

Electronic Tools for Self-Management



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Financial Disclosures

- No financial conflicts of interest
- **NHLBI Grant#: 1K07HL108720**
- **NICHD Grant #: 1R21HD084810-01A1**
- HRSA Grant #: U1EMC27863
- PCORI Contract #: CDR-1609-36055
- The content is solely my responsibility and does not necessarily represent the official views of the NHLBI, NICHD, HRSA or PCORI.

Acknowledgements

iManage Team

Naomi Joffe, PhD
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Ashley Walton, PhD
David Scoggins, MA
Steven Edwards
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Jasmine Burks
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Collaborators

BMI Team

–Christie Crosby
–Michael Taylor
–Troy Dee
–Bikash Khadka
–Michal Kouril

Patient & Family Partners

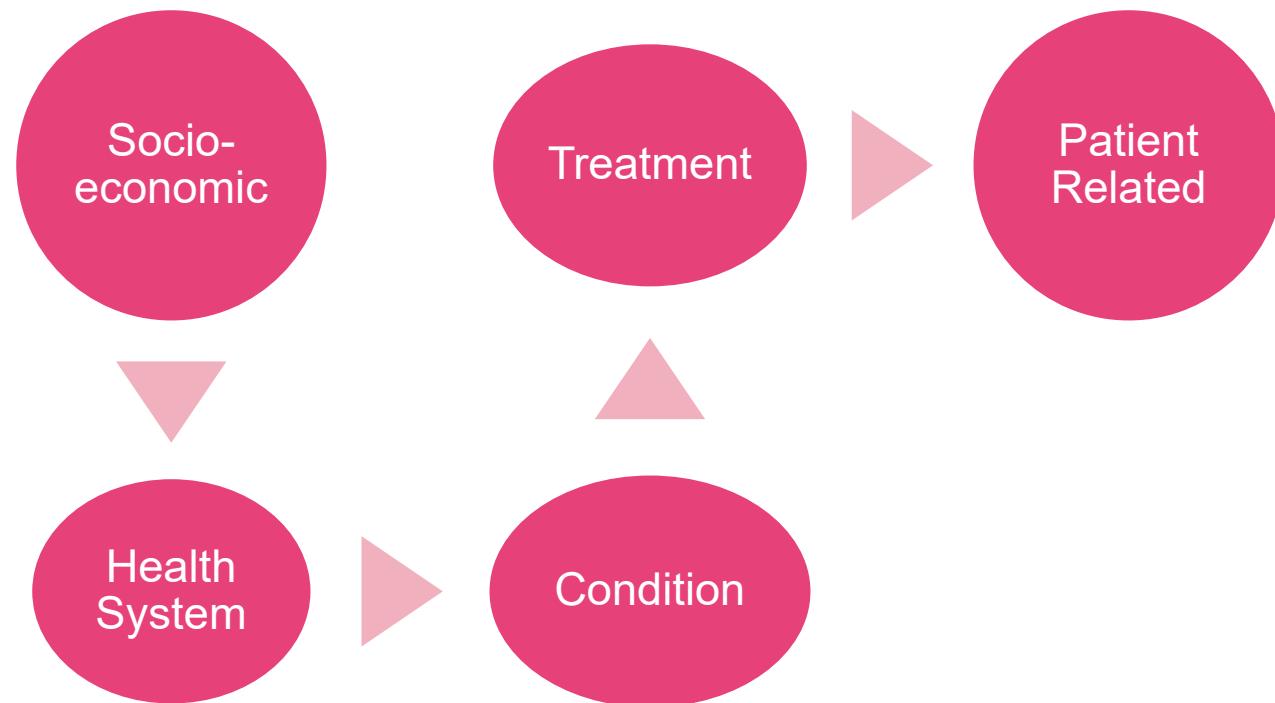


Agenda

- Define self-management
- Brief overview of apps for disease self-management
 - Pain
 - Adherence
 - Multicomponent
- Development of iManage
- Benefits of co-development

Self-Management

- **health behaviors** and **related processes** that patients **engage in** to **care** for a **chronic condition**



Modi AC, Pai AL, Hommel KA, Hood KK, Cortina S, Hilliard ME, et al. Pediatric self-management: a framework for research, practice, and policy. *Pediatrics*. 2012;129(2):e473-85.

DeBaun MR, Telfair J. Transition and sickle cell disease. *Pediatrics*. 2012 Nov 1;130(5):926-35.

Clinical endpoints and patient self-management

- Patient self-management indicators could be used as clinical endpoints
 - American Association of Diabetes Educators (AADE)
 - taking medications, problem solving, healthy eating, and reducing risks

Glasgow, R. E., Peebles, M., & Skovlund, S. E. (2008). Where Is the Patient in Diabetes Performance Measures?: The case for including patient-centered and self-management measures. *Diabetes Care*, 31(5), 1046-1050.

Powers, M. A., et al. (2017). "Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics." *The Diabetes Educator* 43(1): 40-53.

