

Development of the iManage SCD mobile health application for transition

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ABSTRACT

Objective: This paper outlines the design and implementation of iManage SCD, a self-management mobile health application for adolescents and young adults (AYA) with sickle cell disease (SCD) during transition from pediatric to adult health care.

Methods: The Integrate, Design, Assess, Share (IDEAS) framework, emphasizing user insights, iterative design, rigorous assessment, and knowledge sharing, guided the development process. The design team consisted of researchers, psychologists, physicians, social workers, AYA with SCD, and parents of AYA with SCD (n = 16) across three states. Qualitative focus groups and interviews were conducted and analyzed using thematic analysis across the integrate and design phases. Point of use feedback from AYA with SCD was used to assess feasibility and acceptability.

Results: The development process was centered around tenants of the Social-ecological Model of Adolescent and Young Adult Readiness to Transition. Development integrated multidisciplinary perspectives, fostering a person-centered approach. The iterative design process involved collaboration with a digital health firm, Agency39A. Health equity and implementation considerations were addressed at individual, community, and healthcare system levels. Themes that emerged from focus groups with AYA, clinicians, and researchers in the integrate and design phases of development included recommendations for content and user experience features.

Conclusions: iManage SCD emerges as a comprehensive, user-friendly mobile health application, incorporating theoretical principles and direct user input. The development process demonstrated feasibility and acceptability, and the paper discusses dissemination strategies for the Community Health Workers and Mobile Health Programs to Help Young Adults with SCD Transition to Using Adult Healthcare Services (COMETS) study.

1. Introduction

Sickle cell disease (SCD) is the most prevalent inherited hematological disorder in the United States and affects approximately 100,000 individuals.¹ With advances in medical interventions, most adolescents and young adults (AYA) with SCD are now surviving well into adulthood.¹ More than 95 % of babies born with sickle cell disease survive and carry this disease into adulthood.² This emphasizes the critical need for targeted self-management interventions during the transition from

pediatric to adult healthcare.¹

For AYA with SCD, this transition period poses unique challenges, marked by increased disease severity, disengagement from healthcare clinicians, and increased morbidity and mortality.^{2–4} This is also a time of increasing autonomy in managing health.² Recognizing the importance of fostering self-management skills during this vulnerable period, there is a profound need for tools that support AYA with SCD to actively manage their health and navigate the complexities of transitioning to independence. Including AYA patient partners is key to optimizing such

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tools so that they are appealing and engaging to the end user. Thus, the development process demands collaboration with AYA with SCD – ensuring the intervention’s relevance, feasibility, and impact.

People who belong to marginalized racial and ethnic communities, male gender, or those from lower socioeconomic backgrounds often encounter significant obstacles during transitions and exhibit lower rates of transfer to adult healthcare providers.^{5,6} Consequently, they face heightened health issues.^{5,6} It is imperative for research to prioritize breaking down transition barriers for all AYA while also striving to enhance health equity among different demographic groups. Given the growing reliance on smartphones among AYA, including those from racially and ethnically diverse and marginalized backgrounds, mobile health applications (mHealth apps) are promising tools for chronic disease management, such as SCD.^{7,8}

AYA, particularly those living with chronic diseases, actively seek health-related information online and engage with health promotion and disease management apps.⁹ Existing mobile health apps have provided comprehensive self-management of patients with SCD by focusing on medication adherence and pain relief.¹⁰ However, many SCD mHealth apps often fall short in seamlessly integrating user feedback throughout the entire development process, from ideation to prototype testing. Furthermore, a prevalent tendency neglects active user involvement in shaping both the implementation and evaluation processes. The exclusion of behavior change theory, strategies to address social inequities, and the absence of using a person-based approach to development and implementation limits the utility and impact of these mHealth apps.¹¹

This paper details the development journey of iManage SCD, a self-management mHealth app for AYA with SCD, presenting an innovative approach to facilitating SCD management. Notably, the iManage SCD app stands out in its amalgamation of a person-centered iterative design process, comprehensive planning for implementation, and deliberate incorporation of strategies to address health inequities. Additionally, preferred features of mobile health apps geared for AYA with SCD and other chronic diseases were incorporated, including having a centralized, digital, tool for keeping track of medical history.¹² The hypothesis driving the mobile app development process is rooted in the belief that employing such an approach in designing an mHealth app for AYA will yield high levels of feasibility and acceptability, setting it apart in the landscape of health interventions.

2. Materials and methods

The development of the base app for SCD Manage (iManage) has been described.¹³ This next iteration of the iManage SCD app development process was similar to the initial one in integrating user feedback across phases of development but unique relative to the previous process in that it was more extensive (included feedback from more AYA, clinicians and researchers), incorporated a formal digital health and health equity frameworks, and focused on implementation at the patient and healthcare system levels. For this iteration, the team drew upon the Integrated Design and Assessment of digital health Solutions (IDEAS) framework. IDEAS is a framework that can be used to help integrate principles of behavioral theory, design thinking, user-centered design, evaluation, and dissemination into development of effective digital interventions. The following structured four-step approach guided development of iManage SCD (see Fig. 1): 1) Integrate user insights, 2) Design iteratively, 3) Assess vigorously, and 4) Share. Application of this framework ensured a focus on behavior change and person-centric design. Further, we included an in-depth exploration of implementation barriers and strategies, and constructs that address inequities at the intervention, individual, community, and healthcare clinician levels.¹⁴

