medline: 25444653]
5. Donker T, Blankers M, Hedman E, Ljótsson B, Petrie K, Christensen H. Economic evaluations of internet interventions for mental health: a systematic review. *Psychol Med* 2015 Dec;45(16):3357-3376. [doi: 10.1017/S0033291715001427] [Medline: 26235445]
6. Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D, et al. Evidence for effective interventions to reduce mental-health-related stigma and discrimination. *Lancet* 2016 Mar 12;387(10023):1123-1132. [doi: 10.1016/S0140-6736(15)00298-6] [Medline: 26410341]
7. Penn E, Tracy DK. The drugs don't work? Antidepressants and the current and future pharmacological management of depression. *Ther Adv Psychopharmacol* 2012 Oct;2(5):179-188 [FREE Full text] [doi: 10.1177/2045125312445469] [Medline: 23983973]
8. Amick HR, Gartlehner G, Gaynes BN, Forneris C, Asher GN, Morgan LC, et al. Comparative benefits and harms of second generation antidepressants and cognitive behavioral therapies in initial treatment of major depressive disorder: systematic review and meta-analysis. *Br Med J* 2015 Dec 8;351:h6019 [FREE Full text] [doi: 10.1136/bmj.h6019] [Medline: 26645251]
9. Bschor T, Kilarski LL. Are antidepressants effective? A debate on their efficacy for the treatment of major depression in adults. *Expert Rev Neurother* 2016;16(4):367-374. [doi: 10.1586/14737175.2016.1155985] [Medline: 26891111]

10. Wang S, Han C, Lee S, Jun T, Patkar AA, Masand PS, et al. Efficacy of antidepressants: bias in randomized clinical trials and related issues. *Expert Rev Clin Pharmacol* 2018 Jan;11(1):15-25. [doi: [10.1080/17512433.2017.1377070](https://doi.org/10.1080/17512433.2017.1377070)] [Medline: [28893095](https://pubmed.ncbi.nlm.nih.gov/28893095/)]
11. So M, Yamaguchi S, Hashimoto S, Sado M, Furukawa TA, McCrone P. Is computerised CBT really helpful for adult depression?-A meta-analytic re-evaluation of CCBT for adult depression in terms of clinical implementation and methodological validity. *BMC Psychiatry* 2013 Apr 15;13:113 [FREE Full text] [doi: [10.1186/1471-244X-13-113](https://doi.org/10.1186/1471-244X-13-113)] [Medline: [23587347](https://pubmed.ncbi.nlm.nih.gov/23587347/)]
12. Koffel E, Kuhn E, Petsoulis N, Erbes CR, Anders S, Hoffman JE, et al. A randomized controlled pilot study of CBT-I Coach: feasibility, acceptability, and potential impact of a mobile phone application for patients in cognitive behavioral therapy for insomnia. *Health Informatics J* 2018 Mar;24(1):3-13. [doi: [10.1177/1460458216656472](https://doi.org/10.1177/1460458216656472)] [Medline: [27354394](https://pubmed.ncbi.nlm.nih.gov/27354394/)]
13. Kodak A, Fjermestad K, Bjelland I, Gjestad R, Öst LG, Bjaastad JF, et al. Long-term effectiveness of cognitive behavioral therapy for youth with anxiety disorders. *J Anxiety Disord* 2018 Jan;53:58-67 [FREE Full text] [doi: [10.1016/j.janxdis.2017.11.003](https://doi.org/10.1016/j.janxdis.2017.11.003)] [Medline: [29195188](https://pubmed.ncbi.nlm.nih.gov/29195188/)]
14. Segal ZV, Bizzini L, Bondolfi G. Cognitive behaviour therapy reduces long term risk of relapse in recurrent major depressive disorder. *Evid Based Ment Health* 2005 May;8(2):38 [FREE Full text] [doi: [10.1136/ebmh.8.2.38](https://doi.org/10.1136/ebmh.8.2.38)] [Medline: [15851801](https://pubmed.ncbi.nlm.nih.gov/15851801/)]
15. Ferguson S, Harper S, Platz S, Sloan G, Smith K. Developing specialist CBT supervision training in Scotland using blended learning: challenges and opportunities. *Cogn Behav Ther* 2016;9:e26. [doi: [10.1017/s1754470x15000732](https://doi.org/10.1017/s1754470x15000732)]
16. Rakovshik SG, McManus F, Vazquez-Montes M, Muse K, Ougrin D. Is supervision necessary? Examining the effects of internet-based CBT training with and without supervision. *J Consult Clin Psychol* 2016 Mar;84(3):191-199. [doi: [10.1037/ccp0000079](https://doi.org/10.1037/ccp0000079)] [Medline: [26795937](https://pubmed.ncbi.nlm.nih.gov/26795937/)]
17. Maguire N, Grellier B, Clayton K. The impact of CBT training and supervision on burnout, confidence and negative beliefs in a staff group working with homeless people. *Behav Cogn Psychother* 2017 [FREE Full text]
18. Kingston D, Janes-Kelley S, Tyrrell J, Clark L, Hamza D, Holmes P, et al. An integrated web-based mental health intervention of assessment-referral-care to reduce stress, anxiety, and depression in hospitalized pregnant women with medically high-risk pregnancies: a feasibility study protocol of hospital-based implementation. *JMIR Res Protoc* 2015 Jan 16;4(1):e9 [FREE Full text] [doi: [10.2196/resprot.4037](https://doi.org/10.2196/resprot.4037)] [Medline: [25595167](https://pubmed.ncbi.nlm.nih.gov/25595167/)]
19. Karyotaki E, Kleiboer A, Smit F, Turner DT, Pastor AM, Andersson G, et al. Predictors of treatment dropout in self-guided web-based interventions for depression: an 'individual patient data' meta-analysis. *Psychol Med* 2015 Oct;45(13):2717-2726. [doi: [10.1017/S0033291715000665](https://doi.org/10.1017/S0033291715000665)] [Medline: [25881626](https://pubmed.ncbi.nlm.nih.gov/25881626/)]
20. Morris RR, Schueller SM, Picard RW. Efficacy of a web-based, crowdsourced peer-to-peer cognitive reappraisal platform for depression: randomized controlled trial. *J Med Internet Res* 2015 Mar 30;17(3):e72 [FREE Full text] [doi: [10.2196/jmir.4167](https://doi.org/10.2196/jmir.4167)] [Medline: [25835472](https://pubmed.ncbi.nlm.nih.gov/25835472/)]
21. Saini J, Owen A, Hammer A, Brown W, Kulshreshtha A. Zooming towards better health: participant experience in a web-based group cognitive behavioral intervention. *iproc* 2018;4(2):e11773. [doi: [10.2196/11773](https://doi.org/10.2196/11773)]
22. Kazdin AE, Blase SL. Rebooting psychotherapy research and practice to reduce the burden of mental illness. *Perspect Psychol Sci* 2011 Jan;6(1):21-37. [doi: [10.1177/1745691610393527](https://doi.org/10.1177/1745691610393527)] [Medline: [26162113](https://pubmed.ncbi.nlm.nih.gov/26162113/)]
23. de Montjoye YA, Quoidbach J, Robic F, Pentland AS. Predicting Personality Using Novel Mobile Phone-based Metrics. In: *Proceedings of the 6th international conference on Social Computing, Behavioral-Cultural Modeling and Prediction*. Berlin, Heidelberg: Springer-Verlag; 2013 Presented at: SBP'13; April 2-5, 2013; Washington DC, USA p. 48-55. [doi: [10.1007/978-3-642-37210-0\\_6](https://doi.org/10.1007/978-3-642-37210-0_6)]
24. Donker T, Petrie K, Proudfoot J, Clarke J, Birch M, Christensen H. Smartphones for smarter delivery of mental health programs: a systematic review. *J Med Internet Res* 2013 Nov 15;15(11):e247 [FREE Full text] [doi: [10.2196/jmir.2791](https://doi.org/10.2196/jmir.2791)] [Medline: [24240579](https://pubmed.ncbi.nlm.nih.gov/24240579/)]
25. Mechal P, Nemser B, Cosmaciuc R, Cole-Lewis H, Ohemeng-Dapaah S, Dusabe S, et al. Capitalizing on the characteristics of mHealth to evaluate its impact. *J Health Commun* 2012;17(Suppl 1):62-66. [doi: [10.1080/10810730.2012.679847](https://doi.org/10.1080/10810730.2012.679847)] [Medline: [22548600](https://pubmed.ncbi.nlm.nih.gov/22548600/)]
26. Price M, Yuen EK, Goetter EM, Herbert JD, Forman EM, Acierno R, et al. mHealth: a mechanism to deliver more accessible, more effective mental health care. *Clin Psychol Psychother* 2014;21(5):427-436 [FREE Full text] [doi: [10.1002/cpp.1855](https://doi.org/10.1002/cpp.1855)] [Medline: [23918764](https://pubmed.ncbi.nlm.nih.gov/23918764/)]
27. Sumsion T. *Client-centered Practice In Occupational Therapy: A Guide To Implementation*. London, UK: Churchill Livingstone; 2006.
28. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. *Health Aff (Millwood)* 2015 Mar;34(3):431-437. [doi: [10.1377/hlthaff.2014.0452](https://doi.org/10.1377/hlthaff.2014.0452)] [Medline: [25732493](https://pubmed.ncbi.nlm.nih.gov/25732493/)]
29. Greer JA, Jacobs J, Pensak N, MacDonald JJ, Fuh C, Perez GK, et al. Randomized trial of a tailored cognitive-behavioral therapy mobile application for anxiety in patients with incurable cancer. *Oncologist* 2019 Aug;24(8):1111-1120. [doi: [10.1634/theoncologist.2018-0536](https://doi.org/10.1634/theoncologist.2018-0536)] [Medline: [30683710](https://pubmed.ncbi.nlm.nih.gov/30683710/)]
30. Rathbone AL, Clarry L, Prescott J. Assessing the efficacy of mobile health apps using the basic principles of cognitive behavioral therapy: systematic review. *J Med Internet Res* 2017 Nov 28;19(11):e399 [FREE Full text] [doi: [10.2196/jmir.8598](https://doi.org/10.2196/jmir.8598)] [Medline: [29187342](https://pubmed.ncbi.nlm.nih.gov/29187342/)]

31. Addepally SA, Purkayastha S. Mobile-Application Based Cognitive Behavior Therapy (CBT) for Identifying and Managing Depression and Anxiety. In: Proceedings of the International Conference on Digital Human Modeling and Applications in Health, Safety, Ergonomics and Risk Management. 2017 Presented at: DHM'17; July 9-14, 2017; Vancouver, Canada. [doi: [10.1007/978-3-319-58466-9\\_1](https://doi.org/10.1007/978-3-319-58466-9_1)]
32. MoodGYM CBT training program. URL: <https://moodgym.com.au/> [accessed 2018-07-30]
33. Apache Cordova. Platform Support URL: <https://cordova.apache.org/docs/en/latest/guide/support/index.html> [accessed 2018-07-31]
34. Apache Cordova. Architectural overview of Cordova platform URL: <https://cordova.apache.org/docs/en/latest/guide/overview/index.html#architecture> [accessed 2018-07-31]
35. Polymer Project. URL: <https://www.polymer-project.org/> [accessed 2018-08-01]
36. Android Developers. Material Design for Android URL: <https://developer.android.com/guide/topics/ui/look-and-feel/> [accessed 2018-08-01]
37. GitHub. The Crosswalk Project URL: <http://crosswalk-project.org/> [accessed 2018-07-31]
38. Singh K, Drouin K, Newmark LP, Lee J, Faxvaag A, Rozenblum R, et al. Many mobile health apps target high-need, high-cost populations, but gaps remain. *Health Aff (Millwood)* 2016 Dec 1;35(12):2310-2318. [doi: [10.1377/hlthaff.2016.0578](https://doi.org/10.1377/hlthaff.2016.0578)] [Medline: [27920321](https://pubmed.ncbi.nlm.nih.gov/27920321/)]
39. Christensen H, Griffiths KM, Korten AE, Brittliffe K, Groves C. A comparison of changes in anxiety and depression symptoms of spontaneous users and trial participants of a cognitive behavior therapy website. *J Med Internet Res* 2004 Dec 22;6(4):e46 [FREE Full text] [doi: [10.2196/jmir.6.4.e46](https://doi.org/10.2196/jmir.6.4.e46)] [Medline: [15631970](https://pubmed.ncbi.nlm.nih.gov/15631970/)]
40. Goldberg D, Bridges K, Duncan-Jones P, Grayson D. Detecting anxiety and depression in general medical settings. *Br Med J* 1988 Oct 8;297(6653):897-899 [FREE Full text] [doi: [10.1136/bmj.297.6653.897](https://doi.org/10.1136/bmj.297.6653.897)] [Medline: [3140969](https://pubmed.ncbi.nlm.nih.gov/3140969/)]
41. Parslow RA, Christensen H, Griffiths KM, Groves C. The warpy thoughts scale: a new 20-item instrument to measure dysfunctional attitudes. *Cogn Behav Ther* 2006;35(2):106-116. [doi: [10.1080/16506070500372279](https://doi.org/10.1080/16506070500372279)] [Medline: [16754265](https://pubmed.ncbi.nlm.nih.gov/16754265/)]
42. Tennant C, Andrews G. A scale to measure the stress of life events. *Aust N Z J Psychiatry* 1976 Mar;10(1):27-32. [doi: [10.3109/00048677609159482](https://doi.org/10.3109/00048677609159482)] [Medline: [1065311](https://pubmed.ncbi.nlm.nih.gov/1065311/)]
43. Parker G, Roussos J, Hadzi-Pavlovic D, Mitchell P, Wilhelm K, Austin MP. The development of a refined measure of dysfunctional parenting and assessment of its relevance in patients with affective disorders. *Psychol Med* 1997 Sep;27(5):1193-1203. [doi: [10.1017/s003329179700545x](https://doi.org/10.1017/s003329179700545x)] [Medline: [9300523](https://pubmed.ncbi.nlm.nih.gov/9300523/)]
44. MacPhillamy DJ, Lewinsohn PM. The pleasant events schedule: studies on reliability, validity, and scale intercorrelation. *J Consult Clin Psychol* 1982;50(3):363-380. [doi: [10.1037//0022-006x.50.3.363](https://doi.org/10.1037//0022-006x.50.3.363)]
45. Allen GJ, Giat C, Cherney RJ. Locus of control, test anxiety, and student performance in a personalized instruction course. *J Educ Psychol* 1974 Dec;66(6):968-973. [doi: [10.1037/h0021543](https://doi.org/10.1037/h0021543)] [Medline: [4443477](https://pubmed.ncbi.nlm.nih.gov/4443477/)]
46. Keeley J, Zayac R, Correia C. Curvilinear relationships between statistics anxiety and performance among undergraduate students: evidence for optimal anxiety. *Stat Educ Res J* 2008;7(1) [FREE Full text]
47. Farrer LM, Gulliver A, Bennett K, Fassnacht DB, Griffiths KM. Demographic and psychosocial predictors of major depression and generalised anxiety disorder in Australian university students. *BMC Psychiatry* 2016 Jul 15;16:241 [FREE Full text] [doi: [10.1186/s12888-016-0961-z](https://doi.org/10.1186/s12888-016-0961-z)] [Medline: [27422284](https://pubmed.ncbi.nlm.nih.gov/27422284/)]
48. Nielsen J, Mack R. Usability Inspection Methods. New York, USA: Wiley; 1994.
49. REDCap. URL: <https://www.project-redcap.org/> [accessed 2019-12-13]
50. Martínez-Pérez B, de la Torre-Díez I, López-Coronado M. Mobile health applications for the most prevalent conditions by the World Health Organization: review and analysis. *J Med Internet Res* 2013 Jun 14;15(6):e120 [FREE Full text] [doi: [10.2196/jmir.2600](https://doi.org/10.2196/jmir.2600)] [Medline: [23770578](https://pubmed.ncbi.nlm.nih.gov/23770578/)]
51. Watts S, Mackenzie A, Thomas C, Griskaitis A, Mewton L, Williams A, et al. CBT for depression: a pilot RCT comparing mobile phone vs computer. *BMC Psychiatry* 2013 Feb 7;13:49 [FREE Full text] [doi: [10.1186/1471-244X-13-49](https://doi.org/10.1186/1471-244X-13-49)] [Medline: [23391304](https://pubmed.ncbi.nlm.nih.gov/23391304/)]
52. Lan A, Lee A, Munroe K, McRae C, Kaleis L, Keshavjee K, et al. Review of cognitive behavioural therapy mobile apps using a reference architecture embedded in the patient-provider relationship. *Biomed Eng Online* 2018 Dec 17;17(1):183 [FREE Full text] [doi: [10.1186/s12938-018-0611-4](https://doi.org/10.1186/s12938-018-0611-4)] [Medline: [30558610](https://pubmed.ncbi.nlm.nih.gov/30558610/)]
53. Jarzabek S, Cheong K, Lim Y, Wong J, Kayanoth R, Teng J. CBT Assistant Platform: web/mobile co-design solution for cognitive behavioural therapy. *J Hosp Manag Health Policy* 2018;2:34. [doi: [10.21037/jhmhp.2018.06.02](https://doi.org/10.21037/jhmhp.2018.06.02)]

