Electronic Tools for Self-Management

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- The content is solely my responsibility and does not necessarily represent the official views of the NHLBI, NICHD, HRSA or PCORI.

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iManage Team

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BMI Team

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Collaborators

Patient &
Family Partners

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Agenda

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

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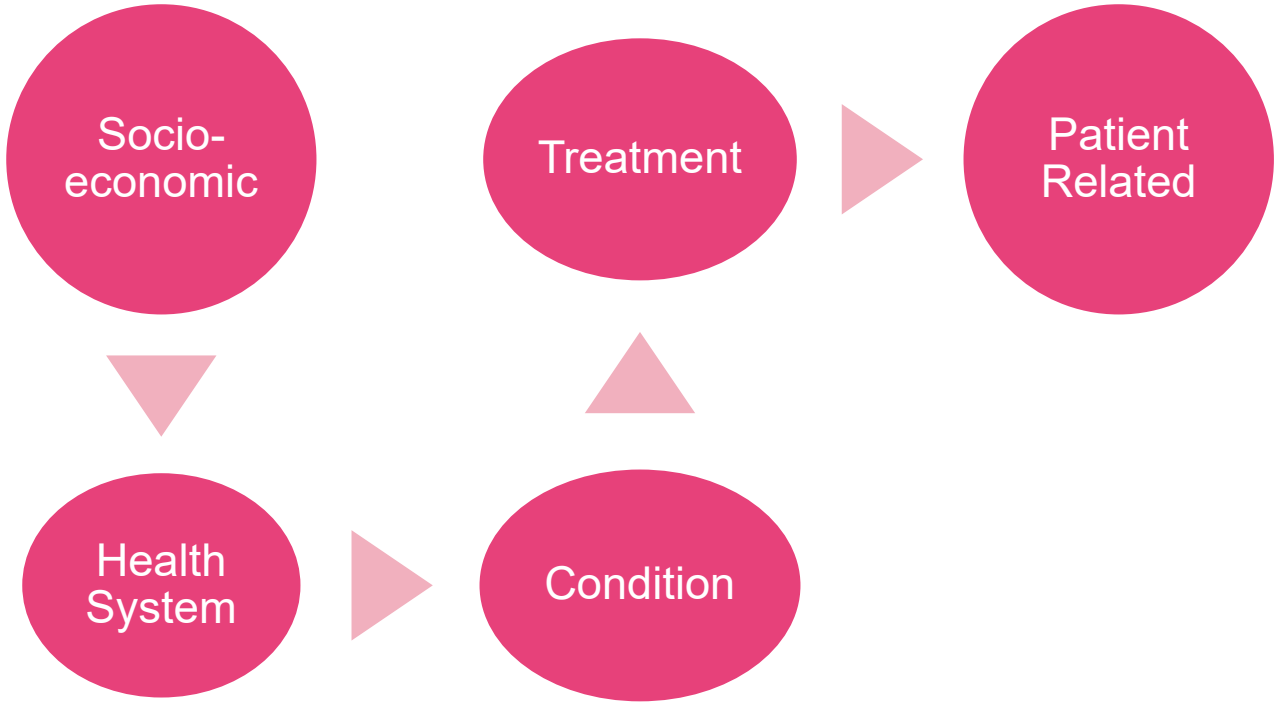
Self-Management

- **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.

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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., Peeples, 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.

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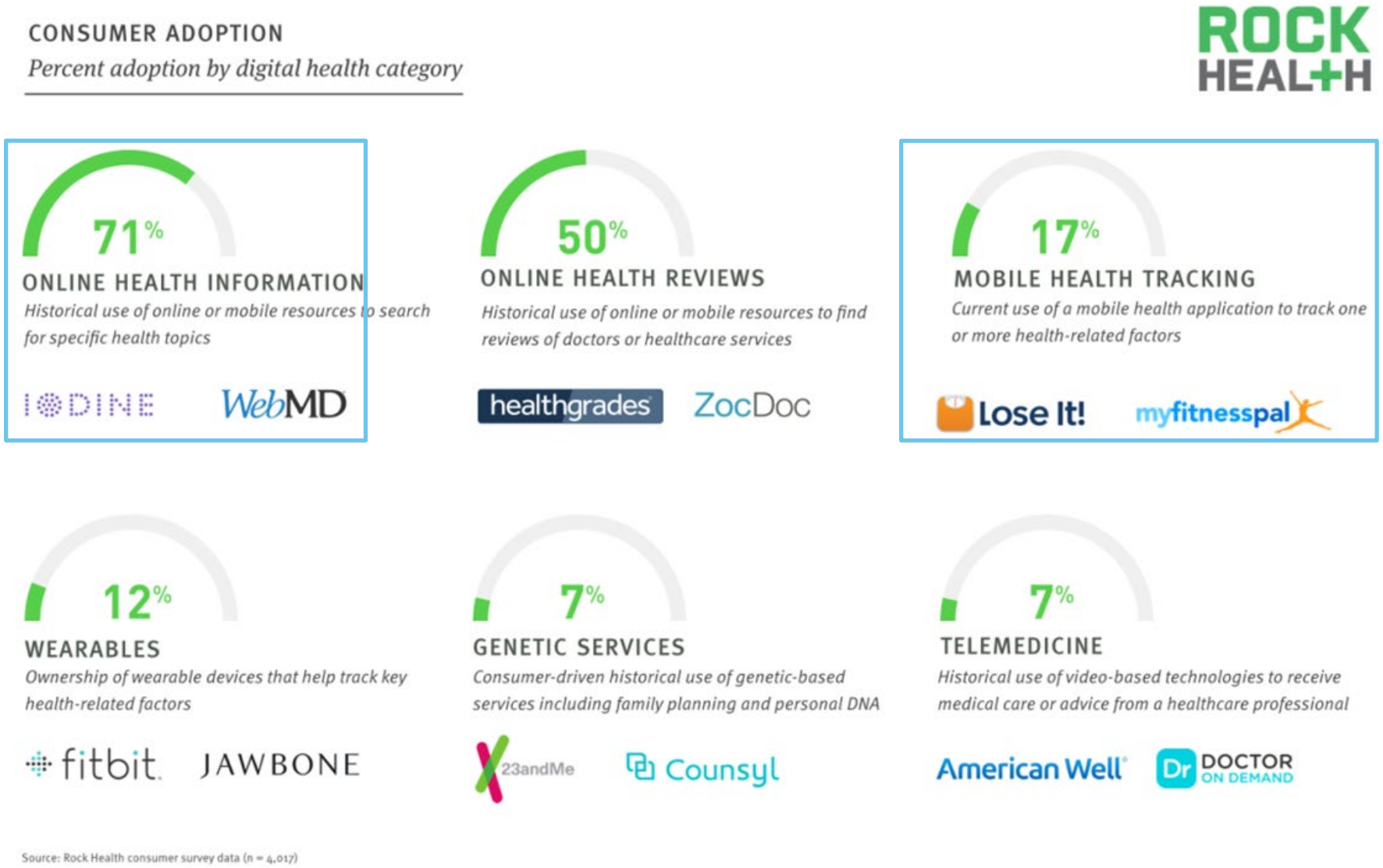
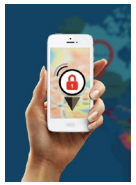
Adoption of Health Technology



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).