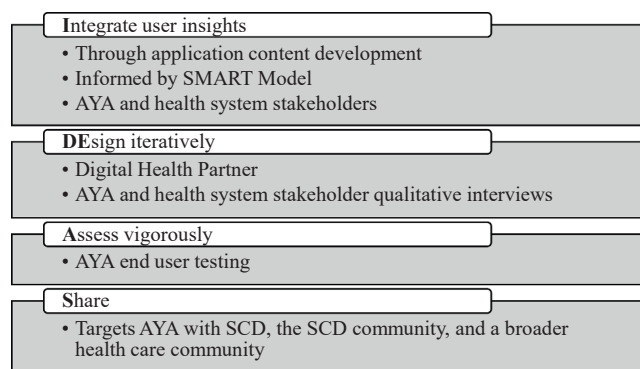


Fig. 1. Application of IDEAS framework to iManage SCD.

2.1. Phase I: integration of user insights through mHealth app content development

The IDEAS framework’s first step involved the systematic integration of user insights to develop content. With the goal of developing an mHealth app that specifically addresses disease self-management for AYA during transition, this initial phase extensively utilized the SMART model – the Social-ecological Model of Adolescent and Young Adult Readiness to Transition – as a conceptual framework. This model states that there are pre-existing factors and modifiable factors of patients, parents, and clinicians alike that contribute to transition readiness. Modifiable factors that should be targeted to help improve transition include knowledge, skills, confidence (or self-efficacy), and social supports to support chronic disease management. MHealth content development focused on two SMART modifiable variables, (1) disease knowledge and (2) self-management skills/efficacy.¹⁵ These elements of the SMART model were targeted because patients, parents, and clinicians of those with SCD agree that the ability to independently perform chronic disease self-management is critical to staying healthy during this turbulent transition period.^{16,17} Self-management behaviors refer to daily, self-motivated, collaborative activities to manage symptoms. Self-management behaviors specific to SCD include self-awareness, emotional support, nutrition, hydration, avoidance of drinking alcohol, smoking and drugs; adherence to clinician orders, such as taking daily hydroxyurea or obtaining regular transfusion or chelation therapy.

Weekly intervention development sessions, facilitated through videoconferencing (Zoom), provided a collaborative platform for in-depth discussions about content and feedback gathering. Each session was centered around the tenants of the SMART Model, and group discussions were facilitated to identify relevant competencies, materials, and key messages for each tenant identified. These sessions engaged a diverse group of collaborators (here forth called the “design team”), including researchers, psychologists, physicians, social workers, AYA with SCD, and parents of AYA with SCD across three academic health systems located in New York, Pennsylvania, and Ohio. AYA design team members ranged in age from 20 to 30 years and had recent personal experience with the transition process. There were two categories of collaborator sessions, “internal” (co-investigator collaborator only) and “external” (all collaborator). Sessions were recorded and transcribed verbatim for review.

Thematic analysis, utilizing NVIVO13, was employed for the verbatim transcriptions of the content development sessions. Two trained independent qualitative reviewers, who were not part of the design team, directed content analysis, ensuring consistency and accuracy within identified themes.¹⁸

2.2. Phase II: iterative design process

Our digital health partner for app development, Agency39A, was

selected after an open request for proposals (RFP) process. The RFP required prospective agencies to propose design and implementation solutions in four main domains: (1) app features (i.e., discussion boards, gamification, pain and mood tracking), (2) technical architecture, (3) platform security, (4) data infrastructure and export tools. The team interviewed the top two applicants and then research team leadership scored the proposal and interview responses based on the criteria listed above. The final agency was chosen via a consensus meeting. A consensus meeting led to the selection of Agency39A whose mission is to create user-focused solutions through research, design, and technology. Their approach is guided by deep collaboration and human-centered approaches, and they had prior experience working with large, academic, health systems.

Agency39A led iterative design sessions, user experience testing, and technical development. Design team interviews, conducted with clinicians, researchers, and AYA with SCD, informed design sprints, prototypes, and refinement. Interviews explored aspects of the patients’ digital-self and how they: use digital tools in everyday life; communicate with friends, family, and specific communities; learn and discover new information; manage pain and improve well-being. Interviews were also used to validate the utility of current or proposed app features, identify areas for new or potential features, and create a “wish list” of features out of scope for this project.

All interviews were either held via phone or video were recorded, and transcribed verbatim. A semi-structured interview guide was created by Agency39A and the design team to understand what design and user experiences elements should be included in iManage SCD. The interview guide consisted of questions in the following domains: 1) Treatment (ex., “how do you keep track of your doctors’ appointments”), 2) Pain (ex., “what types of things to do you to manage pain related to your SCD?”), 3) Knowledge (ex. “when you need information about SCD or managing your SCD, where do you look?”), 4) Lifestyle and Goals (ex., “How has your approach or methods to managing SCD changed from your teenage years through today?”), 5) Communication and Support (ex., How do you communicate with friends and family about SCD?), and 6) Envisioning the future (ex., “Looking back on your experience in your teens, what would have been one thing you wish you had to help your day-to-day?”). Thematic analysis was used to identify patterns within these data. Themes were extrapolated from identified patterns that allowed for deeper understanding of collaborator input on user experience and design features of iManage SCD.