## Abbreviations

- API:** application programming interface
- APK:** Android package
- CBT:** cognitive behavioral therapy
- GA:** Google Analytics
- mHealth:** mobile health
- UI:** user interface

*Edited by A Kushniruk; submitted 26.03.19; peer-reviewed by K Stasiak, S Baptista, I Gabashvili, E Borycki, M Kelley; comments to author 28.06.19; revised version received 09.10.19; accepted 25.11.19; published 03.02.20.*

*Please cite as:*

*Purkayastha S, Addepally SA, Bucher S*

*Engagement and Usability of a Cognitive Behavioral Therapy Mobile App Compared With Web-Based Cognitive Behavioral Therapy Among College Students: Randomized Heuristic Trial*

*JMIR Hum Factors 2020;7(1):e14146*

URL: <http://humanfactors.jmir.org/2020/1/e14146/>

doi: [10.2196/14146](https://doi.org/10.2196/14146)

PMID: [32012043](https://pubmed.ncbi.nlm.nih.gov/32012043/)

©Saptarshi Purkayastha, Siva Abhishek Addepally, Sherri Bucher. Originally published in JMIR Human Factors (<http://humanfactors.jmir.org>), 03.02.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Human Factors, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# Effectiveness of the ColorApp Mobile App for Health Education and Promotion for Colorectal Cancer: Quasi-Experimental Study

Nor Azwany Yaacob<sup>1\*</sup>, MD, MCM; Muhamad Fadhil Mohamad Marzuki<sup>1\*</sup>, MBBS, MPH, DrPH; Najib Majdi Yaacob<sup>2</sup>, MD, MPH, DrPH; Shahrul Bariyah Ahmad<sup>3</sup>, MBBS, MPH; Muhammad Radzi Abu Hassan<sup>4</sup>, MB BCh BAO, MMed

<sup>1</sup>Department of Community Medicine, School of Medical Sciences, Universiti Sains Malaysia Health Campus, Kubang Kerian, Kelantan, Malaysia

<sup>2</sup>Unit of Biostatistics and Research Methodology, School of Medical Sciences, Universiti Sains Malaysia Health Campus, Kubang Kerian, Malaysia

<sup>3</sup>Non-Communicable Disease Control Unit, Kedah State Health Department, Alor Setar, Kedah, Malaysia

<sup>4</sup>Clinical Research Centre, Hospital Sultanah Bahiyah, Alor Setar, Kedah, Malaysia

\*these authors contributed equally

**Corresponding Author:**

Nor Azwany Yaacob, MD, MCM  
Department of Community Medicine  
School of Medical Sciences  
Universiti Sains Malaysia Health Campus  
Universiti Sains Malaysia  
Kubang Kerian, Kelantan, 16150  
Malaysia  
Phone: 60 9767 6622 ext 6621  
Email: [azwany@usm.my](mailto:azwany@usm.my)

## Abstract

**Background:** Lack of knowledge and poor attitude are barriers to colorectal cancer screening participation. Printed material, such as pamphlets and posters, have been the main approach in health education on disease prevention in Malaysia. Current information technology advancements have led to an increasing trend of the public reading from websites and mobile apps using their mobile phones. Thus, health information dissemination should also be diverted to websites and mobile apps. Increasing knowledge and awareness could increase screening participation and prevent late detection of diseases such as colorectal cancer.

**Objective:** This study aimed to assess the effectiveness of the ColorApp mobile app in improving the knowledge and attitude on colorectal cancer among users aged 50 years and older, who are the population at risk for the disease in Kedah.

**Methods:** A quasi-experimental study was conducted with 100 participants in Kedah, Malaysia. Participants from five randomly selected community empowerment programs in Kota Setar district were in the intervention group; Kuala Muda district was the control group. Participants were given a self-administered validated questionnaire on knowledge and attitudes toward colorectal cancer. A mobile app, ColorApp (Colorectal Cancer Application), was developed as a new educational tool for colorectal cancer prevention. The intervention group used the app for two weeks. The same questionnaire was redistributed to both groups after two weeks. The mean percentage scores for knowledge and attitude between groups were compared using repeated measure ANCOVA.

**Results:** There was no significant difference in age, sex, highest education level, current occupation, and diabetic status between the two groups. The number of smokers was significantly higher in the intervention group compared with the control group and was controlled for during analysis. The intervention group showed a significantly higher mean knowledge score compared with the control group with regards to time (Huynh-Feldt:  $F_{1,95}=19.81$ ,  $P<.001$ ). However, there was no significant difference in mean attitude scores between the intervention and control groups with regards to time ( $F_{1,95}=0.36$ ,  $P=.55$ ).

**Conclusions:** The ColorApp mobile app may be an adjunct approach in educating the public on colorectal cancer.

(*JMIR Hum Factors* 2020;7(1):e15487) doi:[10.2196/15487](https://doi.org/10.2196/15487)

**KEYWORDS**

colorectal cancer; mobile app; effectiveness; knowledge; attitude

## Introduction

There were 1.7 million new cases of colorectal cancer in 2015, with 832,000 deaths globally [1]. It is the third most commonly diagnosed type of cancer. However, colorectal cancer was reported by the National Cancer Registry as the second most common cancer in Malaysia between 2007 and 2011. The total number of cancer cases registered was 13,693 or 13.2% of all cancer types. The age-standardized rate of colorectal cancer was 14.6 per 100,000 population for males and 11.1 per 100,000 population for females [2]. There is a wide disparity in the country-specific incidence in Southeast Asia, with the highest incidence reported in Singapore (age-standardized rate 33.7 per 100,000 population) [3]. However, trends for both the incidence and the mortality rates for Singapore have been stable and even declining since 2000. Other countries, such as Indonesia, Thailand, Vietnam, and Myanmar, have comparatively lower incidence rates of colorectal cancer than Malaysia [4].

People living in Malaysia, Singapore, India, and Brunei were reported to have a significantly more negative response toward and lack of intention to undergo colorectal cancer screening compared with people in the Philippines and Japan. The public's low knowledge and awareness, as well as their poor attitude toward screening, may explain the negative perception and lead to a low rate of screening [5]. Those at high risk of getting colorectal cancer were also reported to have low intention; only 38% of them were willing to be screened [6]. Furthermore, the intention to go for screening among people aged 50 years and older is the lowest compared with younger age groups. Lack of knowledge or education is the most critical barrier reported in many studies [5,7-11]. Poor knowledge by the general public about the risk factors, signs, symptoms, and screening tests available leads to low awareness of the importance of preventive action including taking a screening test. In addition, background education level plays an important role in determining health literacy, especially in rural areas. Health education and promotion on colorectal cancer are still not as rigorous as the lung, breast, and cervical cancer prevention activities in Malaysia despite increasing incidence from year to year [11]. Therefore, the awareness program for colorectal cancer and health promotion and education need to be strengthened in Malaysia.

Mobile phone usage is on the rise leading to high demand for mobile phone apps [12]. These apps could be used for social interaction, education, entertainment, as well as personal health. Mobile apps have been shown to have a potential role in health awareness and behavioral changes [13,14]. The mobile phone has been studied as a platform for intervention programs, such as text messaging interventions for smoking cessation [15,16], for diabetic education [17], to monitor patient health status [18], to increase physical activity [13], and for dietary management [19]. The integration of multiple functions of a mobile phone with a mobile app enables not only health education but also the monitoring of user progress, providing health reminders, and sharing outcomes with health care providers or friends to maintain user motivation. A mobile app also provides a useful and faster way to disseminate information, such as risk factors and preventive measures, at a low cost [12]. By 2010, there

were more than 7000 apps developed for health education and promotion purposes [20].

A mobile app named ColorApp (Colorectal Cancer Application), intended for the population at risk in Malaysia, was developed as a new tool for health education and promotion on colorectal cancer [21]. Its usability has been shown in a usability study published previously [21]. However, we do not know whether this usable mobile app can improve the knowledge and attitudes of users on colorectal cancer. Therefore, this study aimed to assess the effectiveness of the ColorApp mobile app in improving the knowledge and attitudes on colorectal cancer among users aged 50 years and older who are the population at risk for the disease in Kedah.

## Methods

### Overview

A quasi-experimental study was conducted in the state of Kedah, Malaysia. The two most populous districts with good broadband coverage were selected. These districts have active community empowerment programs at different localities. This community empowerment program, known by the acronym KOSPEN, aimed to empower people to achieve better health by reducing the behavioral and modifiable noncommunicable disease risk factors [22]. Kota Setar district was chosen as the intervention district and Kuala Muda district as the control district. Five KOSPEN localities in each district were randomly selected. Ten eligible program participants were randomly selected from each locality to achieve a total of 100 participants, 50 in each group. Eligible participants were those aged 50 years and older, who owned an Android mobile phone and had never been diagnosed with any type of cancer. This study was approved by the National Medical Research Registry, Malaysia (NMRR-17-2623-38675 [IIR]) and Human Research Ethics Committee USM, Malaysia (USM/JEPeM/17110601).

There were two tools—one apps and one questionnaire—used in this research study, which are described subsequently.

### ColorApp Mobile App

ColorApp is a newly developed mobile app for health promotion and education on colorectal cancer. It consists of 10 interfaces on introduction to colorectal cancer, signs and symptoms, risk factors, preventions, screening programs in Malaysia, and immunochemical fecal occult blood test kits. It also has two interactive pages to stratify the user's risk of disease and a health calculator that provides a recommendation on the need for screening as well as ideal body weight, recommended blood pressure, glucose, and cholesterol level. A video on colorectal cancer is also available. ColorApp has been tested and proven to be usable by the intended users. The development process and usability study have been published recently [21].

### Self-Adminstrated Questionnaire on Knowledge and Attitude on Colorectal Cancer

This is a validated Malay version of a self-administered questionnaire that consists of four sections: sociodemographic information, knowledge of the general aspects of colorectal cancer, attitude on colorectal cancer, and practices of lifestyle



and colorectal cancer screening [23]. Due to time and logistic constraints, this study only assessed the immediate changes, which were knowledge and attitude on colorectal cancer. Practice change on colorectal cancer screening required a longer duration of follow-up; thus, it was not possible to be covered during the study period. The number of items for knowledge and attitude were 29 and 10, respectively. A 5-point Likert scale was used: strongly agree, agree, neutral, disagree, and strongly disagree. There were positive and negative items; scores of 5 to 1 were used for positive items and reverse scores for negative items. Summation of the total score for each domain was converted into a percentage score. The mean percentage score of knowledge and attitude before and after using ColorApp were computed and compared. The Cronbach alphas for knowledge and attitude domain were .65 and .82, respectively. The self-administered questionnaire on knowledge and attitude on colorectal cancer is attached in [Multimedia Appendix 1](#).

### Data Collection Method

Participants were invited to participate in this study through our program coordinator. During the preintervention period, participants were invited to a community health program at selected localities. A health talk on local public health concerns was conducted to gather all the participants and as an add-on benefit for all. The participants were then given a validated self-administered questionnaire on colorectal cancer knowledge and attitude. On completion of the questionnaire, participants from the intervention group were introduced to ColorApp and asked to install it onto their mobile phone. The ColorApp prototype was published in the Google Play store as a beta option; only users who were provided with the app link were

able to install it to avoid cross-contamination (ie, users using the app that did not sign up as participants in our study). Participants in the intervention group were instructed to use ColorApp for two weeks at their own convenience. No mobile app was introduced to the control group. The same questionnaire was readministered after two weeks of using ColorApp during a second community health activity at each locality. For the benefit of the participants, they were given a health talk on colorectal cancer. The control group participants were also introduced to ColorApp after all participants submitted the postintervention questionnaire. The mean percentage scores for knowledge and attitude between groups were compared using repeated measures ANCOVA (analysis of covariance) because it adjusted for the age and smoking status of participants. Age was controlled during the study design, and smoking status was controlled because it showed a significant difference between the intervention and control groups.