Adoption of Health Technology



CONSUMER ADOPTION

Percent adoption by digital health category



Source: Rock Health consumer survey data (n = 4,017)



Ramsey, 2017

Mobile Technology



Adherence rates for use of mobile technology for all ages are around 80%

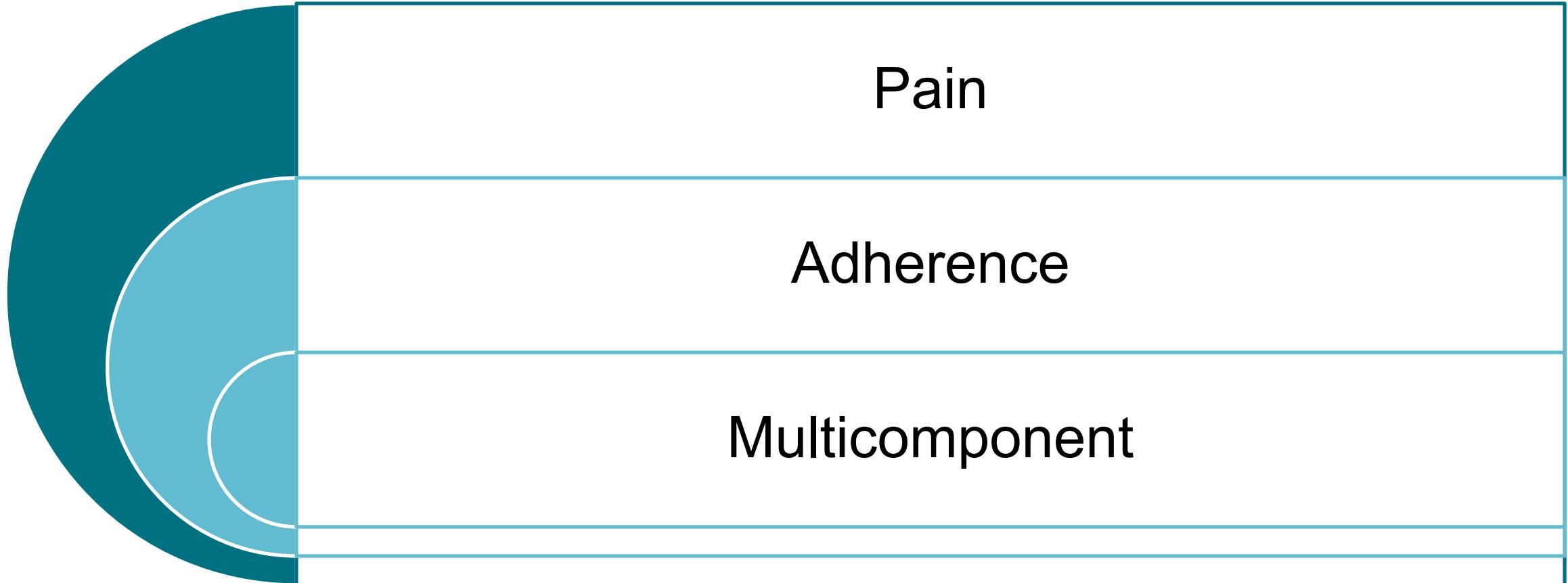
Smartphone applications appear to be easy to use and are well accepted by patients with chronic conditions

Technology could be used to support goal setting, give feedback and promote engagement

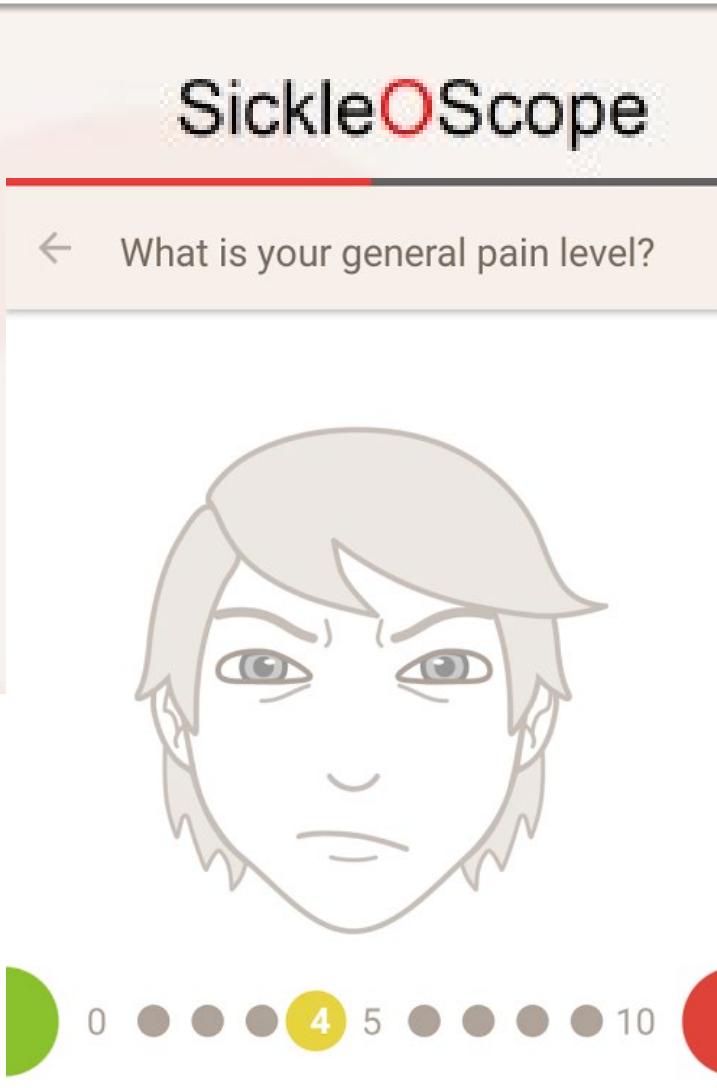
Newer field so limited information available on efficacy cost-savings and efficacy of app-based interventions for pain and adherence

Vardeh D, Edwards R, Jamison R, Eccleston C. There's an app for that: mobile technology is a new advantage in managing chronic pain. Pain. 2013;21:1-8. Badawy SM, Kuhns LM. Economic Evaluation of Text-Messaging and Smartphone-Based Interventions to Improve Medication Adherence in Adolescents with Chronic Health Conditions: A Systematic Review. JMIR mHealth and uHealth. 2016;4(4); Vardeh D, Edwards R, Jamison R, Eccleston C. There's an app for that: mobile technology is a new advantage in managing chronic pain. Pain. 2013;21:1-8; Badawy SM, Kuhns LM. Texting and Mobile Phone App Interventions for Improving Adherence to Preventive Behavior in Adolescents: A Systematic Review. JMIR mHealth and uHealth. 2017;5(4).