Using themes identified via these interviews, we connected empirically-validated principles of behavior change including extrinsic motivation, contingent reward, fixed ratio reinforcement, differential reinforcement, triggers, and effort/motivation to identify app features and improve engagement.^{19–25}

To address implementation barriers identified in the interviews, the following considerations identified in Kowatsch et al.²⁶ were adopted²⁶: 1) User Expectations for Technology: Understanding and aligning with user expectations regarding technology to ensure a seamless and user-friendly experience. This consideration was adopted through obtaining formal and information feedback from collaborators. 2) Disease Characteristics Impacting Use: Addressing specific disease-related characteristics, such as pain episodes, that might influence app utilization. This consideration was addressed through the integration of encouraging messages reminding users to engage with the mHealth app, the integration of pain and mood trackers, and the inclusion of message boards specific to conversations about pain episodes. 3) Cultural and Developmental Norms for App Use: Recognizing and accommodating cultural and developmental norms related to app usage, including the need for reminders at specific times due to competing activities. This consideration led to the inclusion of push notifications for medication refill reminders. 4) Social Support Integration: Incorporating features that foster social support, exemplified by the inclusion of a discussion feature to promote engagement. 5) Compatibility with Existing Healthcare Technology: Ensuring synergy with existing healthcare

technology, such as integration with platforms like MyChart, to streamline user interactions through consistent communication with health systems to proactively plan for integration where feasible post-clinical trial. And 6) Future Funding and IT Support: Proactively planning for future sustainability by addressing considerations like securing funding and outlining strategies to ensure continued IT support post-trial.

2.3. Phase III: assess vigorously

This phase focused on evaluating the feasibility and acceptability of the iManage SCD app. Feasibility assessments encompassed technical compatibility and user interaction in simulated real-world scenarios. Technical feasibility involved evaluating the app’s compatibility with various devices and operating systems. User interaction feasibility focused on the ease of use, intuitiveness, and accessibility of the mHealth app for individuals with varying levels of technological proficiency. Acceptability evaluations through point-of-use feedback and collaborator report provided a comprehensive understanding of user satisfaction and further areas for refinement. This thorough assessment plan was intricately connected with the larger Community Health Worker and Mobile Health Programs to Help Young Adults with Sickle Cell Disease Transition to Using Adult Healthcare Services (COMETS) Trial. The COMETS Trial is a 3-arm pragmatic randomized trial comparing the effectiveness of iManage SCD to a peer community health worker to usual care on health-related quality of life for AYA with SCD.^{27,28}

2.4. Phase IV: share

Because this app was created by AYA with SCD and their clinicians, dissemination of the mHealth app has the potential to improve care for AYA with SCD nationally. Thus, the app development team crafted a strategic dissemination plan targeting AYA with SCD and the SCD community, health care teams, the research community, and the larger healthcare community.

See [Table 1](#) for a description of methods used by project phase.

2.5. Data availability

All aspects of this project were reviewed by the Institutional Review Board at Northwell Health and deemed not human subjects research. All data are available upon request.

Table 1
Methods used across iManage SCD phase.

| Phase | Goal | Methodology |
|-----------|---|---|
| Phase I | To develop iManage SCD app content in accordance with both conceptual frameworks and user insight. | Conceptual basis of SMART Model; Focus group iterative design sessions; thematic analysis |
| Phase II | To refine iManage SCD app user experience and integrate end user design preferences in accordance with theoretical constructs and user insight. | Principles of extrinsic motivation, contingent reward, fixed ratio reinforcement, differential reinforcement; in-depth interviews with collaborators; thematic analysis |
| Phase III | To assess feasibility and acceptability of iManage SCD | Point of use feedback |
| Phase IV | To assess the comparative effectiveness of iManage SCD on health-related quality of life and disease self-management for AYA with SCD | Pragmatic randomized trial (PCORI-funded COMETS study) |

3. Results

3.1. Phase I: integration of user insights through mHealth app content development

In Phase I, fourteen design team meetings transpired, comprising 8 internal sessions and 6 external engagements with AYA with SCD. Each meeting was one hour in duration. This collaborative effort involved sixteen design team members total, including six AYA design team members and ten co-investigator design team members. AYA design team members ranged in age from 20 to 30 years. During discussions, it became evident that health system limitations would impede the mHealth app’s effectiveness due to the slow adoption of patient-facing technology by health systems and little knowledge and guidance by health system IT staff on integration of mHealth apps into current IT infrastructure. It was also recognized that maintaining the app independent of the health care system would offer distinct advantages. Consequently, the decision was made to keep the app autonomous, available for download from app stores rather than integrating it into the health system.

Sessions contributed to the development of mHealth app content based on SMART model tenants. The tenants of self-management, self-efficacy, and SCD knowledge were further broken down into competencies based on attendee consensus. Each competency served as a section in the mHealth app and was accompanied by questions to better understand the user’s current level of engagement with the competency, materials to help educate the user on the competency, and key messages delivered within the mHealth app. For example, one competency identified in the self-management tenant was tracking and managing pain. One question asked in the app to gauge this competency is “Trying to keep track of your pain and when it changes? Trying to figure out how stress is affecting you or your SCD symptoms?”. Responses to this question navigate users to app features, including psychoeducational materials and the mHealth app’s pain and mood tracker. See Table 2.