## Results

### Overview

There was no difference in terms of age, sex, highest education level, and current occupation between the control and intervention groups. However, there was a significant difference in smoking status; more participants from the intervention group smoked compared with the control group ([Table 1](#)).

Comparisons of the mean percentage scores of knowledge and attitude on colorectal cancer between the intervention and control groups with consideration of time pre- and postusage of the mobile app comprised three separate results.

**Table 1.** Sociodemographic and health characteristics of participants by intervention and control group (N=100).

Variables	Intervention (n=50)	Control (n=50)	P value
Age (years), mean (SD)	56.0 (5.69) <sup>a</sup>	55.8 (4.76) <sup>a</sup>	.86 <sup>a</sup>
<b>Sex, n (%)</b>			
Male	25 (50)	25 (50)	>.99 <sup>b</sup>
Female	25 (50)	25 (50)	
<b>Highest education, n (%)</b>			
Tertiary	7 (14)	3 (6)	.40 <sup>b</sup>
Secondary	33 (66)	35 (70)	
Primary	10 (20)	12 (24)	
<b>Current occupation, n (%)</b>			
Employed	17 (34)	22 (44)	.31 <sup>b</sup>
Unemployed	33 (66)	28 (56)	
<b>Smoking status, n (%)</b>			
Yes	17 (34)	7 (14)	.02 <sup>b</sup>
No	33 (66)	43 (86)	
<b>Diabetes status, n (%)</b>			
Yes	10 (20)	6 (12)	.28 <sup>b</sup>
No	40 (80)	44 (88)	
<b>Body mass index category, n (%)</b>			
Underweight	3 (6)	1 (2)	.61 <sup>c</sup>
Ideal body weight	14 (28)	18 (36)	
Overweight	19 (38)	20 (40)	
Obese	14 (28)	11 (22)	

<sup>a</sup>Independent *t* test.<sup>b</sup>Chi-square test.<sup>c</sup>Fisher exact test.

### Within-Group Difference (Time Effect)

The time-effect mixed-design repeated measures ANCOVA analysis showed that there was a significant increment in knowledge scores among participants in the intervention group after using the mobile app (Wilks' lambda,  $F_{1,47}=7.38$ ,  $P=.007$ ). Participants in the intervention group had significantly better knowledge postintervention compared with preintervention. Within the control group, knowledge scores were observed to be lower at postintervention; however, it was not statistically significant (Wilks' lambda,  $F_{1,47}=0.71$ ,  $P=.40$ ).

The time-effect mixed-design repeated measures ANCOVA analysis for attitude showed that there was no significant change of mean attitude score after using the mobile app. The mean percentage score difference in attitude before and after ColorApp usage was not significant for the intervention group (Wilks' lambda,  $F_{1,47}=0.28$ ,  $P=.60$ ) or the control group (Wilks' lambda,  $F_{1,47}=1.68$ ,  $P=.20$ ). Participants' attitudes from both groups did not change significantly postintervention.

The comparison of adjusted mean percentage scores of knowledge and attitude within the intervention group are shown in [Table 2](#).

**Table 2.** Comparison of adjusted mean percentage scores of knowledge and attitude within the intervention and control group (n=50).<sup>a</sup>

Time	Intervention group		Control group	
	Adjusted mean difference (95% CI)	P value	Adjusted mean difference (95% CI)	P value
Postintervention knowledge score–preintervention knowledge score	2.65 (0.75, 4.55)	.007	0.66 (–0.91, 2.23)	.40
Postintervention attitude score–preintervention attitude score	0.77 (–2.17, 3.70)	.60	–3.00 (–7.65, 1.65)	.20

<sup>a</sup>Two-way mixed-design repeated measure ANCOVA was applied and adjusted for smoking.

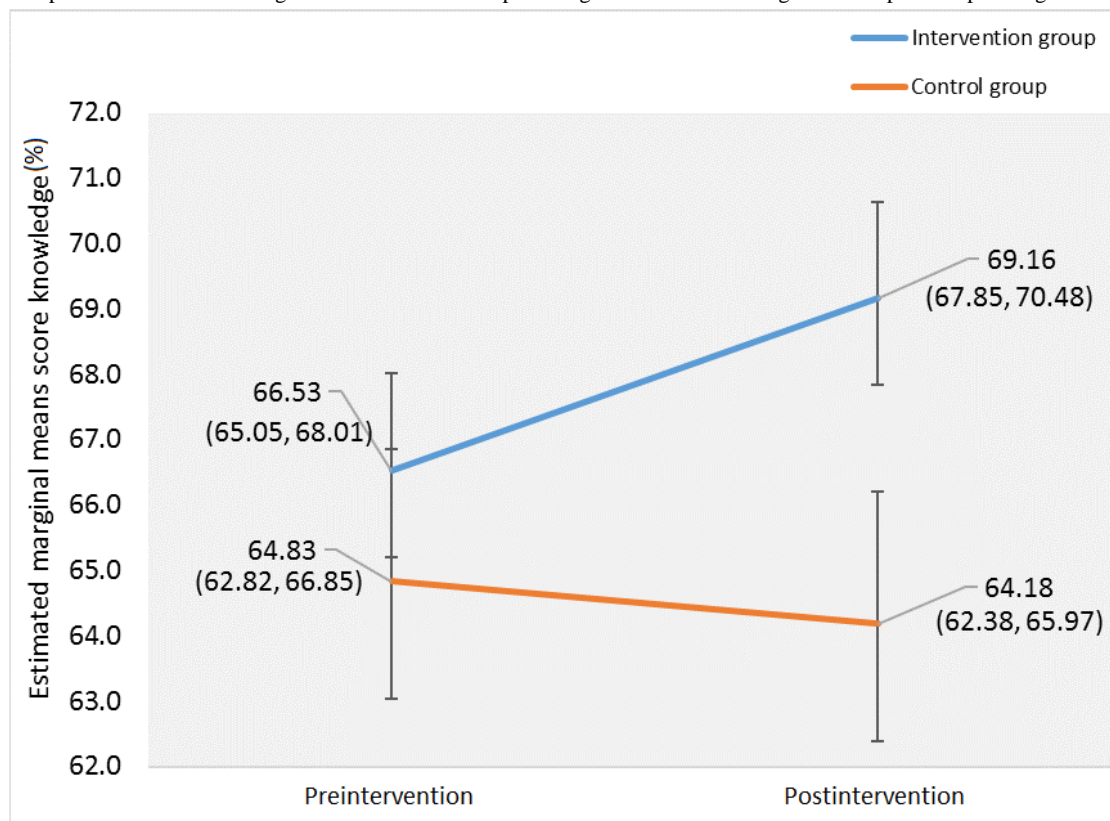
**Between-Group Difference (Intervention Effect)**

The intervention-effect mixed-design repeated measures ANCOVA analysis showed that there was an overall significant difference in mean percentage score of knowledge between intervention and control groups regardless of time ( $F_{1,95}=11.36, P=.001$ ). For attitude, there was no overall significant difference between the intervention and control groups on the mean percentage score of attitude regardless of time ( $F_{1,95}=0.42, P=.52$ ). The adjusted mean difference between intervention and control for percentage score knowledge was 3.34 (95% CI 1.37-5.31,  $P=.001$ ) and for attitude was –0.784 (95% CI –3.18 to 1.62,  $P=.34$ ).

**Between-Group Difference Based on Time (Interaction Effect)**

Two-way mixed-design repeated measures ANCOVA was applied and adjusted for age and smoking status. There was no mean percentage score difference between groups during preintervention (Huynh-Feldt:  $F_{1,95}=1.82, P=.21$ ); however, there was a significant difference between groups during postintervention (Huynh-Feldt:  $F_{1,95}=19.81, P<.001$ ; partial eta squared=0.610). There was a significant difference in mean percentage score knowledge between the intervention and control groups with regards to time (Wilk’s lambda,  $F_{1,95}=6.20, P=.02$ ). The interaction effect produced a significant difference in mean percentage score knowledge with consideration of time between pre and post usage of ColorApp (Figure 1).

**Figure 1.** Profile plot of the estimated marginal means of the mean percentage scores for knowledge between pre- and postusage of ColorApp.



For attitude, there was no difference between groups during preintervention (Huynh-Feldt:  $F_{1,95}=0.36, P=.55$ ) and postintervention (Huynh-Feldt:  $F_{1,95}=2.24, P=.14$ ). There was also no significant difference in mean percentage score attitude

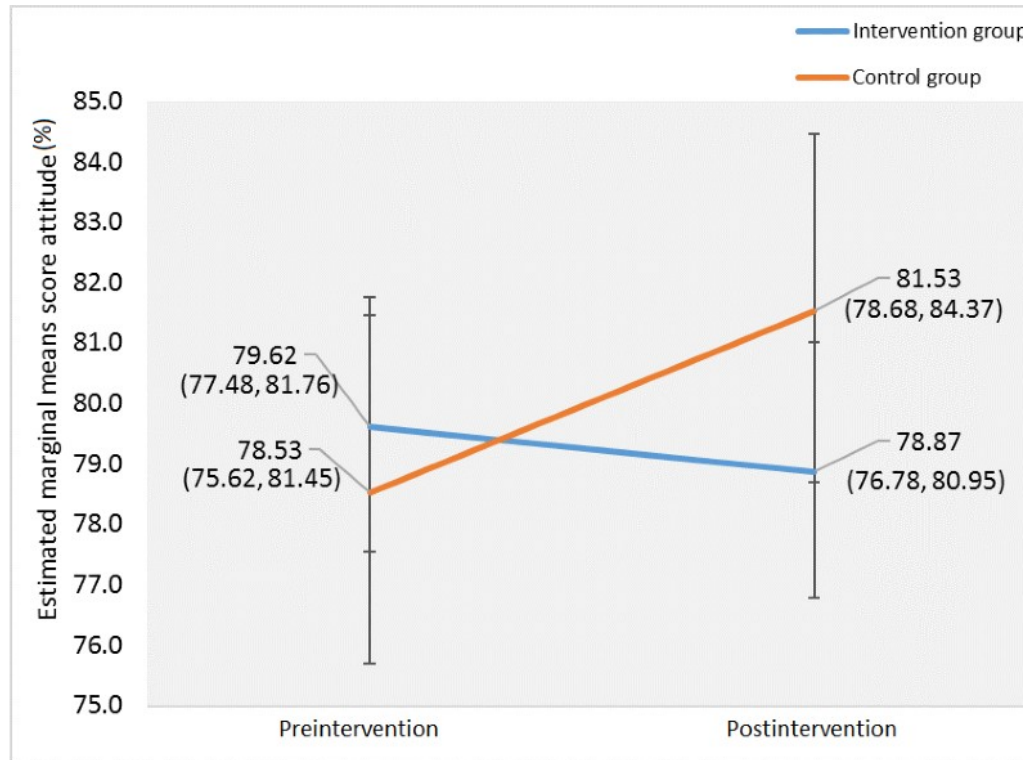
between the intervention and control groups with regard to time (Wilks’ lambda,  $F_{1,95}=1.98, P=.16$ ). The interaction effect produced no significant difference in the mean percentage score

attitude with consideration of time between pre- and postusage of ColorApp (Figure 2).

Based on the analysis, the intervention group showed a significant improvement in their knowledge score after using

ColorApp, but not their attitude score. The partial eta squared for intervention effect was 0.610, indicating a large effect size based on Cohen's guidelines [24].

**Figure 2.** Profile plot of the estimated marginal means of the mean percentage scores for attitude between pre- and postusage of ColorApp.



## Discussion

This study shows an improvement in knowledge of colorectal cancer after the use of the ColorApp app, but it did not affect attitude toward preventing colorectal cancer. ColorApp was developed to be used by people aged 50 years and older who are at higher risk of getting colorectal cancer. It was designed to improve their general knowledge of colorectal cancer and attitudes toward their disease susceptibility, disease prevention through a healthier lifestyle, and taking a screening test. A quasi-experimental study was conducted because this was a population-based study in which it was not feasible to randomize at the individual level without contaminating the control group [25]. Two different districts were used to avoid cross-contamination (participants in the control group were unable to download and use the mobile app). However, districts (or geographical regions) with similar population characteristics were chosen to ensure comparability between groups, as shown by the baseline participants' characteristics. Factors such as age, gender, educational level, and occupation, which may influence the level of knowledge and attitudes on colorectal cancer, were similar at baseline. The smoking habit was significantly different between the intervention and control groups and was controlled during the multivariate analysis.

The time-intervention effect showed a significant improvement of overall knowledge on colorectal cancer among participants in the intervention group compared with the control group. This indicates that ColorApp can be a tool to deliver health

information on colorectal cancer even to older users. This app provides information on the epidemiology of colorectal cancer in Malaysia, signs and symptoms, risk factors, prevention, and colorectal cancer screening methods, as described in detail in the development publication [21]. Many studies have supported the use of mobile phones in improving the user's or patient's knowledge and awareness of the disease. A systematic review of health care apps for mobile phones found more than 15 apps that focused on disease management for chronic illness were able to improve patients' knowledge. Thus, mobile apps are able to play an important role in disseminating evidence-based health information and are a tool for disease self-management, remote monitoring, and mobile clinical communication [26]. A study in China suggested that the use of a mobile app could improve the user's experience, especially on the accessibility to health information, leading to positive health outcomes [27]. In another study involving diabetic patients in England, the majority of participants agreed that a mobile health app had great potential in health promotion and was beneficial and helpful for them to live a healthier lifestyle [28]. Therefore, increasing mobile phone ownership should be fully used in delivering health education and promotion to intended users. It can be a good complement to other modalities of health education to enhance the effect of education to change people's behavior.

However, this study found no significant improvement in the overall attitude of participants on the prevention of colorectal cancer in the intervention group compared with the control

group. The participants in the intervention group were given only two weeks to use the ColorApp app before conducting the postintervention assessment. The duration may have been inadequate to assess attitude change on colorectal cancer. Changing attitudes toward perceived susceptibility to the disease and the benefits of taking preventive action (eg, choosing a healthy lifestyle) and health-seeking behavior (eg, taking a stool screening test) is not as easy as improving people's knowledge. Attitude change also requires consistent and congruent information that needs to be delivered through various information dissemination methods and includes messages that are high in affect or emotion and connect attitudes to past behaviors [29].

Changing attitudes is even more challenging when the health education messages contradict the user's beliefs, ethics, and cultural values [30]. By going through all pages of the app, reading the information available, and using the interactive function, users may gain more knowledge about colorectal cancer. Early detection of cancer, even by means of a noninvasive procedure, can also be an unpleasant life experience. Changing attitudes toward a healthier lifestyle, such as eating more vegetables, being physically active, and stopping smoking, may take longer because they involve their personal value(s).