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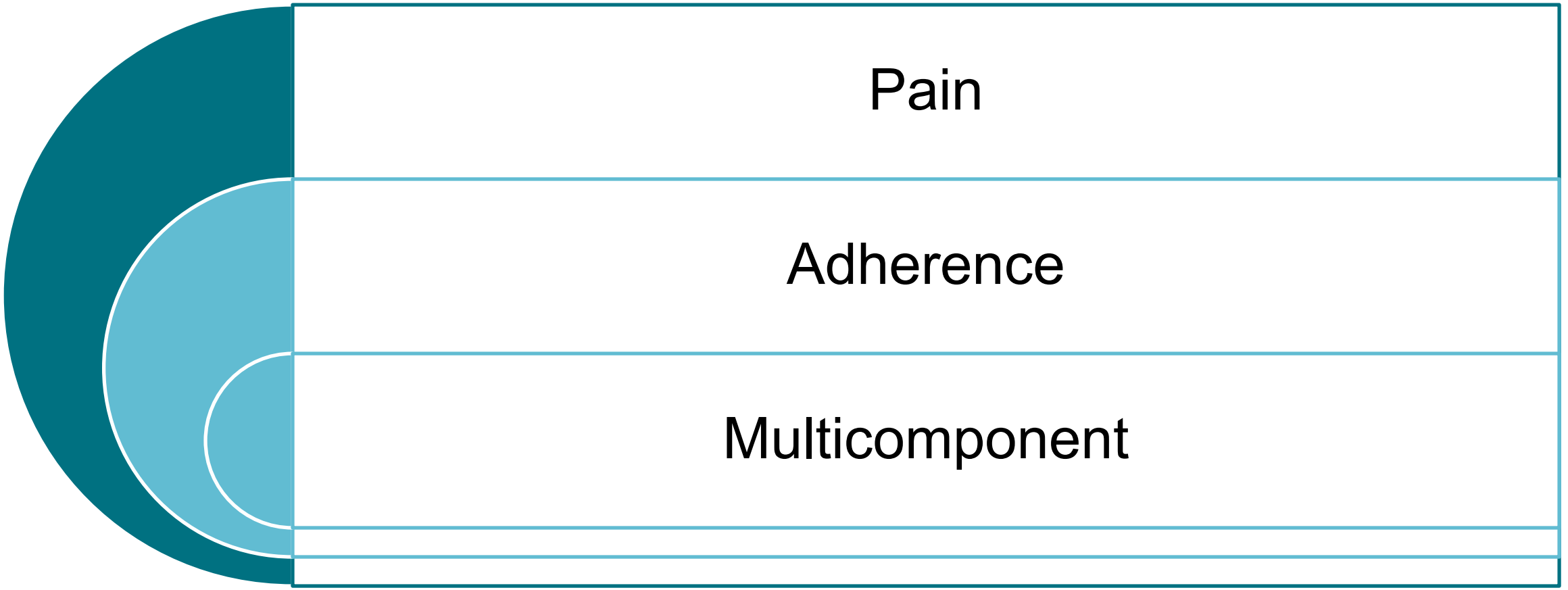
Self-Management Domains



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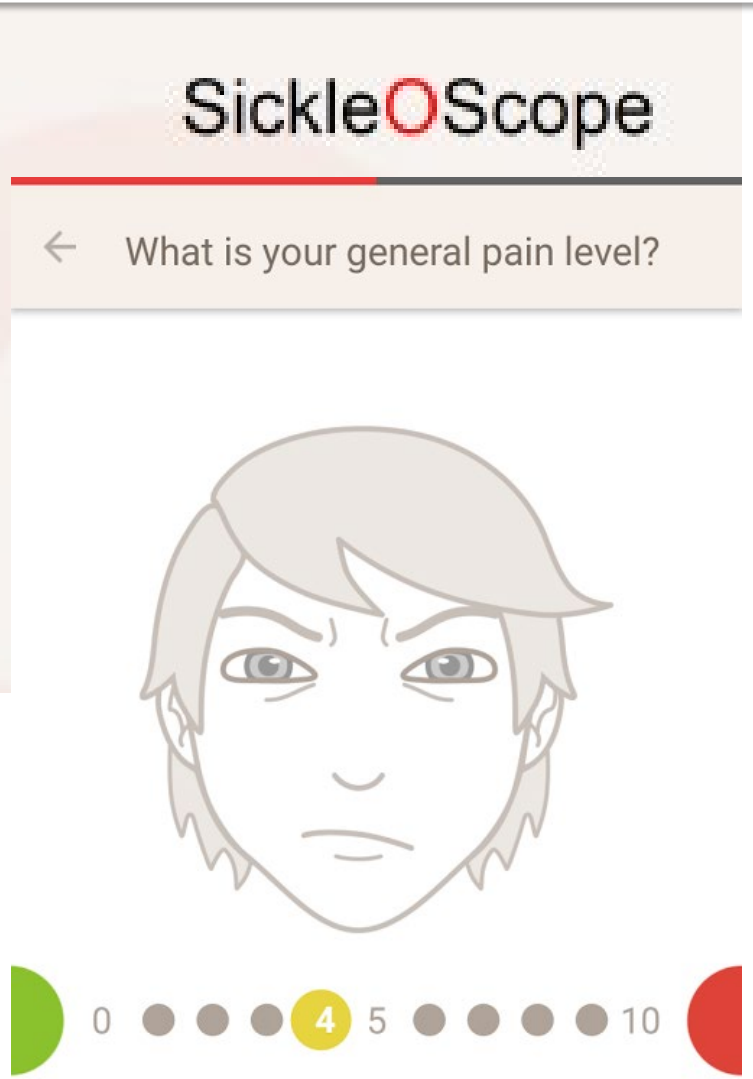
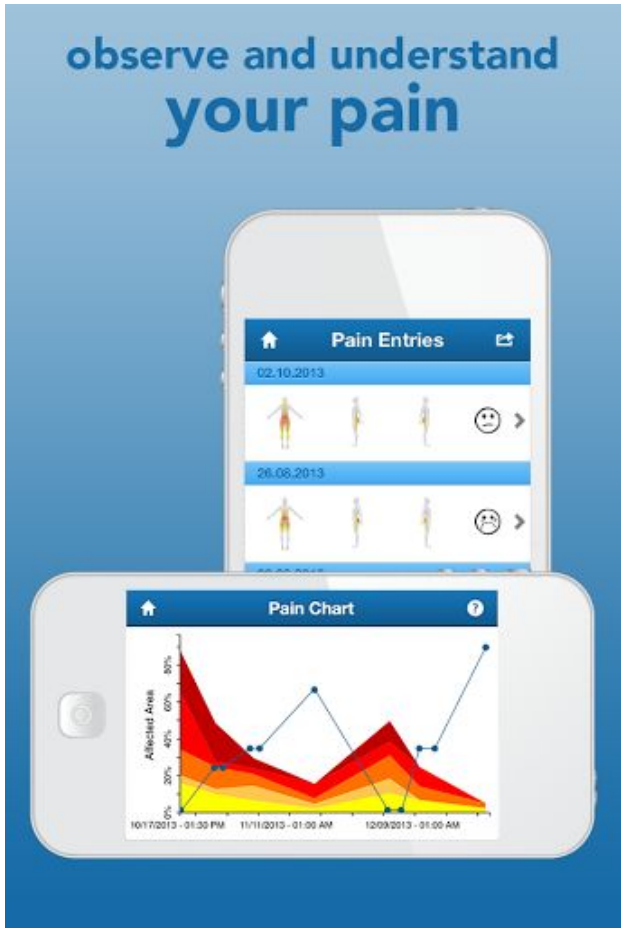
Tracking & Understanding Pain