The ensuing thematic analysis delved into AYA content-related preferences and needs for self-management. The overarching theme of ‘self-management’ encapsulated the broader goal of empowering AYA to take an active role in their health management. The analysis uncovered alignment and misalignment between researchers and AYA content needs providing nuanced insights into potential areas for improvement in the mHealth app’s content. For example, the design team was aligned on the key theme of accountability/engagement in iManage SCD. Both groups independently mentioned that AYA with SCD may find little reason to access the standalone iManage SCD app without reminders or encouragement. The group identified and agreed that this barrier was the most important to address as part of development and design. Subsequently, the design team agreed on strategies to address this, including sending reminders to AYA to log into the app 1–2 times per week. One item within the self-management theme that AYA design team members brought up that was not later discussed with co-investigators alone was related to the domains of content delivered through iManage SCD. The collaborator mentioned they and their peers are most interested in content related to learning to live independently and managing pain and stated they are less interested in content related to educational and vocational planning. However, co-investigators believed that content related to educational and vocational planning was imperative and aligned with empirical evidence supporting inclusion of this content. Therefore, specific content about educational and vocational planning was included in iManage SCD.

3.2. Phase II: iterative design process

Eight design team interviews offered insights into various dimensions of AYA with SCD experiences. Five design team members identified as individuals with SCD, including one participant who identified as both someone with SCD and a researcher. All individuals

Table 2
SMART model tenants mapped to mHealth app competencies and features.

| SMART model tenant | Competency | App features |
|--------------------|--|--|
| Self-Management | Tracking health issues | Medical summary |
| | Tracking and managing pain | Pain tracker; challenge to track pain consecutively for four weeks; app chapters on pain management strategies |
| | Managing stress/mood | Mood tracker; challenge to track mood for four consecutive weeks |
| Self-Efficacy | Scheduling appointments | App chapters dedicated to communication with clinicians; section to identify and record contact information of care team |
| | Answering questions about insurance | App chapter dedicated to insurance |
| | Preparing for appointments | App chapter dedicated to aspects of appointment preparation; Notes section encouraging record of questions for care team |
| | Communicating (engaging) with healthcare clinicians/team | App chapter dedicated to questions user want to ask during appointments; Notes section encouraging record of questions for care team |
| | Ordering medications (OTC vs. prescription: non-opioid and opioid) | App chapters on taking medications as prescribed and managing medications; app medication log; app medication refill reminders |
| | | App chapter on the cause of SCD |
| SCD Knowledge | Basic, relevant genetics of SCD | App chapters on the ways in which SCD may impact health now and in the future and the importance of recognizing symptoms and triggers; medical summary; pain and mood trackers |
| | Common complications of SCD | |
| | Types of treatments and risks when non-adherent | |
| | General healthy behaviors for patients w/ SCD | App chapters on alcohol and tobacco use, pain crises, and sexuality; exercise and water trackers. |

with SCD identified as Black and ranged in age from 20 to 30 years. The remaining three design team members identified as clinical staff who routinely care for AYA with SCD as they transition from pediatric to adult care. Their professional experiences included transition coordinator, psychologist, and physician. Interviews ranged in duration from 45 to 60 min. Thematic analysis across participant interviews, inclusive of both AYA with SCD and clinical staff, revealed the following themes:

- 1) Social Behaviors and Entertainment: This theme illuminated the intricate interplay between individuals’ social context, current social medical and entertainment preferences, and their health management strategies. Further, it emphasized the pivotal role of a supportive social environment in fostering well-being and resilience. This theme underscored the importance of interactive and user-friendly features and the need for accountability to instill a sense of responsibility among users.
- 2) Treatment, Pain Impact, and Pain Management: This theme underscored the diverse perspectives by AYA design team members and clinicians on medical interventions and healthcare practices, emphasizing the need for user-friendly interfaces, individualized treatment plans, and tailored pain management strategies. It emphasized that there should not be prescriptive sections dedicated

- to specific types of treatments and pain management strategies. Rather, there should be sections dedicated to educating users on these topics and places within the app for individuals to record their own treatments and pain management plans.
- 3) SCD Knowledge and Transition: This theme emphasized the frequently with which design team members reported using social media to find and share valuable information about SCD. Some design team members reported that their health care clinicians were the source of the greatest amount of information about SCD. They also confirmed that most web-based information is largely ignored and sometimes distrusted.
- 4) Lifestyle and Goals: This theme emphasized the necessity for the mHealth app to accommodate individualized lifestyle preferences and health-related goals. Having manageable goals was also important as design team members stressed the significance of including realistic and achievable health-related objectives. Design team members reported that they have developed healthy habits to facilitate participation in goals such as attending college, entering the workforce, and participating in social activities. They have been able to achieve these goals by developing and maintaining healthy habits, such as drinking water.
- 5) Communication and Support: This theme underscored the importance of effective communication channels and emotional support within the mHealth app. It shed light on the frequency and timing of communication (via mechanisms like SMS messages and push notifications) and described AYA preferences regarding the timing and frequency of health-related notifications and interactions within the mHealth app.
- 6) Envisioning the Future: This theme captured design team members' hopes and expectations regarding their health journey, emphasizing the need for tools to envision and actively work towards a healthier future.