Although this study was unable to show a significant change in attitude toward colorectal screening, this should not be the

reason for not using mobile apps as a means of health promotion and education because other studies have proved an association between knowledge of colorectal cancer and colorectal cancer screening rates [31-33]. A qualitative study was conducted with a focus group of 55 African Americans aged 50 years and older, which found that lack of knowledge is one of the major barriers to screening [31]. A similar finding was seen in other studies, such as a study involving 247 participants in New Mexico during a community event [32] and another study involving 1060 randomly selected visitors at Razavi Hospital of Mashhad, Iran [33]. Looking at the local context, studies have shown that knowledge and awareness of colorectal cancer among the Malaysian population is still low [5,34,35]. Therefore, any means that may improve the knowledge of the population on colorectal cancer should be fully utilized to increase screening participation. However, a longer period of study intervention and follow-up may provide better evidence for the effectiveness of an educational intervention.

In conclusion, the advancements in communication technology should be fully used by health care providers in disseminating health education messages to the target population. A mobile app such as ColorApp is a way forward for health promotion and education, particularly in the prevention and early detection of colorectal cancer. ColorApp is currently published in version 14. It can be downloaded for free from the Google Play store.

---

## Acknowledgments

We would like to express our gratitude to the National Medical Research Registry, Ministry of Health Malaysia; Human Research Ethics Committee, Universiti Sains Malaysia; State Director of Health, Kedah State of Health Department, Kedah Darul Aman; and KOSPEN Community in Kota Setar and Kuala Muda Kedah.

---

## Conflicts of Interest

None declared.

---

## Multimedia Appendix 1

Self-administered questionnaire on knowledge and attitude on colorectal cancer.

[DOC File, 105 KB - [humanfactors\\_v7i1e15487\\_app1.doc](#)]

---

## References

1. Global Burden of Disease Cancer Collaboration, Fitzmaurice C, Akinyemiju TF, Al Lami FH, Alam T, Alizadeh-Navaei R, et al. Global, regional, and national cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life-years for 29 cancer groups, 1990 to 2016: a systematic analysis for the global burden of disease study. *JAMA Oncol* 2018 Nov 01;4(11):1553-1568 [FREE Full text] [doi: [10.1001/jamaoncol.2018.2706](https://doi.org/10.1001/jamaoncol.2018.2706)] [Medline: [29860482](https://pubmed.ncbi.nlm.nih.gov/29860482/)]
2. Manan A. Malaysian National Cancer Registry Report 2007-2011. Putrajaya, Malaysia: Ministry of Health Malaysia; 2016. URL: <https://tinyurl.com/rvhf578>
3. National Registry of Disease Office. Singapore Cancer Registry Interim Annual Report Trends in Cancer Incidence in Singapore 2010-2014. 2015 May 26. URL: [https://www.nrdo.gov.sg/docs/librariesprovider3/default-document-library/cancer-trends-2010-2014\\_interim-annual-report\\_final-public\).pdf?sfvrsn=0](https://www.nrdo.gov.sg/docs/librariesprovider3/default-document-library/cancer-trends-2010-2014_interim-annual-report_final-public).pdf?sfvrsn=0)
4. Torre LA, Bray F, Siegel RL, Ferlay J, Lortet-Tieulent J, Jemal A. Global cancer statistics, 2012. *CA Cancer J Clin* 2015 Mar;65(2):87-108 [FREE Full text] [doi: [10.3322/caac.21262](https://doi.org/10.3322/caac.21262)] [Medline: [25651787](https://pubmed.ncbi.nlm.nih.gov/25651787/)]
5. Koo JH, Leong RW, Ching J, Yeoh K, Wu D, Murdani A, Asia Pacific Working Group in Colorectal Cancer. Knowledge of, attitudes toward, and barriers to participation of colorectal cancer screening tests in the Asia-Pacific region: a multicenter study. *Gastrointest Endosc* 2012 Jul;76(1):126-135. [doi: [10.1016/j.gie.2012.03.168](https://doi.org/10.1016/j.gie.2012.03.168)] [Medline: [22726471](https://pubmed.ncbi.nlm.nih.gov/22726471/)]

6. Hilmi I, Hartono JL, Goh K. Negative perception in those at highest risk--potential challenges in colorectal cancer screening in an urban asian population. *Asian Pac J Cancer Prev* 2010;11(3):815-822 [FREE Full text] [Medline: [21039060](#)]
7. Wong MC, Hirai HW, Luk AK, Lam TY, Ching JY, Griffiths SM, et al. The knowledge of colorectal cancer symptoms and risk factors among 10,078 screening participants: are high risk individuals more knowledgeable? *PLoS One* 2013;8(4):e60366 [FREE Full text] [doi: [10.1371/journal.pone.0060366](#)] [Medline: [23573248](#)]
8. Sung JJ, Lau JY, Goh K, Leung W, Asia Pacific Working Group on Colorectal Cancer. Increasing incidence of colorectal cancer in Asia: implications for screening. *Lancet Oncol* 2005 Nov;6(11):871-876. [doi: [10.1016/S1470-2045\(05\)70422-8](#)] [Medline: [16257795](#)]
9. Sung JJ, Lau JY, Young GP, Sano Y, Chiu HM, Byeon JS, Asia Pacific Working Group on Colorectal Cancer. Asia Pacific consensus recommendations for colorectal cancer screening. *Gut* 2008 Aug;57(8):1166-1176. [doi: [10.1136/gut.2007.146316](#)] [Medline: [18628378](#)]
10. Yusoff HM, Daud N, Noor NM, Rahim AA. Participation and barriers to colorectal cancer screening in Malaysia. *Asian Pac J Cancer Prev* 2012;13(8):3983-3987 [FREE Full text] [doi: [10.7314/apjcp.2012.13.8.3983](#)] [Medline: [23098504](#)]
11. Harny MY, Norwati D, Noor NM, Amry AR. Knowledge and attitude of colorectal cancer screening among moderate risk patients in West Malaysia. *Asian Pac J Cancer Prev* 2011;12(8):1957-1960 [FREE Full text] [Medline: [22292632](#)]
12. Bert F, Giacometti M, Gualano MR, Siliquini R. Smartphones and health promotion: a review of the evidence. *J Med Syst* 2014 Jan;38(1):9995. [doi: [10.1007/s10916-013-9995-7](#)] [Medline: [24346929](#)]
13. Fukuoka Y, Komatsu J, Suarez L, Vittinghoff E, Haskell W, Noorishad T, et al. The mPED randomized controlled clinical trial: applying mobile persuasive technologies to increase physical activity in sedentary women protocol. *BMC Public Health* 2011 Dec 14;11(1):933. [doi: [10.1186/1471-2458-11-933](#)]
14. Vervloet M, van Dijk L, Santen-Reestman J, van Vlijmen B, Bouvy ML, de Bakker DH. Improving medication adherence in diabetes type 2 patients through Real Time Medication Monitoring: a Randomised Controlled Trial to evaluate the effect of monitoring patients' medication use combined with short message service (SMS) reminders. *BMC Health Serv Res* 2011 Jan 10;11(1):5. [doi: [10.1186/1472-6963-11-5](#)]
15. Obermayer JL, Riley WT, Asif O, Jean-Mary J. College smoking-cessation using cell phone text messaging. *J Am Coll Health* 2004;53(2):71-78. [doi: [10.3200/JACH.53.2.71-78](#)] [Medline: [15495883](#)]
16. Haug S, Meyer C, Schorr G, Bauer S, John U. Continuous individual support of smoking cessation using text messaging: a pilot experimental study. *Nicotine Tob Res* 2009 Aug;11(8):915-923. [doi: [10.1093/ntr/ntp084](#)] [Medline: [19542517](#)]
17. Wangberg SC, Årsand E, Andersson N. Diabetes education via mobile text messaging. *J Telemed Telecare* 2016 Dec 02;12(1\_suppl):55-56. [doi: [10.1258/135763306777978515](#)]
18. Scherr D, Zweiker R, Kollmann A, Kastner P, Schreier G, Fruhwald FM. Mobile phone-based surveillance of cardiac patients at home. *J Telemed Telecare* 2016 Jun 22;12(5):255-261. [doi: [10.1258/135763306777889046](#)]
19. Chen Y, Wong J, Ayob A, Othman N, Poh B. Can Malaysian young adults report dietary intake using a food diary mobile application? A pilot study on acceptability and compliance. *Nutrients* 2017 Jan 13;9(1):E62 [FREE Full text] [doi: [10.3390/nu9010062](#)] [Medline: [28098770](#)]
20. Kailas A, Chia-Chin C, Watanabe F. From mobile phones to personal wellness dashboards. *IEEE Pulse* 2010 Jul;1(1):57-63. [doi: [10.1109/mpul.2010.937244](#)]
21. Mohamad Marzuki MF, Yaacob NA, Bin Yaacob NM, Abu Hassan MR, Ahmad SB. Usable mobile app for community education on colorectal cancer: development process and usability study. *JMIR Hum Factors* 2019 Apr 16;6(2):e12103 [FREE Full text] [doi: [10.2196/12103](#)] [Medline: [30990454](#)]
22. Lim K. Technical Report: Evaluation of Effectiveness of Implementation of Komuniti Sihat Perkasa Negara (KOSPEN) Programme in Malaysia?Phase 1. Kuala Lumpur: Institute of Public Health; 2015. URL: <http://iku.moh.gov.my/images/IKU/Document/REPORT/2014/KOSPEN2014.pdf>
23. Idora I. A Study on Knowledge, Attitude and Practice on Colorectal Cancer Screening Among Average Risk Malay Patients Attending Selising Health Clinic, in Department of Family Medicine [dissertation]. Penang, Malaysia: Universiti Sains Malaysia; 2011. URL: [http://eprints.usm.my/37875/1/Pages\\_from\\_Idora\\_Ibrahim-RD\\_surgery.pdf](http://eprints.usm.my/37875/1/Pages_from_Idora_Ibrahim-RD_surgery.pdf)
24. Coe R. It's the effect size, stupid. What effect size is and why it is important. 2002 Presented at: Annual Conference of the British Educational Research Association; September 12-14, 2002; Exeter, England. [doi: [10.4135/9781506326139.n224](#)]
25. Harris AD, McGregor JC, Perencevich EN, Furuno JP, Zhu J, Peterson DE, et al. The use and interpretation of quasi-experimental studies in medical informatics. *J Am Med Inform Assoc* 2006;13(1):16-23 [FREE Full text] [doi: [10.1197/jamia.M1749](#)] [Medline: [16221933](#)]
26. Mosa AS, Yoo I, Sheets L. A systematic review of healthcare applications for smartphones. *BMC Med Inform Decis Mak* 2012 Jul 10;12:67 [FREE Full text] [doi: [10.1186/1472-6947-12-67](#)] [Medline: [22781312](#)]
27. Lu C, Hu Y, Xie J, Fu Q, Leigh I, Governor S, et al. The use of mobile health applications to improve patient experience: cross-sectional study in Chinese public hospitals. *JMIR Mhealth Uhealth* 2018 May 23;6(5):e126 [FREE Full text] [doi: [10.2196/mhealth.9145](#)] [Medline: [29792290](#)]
28. Kingsley R, Peletidi A, Ismail M, Hashim Z, Bandeira P, Bonnah J. Awareness and use of mHealth apps: a study from England. *Pharmacy (Basel)* 2017 Jun 14;5(2):33 [FREE Full text] [doi: [10.3390/pharmacy5020033](#)] [Medline: [28970445](#)]

29. Zanna MP, Rempel JK. Attitudes: A New Look at an Old Concept. 2008. URL: [https://www.researchgate.net/publication/232492035 Attitudes A new look at an old concept](https://www.researchgate.net/publication/232492035_Attitudes_A_new_look_at_an_old_concept)
30. Gardner G. Environmental Problems and Human Behavior. Boston, MA: Allyn and Bacon; 1996. Educational interventions: changing attitudes and providing information URL: <https://www.csub.edu/~craupp/psyc332/Chapter4.pdf>
31. Greiner KA, Born W, Nollen N, Ahluwalia JS. Knowledge and perceptions of colorectal cancer screening among urban African Americans. *J Gen Intern Med* 2005 Nov;20(11):977-983. [doi: [10.1007/s11606-005-0244-8](https://doi.org/10.1007/s11606-005-0244-8)]
32. Sanchez JI, Palacios R, Thompson B, Martinez V, O'Connell MA. Assessing colorectal cancer screening behaviors and knowledge among at-risk Hispanics in southern New Mexico. *J Cancer Ther* 2013 Jul;4(6B):15-25 [FREE Full text] [doi: [10.4236/jct.2013.46A2003](https://doi.org/10.4236/jct.2013.46A2003)] [Medline: [25621179](https://pubmed.ncbi.nlm.nih.gov/25621179/)]
33. Bidouei F, Abdolhosseini S, Jafarzadeh N, Izanloo A, Ghaffarzadehgan K, Abdolhosseini A, et al. Knowledge and perception toward colorectal cancer screening in east of Iran. *Int J Health Policy Manag* 2014;3(1):11-15. [doi: [10.15171/ijhpm.2014.48](https://doi.org/10.15171/ijhpm.2014.48)]
34. Su TT, Goh JY, Tan J, Muhaimah AR, Pigeneswaren Y, Khairun NS, et al. Level of colorectal cancer awareness: a cross sectional exploratory study among multi-ethnic rural population in Malaysia. *BMC Cancer* 2013 Aug 7;13(1):376. [doi: [10.1186/1471-2407-13-376](https://doi.org/10.1186/1471-2407-13-376)]
35. Mohd Suan MA, Mohammed NS, Abu Hassan MR. Colorectal cancer awareness and screening preference: a survey during the Malaysian World Digestive Day Campaign. *Asian Pac J Cancer Prev* 2015;16(18):8345-8349 [FREE Full text] [doi: [10.7314/apjcp.2015.16.18.8345](https://doi.org/10.7314/apjcp.2015.16.18.8345)] [Medline: [26745083](https://pubmed.ncbi.nlm.nih.gov/26745083/)]

## Abbreviations

**ANCOVA:** analysis of covariance

*Edited by A Kushniruk; submitted 14.07.19; peer-reviewed by S Mohd Hairon, WC Su, E Borycki, D Chrimes; comments to author 21.08.19; revised version received 17.11.19; accepted 26.11.19; published 25.02.20.*

*Please cite as:*

*Yaacob NA, Mohamad Marzuki MF, Yaacob NM, Ahmad SB, Abu Hassan MR*

*Effectiveness of the ColorApp Mobile App for Health Education and Promotion for Colorectal Cancer: Quasi-Experimental Study*  
*JMIR Hum Factors* 2020;7(1):e15487

*URL:* <https://humanfactors.jmir.org/2020/1/e15487>

*doi:* [10.2196/15487](https://doi.org/10.2196/15487)

*PMID:* [32130119](https://pubmed.ncbi.nlm.nih.gov/32130119/)

©Nor Azwany Yaacob, Muhamad Fadhil Mohamad Marzuki, Najib Majdi Yaacob, Shahrul Bariyah Ahmad, Muhammad Radzi Abu Hassan. Originally published in *JMIR Human Factors* (<http://humanfactors.jmir.org>), 25.02.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in *JMIR Human Factors*, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

Original Paper

# Influencing Pain Inferences Using Random Numerical Anchoring: Randomized Controlled Trial

Rebecca Elizabeth Lewinson<sup>1</sup>, BSc, MA; Joel D Katz<sup>1</sup>, PhD

Department of Psychology, Faculty of Health, York University, Toronto, ON, Canada

**Corresponding Author:**

Rebecca Elizabeth Lewinson, BSc, MA

Department of Psychology

Faculty of Health

York University

4700 Keele Street

Toronto, ON, M3J 1P3

Canada

Phone: 1 6137911869

Email: [lewinson@yorku.ca](mailto:lewinson@yorku.ca)

## Abstract

**Background:** Numerical anchoring occurs when exposure to a numeric quantity influences a person's subsequent judgment involving other quantities. This could be applicable to the evaluation of pain, where exposure to an unrelated number before the evaluation of pain could influence pain ratings.