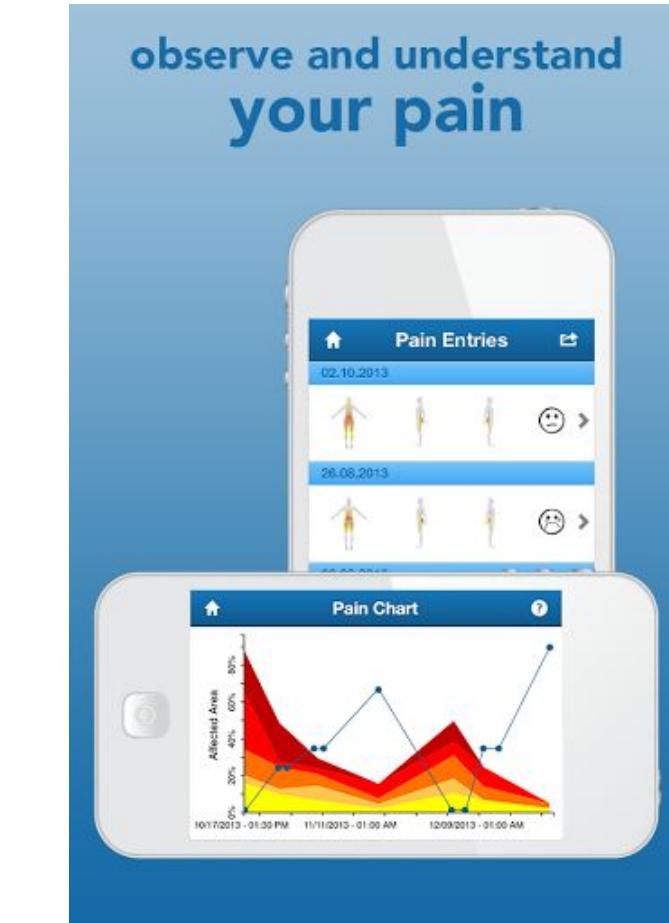
Self-Management Domains



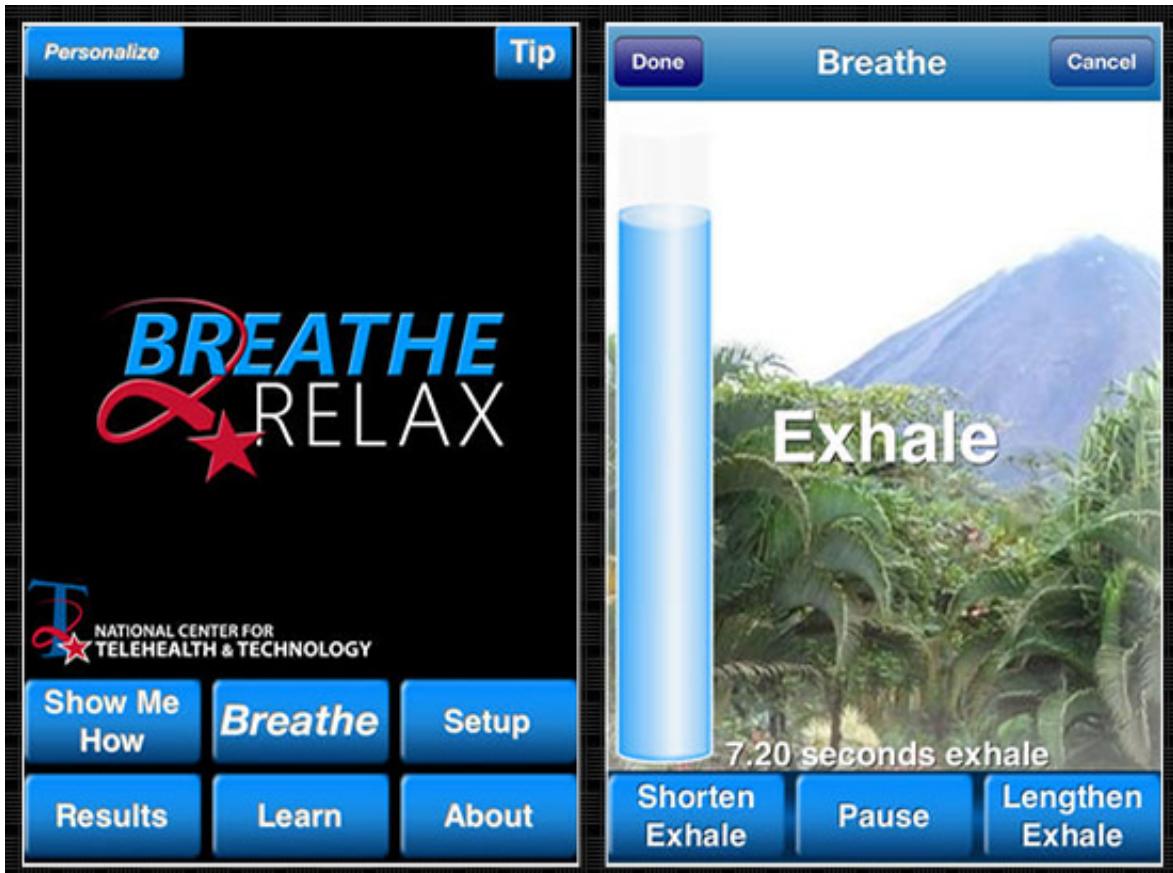
Tracking & Understanding Pain



CatchMyPain



Pain Management



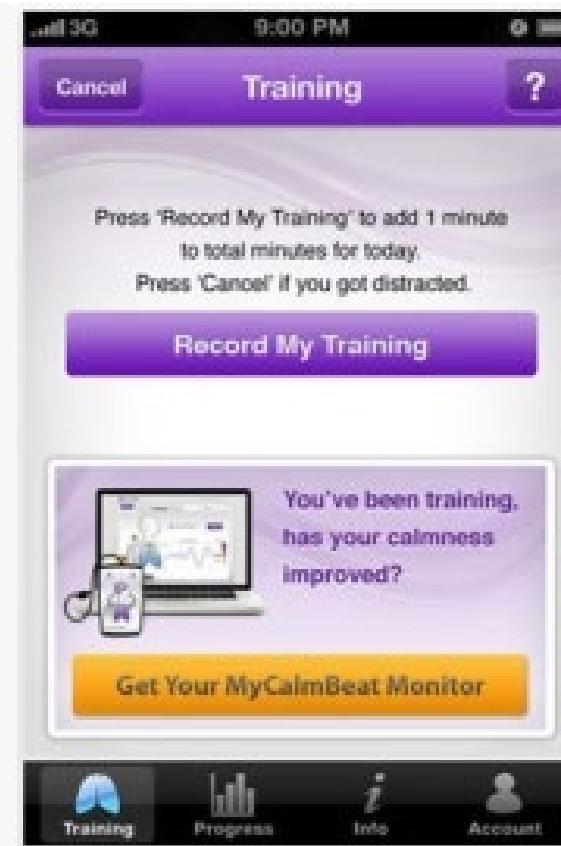
The image shows the 'Breathe & Relax' app interface. On the left, a dark screen displays the app's logo 'BREATHE & RELAX' with a red infinity symbol and a red star. Below the logo are the 'NATIONAL CENTER FOR TELEHEALTH & TECHNOLOGY' logo and several blue buttons: 'Show Me How', 'Breathe', 'Setup', 'Results', 'Learn', and 'About'. On the right, a 'Tip' screen shows a landscape with a volcano and palm trees. A blue cylinder on the left side of the screen is labeled 'Exhale' and '7.20 seconds exhale'. Below the cylinder are buttons for 'Shorten Exhale', 'Pause', and 'Lengthen Exhale'. The top of the screen has 'Done' and 'Cancel' buttons.



MyCalmBeat

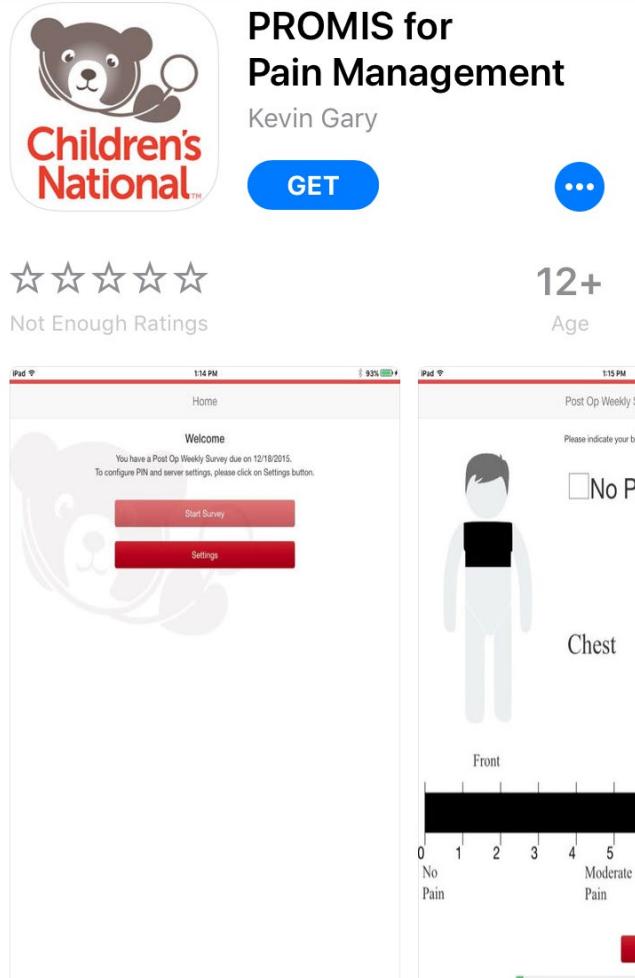


The 'Training' screen shows a diagram of human lungs. Below the lungs is a digital timer displaying '4:02'. To the right of the timer is the text 'BREATHING RATE' and '6.5 breaths per minute'. A purple 'Pause' button is located at the bottom right of the timer area. At the very bottom are four navigation icons: 'Training' (highlighted in blue), 'Progress', 'Info', and 'Account'.



The 'Training' screen displays a summary message: 'Press "Record My Training" to add 1 minute to total minutes for today. Press "Cancel" if you get distracted.' Below this is a purple button labeled 'Record My Training'. Further down, there is a small icon of a computer monitor and a smartphone, with the text 'You've been training, has your calmness improved?'. At the bottom is an orange button labeled 'Get Your MyCalmBeat Monitor'. At the very bottom are four navigation icons: 'Training' (highlighted in blue), 'Progress', 'Info', and 'Account'.

Future Directions



PROMIS for Pain Management

- App for adolescents with sickle cell disease and post-operative back pain
- Uses the NIH Pain Reported Outcomes Measurement Information System (PROMIS, www.nihpromis.org) tools for managing pain
- Currently reserved for research participants

Technology &



Improving
Medication
Adherence

Mango Health – Medication Manager



By Mango Health

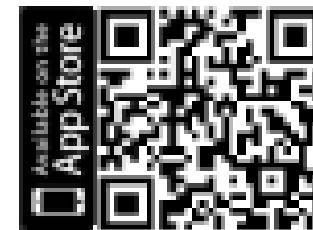


Scan

the QR Code with your
smartphone to learn more.