3.2.1. Health equity and implementation strategies

In Phase II, we also utilized Ramasawmy et al.³⁰ and the National Academies of Sciences Engineering, and Medicine Consensus Report on Communities in Action: Pathways to Health” to guide the selection of features/strategies to address health equity at the individual, healthcare system and community levels.^{29,30} For example, to address technological literacy concerns at the individual level, instructional videos were seamlessly integrated into the mHealth app, delivering real-time guidance and technical assistance. Design team members testing the app were also able to contact study staff through the app when they needed assistance with app functionality, identified a bug in the app, or had suggestions for future app iterations. This ensures a smooth user experience and promotes proficiency in navigating the mHealth app. Feedback received from design team members during this phase was implemented to facilitate a more seamless experience for COMETS trial users. At the end of this phase, changes were made in the process by which users report bugs and suggestions that reflect processes used by other standalone apps. This process includes a “help” button in the app that allows users to communicate with app administrators.

At the healthcare systems level to facilitate access to care, the mHealth app includes patient-partner super users. Patient-partner super users were identified by the study team and received training on the app functions as a part of onboarding. Most super users were AYA design team members. Super users were required to log in to the app at least three times a week, engage in the discussion boards one to two times per week, and start at least two discussion topics per month. These super users take the lead in initiating, responding to, and escalating issues to the clinical team when necessary. This approach not only amplifies user support but also establishes a network of individuals who can provide invaluable firsthand insights into the app’s efficacy.

A discussion board within the mHealth app fosters a sense of community and peer support (community level factors). This feature serves

as a catalyst for relationship-building among users, enriching their collective experience.

To enhance both effective implementation and user engagement, a comprehensive reward system was strategically integrated. This approach, rooted in theories of extrinsic motivation and contingent reward, included points, badges, and monetary incentives aligned with AYA preferences and motivations.^{19–21,25} The use of these theories serves as a powerful incentive mechanism. Users earn points by completing various engagement tasks, such as responding to messages, tracking pain and mood, interacting with their team, utilizing the learning portal, documenting progress on weekly goals, uploading a picture story, responding to discussion posts, and leading discussions. Badge rewards, operating on contingent reward, fixed ratio reinforcement, and differential reinforcement principles, add an additional layer of motivation. These badges are bestowed for consecutive completion of active tasks, with varying durations for streaks, ranging from 3 to 30 days. The goal is to encourage sustained engagement and achievement.

The introduction of monetary incentives takes user engagement to a higher level. Employing contingent reward, fixed ratio reinforcement, and differential reinforcement for high rates, this feature provides monetary rewards for maintaining streaks. The rewards increase progressively, starting from 25 cents for a 3-day streak and reaching \$3 for a 30-day streak, providing tangible recognition for users’ commitment and consistency (see Table 3). Monetary incentives were provided to research participants through ClinCard, a debit card system used for compensation to research subjects. Users are able to use funds anywhere debit cards are accepted. Funds for these monetary incentives were provided through a grant.

To further enhance sustained engagement, a thoughtfully crafted

Table 3
iManage SCD engagement strategy.

| Engagement strategy | Theoretical construct | iManage SCD feature |
|-----------------------|--|---|
| Points | <ul style="list-style-type: none">Extrinsic motivationContingent reward | Users will receive points for completion of engagement tasks: <ul style="list-style-type: none">Responding to text messages (75 %/week) – 30 pointsTracking pain/mood (50 points)Messaging their team (30 points)Accessing the learning portal (30 points)Documenting progress on weekly goal (30 points)Uploading 3 picture story (30 points)Responding to discussion posts (30 points)Suggesting a discussion topic and leading the discussion (50 points) |
| Badges | Contingent reward Fixed ratio reinforcement Differential reinforcement for high rate | Users are awarded badges if active tasks are completed a certain number of consecutive days. If daily tracking of mood/pain occurs for 3 consecutive days, badge is awarded. Users will also be awarded badges for longer streaks. iManage SCD can award 3, 6, 12, 18 and 30-day streaks. |
| Monetary incentives | Contingent reward Fixed ratio reinforcement Differential reinforcement for high rate | For a 3-day streak, users will receive 25 cents. For longer streaks: <ul style="list-style-type: none">days = \$0.5012 days = \$118 days = \$230 days = \$3 |
| Reminder notification | Trigger Effort/motivation | Users will set a time to be reminded to track their mood/pain each day. Reminder will state how close to obtaining a badge (streak). |

reminder notification system was implemented. This feature prompts users to track health behaviors, like their mood and pain, medications, exercise, and water intake, daily. It not only facilitates consistent engagement but also provides valuable information on progress toward obtaining badges or maintaining streaks, ensuring users remain informed and motivated on their self-management journey.

3.3. Phase III: assess vigorously

The assessment phase was designed to evaluate the feasibility, acceptability, and user engagement of the iManage SCD mHealth app. This comprehensive assessment plan aimed to provide valuable insights into the mHealth app’s performance and its potential impact on the target user group, AYA with SCD.