**Objective:** This study aimed to determine whether exposure to a random numeric anchor influences subsequent pain intensity ratings of a hypothetical patient.

**Methods:** In this study, 385 participants read a vignette describing a patient with chronic pain before being randomly assigned to one of four groups. Groups 1 and 2 spun an 11-wedge number wheel (0-10), which was, unbeknown to the participants, programmed to stop on a high number (8) or a low number (2), respectively. Group 3 spun a similar letter wheel (A-K), which was programmed to stop on either the letter C or I (control 1). Group 4 did not spin a wheel (control 2). Participants were then asked to rate the patient's pain intensity using a 0 to 10 numeric rating scale.

**Results:** The high-number group rated the patient's pain (median 8, IQR 2) significantly higher than the letter wheel control (median 7, IQR 2;  $P=.02$ ) and the low-number group (median 6, IQR 2;  $P<.001$ ). The low-number group rated the pain significantly lower than controls 1 and 2 (median 7, IQR 2; both  $P=.045$ ).

**Conclusions:** Pain ratings were influenced by prior exposure to a random number with no relevant information about the patient's pain, indicating anchoring had occurred. However, contrary to the traditional definition of anchoring where anchoring occurs even when participants are unaware of the anchor's influence, in this study, the anchoring effect was seen only in participants who believed that the anchor had influenced them. This suggests that anchoring effects could potentially occur among health care providers tasked with evaluating a patient's pain and should be evaluated further.

(*JMIR Hum Factors* 2020;7(1):e17533) doi:[10.2196/17533](https://doi.org/10.2196/17533)

**KEYWORDS**

pain; heuristics; chronic pain; pain inference; numerical anchoring; anchoring effect; mechanical Turk

## Introduction

**Background**

Health care providers are often required to assess and treat pain; however, it is recognized that health care provider ratings of a patient's pain intensity may be biased and inaccurate [1]. Patients, health care providers, and environmental or situational factors contribute to the providers' perception and interpretation

of a patient's pain intensity. Examples of factors that have been shown to be associated with biased provider ratings include past work experience [2], physician gender [3], and availability of medical evidence [4]. In these circumstances, provider ratings often do not align with patient ratings and instead tend to over- or under-estimate the patient's self-report [2,4,5]. It is, therefore, important to consider the processes by which situational factors contribute to biased provider ratings [6].



## Numerical Anchoring

One rarely studied situational factor that appears to contribute to biased health care provider ratings of a patient's pain intensity has been termed *numerical anchoring*. Numerical anchoring reflects a cognitive bias in which prior exposure to a numeric value influences subsequent numerical decisions. For example, Tversky and Kahneman [7] asked participants to estimate the number of African countries in the United Nations before they spun a rigged wheel with numbers between 0 and 100. The wheel was designed to stop at the number 10 or 65. Participants who spun the wheel that stopped on the number 10 estimated that there were 25 African countries in the United Nations, whereas those who spun the wheel that stopped on the number 65 estimated that there were 45 African countries in the United Nations. Thus, exposure to a prior number anchored participants to a lower or higher value and influenced their response to a later unrelated question. It should be noted that what makes these results especially interesting is that given the situational context of a *random* spinning wheel, the numeric anchor was totally unrelated to the estimation task. The anchor could not possibly provide any useful information about the estimation task, and yet it clearly influenced the participants' responses. Many studies have since replicated the findings of Tversky and Kahneman [7], namely, that exposure to higher numeric anchors is associated with higher numeric values in subsequent ratings, whereas exposure to lower numeric anchors is associated with lower numeric values [8-11].

Not all anchors are unrelated to the subsequent decision-making process. Anchoring effects have also been studied in relation to pain but to a much lesser extent. Riva et al [6] demonstrated that there may be an anchoring bias in health care professionals' perceptions of the patient's pain. The researchers recruited 423 health care professionals who read vignettes describing a patient presenting with a headache. Participants randomized to the experimental arm were asked to rate the patient's level of pain immediately after reading the vignette and again after learning of the patient's pain rating, whereas control group participants were asked to rate the patient's level of pain only after learning of the patient's self-reported pain level. Health care professionals in the experimental condition tended to maintain their original pain rating or did not sufficiently alter it after hearing the patient's subjective pain rating. In contrast, those in the control condition tended to agree with the patient's subjective pain rating. The results of the experimental condition indicate that on the one hand, once an initial judgment of pain had been made by the health care professionals, the patient's self-reported pain rating did not influence the professionals' final decision of the patient's pain intensity [6]. On the other hand, under the appropriate groups, the presence of a pain-related numeric anchor in the form of a patient's pain rating may unintentionally influence a health care provider's evaluation of the patient's pain.

## Objectives

Pain-related numeric anchors appear to influence a health care provider's perception of the patient's pain [6]. However, it

remains to be seen whether a *random* numeric anchor, with no relevance to the subsequent estimation task, can influence an individual's perception of someone else's pain. This has relevance to health care providers, as it would indicate that numeric quantities unrelated to the patient may influence how a health care provider evaluates the patient's pain. It would also demonstrate a novel situational factor that operates through a cognitive bias to unwittingly influence the health care provider's estimate of the patient's pain. This study aimed to provide a preliminary assessment of whether exposure to a *random* numeric anchor influences subsequent estimates of a hypothetical patient's pain intensity ratings.

## Hypotheses

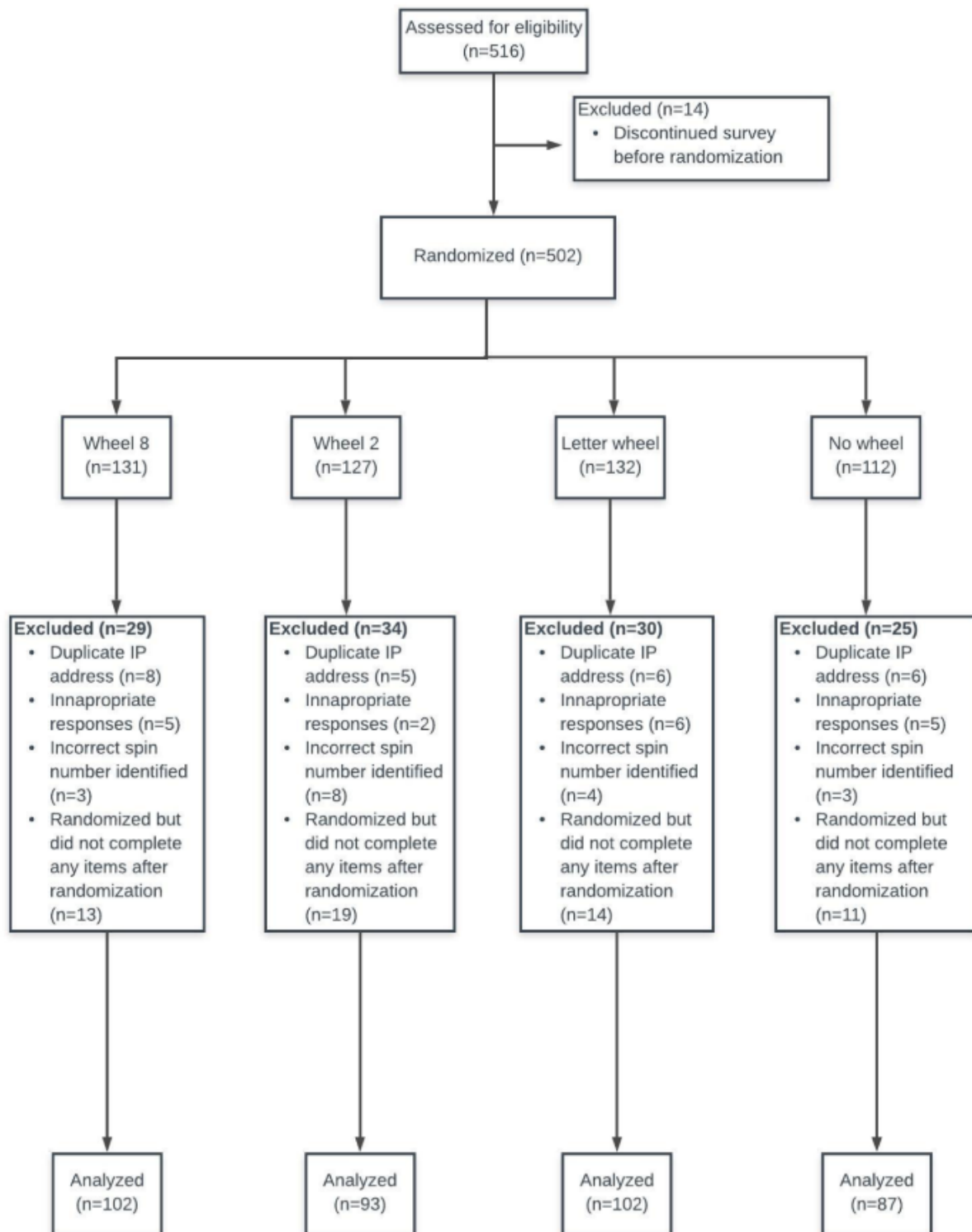
This study tested four hypotheses. The study's primary hypothesis (H1) was that participants who were exposed to a random numerical anchor would be influenced by that anchor, with the median pain rating of participants who were exposed to a high numerical anchor being significantly higher than the median pain rating of those who were exposed to a low numerical anchor. The second hypothesis (H2) was that the two groups of control participants who were not exposed to a numerical anchor would not differ in their initial pain intensity ratings. The third hypothesis (H3) was that participants who were originally not exposed to a numerical anchor would instead anchor to their original pain ratings when asked to rerate the patient's pain, even if they were subsequently exposed to a high anchor. The fourth hypothesis (H4) was that participants who were exposed to a numerical anchor would deny that the anchor influenced their subsequent pain rating and that pain ratings would not differ between those who reported vs those who denied being influenced.

## Methods

### Participants

A total of 516 participants were recruited through Mechanical Turk (MTurk, version May 2018; Seattle, Washington), a Web-based study recruitment website that has millions of users worldwide who participate in Human Intelligence Tasks in exchange for money [12]. The inclusion criterion was that participants must be fluent in English. Recruitment and survey completion occurred over the period of one day in May of 2018. Of the 516 participants, 385 participants (223 men and 162 women; mean age 35.85 years, SD 10.96; range 19-72 years) were included in the final analysis. Figure 1 shows the flowchart depicting participant recruitment. Participants were excluded from analysis for incorrectly identifying the number that they spun, for duplicate IP addresses, for discontinuing the survey after randomization, or for inappropriate responses to open-ended items. Some examples of inappropriate responses included pasting portions of Wikipedia articles or writing responses unrelated to the questions being asked.

Figure 1. Flow chart of participant recruitment.



**Procedures**

This study was reviewed and approved by the York University Research Ethics Board (Human Participants Review Committee certificate #e2018-017). Participants were recruited through MTurk, where the study was entitled “Answer a psychology survey about pain.” Participants would also see the brief description: “Complete psychological questions and complete a small task on the computer.” MTurk users were compensated

US \$1 to participate in the study, which took approximately 20 min to complete. We had no restrictions on the location or prior approval rating of the MTurk users. In addition to the survey responses, we also recorded the MTurk user’s internet protocol addresses to eliminate participants who may have attempted to complete the task more than once using multiple MTurk accounts. At the end of the survey, participants received a random code which they subsequently submitted to MTurk to

receive payment and confirm that they had completed the survey.

