

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



Digital Healthcare Innovations to Engage and Empower Patients in Their Care

Presented by:

Kimberley D. Lakes, Ph.D.
David H. Gustafson, Ph.D.
Sunit P. Jariwala, M.D.

Moderated by:

Sheena Patel, M.P.H.
Agency for Healthcare Research and Quality

October 11, 2023

Agenda



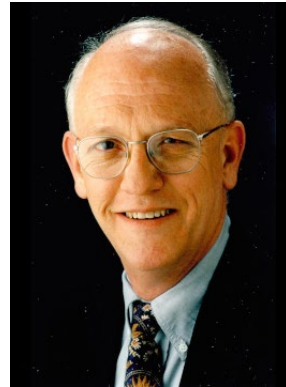
- Welcome and Introductions
- Presentations
- Q&A Session With Presenters
- Instructions for Obtaining CME Credits

Note: You will be notified by email once the slides and recording are available.

Presenter and Moderator Disclosures



Kimberley D. Lakes, Ph.D.
Presenter



David H. Gustafson, Ph.D.
Presenter



Sunit P. Jariwala, M.D.
Presenter



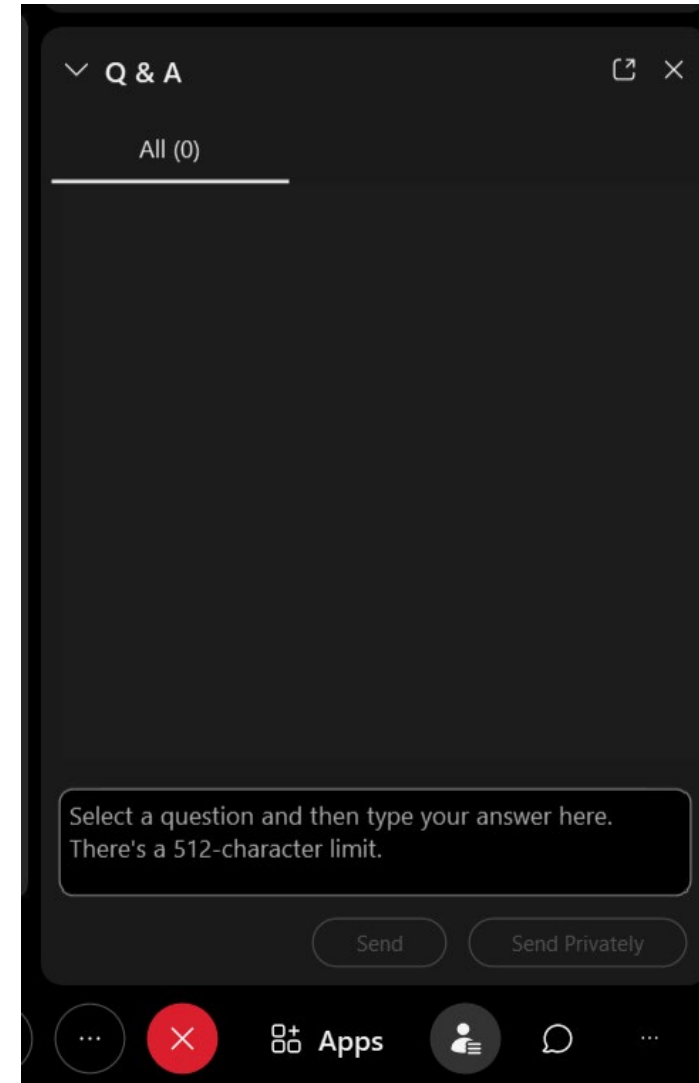
Sheena Patel, M.P.H.
Moderator

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- Faculty: Dr. Lakes and Dr. Gustafson have no disclosures. Dr. Jariwala is a principal investigator for Aevice and Sonde Health.

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- Please address your questions to “All Panelists” in the drop-down menu.
- Please include the presenter’s name or their presentation order number (first, second, or third) with your question.
- Select “Send” to submit your question to the moderator.
- Questions will be read aloud by the moderator.

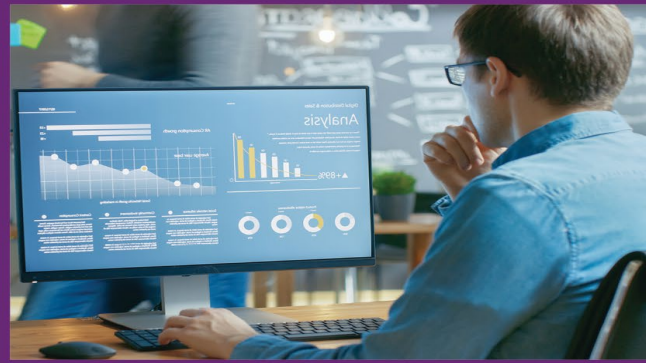


Learning Objectives



At the conclusion of this webinar, participants should be able to:

1. Describe how wearable technology can be used to engage adolescents in managing their mental health.
2. Identify how older adults can use self-management tools to make informed healthcare decisions.
3. Discuss the importance of involving both patients and healthcare providers in the development and implementation of mobile interventions.



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



Digital Healthcare Innovations: Engaging and Empowering Adolescents with ADHD

Kimberley D. Lakes, Ph.D.

Professor, Department of Psychiatry and Neuroscience, School of Medicine,
University of California, Riverside

Research Impact



Patient-centered digital healthcare technologies designed to promote co-regulation (adolescent/parent) can help support timely and targeted mental health intervention for youth at risk for poor outcomes.

Attention Deficit Hyperactivity Disorder (ADHD)



- Most prevalent childhood psychiatric condition
- Characterized by deficits in self-regulation
- High annual societal cost in the U.S.¹
 - 19.4 billion among children (\$6799 per child)
 - 13.8 billion among adolescents (\$8349 per adolescent)

¹ Schein J, Adler LA, Childress A, Cloutier M, Gagnon-Sanschagrín P, Davidson M, Kinkead F, Guerin A, Lefebvre P. Economic burden of attention-deficit/hyperactivity disorder among children and adolescents in the United States: a societal perspective. *J Med Econ.* 2022 Jan-Dec;25(1):193-205. doi: 10.1080/13696998.2022.2032097. PMID: 35068300.

ADHD Core Symptoms

Inattention – difficulty in areas such as:

- Giving close attention to details
- Following through with tasks
- Organizing tasks and activities
- Managing time
- Engaging in nonpreferred tasks

Hyperactivity and impulsivity

- Overactive, restless, fidgety
- Difficulty controlling impulses

Current Treatment Challenges

- Need for coordination across points of care
- Limitations in approaches to information-sharing
- Lack of reliable and valid information
- Delays in treatment adjustments
- Deficits in self-monitoring and adherence over time