Mango Health makes it fun and easy to manage your medications and supplements in order to reach your health goals. We help you take care of you.

- Reliable medication reminders
- Drug interaction warnings
- Points and rewards
- Daily Health Diary



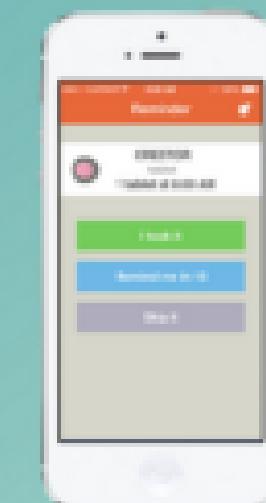
Take control of your
medication schedule



Earn points for the
chance to win rewards



Never miss a dose with
reliable reminders



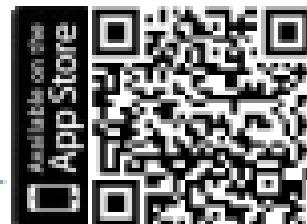
MyMedSchedule Mobile



By MedActionPlan.com

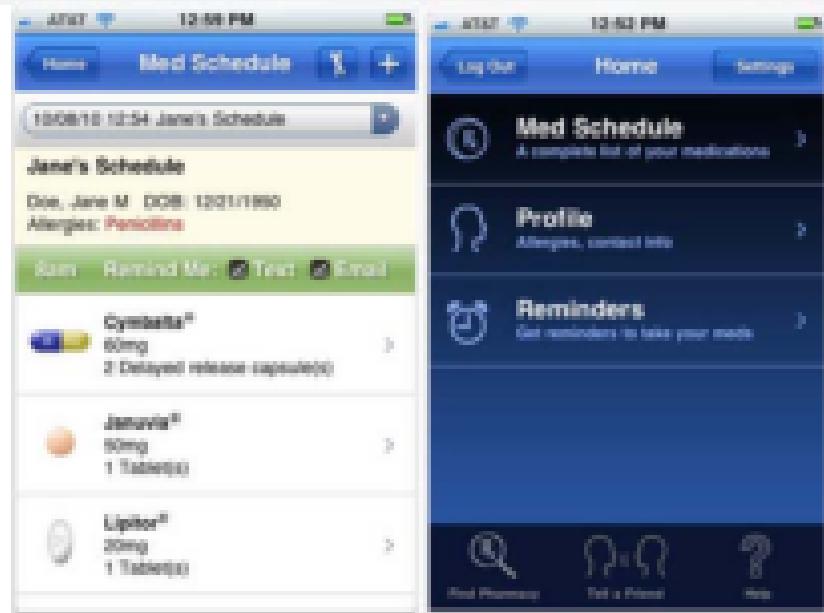


- Print schedules that are easy to create, read, and update
- Keep track of all your medications
- Bring your pill schedule to all your medical and dental appointments
- Graph results to track progress
- Quick and easy data entry
- Receive reminders to take your medications by text or email
- Refill reminders help you reorder prescriptions before they run out
- Works with MedActionPlan.com if your provider has it.



Scan

the QR code with your smartphone to learn more.