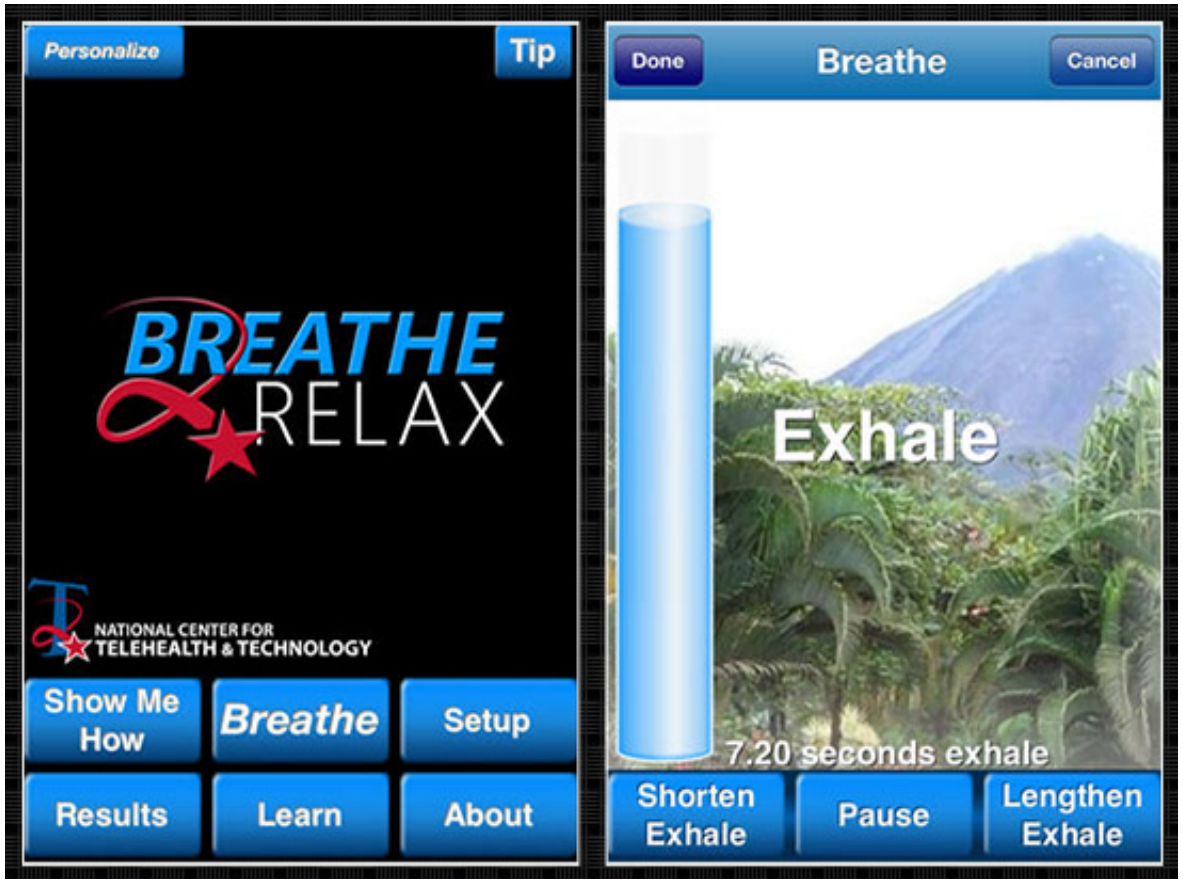


CatchMyPain

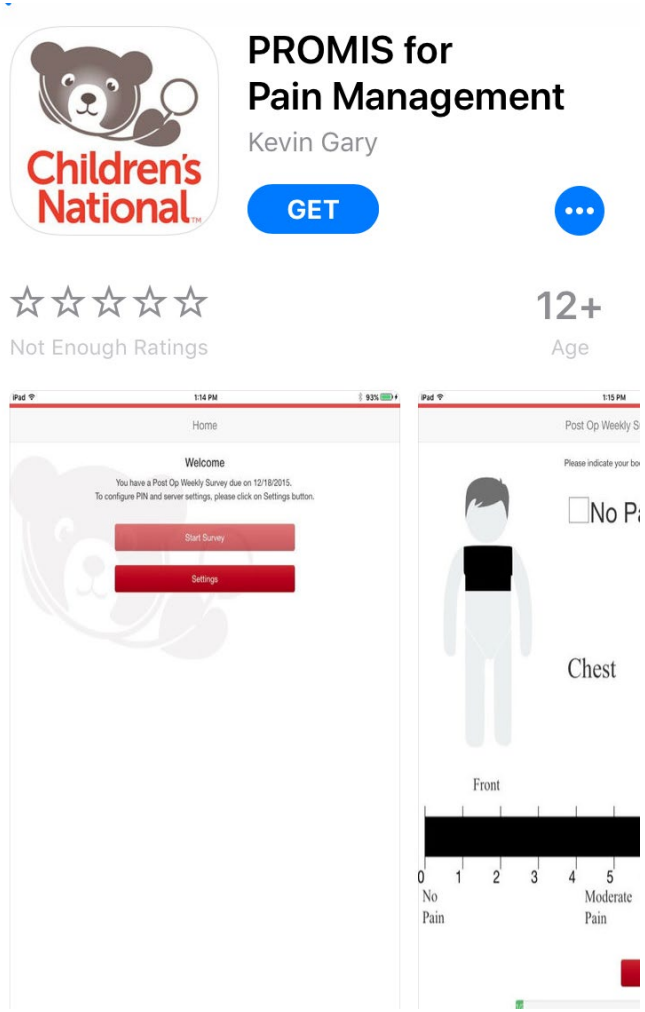


Pain Management

MyCalmBeat

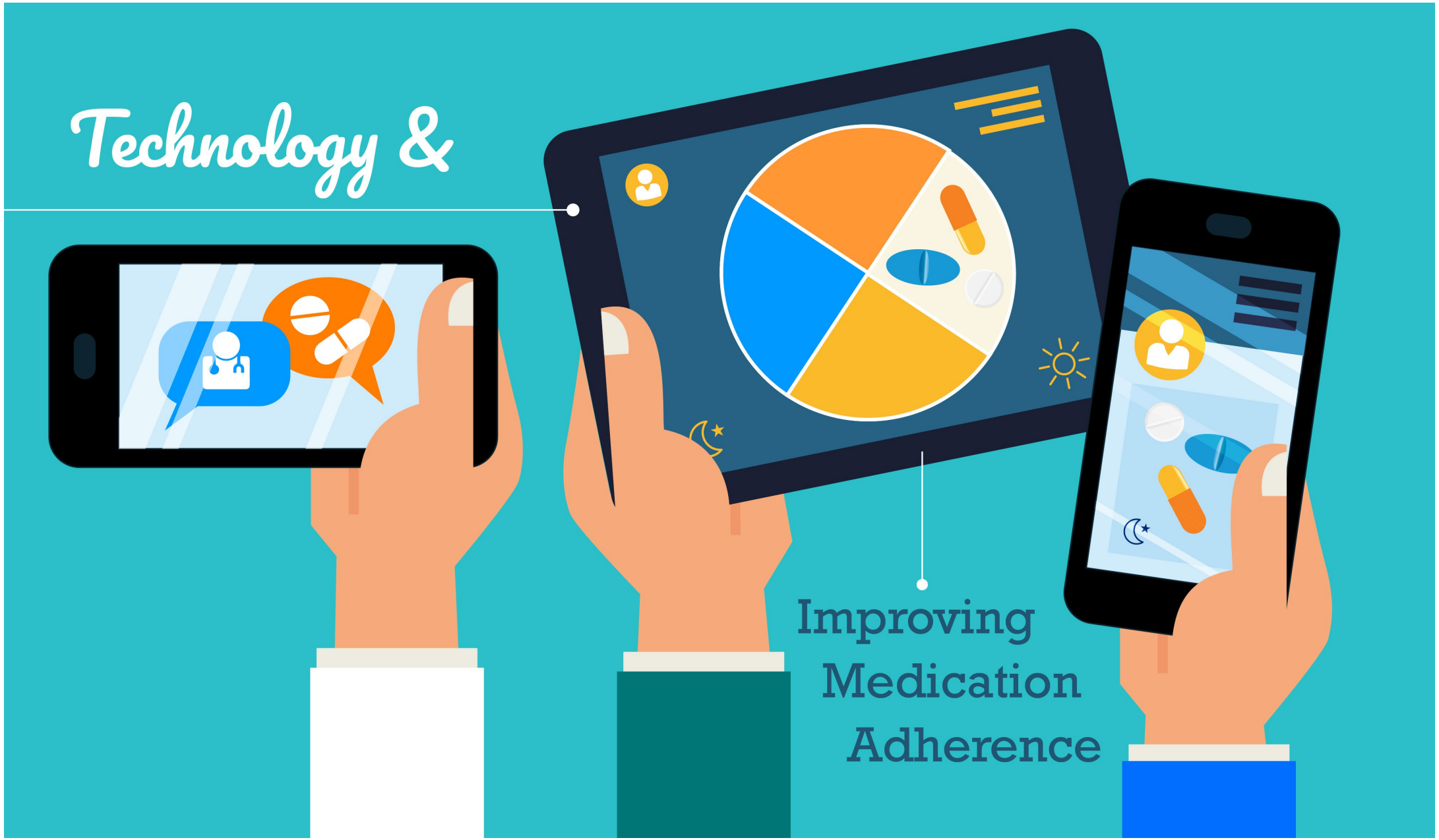


Future Directions



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