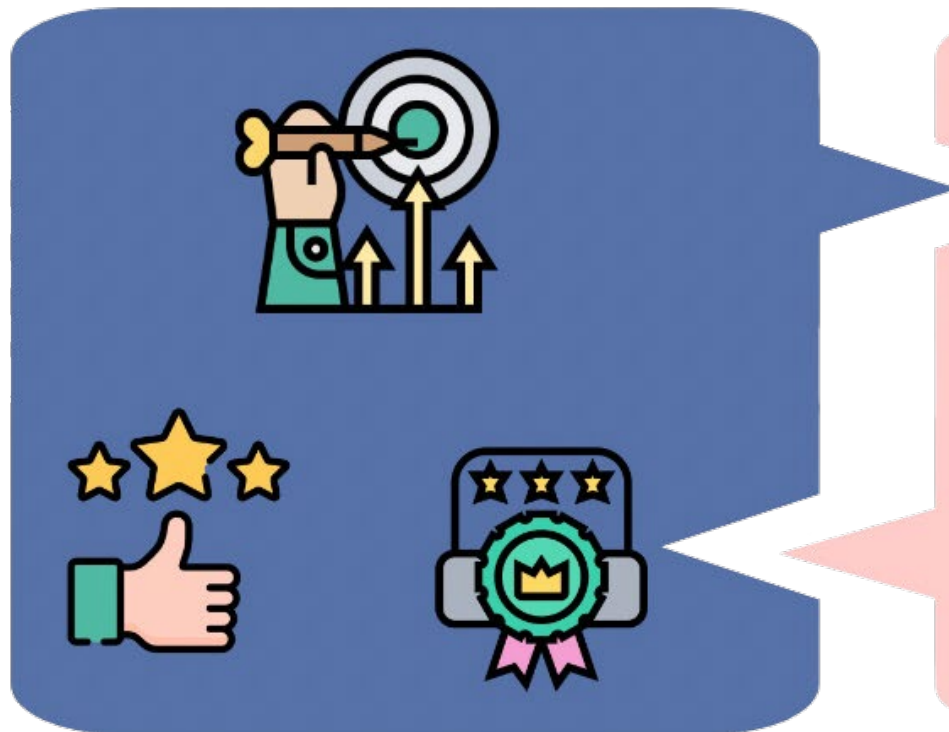


Potential Digital Solutions

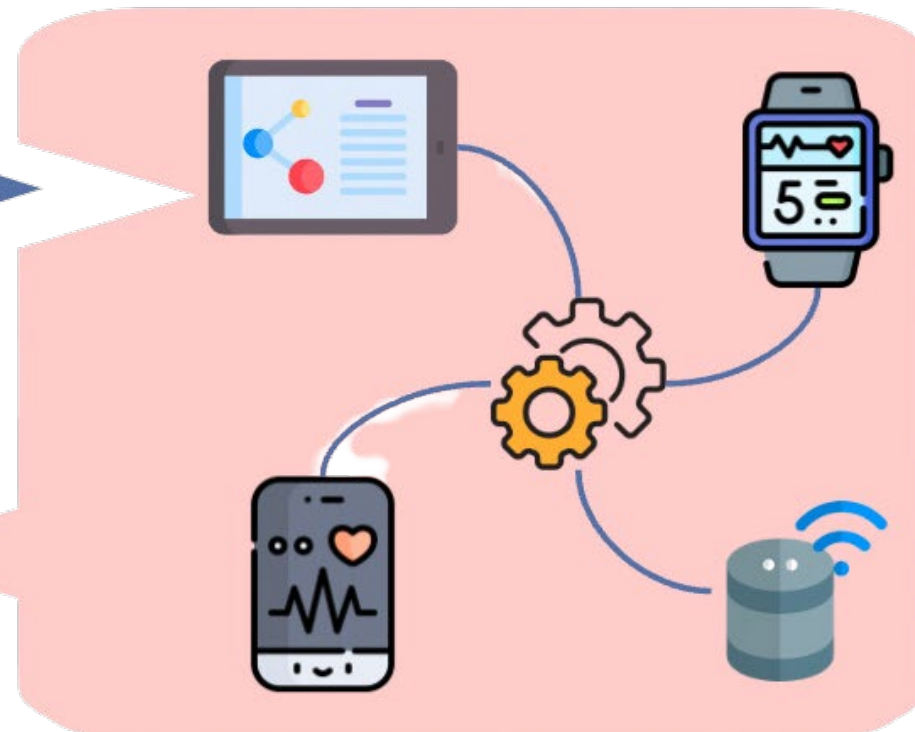
- Support self- and co-regulation
- Capture reliable and valid patient data
- Enhance patient engagement in their care
- Facilitate shared decision making
- Improve timely and targeted intervention

Patient and Caregiver Engagement

Patient-Created Goals
and Reinforcements



Leverage Growing
Technology Ecosystem



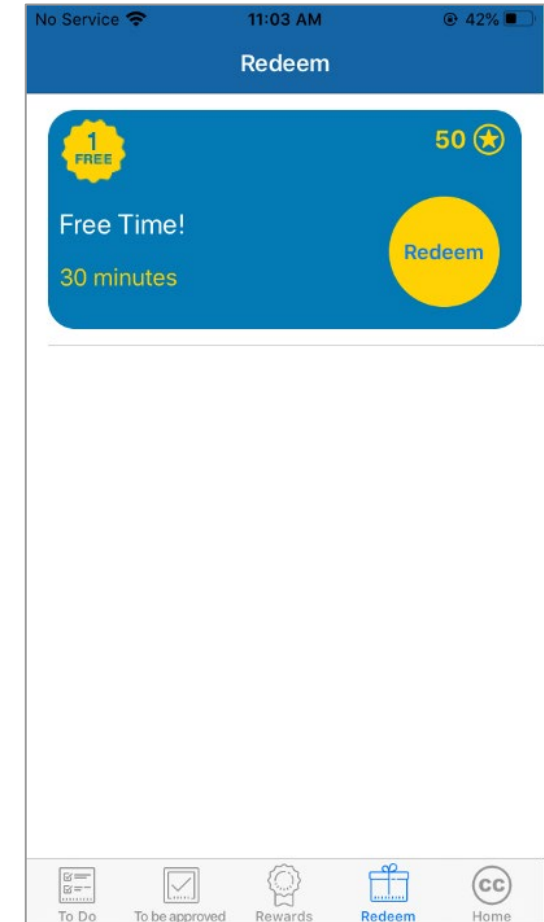
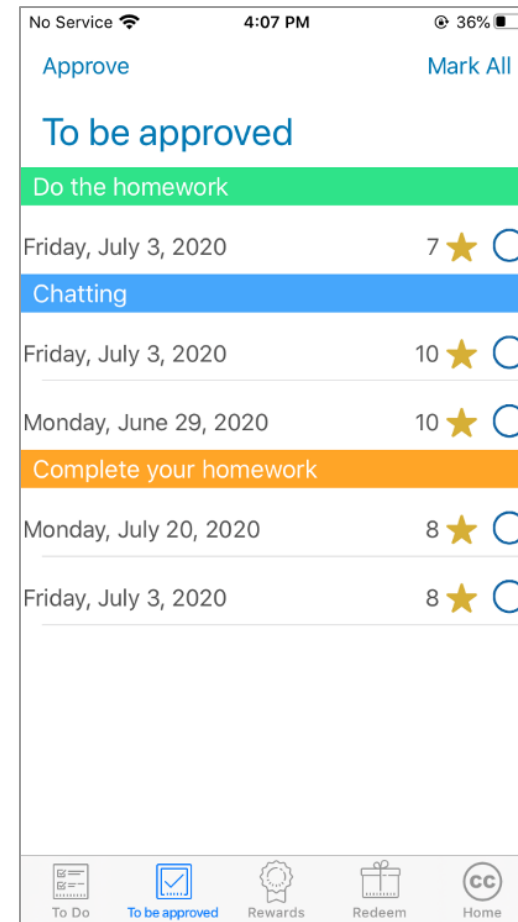
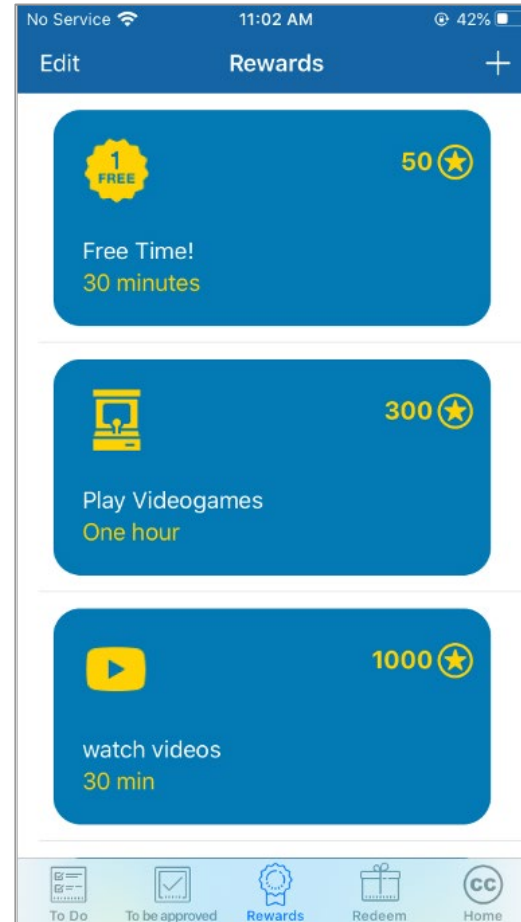
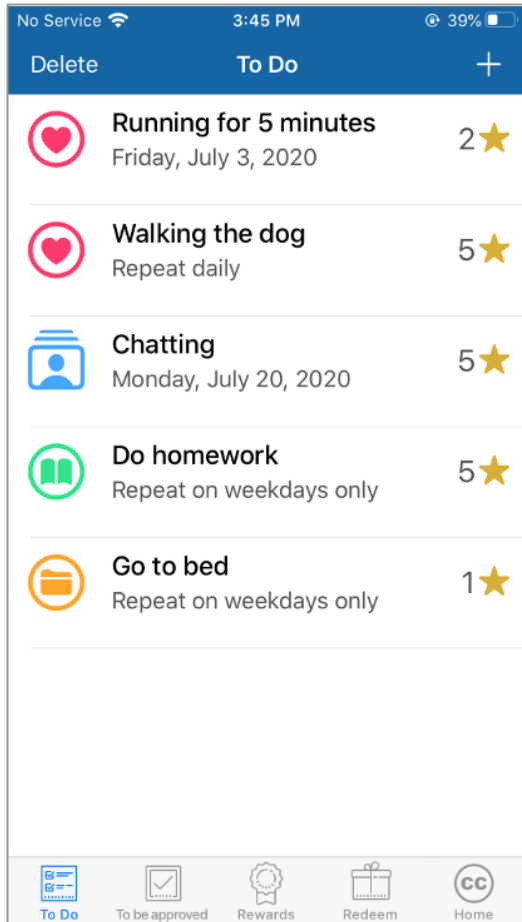
Methods

- Participatory design workshops with stakeholders
 - Adolescents
 - Parents/Caregivers
 - Teachers
 - Clinicians
- Iterative development
- Patient deployment study



Paper prototypes (top) and sketches drawn by children with ADHD (bottom) during participatory design workshops.