Feasibility Assessment: Feasibility was assessed through a multi-pronged approach, encompassing technical feasibility, user interaction feasibility, and overall usability. Point of use feedback from design team members regarding technical feasibility included confirmation of functionality on varying devices and operating systems. Point of use feedback regarding user interaction feasibility included comments on app functionality and layout. For example, one AYA with SCD said, “I like it it’s laid out neat easy to follow n read”. Overall usability assessments were conducted through user testing sessions, where design team members engaged with the app in simulated real-world scenarios.

Acceptability Evaluation: Design team members, including AYA with SCD, provide active point of use feedback on their experiences with the app. Feedback in this area focused on likelihood that they would use the app. For example, one AYA with SCD stated, “The animation also reminds me of [an app I love] so I definitely feel like it has a current feel to it and is age and demographically appropriate.”

Integration with the COMETS Trial: The assessment plan related to the larger COMETS Trial, a research initiative aimed at evaluating the impact of iManage SCD on transition readiness and health outcomes in AYA with SCD. Data collected during the feasibility and acceptability contributed to the broader research objectives of the COMETS Trial. The COMETS Trial is collecting data to assess user engagement. Metrics such as app usage frequency, duration of engagement, and specific features utilized are tracked through analytics tools integrated into the mHealth app. Additional feedback is being gathered through surveys, providing a holistic understanding of how users interacted with the app over time. This synergistic approach ensures that insights gained from the assessment phase directly informed the trial’s outcomes, facilitating a robust evaluation of the app’s effectiveness in a real-world context.

See Table 4 for a summary of results by project phase and Fig. 2 for screenshots of iManage SCD.

3.4. Phase IV: share

Dissemination planning is integral to maximizing the impact of iManage SCD. The dissemination plan involves having AYA with SCD from the design team take a leading role in co-presenting about the app at scientific and community meetings, bringing authenticity and first-hand experiences directly to relevant audiences, thereby fostering a more impactful and meaningful dissemination process.

4. Discussion

The development of iManage SCD represents a successful fusion of theoretical principles and direct input from AYA design team members, culminating in a person-centric, user-friendly mHealth app tailored to effectively engage and support AYA in their self-management journey with SCD. Guided by the IDEAS framework, the goal was to design an mHealth app to facilitate behavior change; yet its effectiveness remains unknown. The focus on implementation and addressing inequities within the design process seems promising, yet it is difficult to evaluate given the scarcity of literature detailing the development approaches of

Table 4
Results by implementation phase.

| Phase | Theme | Quote | App features |
|----------|----------------------------------|--|---|
| Phase I | Engagement | “Because it sounds like they will have no reason to access the app on their own. So I think from a app standalone – which is new because this isn’t a standalone app right now, the biggest thing is the engagement – getting them to go into the app. Then I think they gave us lots of ideas about things for that. Keeping them engaged, I think, through the text bank will be extremely important, but again, I think they gave us good ideas about that and they really want the discussion boards.” | Reminders; discussion board; monetary incentives for participation |
| | Manageable Goals | “And so – yeah. I think that part of what I was hearing ... from young adults ... is that when you set a big goal that’s much longer term, when you can’t meet it for whatever reason – whether it’s because your health just didn’t go the way you expected it to or because other things came up in your life, you’re just – you feel so much worse about yourself than if you didn’t meet a smaller weekly goal.” | Weekly “challenges” |
| | Self-management | “They really talk about self-management as the thing that they’re most interested in and I think in the transition when it was also the independent living skills. So I feel like that those and pain are the top three type of things that we really need to content around those first and then maybe other things. They didn’t seem as excited by the educational/vocational stuff in this one.” | App chapters on independent living, transition to adulthood, pain management. |
| | Accountability | “I think that’s really important and I think the other thing that came out as a theme in our qualitative work was just the accountability. They really liked the action plans, because it held them accountable.” | |
| Phase II | Social Behaviors & Entertainment | “Like a newsfeed, even some of the doctors may upload they’re information because they are, they have other studies that are geared towards sickle cell. So I think that would be great for them, but it | Newsfeeds create a FOMO reason to return |

(continued on next page)

Table 4 (continued)

| Phase | Theme | Quote | App features |
|-------|---|--|--|
| | Treatment, Pain Impact, and Pain Management | would have to be in a way that they can sort of digest that information." "I would put my hospital appointments. I usually put it on my calendar. I'll put notes in my phone or on the actual notebook that I have. I'll usually try to keep, if I have like a nurse or someone who will help me a lot in the hospital, I'll write their name down just in case I might forget. | Create reminders that patients and their families can co-create (water, blankets, food, ibuprofen, water) |
| | SCD Knowledge and Transition | "Throughout college I would say I felt like I was maybe more on top of things 'cause I didn't want to get sick. So I made sure to as continuing to like go to doctors...But I do feel as though my freshman year, because of the transition, it was a bit more overwhelming for me." | The ability to share personal stories, best-practices, pain management techniques in a persistent format (not message based) so patients can search, find, and learn from each other |
| | Lifestyle & Goals | "Yeah. I wouldn't say...I have a goal to...drink a gallon a day. I think I do have that, that cognitive mindset, but I never like actually write down and hold myself accountable if I'm reaching those goals. But it's always, like in the back of my mind." | Create interactions and educational modules that shift goals toward habits and behavior modification rather than checklists and redundant reminders (A 21-day hydration challenge versus drink 8oz each day) |
| | Communication & Support | "I have had situations where I did not speak up and found myself sicker because they didn't know what they were doing." | Integrated medical summary that communicates disease attributes and pain plans |
| | Envisioning the Future | "You had to go through multiple numbers to reach them. So maybe there's like a button where you can call the doctors on call. Something like that maybe..." | Access to nurses and physicians through care team feature |
| | Phase III Feasibility | I like is it's laid out neat easy to follow n read | N/A |
| | Acceptability | The animation also reminds me of [an app I love] so I definitely feel like it has a current feel to it and is age and demographically appropriate. | N/A |