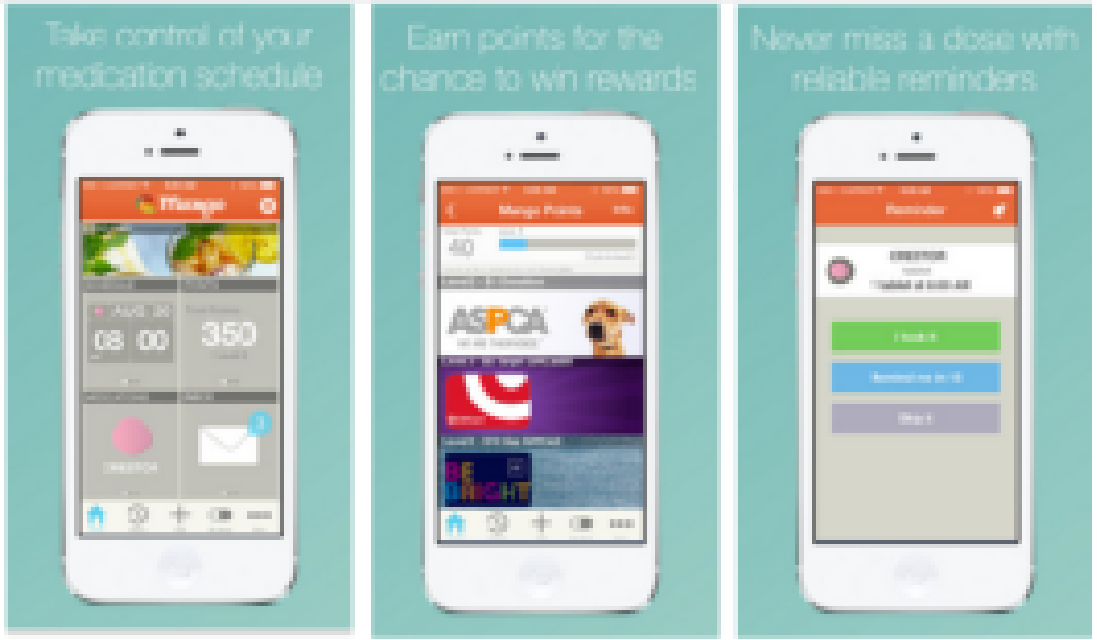
Mango Health – Medication Manager

By Mango Health

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

Scan the QR Code with your smartphone to learn more.