Smartphone Application for Parents



Smartwatch Application for Children



Smartwatch Application for Children: Redeem Rewards



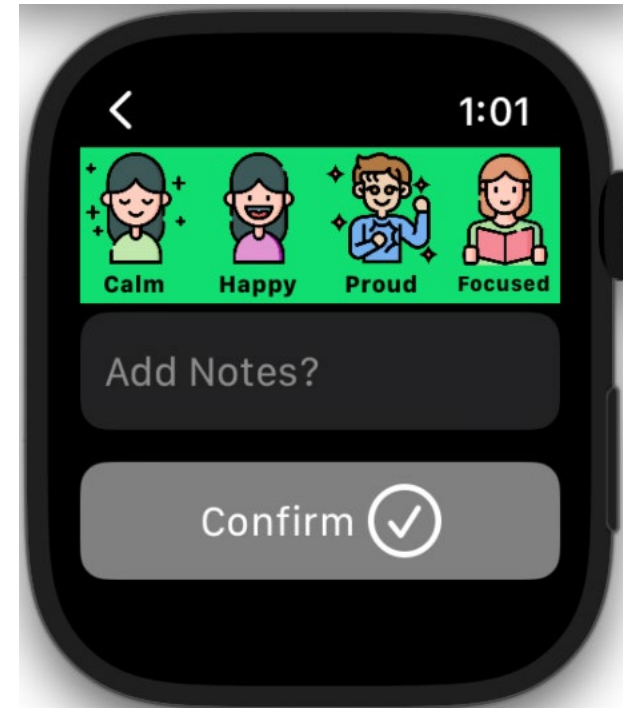
Smartwatch Application for Children: Add Activity



Emotion Regulation: Self-Monitoring



Simplified input based on zones of regulation



Optional addition of details or emotion labeling through voice input

Selected Key Findings

- Adolescents identified unique benefits of wearables (e.g., discrete, reduce stigmatization).
- Digital technologies can provide support for ADHD challenges, including time and task management and adherence to treatment and health behaviors.
- Support of organizational skills was noted by parents during pandemic-related distance learning.
- Systems can promote shared decision making around behavioral targets and reward systems within families.

Selected Key Findings

- Informatics can increase awareness among adolescents and their caregivers.
- Preferences for data visualization differ by user.
- Interventions need to balance self- with co-regulation (i.e., parent/child regulation).
- Data collected through wearables can promote the opportunity to reflect, discuss, and learn from lived experiences.
- Using digital technologies to support parent-child communication can decrease parent-child conflict.

Research in Progress & Timeline



- Participatory design and development for stakeholders in multiple points of care; deployment study with children & systems of care (2022-2024)
 - Adolescents with ADHD
 - Caregivers
 - Educators
 - Psychiatrists, psychologists, mental health clinicians
 - Primary care physicians

Research in Progress & Timeline



- Randomized Clinical Trial (2024-2027)
 - 60 youth with ADHD & their systems of care
 - Measurement of key outcomes across users
 - Child: engagement in care, ADHD symptoms, adherence, perceptions of shared decision-making
 - Caregiver: engagement in care, access to timely data, adherence to caregiver strategies, perceptions of shared decision making
 - Provider: access to and use of timely, meaningful data; perceptions of shared decision making; impact of quality of care, impact on provider workflow
 - Educator: access to and use of timely, meaningful data; perceptions of shared decision making; impact on educational interventions; impact on educator workflow

Lessons Learned

- Researchers must commit to creating usable and appealing DHI as equally important goals to creating clinically efficacious, evidence-based tools. Accomplishing both requires a commitment, upfront, to the resources, time, and effort required.
- Digital health technologies must address needs and privacy preferences of various users.
- Co-design with patients and interdisciplinary “experts” leads to better and more inclusive design. However, researchers must carefully engage these groups – sometimes separately – to ensure that diverse views are considered.

Lessons Learned

- Designers focused on technologies to support children must consider the needs of the child and multiple users in a child's care network.
- Co-design via participatory design workshops can help designers understand the challenges at different points of care and existing workflows.
- Design must reduce, not add to, the burden of care for caregivers, educators, and clinicians.
- Interdisciplinary research agendas must simultaneously address the needs of diverse fields across technological and clinical sciences.

Research Team

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AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



Are Smart Displays Better than Laptops for Delivering Interventions to Older Adults?

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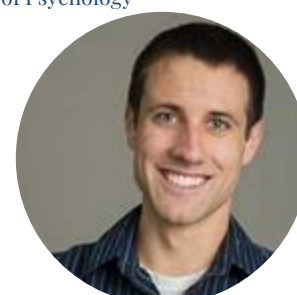
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Kasey Thompson
Program Coordinator

Who Are We?



- Center for Health Enhancement Systems Studies at the University of Wisconsin - Madison
- 50+ clinicians, scientists, and engineers working on:
 - Technologies to help people cope
 - Organizational change: quality improvement and sustainability
- **Mission: No one should have to suffer twice**
 - Multi-disciplinary (e.g., systems engineering; communication sciences, statistics, psychology, computer science, nursing; medicine)

Active Aging Research Center



- Urban (Milwaukee); Suburban (Waukesha); Rural (Richland)
- Community based participatory research
 - Offices in all three areas (ADRCs)
 - Interviewed 200+ older adults
 - Assets
 - Needs

Our Customers Think:

Isolation and Loneliness

Community Opportunities

Transportation

Clinicians Think:

Falls, dementia/confusion, behavioral challenges, medication errors, unreliable caregivers, inability to pay.

Of Course

- Both are right;
- But the customer is always really right; Right??
 - So, our goal was to:
Improve quality of life

Three Essential Ingredients of Quality of life

Coping
Competence

Social
Relatedness

Autonomous
Motivation

Quality
of Life

We Developed Elder Tree



- Home page: Thought of the day
Search
What's new
- Personal: To Do's
Health tracker
Bookmarks
- Conversations: Private
(Asynchronous) Public
Ask an expert
- Tools: Resources
Active living tips
Map your trip
Games & relaxation
Reminders

Study

- N = 310 (rural, urban, suburban)
- ET vs control

Results after 12 months

Among people who had

- **3+ PCP visits, ET patients improved more:**
 - Mental Quality of Life (p = .005)
 - Depression (p = .01)
 - Social support (.007)
- **The more chronic conditions; the more effective we were.**

But Lost 25% of Subjects and Use Went Down

- Laptops
 - Require typing (older adults have tremors)
 - Must remember password (easy to forget)
- **Is voice activation more appealing, usable, effective?**
 - You just talk to it
 - It talks to you to remind
 - You don't have to be at a desk

Would Voice Activation Help?



Compare Elder Tree (an eHealth system offering social support, coping, and motivational tools) on a smart display, versus a laptop.