other SCD mHealth apps. In general, features highlighted in this iManage development study are consistent with other digital solutions for AYA with chronic illness, including medication adherence assistance, social interaction with peers, rewards to encourage self-management behaviors, and gamification features.³¹ Furthermore, features highlighted in this iManage development study are also consistent with recommendations for digital solutions specific for AYA with SCD that focus on self-management and transitional care needs. Similar recommendations include educational content around medications, SCD

diagnosis and genetics, preventing crises and pain management, as well as features promoting social support (i.e. forum or chat to communicate with other youth with SCD) and interactive features.³²

Phase I laid a robust foundation for iManage SCD by developing content guided by SMART theoretical principles with AYA design team member input. The collaborative efforts during thematic analysis, involving qualitative reviewers, ensured validity and reliability of insights garnered. The resulting themes not only validate the content but also provide a roadmap for refinement and optimization, enhancing the mHealth app's ability to serve as a supportive tool for AYA with SCD.

The qualitative interviews in Phase II not only fortified the mHealth app's development, but also established a comprehensive understanding of real-world needs and experiences of AYA with SCD. The identified themes serve as a roadmap for person-centric design, addressing both immediate health concerns and broader goals. These nuanced themes provided a foundation for crafting a responsive and impactful mHealth app, aligning closely with the multifaceted needs and desires of the target audience.

The iterative design process proved beneficial, resulting in an mHealth app characterized by supportive feedback from all collaborator types, making it ready for implementation. The app's inclusion of AYA preferred features will elevate its appeal to AYA, potentially facilitating demand for dissemination by health systems and other organizations. Further, aligning app features with AYA preferences increases the likelihood of AYA with SCD engaging with this standalone app. This process is generalizable and beneficial for others to adopt. Including AYA design team members from ideation to prototype testing is important and feasible with thoughtful planning, a strong theoretical grounding, and a framework – like the IDEAS framework – to guide development and implementation. The next steps involve assessment of the app as part of the PCORI-funded clinical trial.

This mHealth development, feasibility and acceptability study has several limitations. First, we had a small sample size of AYA users with SCD, which may not be representative of the broader population or diverse user groups, potentially limiting the generalizability of our findings. Second, our AYA design team members were obtained from a convenience sample of patients receiving care from one pediatric sickle cell center, who were engaged and self-selected, introducing the possibility of selection bias. The feasibility and acceptability outcomes focused on user perceptions, usability, and initial engagement with the app, which may not capture all aspects of its potential impact or effectiveness. Engagement, which was defined app usage frequency, duration of engagement, and specific features utilized, is multi-faceted. Further work is needed to understand drivers of specific aspects of engagement more deeply. In addition, some of the features included to enhance engagement, including monetary incentives, may not be feasible to include in a real-world setting. Finally, the development process not only included AYA users with SCD, but also clinicians and other professionals. While the study team made efforts to prioritize the opinions and perspectives of these AYA and create a level atmosphere, AYA design team members may have felt pressured to minimize dislikes of certain features due to likability bias, particularly if the professionals were particularly enthusiastic about a feature.

Lessons learned from the development process underscore key insights, such as the necessity to tailor the mHealth app to user preferences for optimal engagement, and the strategic challenges of navigating tech-health system partnerships. Health system constraints highlighted the advantage of moving faster outside the health system. User-friendliness emerged as a key principle, emphasizing the need to meet user needs effectively. The emphasis on user-friendliness and relevance, along with an acknowledgment of the slow pace of health system movement, underscore the importance of crafting solutions that align with both user expectations and the practical realities of healthcare systems. Partnering with an outside development firm to conduct interviews and obtain feedback reduces potential researcher bias in the design and implementation of specific app features but may introduce other forms of bias.