MyMedSchedule Mobile

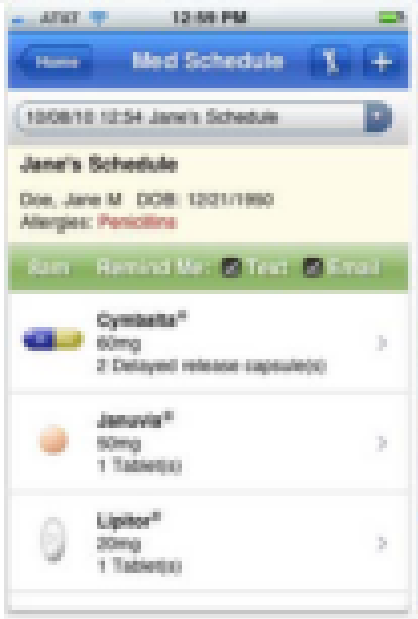
By MedActionPlan.com

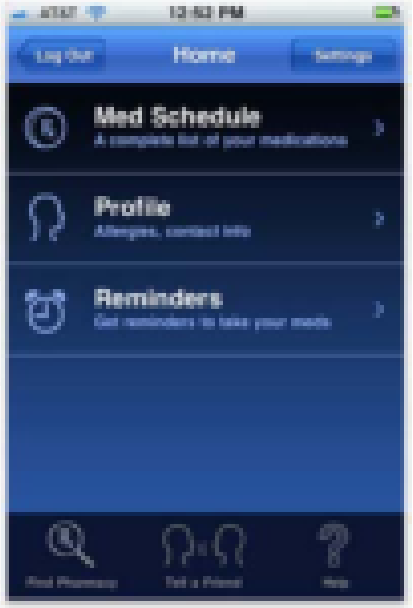
- Print schedules that are easy to create, read, and update
- Keep track of all your medications
- Bring your pill schedule to all your medical and dental appointments
- Graph results to track progress
- Quick and easy data entry
- Receive reminders to take your medications by text or email
- Refill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

Available on the App Store

Google play

Scan





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

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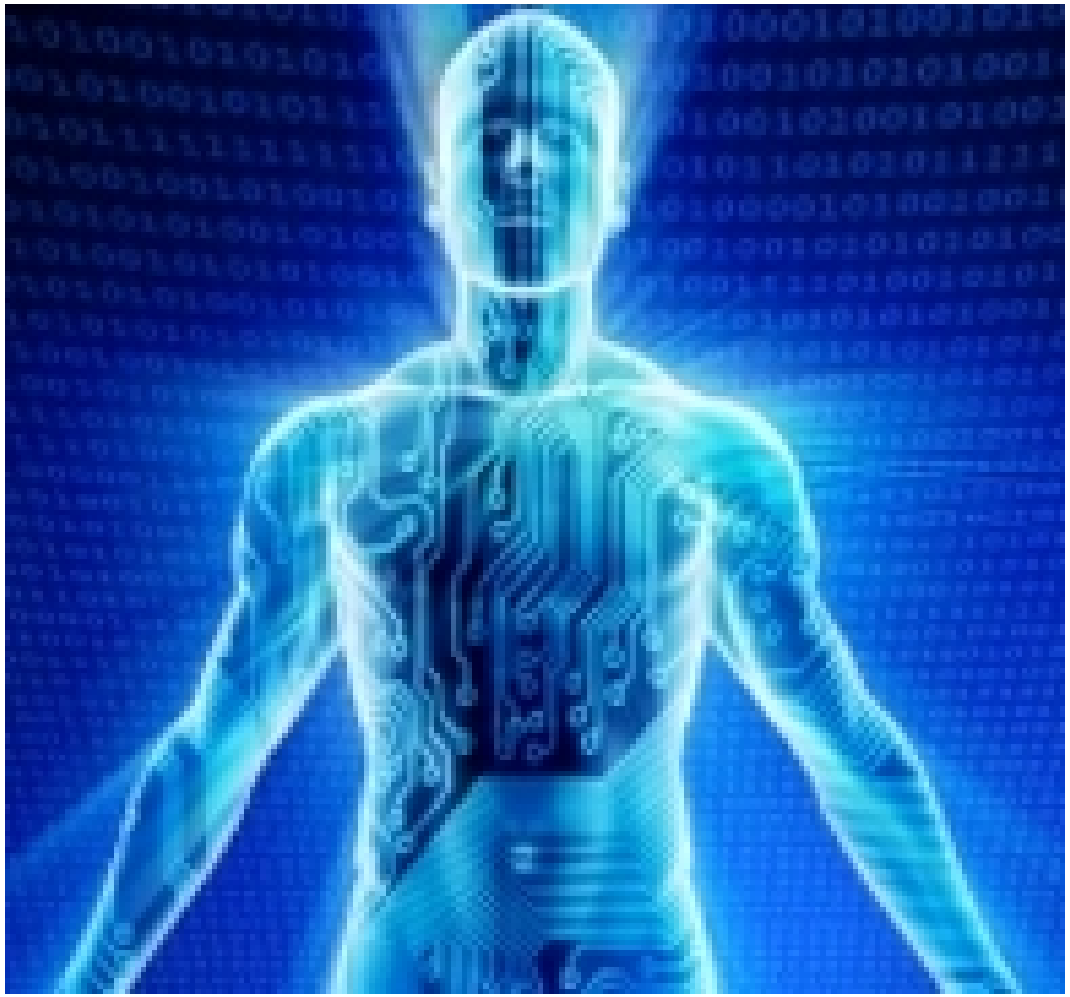
App and Sensors