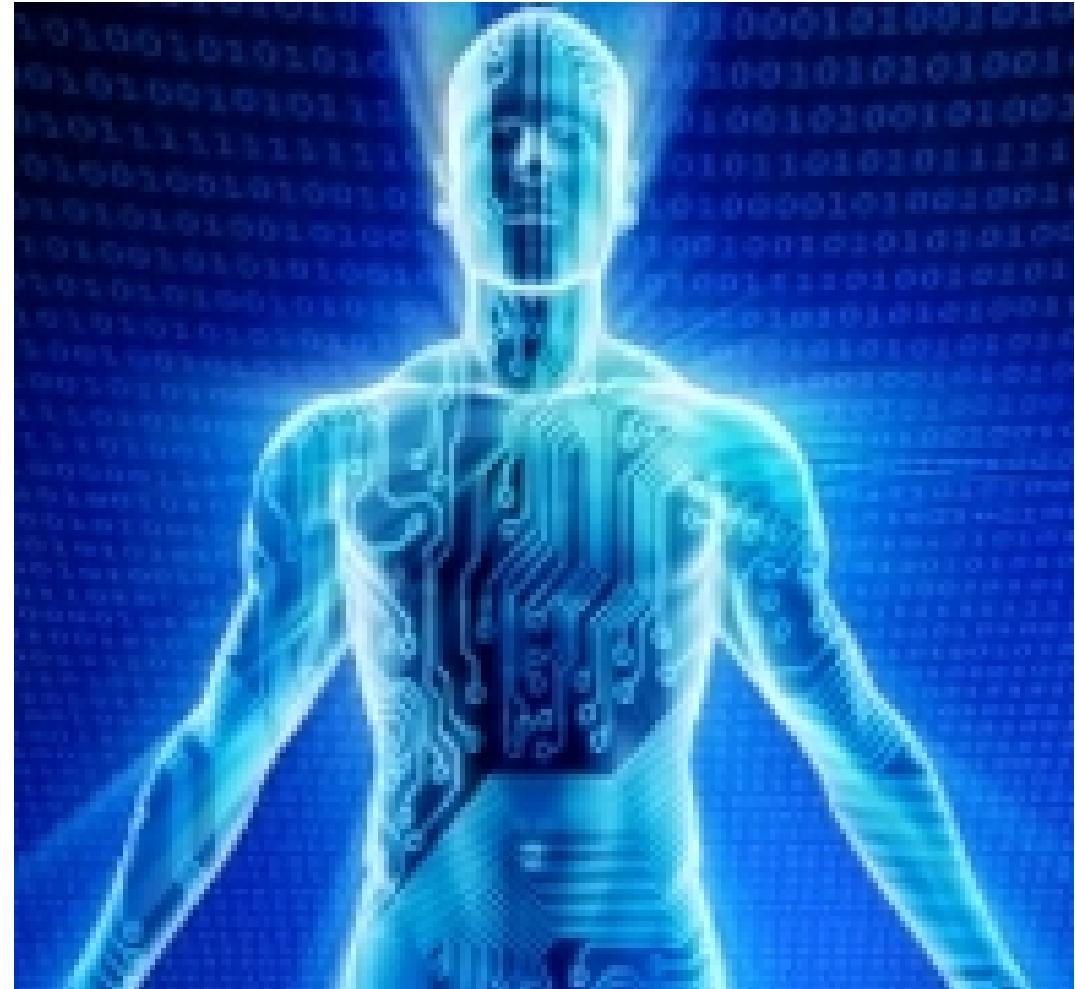
Smart Pill Containers

- Pros
 - Familiar to patients
 - Integrate with mobile apps
 - Patient feedback
 - Possible integration with systems
 - Alerts
- Cons
 - Complicated setup
 - Cost
 - Needs wireless
 - Indirect measurement



App and Sensors

- Smartphone app and compatible blood testing sensor - Florida Atlantic University's College of Engineering and Computer Science – NSF
- Smartphone app and wearable sensor – variations in oxygen saturation
- Ingestible sensors to measure medication adherence



Multicomponent

Self-management

Pain Goals

Golfing

Children

Mindfulness

Living

Disability

Meditaiton
Distraction

Stretching

Walking

Dancing

Playing

Hiking

Exercise

Exercise

Art Set

Goals

Gardening

Activity

Swimming

Crafts

Healthy

Dog-Walking

Fishing

Simple

Positive

Rowing

Biking

Pilates

Breathing

TaiChi

Physical

Changes

Lifestyle

Arts

Coping

Meditation

Goals

sickleWell



Carrier 4:03 PM

Close

Hydrate!

body weight: 75 lbs
(tap to change)

intake goal: 38 oz
current: 18 oz

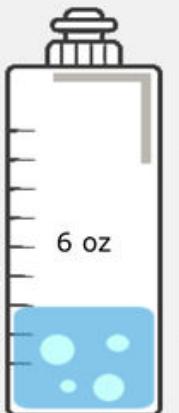


streak record

sports drink

water

juice



log it

3

Carrier 4:03 PM

Sync Home Logout



purplegerald143

0 points

0 0

streak(great days in a row)

This week

Sun	Mon	Tue	Wed	Thu	Fri	Sat
Sleep/Rest	○	○	○	○	●	○
Relaxation	○	○	○	○	●	○
Hydration	○	○	○	○	●	○
Activity	○	○	○	○	●	○
Medication	○	○	○	○	●	○
Pain	○	○	○	○	●	○

3

?

Portable Medical Record



SiKL



Welcome Next

SiKL Version 1.5.0

Welcome to SiKL - your medical record for sickle cell disease.

When you need it

SiKL, your medical history is always with you. If you've got your iPhone or iPod, you've got SiKL. Unlike a paper record, you'll never run out of space...

For emergencies

Emergency Summary

Print a medical summary to show a doctor or paramedic in an emergency.

Your information

Share your medication details and emergency medical history by email. Print sending your details straight to your healthcare provider.

SiKL Test

Personal Details >

Medical Contacts >

Sickle Cell History >

Other Medical History >

Medication >

Emergency Summary >

SiKL Sickle Cell History

Sickle Cell Type Haemoglobin S

Regular Care

Seen by Hospital Doctor

Add Regular Care

Sickle Cell Crisis History

Apr-2013 Aplastic crisis

Managed a

Add Crisis

Usual Bloods

Measured On 28-Feb-2013

Oxygen Sats 98 %

Important Notes



Not a comprehensive list of electronic tools – primarily apps

Likely missed some available apps and some currently under study

No apps focused on health care providers

Goal: an overview of the types of electronic tools and ways they are being used to promote self-management with a focus on patient-centered tools

Integrating Stakeholders into App/Intervention Development

iMANAGE



- Sickle Cell specific self-management app
- Co-designed with AYA and Clinicians
- Originally designed to complement a group intervention
- Now being adapted as a standalone app

Teen/YA Demographics

N=8	
Age, Mean (SD)	19.75 (1.68)
Gender, Male N (%)	5 (63%)
Family Income	
Under \$4000	5 (64%)
\$10000-\$13000	1 (12%)
\$13001-\$16000	1 (12%)
\$30001-\$40000	1 (12%)
SCD Type	
SS, N (%)	7 (87%)
SC, N (%)	1 (13%)
Education	
Partial High School	3 (37.5%)
High School Graduate	3 (37.5%)
Partial High College	2 (25%)

Participants



- Providers (N=6;N=10)
 - Variety of backgrounds (medicine, nursing, social work, psychology, child life & education)
 - Caring for SCD patients for an average of 13.75 years (SD=16.3)