Research Impact

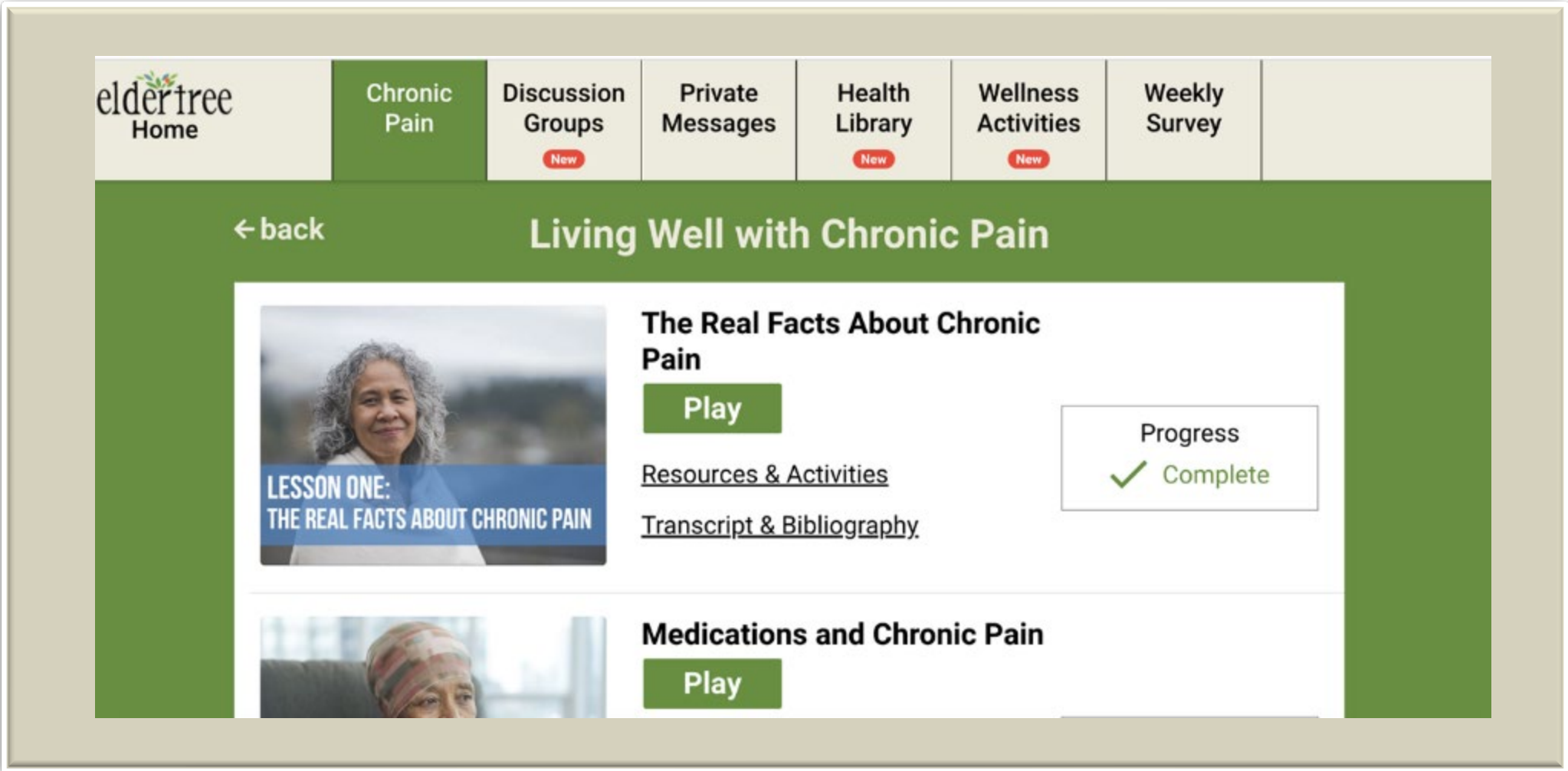


Elder Tree, an evidence-based electronic health intervention with voice-controlled technology, can lead to improved overall health and quality of life for older and disabled adults.

Key Questions

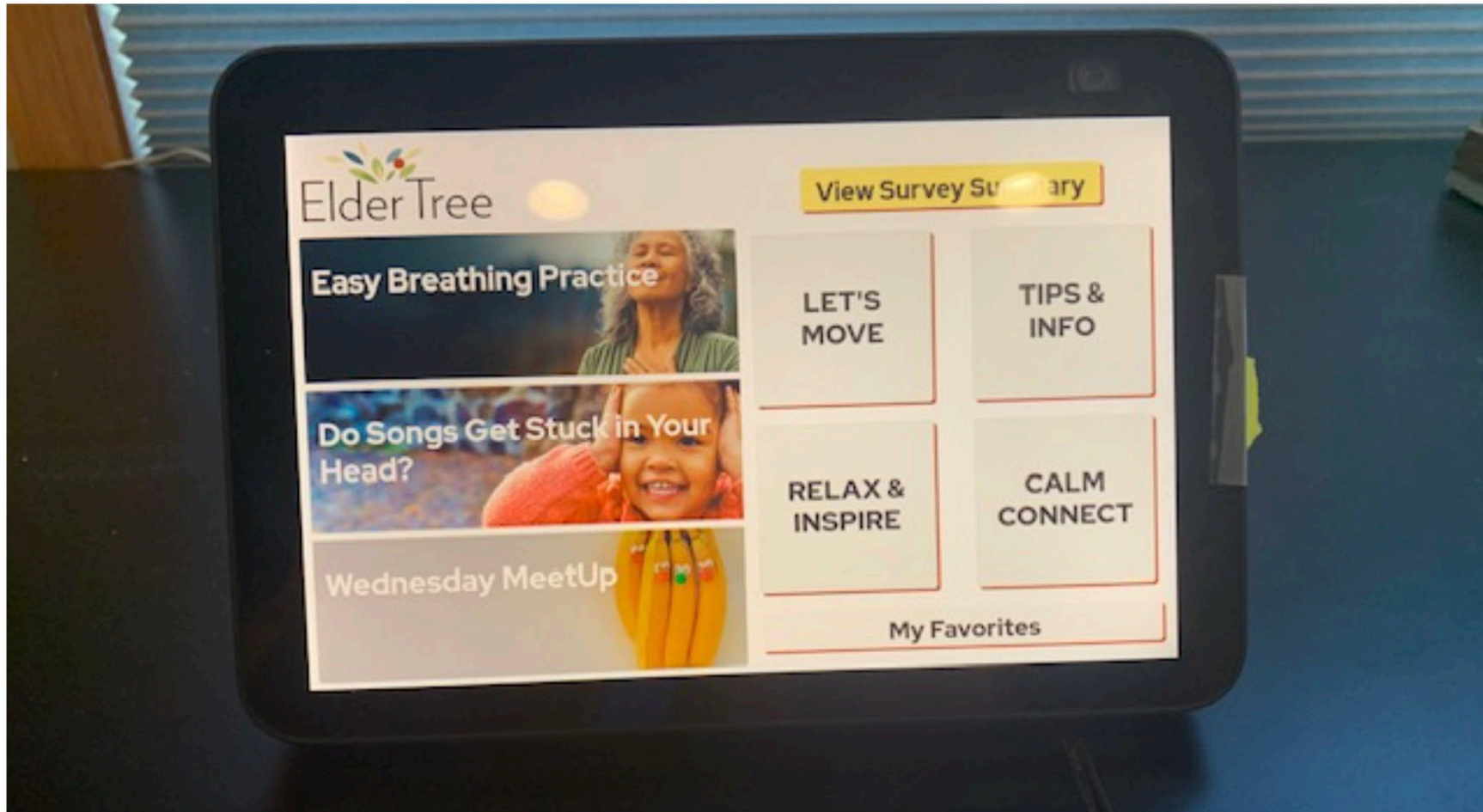
- What improves for people using each system?
- For whom is it more effective?
- What about people with hand tremors or vision problems?
- Which is more attractive? Convenient?
- What is the effect on quality of life?

Laptop Version of Elder Tree



The screenshot displays the 'elder tree Home' website interface. The top navigation bar includes links for 'Chronic Pain', 'Discussion Groups' (marked 'New'), 'Private Messages', 'Health Library' (marked 'New'), 'Wellness Activities' (marked 'New'), and 'Weekly Survey'. The main content area is titled 'Living Well with Chronic Pain' and features a '← back' link. Two video lessons are visible: 'The Real Facts About Chronic Pain' (Lesson One) and 'Medications and Chronic Pain'. The first lesson includes a 'Play' button, a 'Progress Complete' indicator with a green checkmark, and links for 'Resources & Activities' and 'Transcript & Bibliography'.

Screen Size Says Keep It Simple



Results: It Is Not Easy to Create a Smart Display System

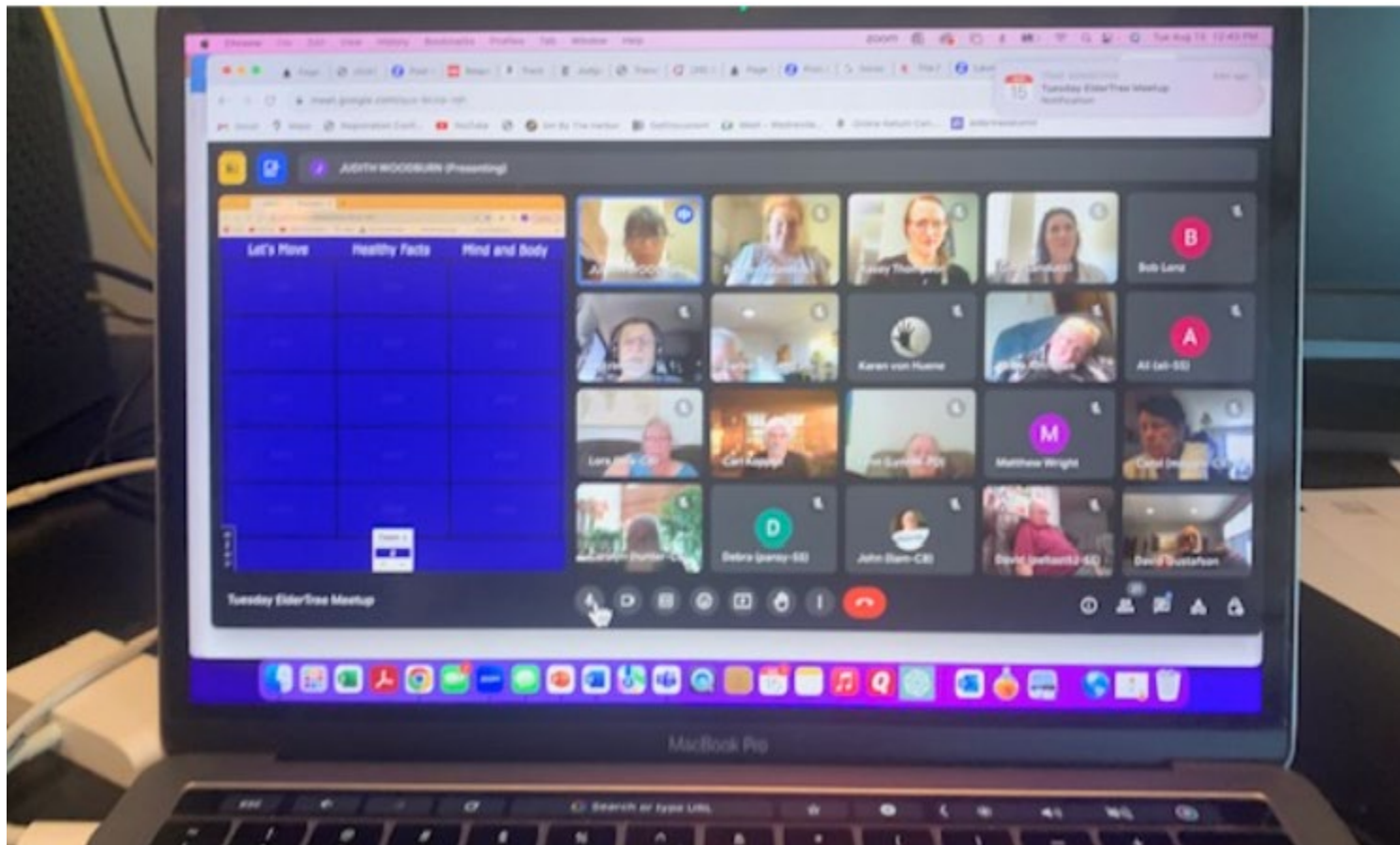
- What worked well on laptops didn't on a smart device
 - Discussion Group: most heavily used on laptop – it was the glue
 - Journaling
 - Screen size
- It is really a different environment
- It led to enhancements in both systems