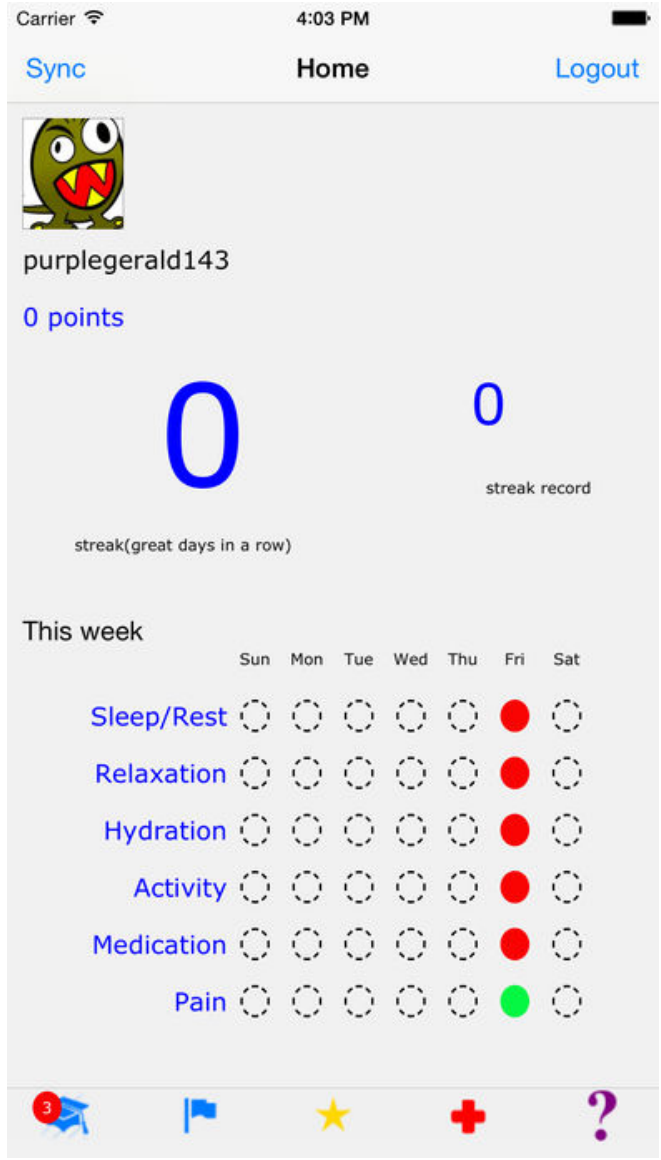
- Smartphone app and compatible blood testing sensor - Florida Atlantic University's College of Engineering and Computer Science – NSF
- Smartphone app and wearable sensor – variations in oxygen saturation
- Ingestible sensors to measure medication adherence



Multicomponent

Goals

sickleWell



Portable Medical Record

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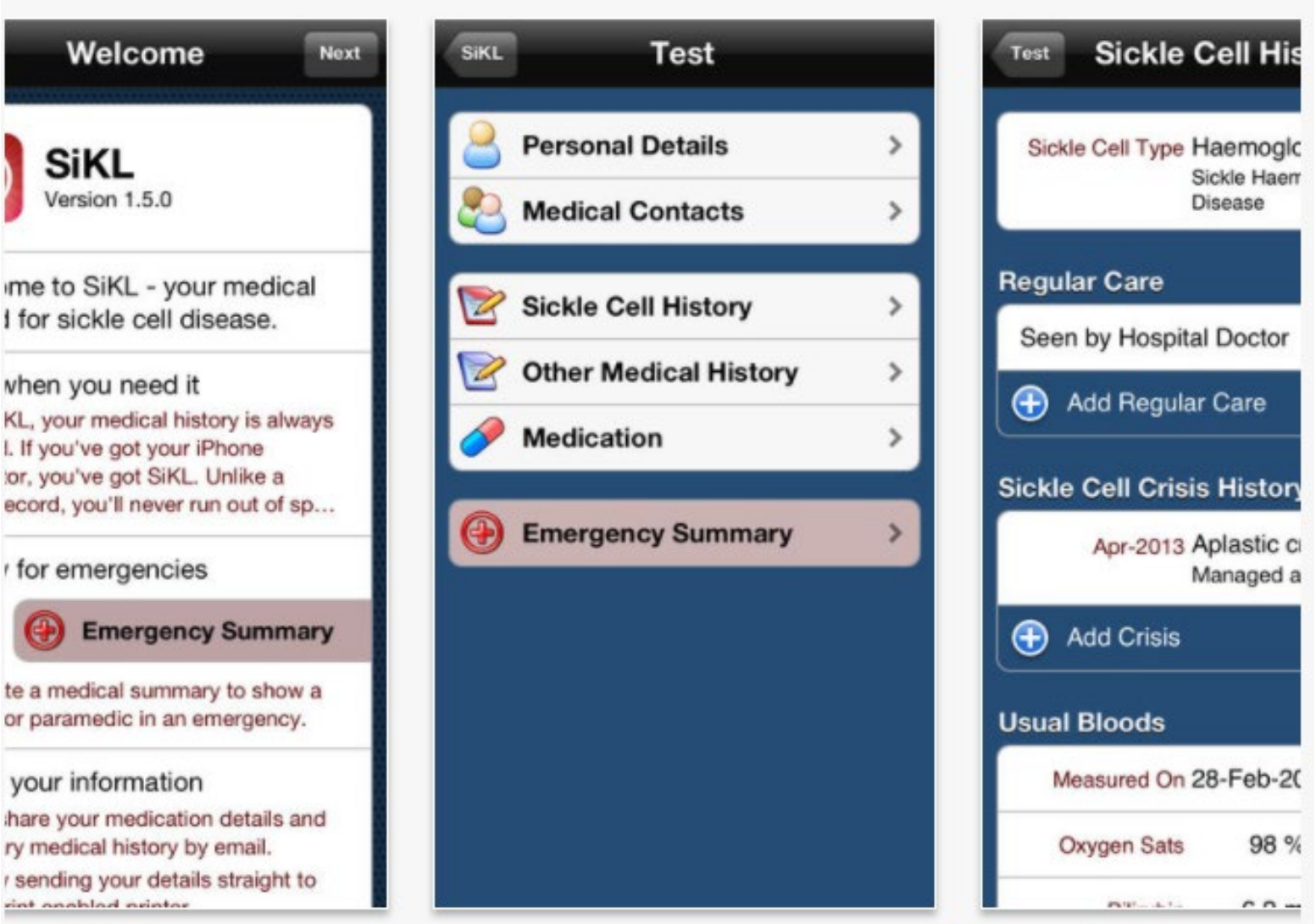
SiKL



Important Notes

- Not a comprehensive list of electronic tools – primarily apps
- Likely missed some available apps and some currently understudy
- 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