PATIENT MAPPING: THEMES

DAILY LIFE

FAMILY

CARE PROVIDER INTERACTION

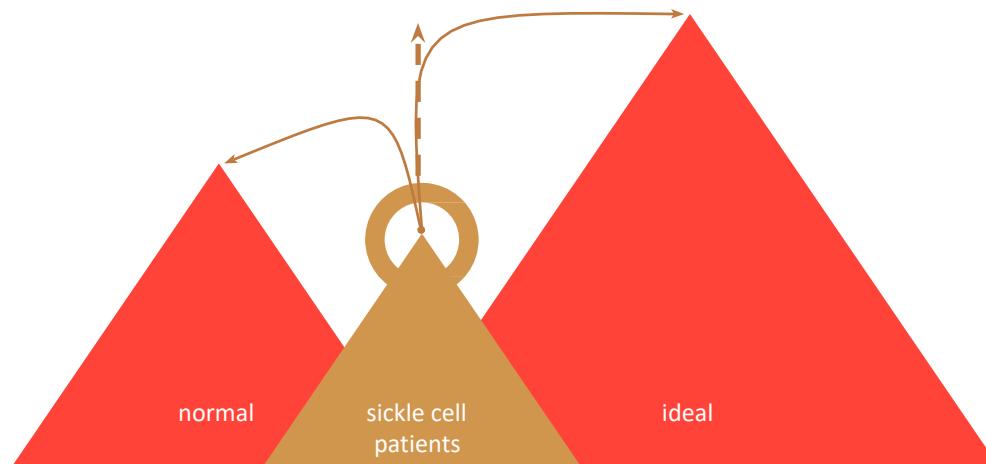
ENVISIONING THE FUTURE

SELF MANAGEMENT

SOCIAL ASPECTS OF SCD

**ATTITUDES TOWARDS
TRANSITIONING**

what we LEARNED



time of transition
increased responsibility
increased expectations
peer pressure
care-free



OPPORTUNITY areas

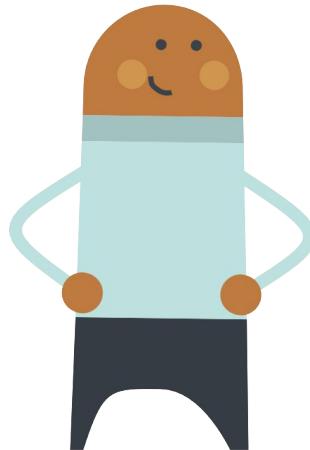
“ redefine self-management as a lifestyle for patients

lifestyle

“ Something I can see

support

“ Only someone with sickle cell can understand me



invent

Does the app engage? Will users persist?



Neurodevelopmental & Cultural Considerations



Step 1: Information gathering

- Literature review is to discover subgroup differences or similarities (e.g. age groups, etc.)
- Qualitative research or surveys for deeper understanding

Step 2: Preliminary adaptation design

- Language translation
- Reading level adjustments
- Culture-specific idioms
- Co-creation – people review and respond to low-fidelity prototypes
- Usability testing
 - Think aloud method

Step 3:

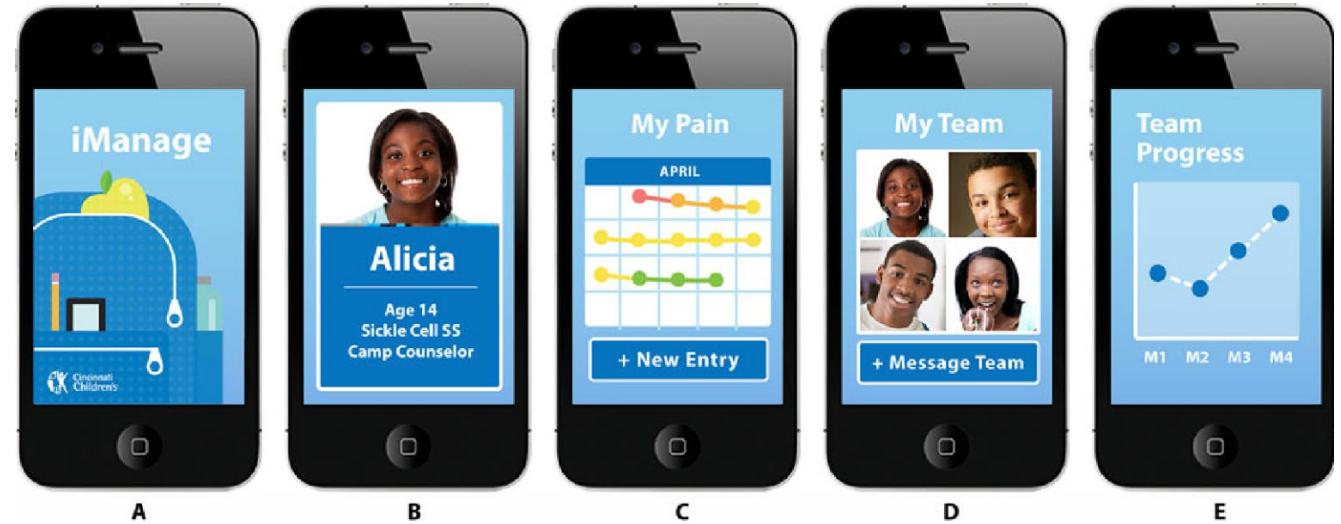
- Pilot testing with feedback (iterative process)
- Functionality
- Instructions
- Understanding and technology issues

Step 4: Adaptation refinement

- Refinement based on user feedback from the previous stage (dress rehearsal)

Prototype

- Visualization
 - help connect health, daily life, and goals
- Customizable
 - Profile
 - Individual goals
 - Reminders (time, back-up)
- Social Interaction
 - Team – monitor progress
 - Message team members
 - Team competition