Problems We Encountered

- We chose Google as our smart device
- **A year into our study, Google stopped supporting the needed back-end programming. UGH!!!!!!!**
 - It's a business
- Moved to Amazon Alexa Show
 - Had to start all over in programming and recruitment
 - Glad we did!

Dropped Dictation and Added MEETUPS

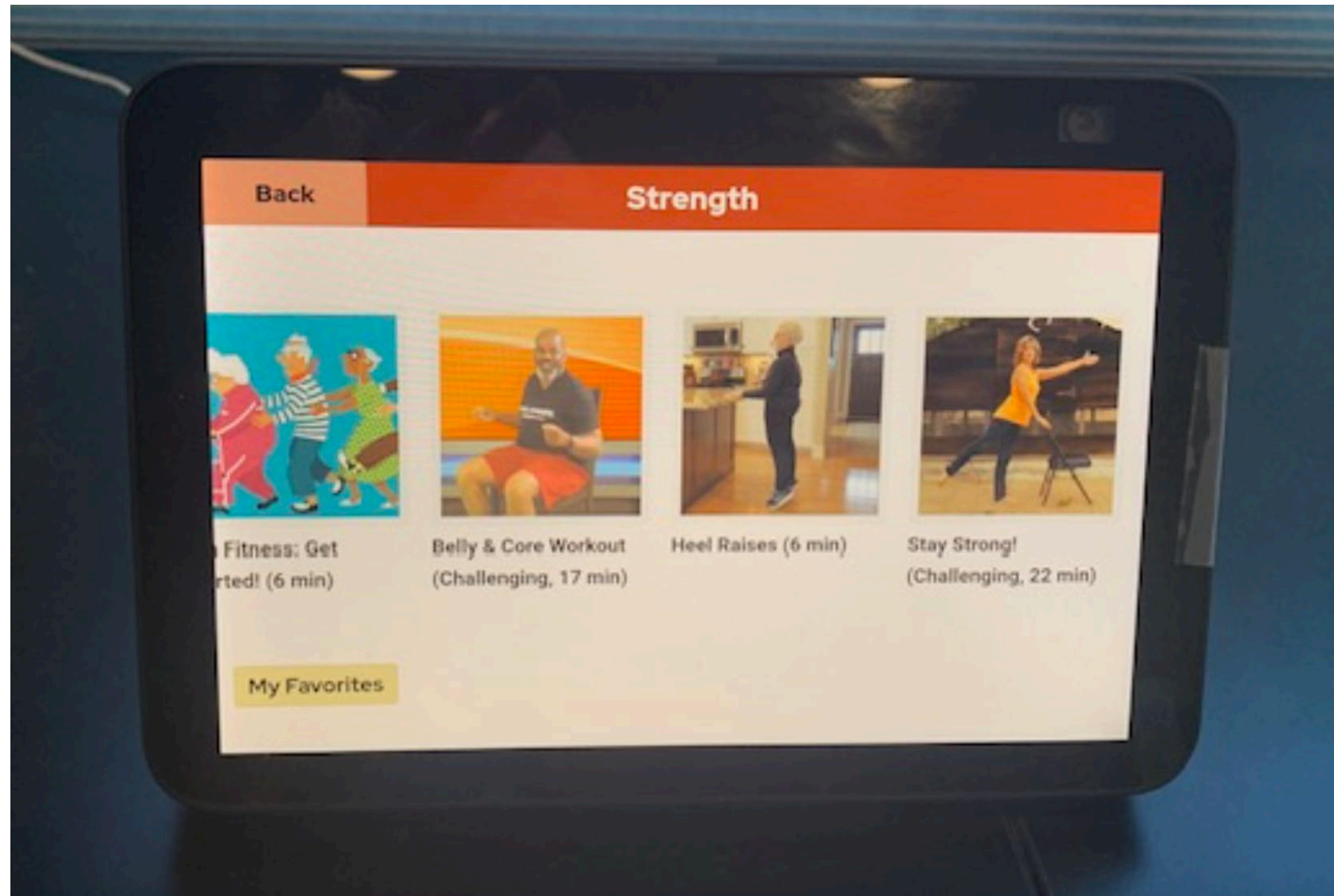
They bring participants together, cultivate a sense of community, create loyalty: >40% attend



What is a Meetup?

- 5 minutes: Welcome
- 20 minutes: Highs and lows over the last week
- 10 minutes: Topic of the week:
 - e.g., Relaxation, Breathing, Healthy foods
- 20 minutes: Facilitated discussion
- 5 minutes: An exercise video (**great way to train & remind**)
- 3 days later: Summary sent out & topic next time

Videos Helped



Rules of the Road Are Important



- **Share the air and share just enough so everyone who wants to share...can!**
- Respect others privacy – and honor your own. Only share what you are comfortable sharing. It's perfectly fine to pass or just listen.
- Mute yourself when you are done speaking.
- **Leave politics and religion at the door.**
- Stick to the topic and actively listen to others.

What Did We Learn?

- Don't believe the hype
 - Smart displays are smooth, intuitive **BUT**,
 - Sold as doing more than they can
 - Must use specific words
 - Misunderstood accents
 - Asynchronous discussion groups no longer great
 - Loss of discussion groups led us to Meetups

Results So Far: Meetups is the Star!



While participants never met in person, they found that meetups were the most impactful part of the study.

The meetings connected participants to each other.

- *The knowledge that you're not alone and that there are other people fighting through difficulties. It's a whole lot different knowing that than sitting at home by yourself thinking you're the only one going through it. (Comad30, Laptop)*
- *Whatever condition you are in, it gives you a way to socialize... It was so nice to see other faces. (Odana04, Smart screen)*

Technical Features Were Key

Led to more relatedness: e.g.,

- Hand-raising function that created organization for who can speak when
- Breakout groups created a closer sense of community.
- Participant A: *I'm shy about speaking up. The hand raising function was nice, because it helped to be called on. Sometimes, I would wait until there weren't a lot of people talking, I would raise my hand. (Comad15, Laptop)*
- Participant B: *We were able to build knowledge. Curated content was key. If you go to YouTube, you can find videos about how to maintain your balance, but it's so disorganized.*

SUSTAINABILITY???

- Tears and anxiety
- How could this be sustainable?
- Who regularly: plans, organizes, presents, moderates discussions, troubleshoots?
 - Could a chatbot do it?
 - We have a test going on: Google Home-stranded participants are doing their own meetups...

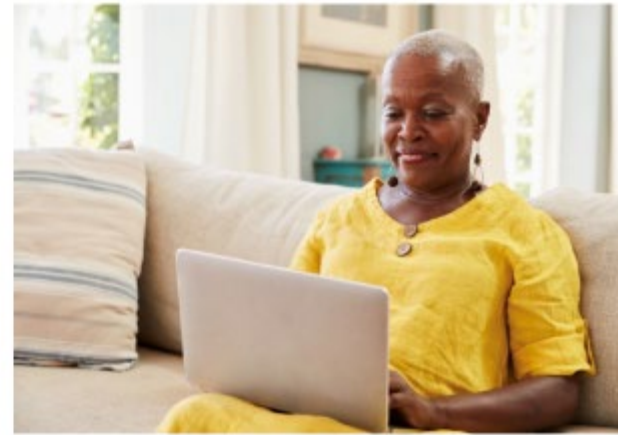
Our Alumni Group Site

WELCOME TO THE ELDERTREE ALUMNI GROUP



GOOGLE MEET LINK

Wednesdays at Noon!



ELDERTREE YOUTUBE

Many of your favorite videos from ElderTree



Stay Connected



Let's Move



Take Care of Your Health



Enjoy Yourself!

Bottom Line

- Smart devices
 - Still can't handle accents
 - Dictation was arduous
 - Limited number of words
 - Very hard to edit
 - Forget: Discussion Group & Journaling
- But after a lot of work, Smart device is running smoothly
 - There appears to be a lot of return use of the apps
 - Very low attrition in the study
 - **Alexa: my preferred device; on it >3 times/week**

Contact Information



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AGENCY FOR HEALTHCARE RESEARCH AND QUALITY



Involving Patients and Healthcare Providers in the Development and Implementation of Mobile Interventions: The ASTHMAXcel Experience

Sunit P. Jariwala, M.D.