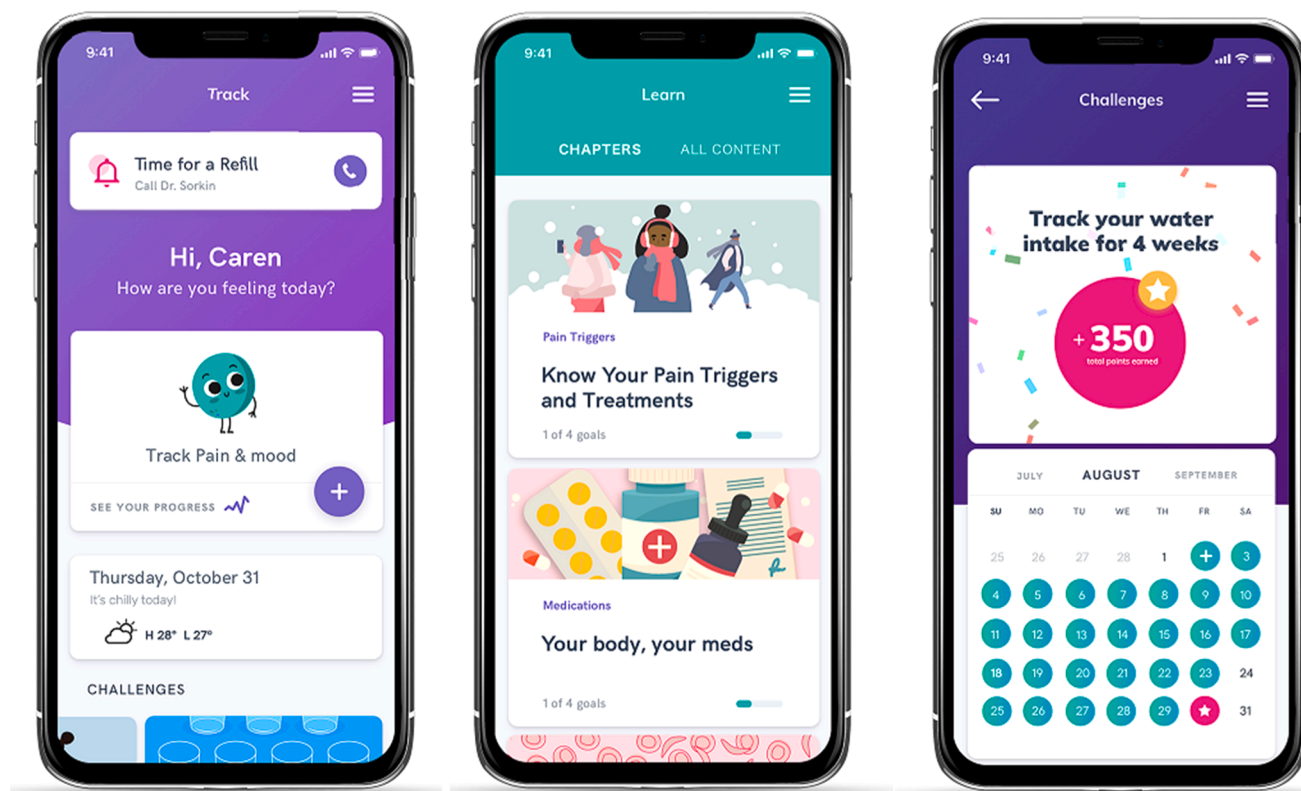


Fig. 2. Screenshots of iManage SCD.

The partnership also illuminated different approaches to app development between the development firm and research team. The development firm forged ahead at a rapid pace, often faster than feasible for health system partners. The two teams had to align on project timeline early on to be successful. There were also differences in approaches to obtaining collaborator feedback. At first, the development firm requested to independently conduct informal conversations with key design team members. Instead, the research team worked with the development firm to create a semi-structured interview and analyze transcripts based on empirical methods.

Future research directions for the iManage SCD project should include conducting a rigorous evaluation of the iManage SCD app's effectiveness in facilitating behavior change and improving health outcomes among AYA with SCD, comparative studies with other mobile health apps,³¹ mobile health apps as adjunct to group interventions (SCThrive),³³ evidence-based interventions (i.e. community health workers, formalized transition program,³⁴ workshops)³⁵ to facilitate behavior change and improve health outcomes, assessing the app's impact on health equity and accessibility, particularly among populations with SCD with limited health literacy or affected by stroke. Given emerging readiness for transition to adult care models such as the Social-Ecological Model of Adolescent and Young Adult Readiness for Transition to Promote Health Equity (SMART-E),⁶ future studies should examine how well iManage addresses health equity factors for AYA with SCD, caregivers, and clinicians.

5. Conclusion

In conclusion, iManage SCD represents a noteworthy achievement in person-centric mHealth app development, with its design rooted in the lived experiences and preferences of AYA with SCD. The lessons learned and the strategic considerations during development contribute valuable insights to the field, paving the way for the continued evolution of mHealth solutions for chronic disease management.

CRediT authorship contribution statement

Tanisha Belton: Writing – review & editing, Supervision, Project administration, Data curation, Conceptualization. **Steffi Shilly:** Writing – original draft, Data curation. **Caren M. Steinway:** Writing – original draft, Project administration, Methodology, Investigation, Data curation, Conceptualization. **Lori Crosby:** Writing – original draft, Methodology, Investigation, Data curation, Conceptualization. **Lisa A Schwartz:** Writing – original draft, Methodology, Investigation, Data curation, Conceptualization. **Sophia Jan:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization. **Kim Smith-Whitley:** Writing – review & editing, Methodology, Investigation, Funding acquisition, Conceptualization.

Ethical Statement

We attest that this work has been carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) and is aligned with the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals.

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Declaration of Competing Interest

The authors declare the following financial interests/personal

relationships which may be considered as potential competing interests: Caren Steinway reports financial support was provided by Patient-Centered Outcomes Research Institute. Kim Smith-Whitley reports employment at Pfizer. Work presented in this manuscript does not represent work completed by or funded by Pfizer. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

Data will be made available on request.

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