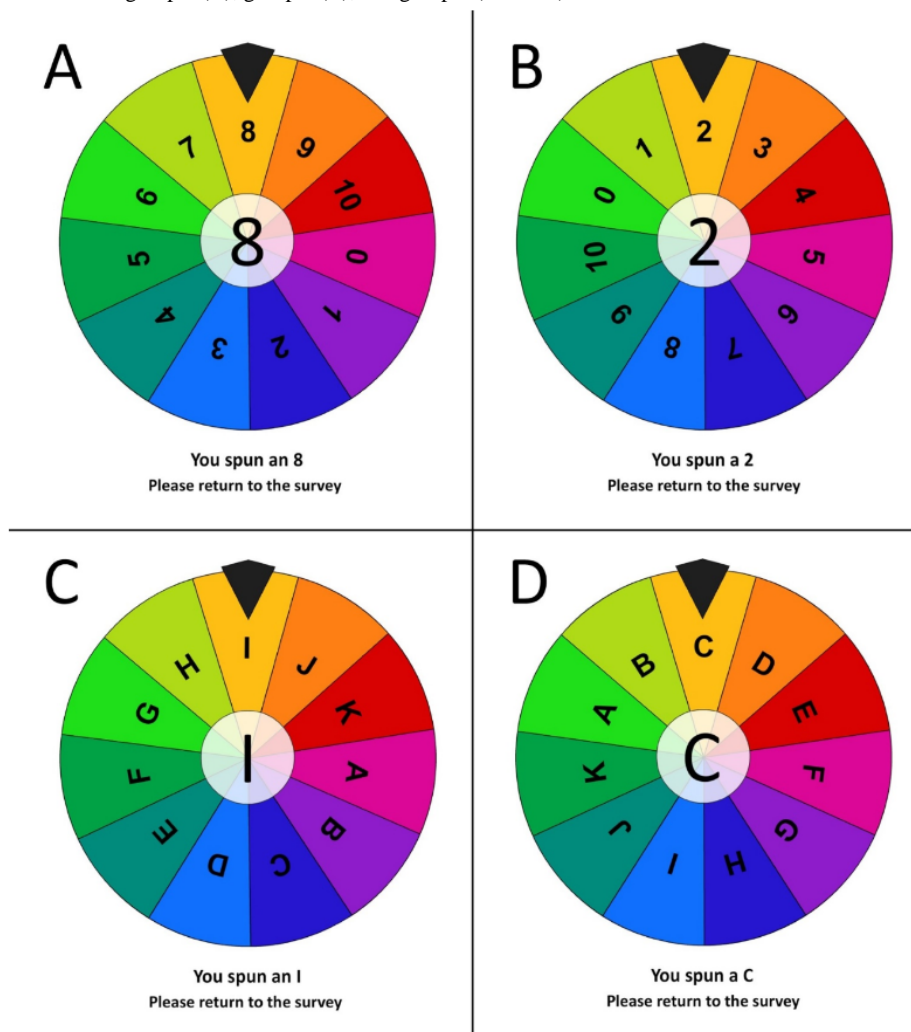
The study was administered using Qualtrics software (version May 2018, Provo, Utah), a Web-based survey management system. Participants were directed to the Qualtrics website, where they first provided informed consent to participate. Each page of the survey consisted of a single question. Participants were unable to return to previous questions after completing an item to maintain the validity of the anchoring process. Participants began the survey by completing demographic questions, including questions regarding their history of pain. We included open-ended questions for participants who endorsed experiencing chronic pain to detail their pain history, which also served as an internal validation question to ensure consistency in participants' responses. Participants who were inconsistent in their responses were removed from the analysis ("inappropriate responses" in Figure 1). Following demographic and pain items, the participants were then randomized into one of four groups using the block randomizer available in Qualtrics. Each group was asked to read the following vignette, which describes the journey of a hypothetical person from injury, postinjury chronic pain, to rehabilitation:

*Steve lives in a modest house on a quiet, tree-lined street very close to a major highway. Last year, as*

*Steve was driving to work one morning, he was involved in a serious collision that nearly cost him his life. He spent months in the hospital and underwent multiple surgeries to repair his leg which was shattered in the crash. After many more months of physical rehabilitation, Steve is left with chronic leg pain and requires a cane to walk especially when the pain acts up. Steve sees his physical therapist once a week for treatment and despite the increased pain he has after each session, he feels the therapy is helping.*

Virtual spinning wheels comprised 11 wedges, were each created using Adobe Flash (version 2018, Adobe, Seattle, Washington) animation for the purposes of this study. Unbeknownst to the participants, these virtual spinning wheels were programmed online to stop at a predetermined value. Participants in group 1 (n=102) and group 2 (n=93) spun a virtual wheel containing the numbers 0 to 10, which was programmed to stop on either a high number (8) or a low number (2), respectively. To control for viewing numeric values, participants in group 3 (n=102) spun a similar wheel containing the letters A to K, which was programmed to stop on either the letter C or I. To control for the spinning of the wheel itself, participants in group 4 (n=87) read the vignette and initially did not spin a wheel. Figure 2 illustrates the wheels used for groups 1, 2, and 3.

Figure 2. Spinning wheels used for group 1 (A), group 2 (B), and group 3 (C and D).



Immediately after spinning the wheel, participants in groups 1 and 2 were asked to recall the number they saw on the wheel and to indicate if they thought the number was higher, lower, or equal to the intensity of pain that the patient in the vignette experiences on a typical day. Participants in group 3 were only asked to recall the letter they saw on the wheel spin. Participants in groups 1, 2, and 3 were then asked to estimate the patient's pain intensity on a typical day using a numeric rating scale (NRS), ranging from 0 (*no pain*) to 10 (*worst possible pain*). Subsequent questions were completed to ascertain whether participants in groups 1, 2, and 3 believed that the anchor had influenced their pain intensity rating of the patient, and if so, in what way. This portion of the survey included a multiple-choice question regarding their belief, with a subsequent open-ended question asking participants to explain why they believed that the anchor did or did not influence their response. Throughout the survey, participants were not given a chance to return to previous questions to maintain the validity of the anchoring process. [Multimedia Appendix 1](#) outlines the full list of anchoring questions that participants were asked.

Participants in group 4 were asked to provide an NRS pain rating immediately after reading the vignette. On providing a pain rating, participants in group 4, who initially did not spin a wheel, were asked to reread the vignette, spin the high-anchor wheel (set to stop on the number 8), and rerate the patient's pain. This was done to determine whether participants in group 4 would anchor to their own original pain rating or if they would be influenced by the numerical anchor.

After completing the experimental task, all participants completed the Pain Catastrophizing Scale (PCS) questionnaire and the Hospital Anxiety and Depression Scale (HADS) questionnaire, as previous studies have indicated that both pain catastrophizing and anxiety or depression can influence pain ratings [13-16].

## Measures

### *Hospital Anxiety and Depression Scale*

HADS measures symptoms of anxiety and depression and has been widely used among both clinical and nonclinical populations [17]. It contains 14 items, consisting of two subscales—seven items comprise the anxiety subscale and seven items comprise the depression subscale. Each item is rated on a 0- to 3-point Likert scale. Higher scores are associated with a higher severity of anxiety or depressive symptoms [17]. Subscale scores range from 0 to 21, where scores equal to or below 7 indicate no clinically relevant findings of depression or anxiety (*normal*). Scores between 8 and 10 are suggestive of a possible mood disorder (*borderline abnormal*), and scores between 11 and 21 are suggestive of the probable presence of a mood disorder (*abnormal*) [15]. HADS has been found to be reliable in detecting states of anxiety and depression and their associated severity. It has good internal consistency ( $\alpha=.82$ ) and has been very well validated in a number of settings [17]. The internal consistency of HADS for this study was 0.91.

### *Pain Catastrophizing Scale*

PCS measures the extent to which an individual experiences pain-related catastrophic thinking, including how much they

think and worry about pain, magnify the amount of pain experienced, and feel helpless toward painful experiences. It consists of 13 items, each rated on a 5-point Likert scale, with scores ranging from 0 to 52. Scores above 30 are considered to be clinically relevant for catastrophizing [14]. Individuals who score higher on PCS also tend to report more intense pain experiences as well as heightened anxiety and depression symptoms [14]. These individuals also tend to use more analgesic medication, have longer hospitalizations, and tend to demonstrate an increase in pain behaviors and pain-related disabilities [14]. PCS has demonstrated good internal consistency ( $\alpha=.87$ ) and has been well validated in both clinical and nonclinical samples [14]. In this study, the internal consistency of PCS was 0.96.

## Sample Size Estimation

Sample size estimation using G\*Power (version 3.1.9.4; University of Düsseldorf, Germany) [18] indicated that 400 participants ( $n=100$  per group) are required for an analysis of variance with an alpha of .05, a power of 0.95, and an effect size of 0.25.

## Data Analysis

Data analyses were conducted with a significance level of .05. Chi-square tests of independence were conducted to determine any significant demographic group differences. A Kruskal-Wallis test was used to determine whether the groups differed in age.

H1 was analyzed using a nonparametric Kruskal-Wallis test, as initial screening of the data revealed a non-normal distribution, necessitating a nonparametric approach to data analysis (see the Results section). The medians of the four groups were compared to determine whether the high and low numerical groups (groups 1 and 2) significantly differed and to determine whether the median pain ratings of groups 3 and 4 were higher than the median pain ratings of group 2 and lower than group 1.

H2, stating that the two control groups (groups 3 and 4) would not significantly differ from one another, was analyzed using a Kruskal-Wallis test.

H3, stating that participants in group 4 would anchor to their original pain ratings rather than be influenced by the high numerical anchor, was analyzed using a Friedman test.

H4, stating that the median pain ratings between participants who believed they had been influenced and participants who believed they had not been influenced by the numerical anchor would not differ, was first analyzed using a chi-square test of independence to determine whether the proportion of participants being influenced by the anchor differed by group. A Kruskal-Wallis test was used to determine if pain intensity ratings were significantly different across groups for those participants who reported they had not been influenced by the anchor and those who felt they had been influenced by the anchor.

## Results

### Demographics

Multimedia Appendix 2 shows the demographic variables for the sample of participants in each of the four groups. The majority of participants self-reported their ethnicity to be white (226/385, 58.7%) or South Asian (97/385, 25.2%). The sample was relatively well educated, with 89.4% (344/385) of participants having at least some postsecondary education. Moreover, 62.6% (241/385) of participants endorsed currently experiencing an ongoing pain problem, with 32.2% (124/385) reporting that they had been diagnosed with chronic pain by a physician. Of the 330 participants on whom longitude and latitude was reported, the majority were located in North America (214/330, 64.8%) or India (95/330, 28.8%), with the remaining participants (21/330, 6.4%) being from South America (8/330, 2.4%), Asia (5/330, 1.5%), Europe (6/330, 1.8%), and Africa (2/330, 0.6%).

### Group Characteristics

Chi-square tests of independence did not demonstrate significant differences between groups in gender, ethnicity, education, or

pain history (see Multimedia Appendix 2). Chi-square tests also did not show significant between groups differences in the number of participants who scored above or below the clinical cutoff for PCS ( $P=.26$ ) or for HADS in the depression ( $P=.51$ ) or anxiety ( $P=.30$ ) subscales or in self-reported chronic pain ( $P=.92$ ). A Kruskal-Wallis test demonstrated that there was no significant difference in groups for age ( $H_3=4.779$ ;  $P=.19$ ). Given that this was a pilot study on the effects of random numerical anchoring on pain inferences, no efforts were made to stratify the sample or analysis.

### Hypothesis 1: The Effects of Numerical Anchoring on Pain Scores

Table 1 shows NRS pain intensity ratings for the four groups.

A visual inspection of the histograms shown in Multimedia Appendix 3 indicated a non-normal distribution of the pain intensity ratings, particularly for group 1. This was confirmed by the Shapiro-Wilk test ( $P<.001$ ,  $P=.01$ ,  $P=.002$ , and  $P=.002$  for groups 1, 2, 3, and 4, respectively). Table 2 shows the frequency of the pain intensity scores across groups, while Figure 3 shows the box plots of pain scores for the four groups.

**Table 1.** Numeric rating scale pain intensity scores for the four groups.

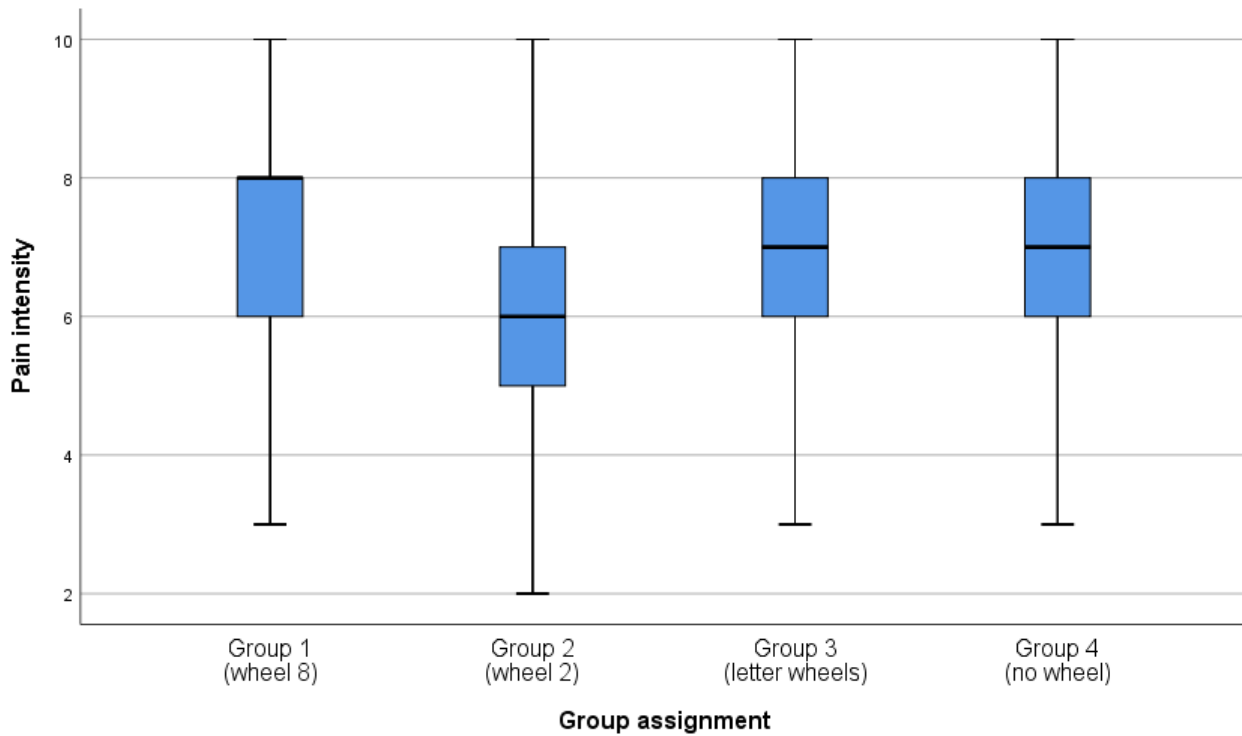
Pain intensity ratings	Wheel 8 (n=102)	Wheel 2 (n=92)	Letter wheel (n=102)	Control (n=87)
Pain intensity rating, median (IQR)	8 (2)	6 (2)	7 (2)	7 (2)
Pain intensity rating after spinning the wheel (group 4 only), median (IQR)	N/A <sup>a</sup>	N/A	N/A	7 (2)

<sup>a</sup>Not applicable.