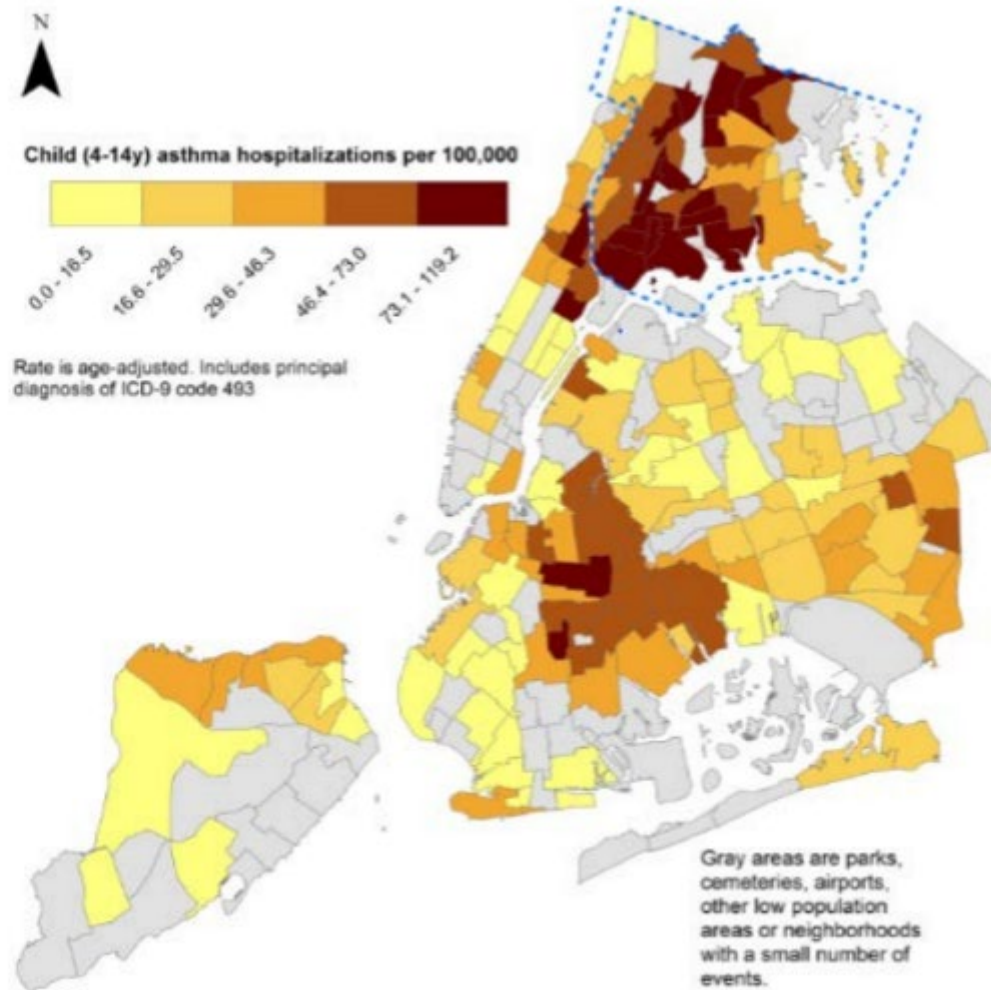
Professor, Allergy/Immunology

Director of Clinical & Research Innovation, Medicine

Co-Director, Montefiore Asthma Center

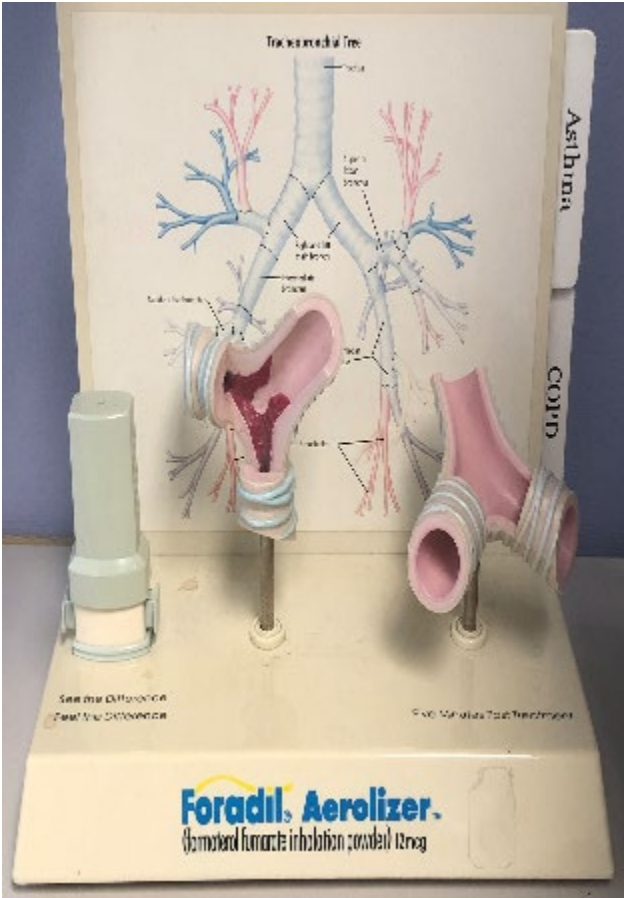
Albert Einstein College of Medicine and Montefiore Medical Center

The Asthma Epidemic in the Bronx



Asthma Hospitalizations (Source: NYC Neighborhood Health Atlas)

Scaling the Montefiore Asthma Center Model

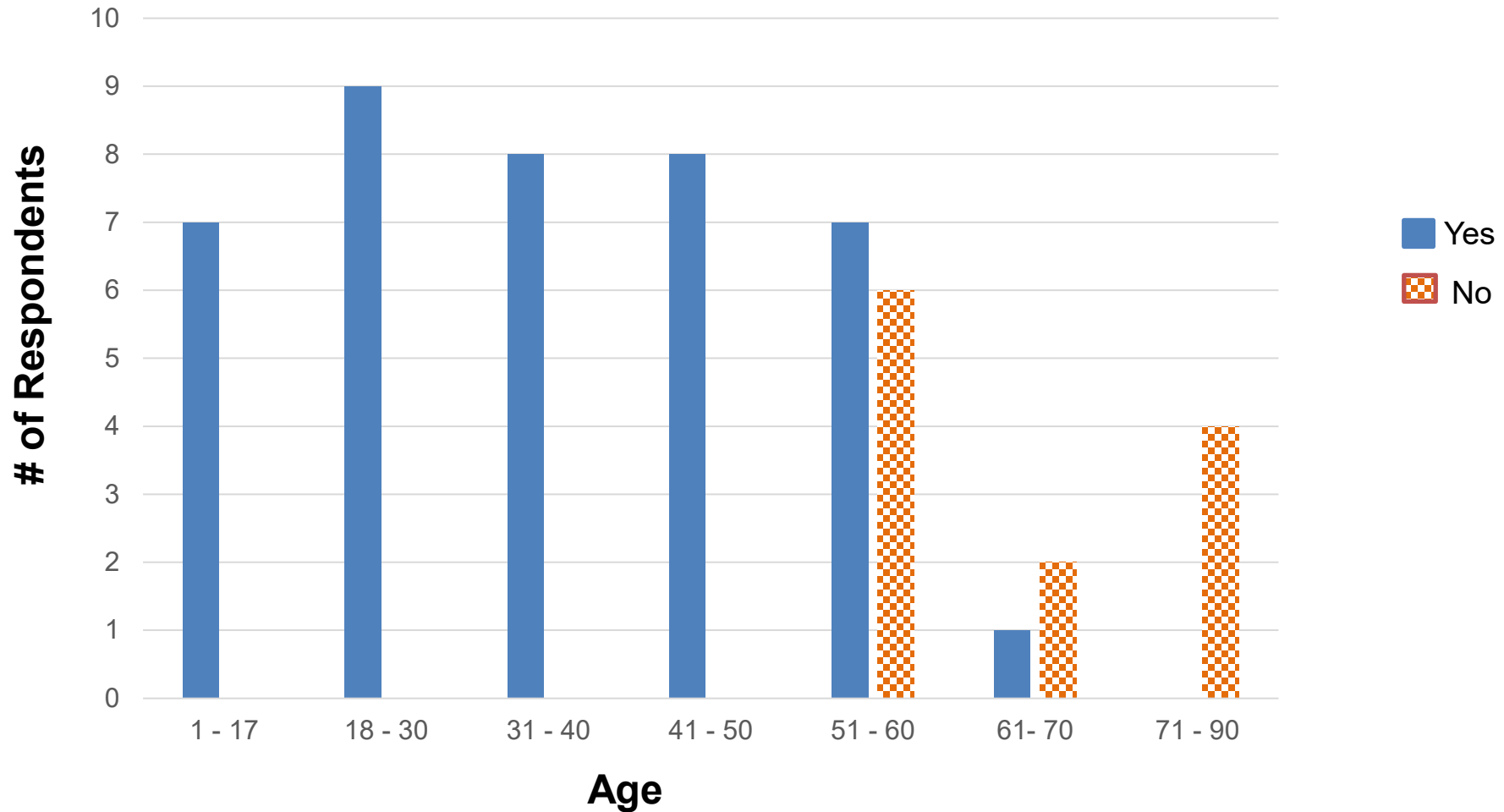


Asthma Apps: Key Limitations

- Only 55% of available asthma apps deliver guideline-based information
- Lack of behavior changes techniques
- Lack of clinically validated asthma apps
- User attrition
- Lack of usability and user-centered design