Participants

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

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

PATIENT MAPPING: THEMES

DAILY LIFE

FAMILY

CARE PROVIDER INTERACTION

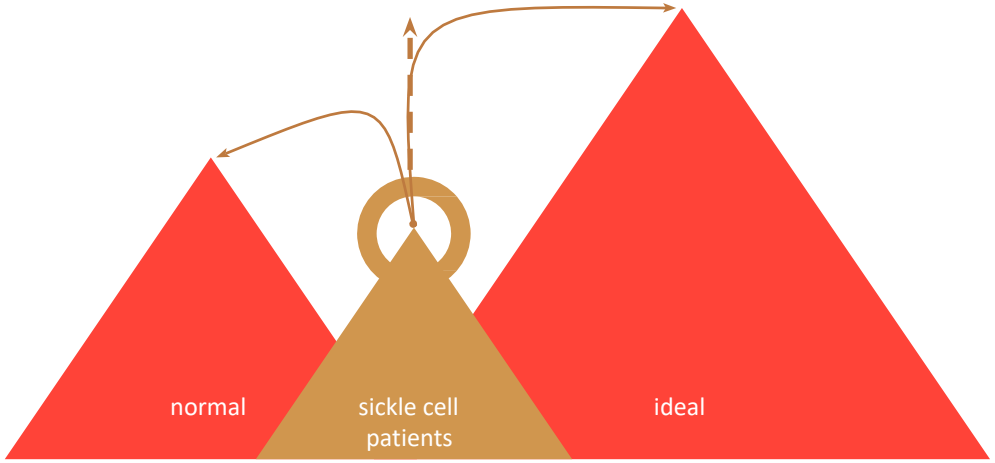
ENVISIONING THE FUTURE

SELF MANAGEMENT

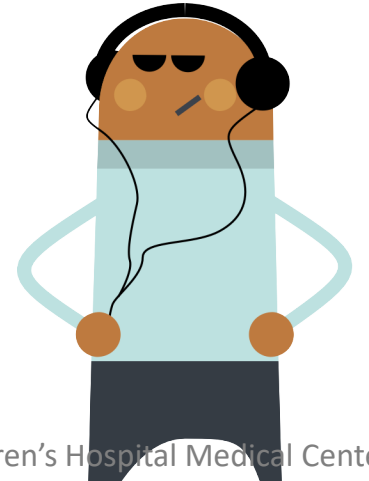
SOCIAL ASPECTS OF SCD

ATTITUDES TOWARDS TRANSITIONING

what we LEARNED



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



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OPPORTUNITY areas

"redefine self-management as a lifestyle for patients"

lifestyle

visualize

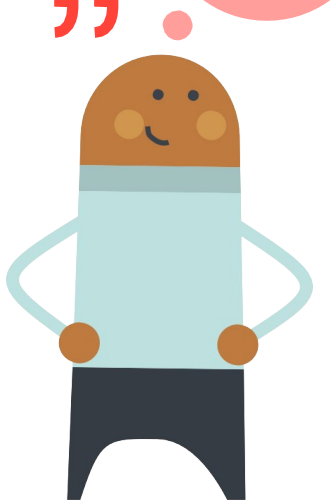
support

"Enhance ability to come up with a creative solution"

invent

"Something I can see"

"Only someone with sickle cell can understand me"



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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:

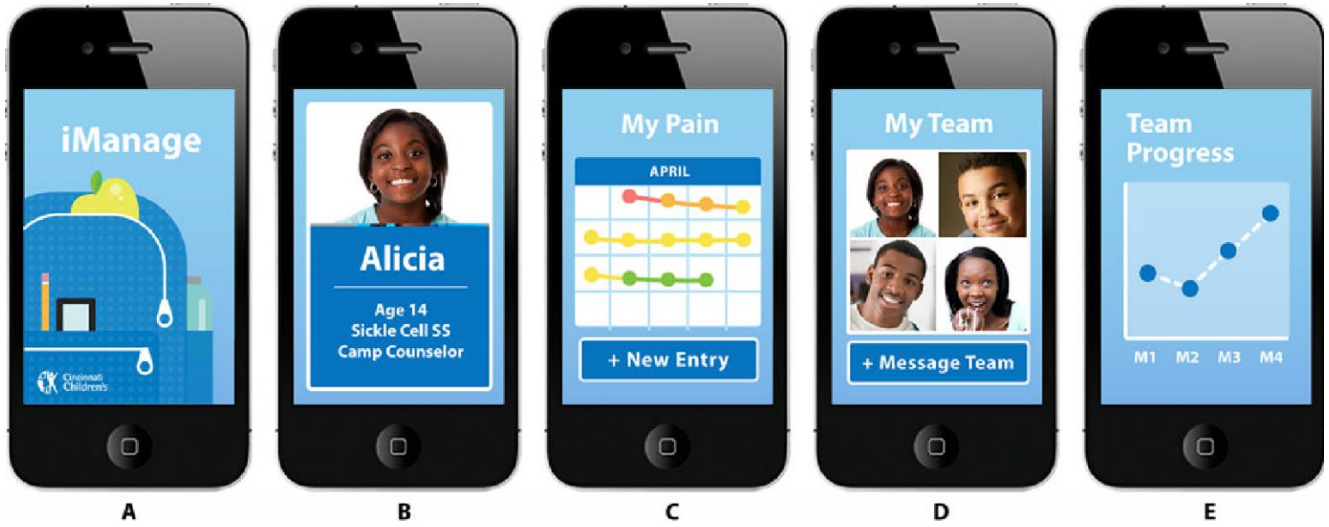
- Pilot testing with feedback (iterative process)
- Functionality
- Instructions
- Understanding and technology issues