**Table 2.** Frequency (percent) of pain intensity ratings for the four groups.

Pain intensity rating (0-10)	Wheel 8 (n=102), n (%)	Wheel 2 (n=92), n (%)	Letter wheel (n=102), n (%)	No wheel (n=87), n (%)
0	0 (0.0)	0 (0)	0 (0.0)	0 (0)
1	0 (0.0)	0 (0)	0 (0.0)	0 (0)
2	0 (0.0)	3 (3)	0 (0.0)	0 (0)
3	2 (2.0)	6 (7)	4 (4.0)	1 (1)
4	6 (6.0)	12 (13)	8 (8.0)	5 (6)
5	15 (15.0)	9 (10)	13 (13.0)	7 (8)
6	12 (12.0)	25 (27)	20 (20.0)	18 (21)
7	12 (12.0)	16 (17)	27 (27.0)	26 (30)
8	40 (39.0)	15 (16)	18 (18.0)	20 (33)
9	9 (9.0)	3 (3)	10 (10.0)	8 (9)
10	6 (6.0)	3 (3)	2 (2.0)	2 (2)

**Figure 3.** Boxplots of pain intensity ratings for groups 1-4.



Kruskal-Wallis tests showed a significant difference between the mean ranks of at least one pair of groups in their pain intensity ratings ( $H_3=19.529$ ;  $P<.001$ ). Dunn pairwise tests revealed that the high-wheel group (median 8, IQR 2) rated the patient’s pain significantly higher than the low-wheel group (median 6, IQR 2;  $P<.001$ ) as well as the letter wheel group (median 7, IQR 2;  $P=.02$ ). There were no significant differences in the pain rating between the high-wheel group and group 4, which initially did not spin a wheel ( $P=.325$ ). The low-wheel group rated the patient’s pain significantly lower than both the letter wheel group ( $P=.045$ ) and group 4, which did not spin a wheel (median 7, IQR 2;  $P=.045$ ).

**Hypothesis 2: Median Pain Ratings of Control Groups**

Significant differences were not observed in pain ratings between groups 3 and 4 ( $P=.230$ ).

**Hypothesis 3: Anchoring After an Initial Judgment Had Been Made**

A Friedman test indicated that there were no significant differences in pain ratings for group 4 between time 1, initially after reading the vignette (mean<sub>rank</sub> 1.55), and time 2, after

rereading the vignette and spinning the high-anchor wheel (mean<sub>rank</sub> 1.45;  $\chi^2_1=3.2$ ;  $P=.07$ ).

**Hypothesis 4: Influence of the Numerical Anchor**

A chi-square test of independence demonstrated that there were significant differences between groups in the proportion of participants who believed that their pain intensity rating of the patient had been influenced by the number they spun ( $\chi^2_3=11.0$   $P=.01$ ).

In particular, participants in group 1 were significantly more likely to believe that they had been influenced by the anchor, whereas participants in group 3 were significantly more likely to believe that they had not been influenced by the anchor. In group 1, 35.3% (36/102) of participants endorsed being influenced in comparison with 20% (19/93) of participants in group 2, 16.7% (17/102) of participants in group 3, and 22% (19/87) of participants in group 4 after these participants had spun the high-anchor wheel. Table 3 shows the participants’ perceptions of whether they had been influenced by their group’s corresponding anchor.

**Table 3.** Participants’ perceptions of whether they were influenced by the anchor that they were exposed to.

Influence	Group 1, (n=102), n (%)	Group 2, (n=92), n (%)	Group 3, (n=102), n (%)	Group 4, (n=87), n (%)	Chi-square (df)	P value
Yes	36 (35.2)	19 (21)	17 (16.7)	19 (22)	11.0 (3)	.01 <sup>a</sup>
No	66 (64.7)	74 (80)	85 (83.3)	67 (77)	N/A <sup>b</sup>	N/A

<sup>a</sup>Significance was at an alpha level of .05.

<sup>b</sup>Not applicable.

A Kruskal-Wallis test indicated that among participants who indicated that they had not been influenced by the anchor, there were no significant differences between groups in pain intensity

ratings ( $H_3=7.214$ ;  $P=.07$ ). In contrast, there were significant differences in pain intensity ratings across groups among those

participants who indicated they had been influenced by the anchor ( $H_3=13.644$ ;  $P=.003$ ). Dunn pairwise tests indicated that participants in group 2 (median 6, IQR 5), who spun the low-anchor wheel, rated the patient's pain significantly lower than participants in group 1 (median 8, IQR 1), who spun the high-anchor wheel ( $P=.003$ ), as well as participants in group 4 (median 8, IQR 2), who initially did not spin a wheel but later spun the high-anchor wheel ( $P=.03$ ). Participants in group 1 who indicated they had been influenced by the anchor reported significantly higher pain intensity ratings than participants in group 3 (median 7, IQR 2), who spun a wheel containing letters ( $P=.006$ ). Finally, among those who believed they had been influenced by the anchor, participants in group 4 rated the patient's pain significantly higher than participants in group 3 ( $P=.046$ ). In addition, a Kruskal-Wallis test indicated that after participants in group 4 had spun the high-anchor wheel and rerated the patient's pain, those who indicated that they had been influenced by the anchor tended to rate the patient's pain as being significantly higher than those who believed they had not been influenced by the anchor ( $H_1=5.881$ ;  $P=.02$ ). In addition, among those who believed that they had been influenced by the anchor in group 4, there were no significant differences in pain ratings between time 1 (mean<sub>rank</sub> 1.56) and time 2 (mean<sub>rank</sub> 1.44;  $\chi^2_1$  0.50;  $P=.480$ ).

## Discussion

### Principal Findings

This study examined whether prior exposure to a pain-unrelated, random numerical anchor would influence the participants' ratings of a hypothetical patient's pain intensity. This was done by asking participants to read a vignette depicting a hypothetical patient with chronic pain, before asking the participants to spin a wheel, which was programmed to land on a high numerical anchor (8), a low numerical anchor (2), or a letter (C or I). A fourth group served as a control condition and did not spin a wheel initially before rating the patient's pain intensity but was later asked to spin the high-anchor wheel and rerate the patient's pain.

The findings supported the main hypothesis in that exposure to a numerical anchor influenced the participants' estimations of a hypothetical patient's pain intensity. Participants who spun a high numerical anchor estimated that the hypothetical patient experienced a much higher pain intensity than did the other three groups. In addition, participants in the low numerical anchor condition had the lowest estimation of pain intensity for the hypothetical patient. Importantly, H2 was supported, as there was no difference in pain intensity ratings between participants who spun a wheel containing a letter and the control group that did not spin a wheel, indicating that the spinning of the wheel itself had no effect on pain intensity ratings. These results are in line with studies that have also used a spinning wheel or similar devices to anchor their participants to a random numerical anchor [7,19].

The third hypothesis was supported in that participants who were originally not exposed to an anchor anchored to their original pain rating when asked to rerate the patient's pain, even

when subsequently exposed to the high anchor. Participants did not adjust their second pain rating when asked to rerate the patient's pain. This was expected, given the results from the study by Riva et al [6], who similarly found that health care providers did not significantly adjust their ratings when asked to rerate a patient's pain, even when given additional information about the patient's own subjective pain rating.

The fourth hypothesis, that the median pain ratings in each group would not differ between those who did and did not believe they had been influenced by the anchor, was unsupported. In the high-anchor group, those participants who believed they had been influenced had a significantly higher median pain rating than those who did not believe they had been influenced. Similarly, in the low-anchor group, those participants who believed they had been influenced had a significantly lower median pain rating than those who did not believe they had been influenced. Although the majority of participants in all four groups indicated that they had not been influenced by the anchor, participants who spun a high-anchor wheel were also more likely than any other group to indicate that they had been influenced by the anchor. This may relate to the abovementioned suggestion. The vignette may have depicted a higher pain rating, and after spinning the wheel and rating the patient's pain as higher, the participants may then have inferred that they must have been influenced. This has been discussed later in detail.

The results also demonstrate that participants who acknowledged the anchor's influence on their pain rating were, in fact, influenced. Among participants who reported that they had been influenced by the anchor, the results were very similar to the overall study findings in that participants who spun a high-anchor wheel rated the patient's pain as being more intense than all other groups. In contrast, the median pain ratings for all four groups were not significantly different among those participants who indicated that they had not been influenced by the anchor. In other words, the anchoring effect was seen only in participants who reported being aware of the anchor's influence on their decision making. These results deviate from previous studies that have examined the role of influence on anchoring effects. Although only one study has looked directly at whether participants believed they had been influenced or not [20], both Chapman and Johnson [21] and Quattrone [22] investigated whether being warned would inhibit the anchoring effect. In all three studies, the anchoring effect was present in all participants who were exposed to the anchor, but anchoring effects were consistently stronger in cases where the anchor was relevant or informative to the target. However, in none of the three studies were the anchors completely random, as they were in this study, despite being uninformative. In the study conducted by Chapman and Johnson [21], participants were anchored to a random dollar amount before being asked target questions about whether they would sell a lottery ticket for that dollar amount. Therefore, although the anchor was random and uninformative, it was not irrelevant to the task at hand. In this study, the anchors used were both irrelevant and random. As such, the results of the previous studies by Chapman and Johnson [21], Wilson et al [20], and Quattrone [22] do not provide a concrete description of the role of influence on random numerical anchoring effects.

The effect of influence that was seen in the three anchoring conditions was also seen in participants in group 4, who initially did not spin a wheel. After rereading the vignette, the participants were asked to spin the high-anchor wheel and rerate the patient's pain. Overall, the participants did not change their pain intensity rating after rerating the pain, which was expected. Riva et al [6] found similar results in that their participants did not change their pain rating when asked to reevaluate a patient's pain and instead anchored to their original rating. In this study, however, after spinning the high-anchor wheel, participants in group 4 were also asked whether they believed that the number they spun had influenced their response. Similar to the other three groups in this study, the anchoring effect was seen only in participants who indicated that they had been influenced by the anchor, whereas those who indicated they had not been influenced tended to evaluate the patient's pain as being less intense and remained consistent with their original pain rating. However, given that the overall participant pain ratings for group 4 did not change between the two time points, it is possible that those who indicated that they had been influenced were the participants who had rated the patient's pain as being more intense to begin with.

### Interpretations

By taking into consideration the entire sample, the results suggest that anchoring has occurred. However, when considering the effect of influence, anchoring only appears to have occurred in those who reported that they had been influenced. These findings are contradictory to the traditional definition of anchoring, where anchoring is conceived as an implicit cognitive process and is thought to occur regardless of the participant's awareness of the anchor's influence on their subsequent decisions.

The effect of influence rarely has been studied in anchoring. Given the traditional anchoring template as designed by Tversky and Kahneman [7], where influence is not explored, the majority of anchoring researchers typically have not included a question aimed at determining the role of influence on participants' decision making [23]. However, Wilson et al [20] did explore the role of influence on anchoring. In a series of two studies, participants were asked to rate how much they believed their answers had been influenced by the anchor on a 9-point Likert scale. Similar to this study, the majority of their participants believed that the anchor had no influence on their response, and higher anchor values were associated with more belief of the anchor's influence. However, in both the studies conducted by Wilson et al [20], anchoring effects were found even in those who did not acknowledge the anchor's influence. We were unable to replicate these results in this study, in that, across groups, the anchoring effect was diminished when participants did not believe that the anchor had influenced them. In other words, the anchoring effect was contingent upon the participants' acknowledgment that they had been influenced by the anchor.

It is possible that these influence effects seen across groups are because of a confirmatory search mechanism, as proposed by Chapman and Johnson [21], in that, after being exposed to a numerical anchor, participants focus on reasons why that number

is consistent with the hypothetical patient's pain, rather than on reasons why the anchor may be inconsistent with the patient's pain intensity. In this way, the numerical anchor may have influenced their decision making. It is interesting, however, that participants in group 3 who spun a letter wheel indicated that they had been influenced by the anchor, despite the anchor being a letter value rather than a numeric one and, therefore, holding no possible relevant information for an NRS. This finding may be because of a demand effect [24,25], where participants may have inferred that they would not have been asked to spin a letter or had their attention subsequently drawn to it through the questions asked of them, if the letter was not relevant or informative in some way. Finally, as noted by Nisbett and Ross [26], these influence effects do not necessarily indicate that those who believed that they were influenced, actually were influenced. Rather, it may be that after being exposed to the anchor, the participants inferred that their judgment must have been influenced based on the response that they gave [20].

### Limitations

This study has a number of limitations that are important to consider. Given that the study was completed online, it is possible that participants were not able to fully attend to the vignette, the wheel, or the subsequent questions. As a result, the anchoring effects and influence effects seen may be instead due to the fact that the participants had very recently been exposed to a number rather than the true anchoring effects, ie, if participants were not attending fully, they may have rated the participant's pain according to the numerical anchor they were exposed to simply because of the availability of the anchor in their memory rather than because that is the pain intensity rating they believe the patient experiences or because of anchoring effects. These same participants might subsequently indicate that they had been influenced by the anchor, as their response was based on the number they had been exposed to. Previous studies have demonstrated that data collected through MTurk are as reliable as data collected in a laboratory setting, with the exception of attention paid to the study itself [27,28]. Typically, this limitation is overcome through the use of validity questions to ensure that the participant is attending the study [27]. This study did contain validity questions, such as asking the participants which number or letter they spun; however, it is possible that additional validity questions regarding the vignette would have helped to more effectively screen out inattention.

A second limitation is that this study has no pilot data on the vignette that was used to give a description of the hypothetical patient. As a result, it is unknown what the patient's baseline pain intensity would be rated as. This information would help to ensure that the vignette itself was not a confounding variable. For instance, if the vignette was shown to depict a pain intensity that is higher without the presence of a numerical anchor, it is possible that the influence effect that was seen in the high-anchor group may have been because of participants inferring that they had been influenced, given the pain intensity rating that they had given.

Finally, this study is limited by the fact that it is one of the first anchoring studies to look at the effect of influence on anchoring effects. As such, the questions regarding influence had not been



previously tested and may not have been valid or may have unwittingly created biased responses.

### Strengths

Despite the abovementioned limitations, the study also has a number of strengths. First, with a relatively large sample size of participants who were recruited globally, it is likely that the data are not only reliable but also cross-culturally validated. Participants were diverse in their age, education, ethnicity, and pain history, which also helps to ensure that the data are valid and generalizable. Although participant characteristics are often unreported in studies that use crowdsourcing such as MTurk [29], these data allow this study's findings to be more easily replicated and interpreted. To ensure that the results would be generalizable, MTurk was chosen as the primary recruitment method for this study, as previous studies have shown that the data collected through MTurk is as reliable as data gathered from undergraduate participants [30,31] or other laboratory-sourced participants [32].

Second, this study is strengthened by the presence of two control conditions. In this way, both the effect of spinning a wheel and the effect of having the wheel land on a number could be controlled. This helps to ensure that the anchoring effects seen are, in fact, because of anchoring effects, as opposed to being because of a confounding variable.

Finally, this study is one of the only studies to have looked at the effect of influence and found that anchoring effects were contingent upon the participant's belief that they had been influenced. Anchoring research has been very robust and well established, but there has been very little research on the effect of influence on anchoring and what these findings mean for the definition of anchoring itself. This study's results may help to

better understand anchoring effects as a whole as well as its underlying cognitive pathways.