Smartphone Access Among Disadvantaged Bronx Patients

Smartphone Access Among Montefiore Asthma Center Patients



ASTHMAXcel Mobile Platform



Developing Apps '101' and Lessons Learned

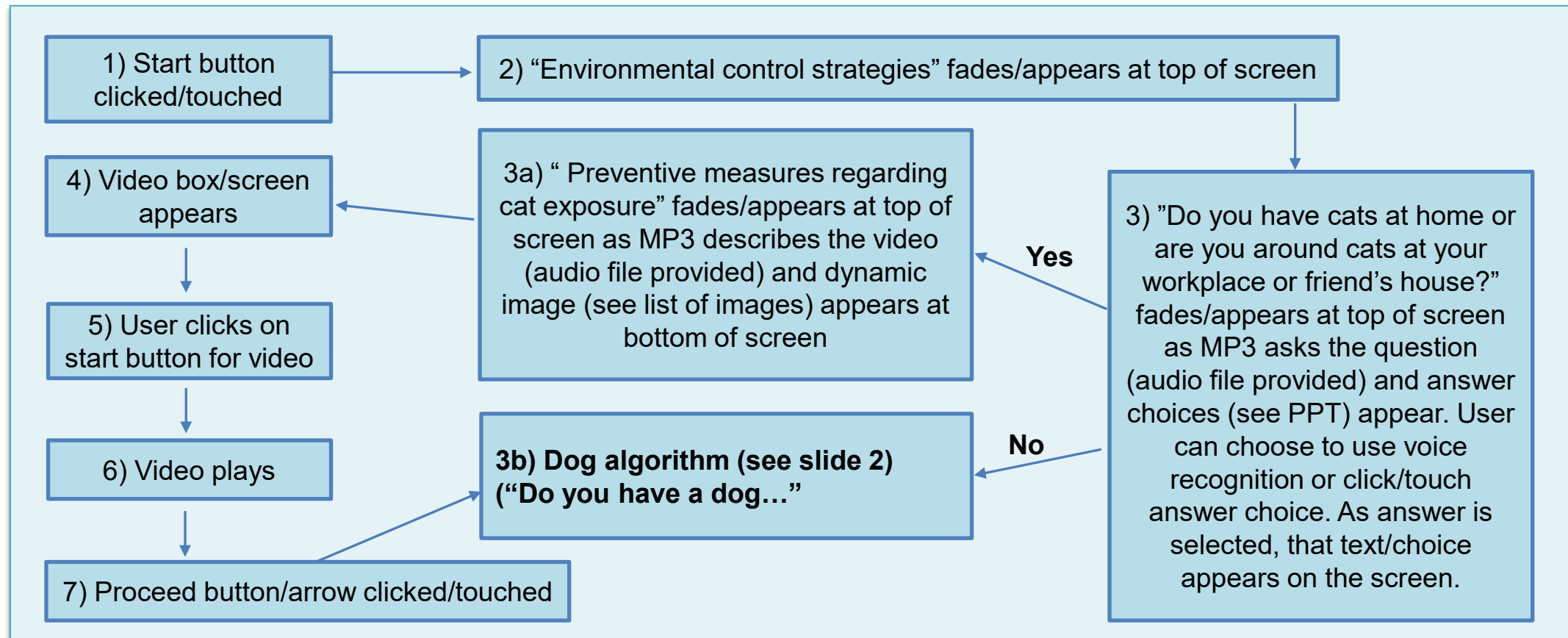


- Address a pain point – ‘You need to have the problem or understand it very well’
- KISS and Minimum Viable Product with rapid iteration
- Team science
- Never too early to launch and get feedback

ASTHMAXcel Minimum Viable Product

Seventh Chapter:

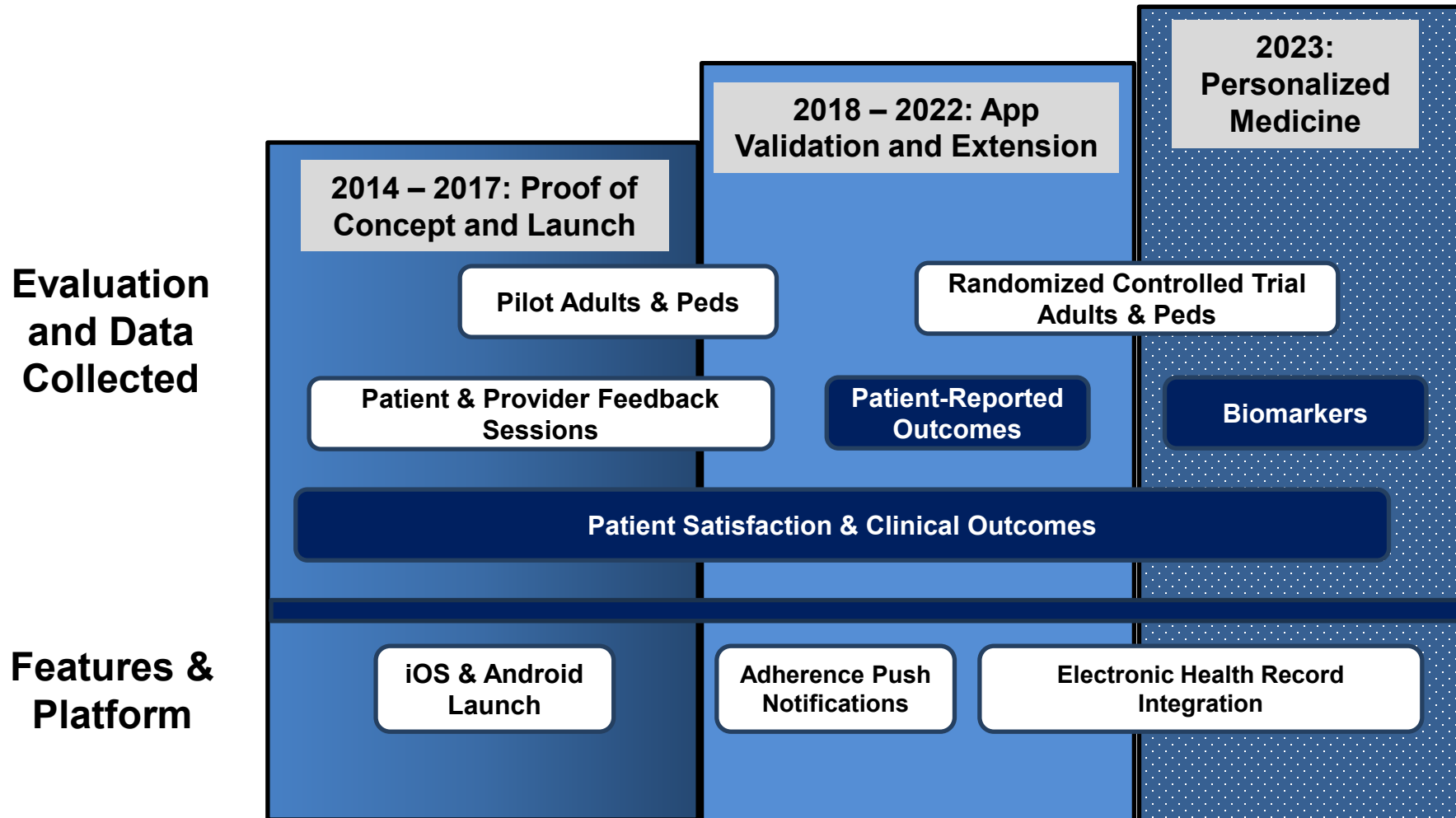
- Title = Environmental control strategies
- Content = conversation + video
- There is a proceed/next button/arrow at the bottom right **and** go back button/arrow at the bottom left of the screen (if go back button is pressed, back to chapters page).
- Each chapter has a radio button (“return to main menu”) to direct back to chapters page