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

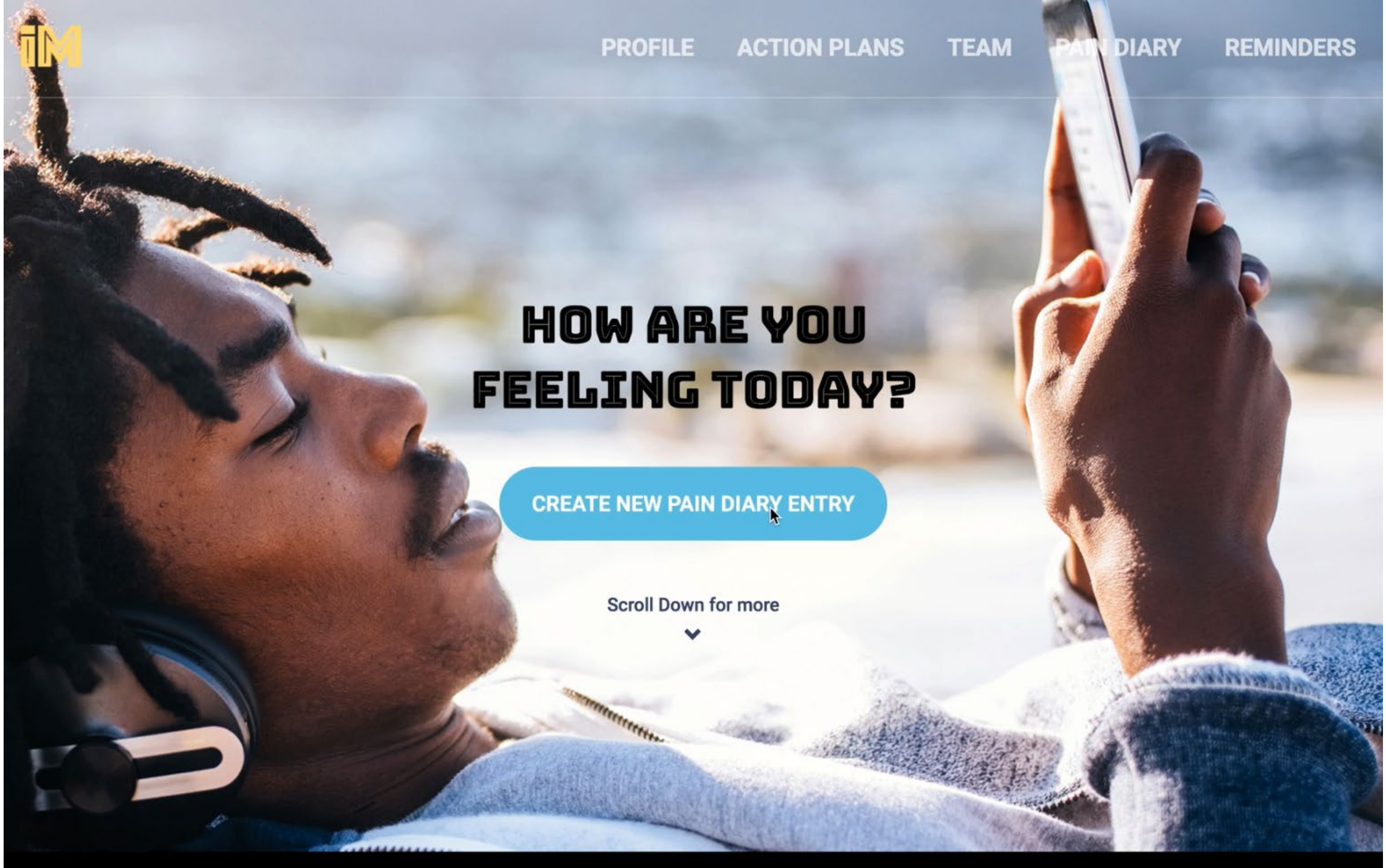
Feasibility & Acceptability

- 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)**


PROFILE
ACTION PLANS
TEAM
PAIN DIARY
REMINDERS
HOW ARE YOU FEELING TODAY?
CREATE NEW PAIN DIARY ENTRY
Scroll Down for more

Intervention Development Team

- Participatory Method
  - 3 AYA
  - 3 Interventionists

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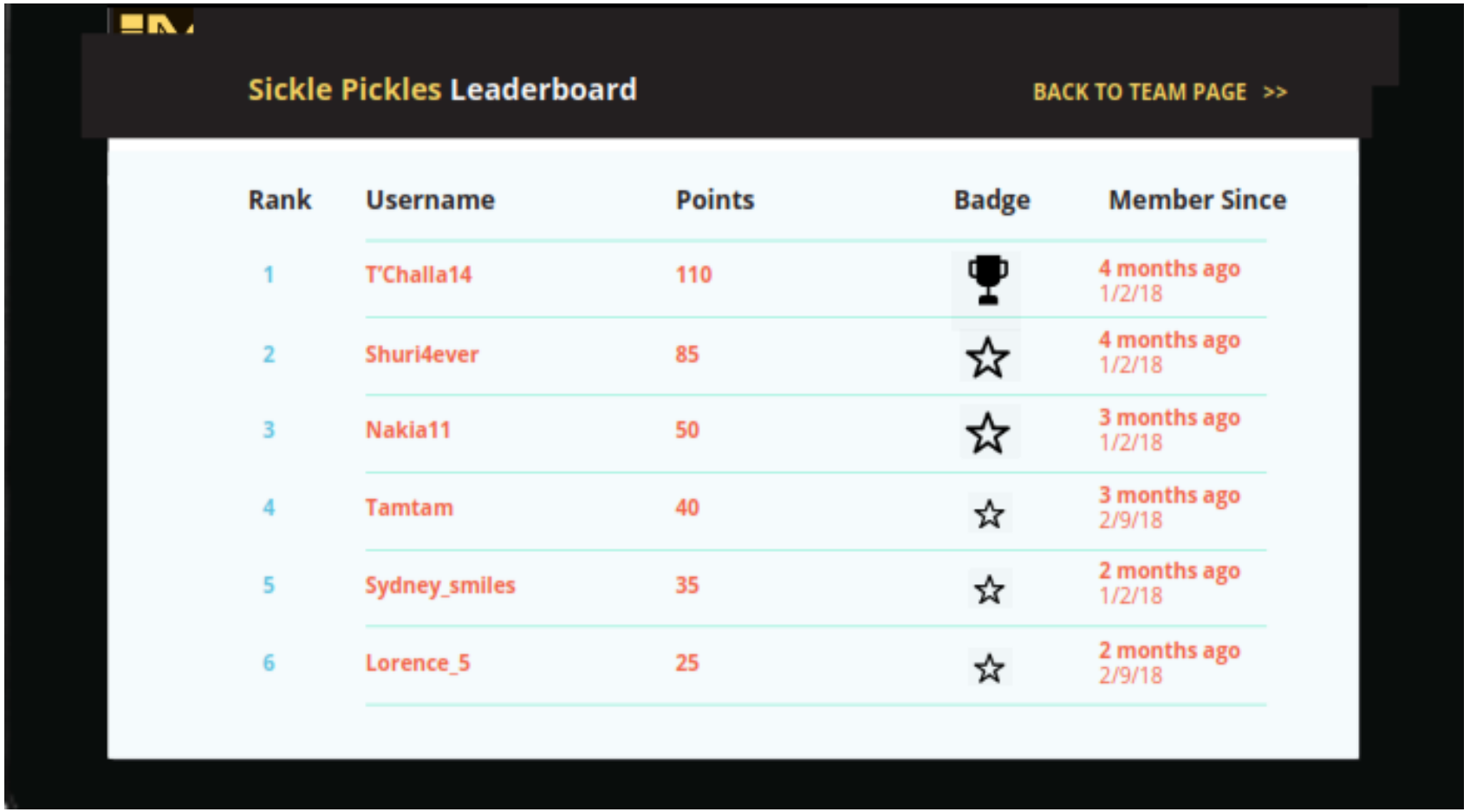
iManage Results

- 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



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

<u>Users receive points for:</u>

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

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