### Future Directions

Future studies should attempt to clarify the role of influence on numerical anchoring. Namely, attempts should be made to replicate anchoring studies while also considering the participant's perception of influence. It may be that the current definition of anchoring is not suitable if the effects of influence are reliably seen across studies, given that the current definition implies that participants are not aware of the anchor's influence on their judgment. Future studies should also expand on this research about how random numerical anchoring might affect the pain response. It would be interesting to determine whether these same random numerical anchors would affect a participant's judgment of their own pain experience in both acute and chronic pain patients. Future studies may also look at how numerical anchoring may be evident in the health care context in relation to how random numerical anchors may influence a health care provider's judgment and treatment of a chronic pain patient's experience.

### Conclusions

The results of this study are consistent with previous studies of numerical anchoring. Exposure to a high numerical anchor influenced participants' subsequent rating of a hypothetical patient's pain to be higher, whereas exposure to a low numerical anchor influenced participants to rate the patient's pain as lower. However, although the majority of participants across groups did not believe they were influenced by the anchor, the anchoring effect was seen only in participants who did indicate that the anchor had influenced their judgments. Further research is necessary to determine the role of influence on anchoring effects and the applicability of anchoring effects in the health care context.

---

### Acknowledgments

JK is supported by a Canadian Institutes of Health Research Canada Research Chair in Health Psychology at York University. The authors thank M Gail Rudakewich of Synapse Visuals for creating the Adobe Flash animation spinning wheels used in this study.

---

### Conflicts of Interest

None declared.

---

**Editorial notice:** This randomized study was not prospectively registered. The editor granted an exception of ICMJE rules for prospective registration of randomized trials because the risk of bias appears low. The authors' argument for non-registration is as follows: "This study does not meet the ICMJE's definition of a clinical trial in that it does not measure the relationship between a health-related intervention and a health outcome. It uses an intervention to induce cognitive bias in the field of pain inferences similar to those induced in other studies of non-healthcare settings".

---

Multimedia Appendix 1

Anchoring questions.

[[DOCX File, 15 KB](#) - [humanfactors\\_v7i1e17533\\_app1.docx](#) ]

---

Multimedia Appendix 2

Demographic information for the four groups.

[[DOCX File, 20 KB](#) - [humanfactors\\_v7i1e17533\\_app2.docx](#) ]

## Multimedia Appendix 3

Frequency distributions of pain intensity ratings for groups 1-4.

[\[PNG File , 57 KB - humanfactors\\_v7i1e17533\\_app3.png \]](#)**References**

1. Tait RC, Chibnall JT, Kalauokalani D. Provider judgments of patients in pain: seeking symptom certainty. *Pain Med* 2009 Jan;10(1):11-34. [doi: [10.1111/j.1526-4637.2008.00527.x](https://doi.org/10.1111/j.1526-4637.2008.00527.x)] [Medline: [18992039](https://pubmed.ncbi.nlm.nih.gov/18992039/)]
2. Choinière M, Melzack R, Girard N, Rondeau J, Paquin M. Comparisons between patients' and nurses' assessment of pain and medication efficacy in severe burn injuries. *Pain* 1990 Feb;40(2):143-152. [doi: [10.1016/0304-3959\(90\)90065-1](https://doi.org/10.1016/0304-3959(90)90065-1)] [Medline: [2308761](https://pubmed.ncbi.nlm.nih.gov/2308761/)]
3. Weisse CS, Sorum PC, Dominguez RE. The influence of gender and race on physicians' pain management decisions. *J Pain* 2003 Nov;4(9):505-510. [doi: [10.1016/j.jpain.2003.08.002](https://doi.org/10.1016/j.jpain.2003.08.002)] [Medline: [14636818](https://pubmed.ncbi.nlm.nih.gov/14636818/)]
4. Chibnall JT, Tait RC, Ross LR. The effects of medical evidence and pain intensity on medical student judgments of chronic pain patients. *J Behav Med* 1997 Jun;20(3):257-271. [doi: [10.1023/a:1025504827787](https://doi.org/10.1023/a:1025504827787)] [Medline: [9212380](https://pubmed.ncbi.nlm.nih.gov/9212380/)]
5. Marquié L, Raufaste E, Lauque D, Mariné C, Ecoiffier M, Sorum P. Pain rating by patients and physicians: evidence of systematic pain miscalibration. *Pain* 2003 Apr;102(3):289-296. [doi: [10.1016/s0304-3959\(02\)00402-5](https://doi.org/10.1016/s0304-3959(02)00402-5)] [Medline: [12670671](https://pubmed.ncbi.nlm.nih.gov/12670671/)]
6. Riva P, Rusconi P, Montali L, Cherubini P. The influence of anchoring on pain judgment. *J Pain Symptom Manage* 2011 Aug;42(2):265-277 [FREE Full text] [doi: [10.1016/j.jpainsymman.2010.10.264](https://doi.org/10.1016/j.jpainsymman.2010.10.264)] [Medline: [21402456](https://pubmed.ncbi.nlm.nih.gov/21402456/)]
7. Tversky A, Kahneman D. Judgment under uncertainty: heuristics and biases. *Science* 1974 Sep 27;185(4157):1124-1131. [doi: [10.1126/science.185.4157.1124](https://doi.org/10.1126/science.185.4157.1124)] [Medline: [17835457](https://pubmed.ncbi.nlm.nih.gov/17835457/)]
8. Furnham A, Boo HC. A literature review of the anchoring effect. *J Socio Econ* 2011 Feb;40(1):35-42. [doi: [10.1016/j.socecon.2010.10.008](https://doi.org/10.1016/j.socecon.2010.10.008)]
9. Blankenship KL, Wegener DT, Petty RE, Detweiler-Bedell B, Macy CL. Elaboration and consequences of anchored estimates: an attitudinal perspective on numerical anchoring. *J Exp Soc Psychol* 2008;44(6):1465-1476. [doi: [10.1016/j.jesp.2008.07.005](https://doi.org/10.1016/j.jesp.2008.07.005)]
10. Wegener DT, Petty RE, Detweiler-Bedell BT, Jarvis WG. Implications of attitude change theories for numerical anchoring: Anchor plausibility and the limits of anchor effectiveness. *J Exp Soc Psychol* 2001 Jan;37(1):62-69. [doi: [10.1006/jesp.2000.1431](https://doi.org/10.1006/jesp.2000.1431)]
11. Kahneman D. *Thinking, Fast And Slow*. Canada: Anchor Canada; 2013.
12. Goodman JK, Cryder CE, Cheema A. Data collection in a flat world: the strengths and weaknesses of Mechanical Turk samples. *J Behav Dec Making* 2013 Jul;26(3):213-224. [doi: [10.1002/bdm.1753](https://doi.org/10.1002/bdm.1753)]
13. Quartana PJ, Campbell CM, Edwards RR. Pain catastrophizing: a critical review. *Expert Rev Neurother* 2009 May;9(5):745-758 [FREE Full text] [doi: [10.1586/ern.09.34](https://doi.org/10.1586/ern.09.34)] [Medline: [19402782](https://pubmed.ncbi.nlm.nih.gov/19402782/)]
14. Sullivan MJ, Bishop SR, Pivik J. The pain catastrophizing scale: development and validation. *Psychol Assess* 1995;7(4):524-532. [doi: [10.1037//1040-3590.7.4.524](https://doi.org/10.1037//1040-3590.7.4.524)]
15. Snaith RP. The hospital anxiety and depression scale. *Health Qual Life Outcomes* 2003 Aug 1;1:29 [FREE Full text] [doi: [10.1186/1477-7525-1-29](https://doi.org/10.1186/1477-7525-1-29)] [Medline: [12914662](https://pubmed.ncbi.nlm.nih.gov/12914662/)]
16. Gerrits MM, van Marwijk HW, van Oppen P, van der Horst H, Penninx BW. Longitudinal association between pain, and depression and anxiety over four years. *J Psychosom Res* 2015 Jan;78(1):64-70. [doi: [10.1016/j.jpsychores.2014.10.011](https://doi.org/10.1016/j.jpsychores.2014.10.011)] [Medline: [25466385](https://pubmed.ncbi.nlm.nih.gov/25466385/)]
17. Bjelland I, Dahl AA, Haug TT, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res* 2002 Feb;52(2):69-77. [doi: [10.1016/s0022-3999\(01\)00296-3](https://doi.org/10.1016/s0022-3999(01)00296-3)] [Medline: [11832252](https://pubmed.ncbi.nlm.nih.gov/11832252/)]
18. Faul F, Erdfelder E, Buchner A, Lang A. Statistical power analyses using G\*Power 3.1: tests for correlation and regression analyses. *Behav Res Methods* 2009 Nov;41(4):1149-1160. [doi: [10.3758/BRM.41.4.1149](https://doi.org/10.3758/BRM.41.4.1149)] [Medline: [19897823](https://pubmed.ncbi.nlm.nih.gov/19897823/)]
19. Mussweiler T, Englich B, Strack F. Anchoring effect. In: Pohl RF, editor. *Cognitive Illusions: A Handbook on Fallacies and Biases in Thinking, Judgement and Memory*. London, UK: Psychological Press; 2004:183-200.
20. Wilson TD, Houston CE, Etling KM, Brekke N. A new look at anchoring effects: basic anchoring and its antecedents. *J Exp Psychol Gen* 1996 Dec;125(4):387-402. [doi: [10.1037//0096-3445.125.4.387](https://doi.org/10.1037//0096-3445.125.4.387)] [Medline: [8945789](https://pubmed.ncbi.nlm.nih.gov/8945789/)]
21. Chapman GB, Johnson EJ. Anchoring, activation, and the construction of values. *Organ Behav Hum Decis Process* 1999 Aug;79(2):115-153. [doi: [10.1006/obhd.1999.2841](https://doi.org/10.1006/obhd.1999.2841)] [Medline: [10433900](https://pubmed.ncbi.nlm.nih.gov/10433900/)]
22. Quattrone GA, Lawrence CP, Finkel SE, Andrus DC. *Explorations in Anchoring: The Effects of Prior Range, Anchor Extremity, and Suggestive Hints*. Stanford, California: Stanford University; 1984.
23. Chapman GB, Johnson EJ. Incorporating the irrelevant: anchors in judgments of belief and value. In: Gilovich T, Griffin D, Kahneman D, editors. *Heuristics and Biases: The Psychology of Intuitive Judgment*. London, UK: Cambridge University Press; 2002:120-138.
24. Grice H. Logic and conversation. In: Cole P, Morgan J, editors. *Speech Acts*. New York: Academic Press; 1975:41-58.
25. Schwarz N. Judgment in a social context: biases, shortcomings, and the logic of conversation. *Adv Exp Soc Psychol* 1994;26:123-162. [doi: [10.1016/s0065-2601\(08\)60153-7](https://doi.org/10.1016/s0065-2601(08)60153-7)]

26. Nisbett RE, Ross L. Human Inference: Strategies and Shortcomings of Social Judgment. New Jersey, United States: Prentice-Hall; 1980.
27. Paolacci G, Chandler J, Ipeirotis PG. Running experiments on amazon mechanical turk. *Judgm Decis Mak* 2010;5(5):411-419 [[FREE Full text](#)]
28. Paolacci G, Chandler J. Inside the Turk: understanding Mechanical Turk as a participant pool. *Curr Dir Psychol Sci* 2014;23(3):184-188. [doi: [10.1177/0963721414531598](https://doi.org/10.1177/0963721414531598)]
29. Créquit P, Mansouri G, Benchoufi M, Vivot A, Ravaud P. Mapping of crowdsourcing in health: systematic review. *J Med Internet Res* 2018 May 15;20(5):e187 [[FREE Full text](#)] [doi: [10.2196/jmir.9330](https://doi.org/10.2196/jmir.9330)] [Medline: [29764795](https://pubmed.ncbi.nlm.nih.gov/29764795/)]
30. Buhrmester M, Kwang T, Gosling SD. Amazon's Mechanical Turk: A new source of inexpensive, yet high-quality, data? *Perspect Psychol Sci* 2011 Jan;6(1):3-5. [doi: [10.1177/1745691610393980](https://doi.org/10.1177/1745691610393980)] [Medline: [26162106](https://pubmed.ncbi.nlm.nih.gov/26162106/)]
31. Bartek MA, Truitt AR, Widmer-Rodriguez S, Tuia J, Bauer ZA, Comstock BA, et al. The promise and pitfalls of using crowdsourcing in research prioritization for back pain: cross-sectional surveys. *J Med Internet Res* 2017 Oct 6;19(10):e341 [[FREE Full text](#)] [doi: [10.2196/jmir.8821](https://doi.org/10.2196/jmir.8821)] [Medline: [28986339](https://pubmed.ncbi.nlm.nih.gov/28986339/)]
32. Saunders DR, Bex PJ, Woods RL. Crowdsourcing a normative natural language dataset: a comparison of Amazon Mechanical Turk and in-lab data collection. *J Med Internet Res* 2013 May 20;15(5):e100 [[FREE Full text](#)] [doi: [10.2196/jmir.2620](https://doi.org/10.2196/jmir.2620)] [Medline: [23689038](https://pubmed.ncbi.nlm.nih.gov/23689038/)]

## Abbreviations

**HADS:** Hospital Anxiety and Depression Scale

**MTurk:** Mechanical Turk

**NRS:** numeric rating scale

**PCS:** Pain Catastrophizing Scale

*Edited by G Eysenbach; submitted 18.12.19; peer-reviewed by N Shah; comments to author 15.01.20; revised version received 23.01.20; accepted 26.01.20; published 09.03.20.*

*Please cite as:*

*Lewinson RE, Katz JD*

*Influencing Pain Inferences Using Random Numerical Anchoring: Randomized Controlled Trial*

*JMIR Hum Factors* 2020;7(1):e17533

URL: <http://humanfactors.jmir.org/2020/1/e17533/>

doi: [10.2196/17533](https://doi.org/10.2196/17533)

PMID: [32149719](https://pubmed.ncbi.nlm.nih.gov/32149719/)

©Rebecca Elizabeth Lewinson, Joel D Katz. Originally published in JMIR Human Factors (<http://humanfactors.jmir.org>), 09.03.2020. This is an open-access article distributed under the terms of the Creative Commons Attribution License (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Human Factors, is properly cited. The complete bibliographic information, a link to the original publication on <http://humanfactors.jmir.org>, as well as this copyright and license information must be included.

---

Publisher:  
JMIR Publications  
130 Queens Quay East.  
Toronto, ON, M5A 3Y5  
Phone: (+1) 416-583-2040  
Email: [support@jmir.org](mailto:support@jmir.org)

---

<https://www.jmirpublications.com/>