Evaluation of the Prototype

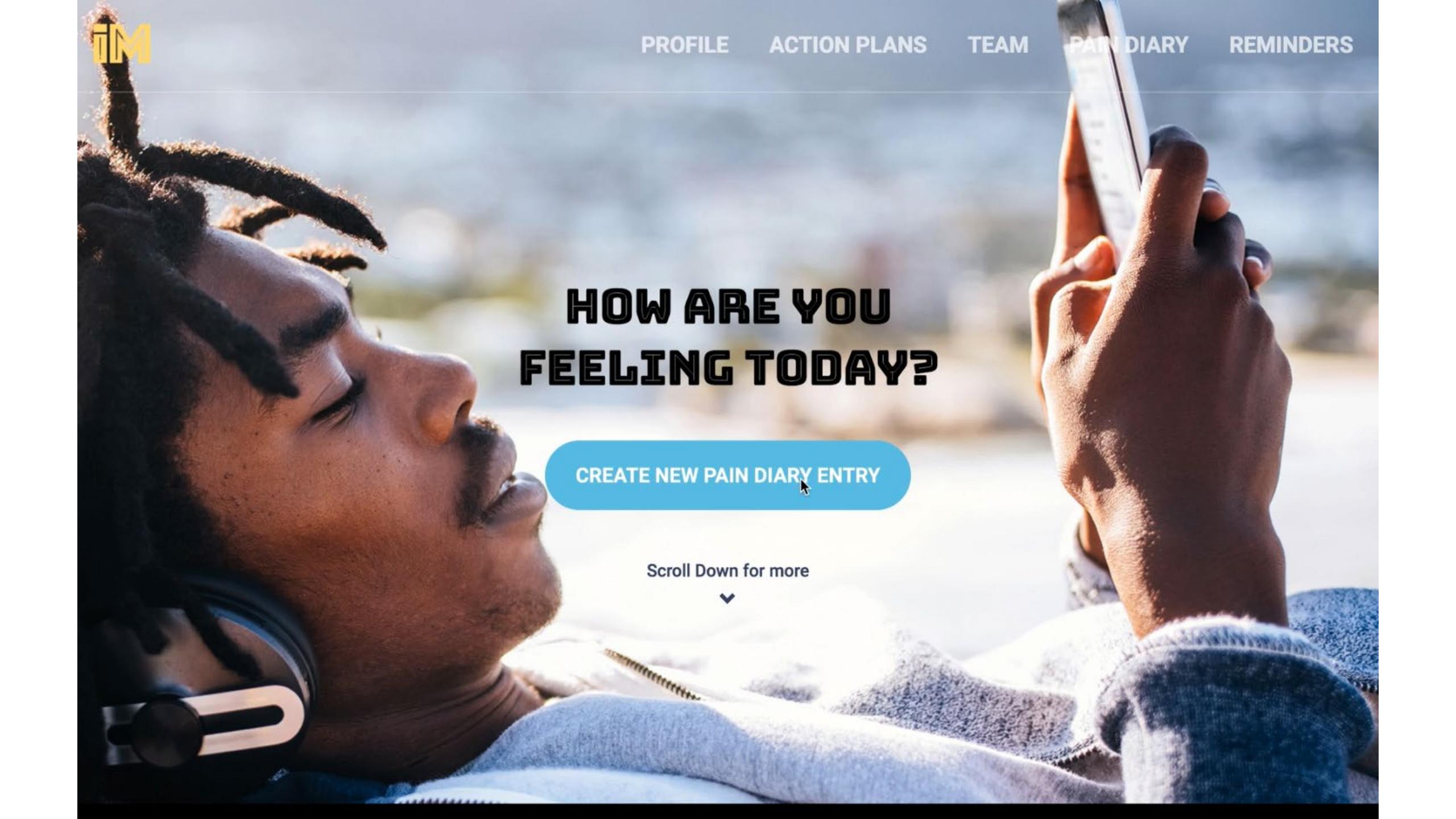
Feasibility & Acceptability

- Easy to use (4.6/5)
- Beneficial for tracking their SCD (5/5)
- Beneficial for noticing changes in their symptoms that would help with self-management (4.8/5)

Evaluation of the Prototype

Engagement/Persistence

- Tailored to their needs and experiences with SCD (4.4/5)
- Choose individual self-management goals (4.8/5)
- Communicate with others about their self-management strategies (4.6/5)**



HOW ARE YOU
FEELING TODAY?

CREATE NEW PAIN DIARY ENTRY

Scroll Down for more



Intervention Development Team

- Participatory Method
 - 3 AYA
 - 3 Interventionists

Increase interactive activities

Integrate health behavior apps

Customization
(3 picture story)

App available – wanted to stay connected

Increase social support
(open messages)

Include in-person when possible

iManage Results



- All participants reported iManage was easy to use and beneficial for SCD management
- App for phone
- Messaging – 1/2
- Most participants felt tracking pain, mood, and action plan progress were beneficial
 - Understanding the relationship between pain and mood

Gamification Example iManage



Sickle Pickles Leaderboard [BACK TO TEAM PAGE >>](#)

Rank	Username	Points	Badge	Member Since
1	T'Challa14	110	🏆	4 months ago 1/2/18
2	Shuri4ever	85	⭐	4 months ago 1/2/18
3	Nakia11	50	⭐	3 months ago 1/2/18
4	Tamtam	40	⭐	3 months ago 2/9/18
5	Sydney_smiles	35	⭐	2 months ago 1/2/18
6	Lorence_5	25	⭐	2 months ago 2/9/18

Users receive points for:

1. Interacting with other users
2. Posting to discussion boards
3. Reporting progress on goals
4. Responding to interactive text messages
5. Sharing/viewing stories

Summary



Number of electronic tools developed across self-management domains: pain, adherence, resources & support, multicomponent, with more disruption on its way

Electronic tools hold promise for increasing self-management - high feasibility and acceptability

More research is needed to determine the efficacy and cost-effectiveness of these tools particularly in sickle cell disease

Technology is only one component to increasing self-management; engagement and communication are key

Benefits of Co-Development for App/Intervention Development

Influencers

Motivations

Visualization

Prioritization

Context