ASTHMAXcel Minimum Viable Product



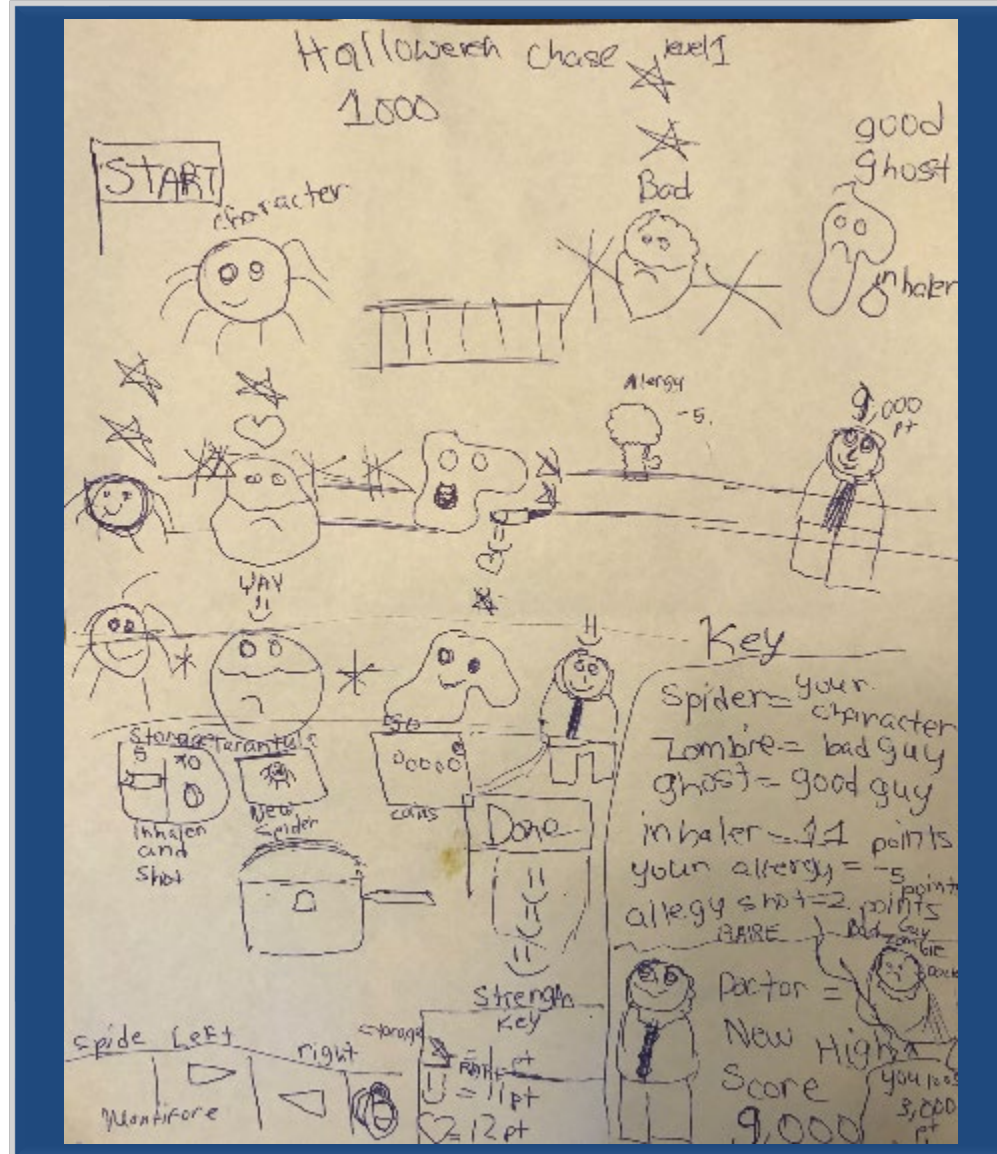
The ASTHMAXcel Journey



User-Centered Design

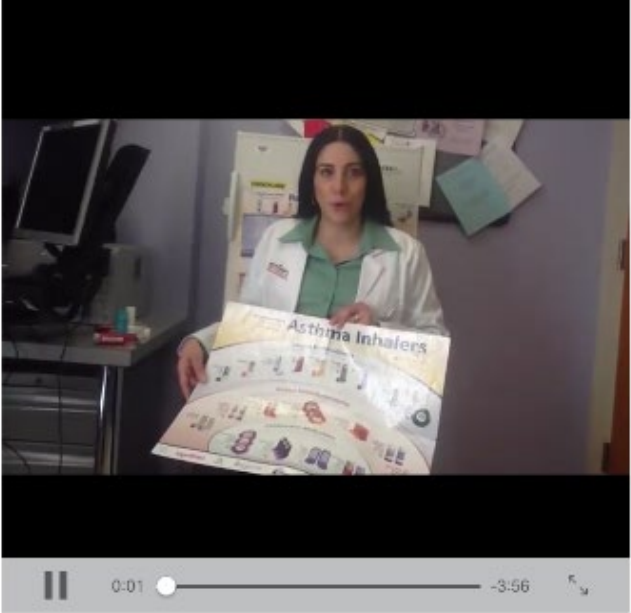
- Pre-development focus groups
- Participatory design sessions
- Field testing with formative and summative evaluation
- Exit interviews
- App usage analytics data

User Interface and User Experience (UI/UX)



User Interface and User Experience (UI/UX)

Medications for asthma and how these work



PREVIOUS


NEXT

Importance of smoking cessation

Smoking can worsen your asthma. Are you willing to quit smoking?

No

Yes




NEXT

Please touch your answer choice or click the 'Microphone' button and say your choice

PREVIOUS


NEXT

Learn



Chapter 1:
How does asthma affect your airways?

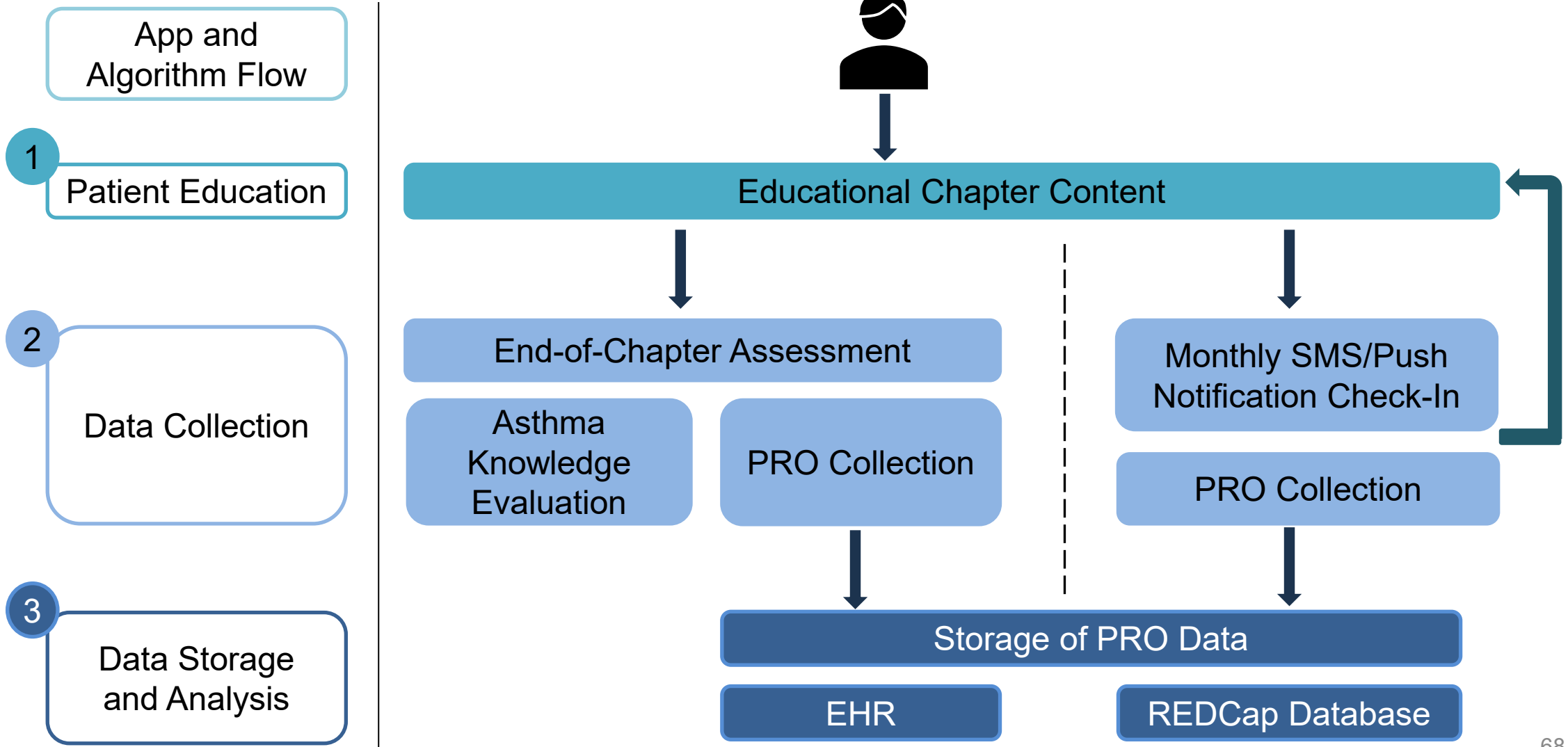
Follow along with Tommy to learn about how asthma causes narrowing of airways, wheezing and shortness of breath.



Chapter 2:
How do asthma medications work?

Learn about the different types of medications and how they affect your lungs to help relieve your asthma symptoms.

The 'Adaptive' ASTHMAXcel Platform



Why Are Patient-Reported Outcomes (PROs) Important?

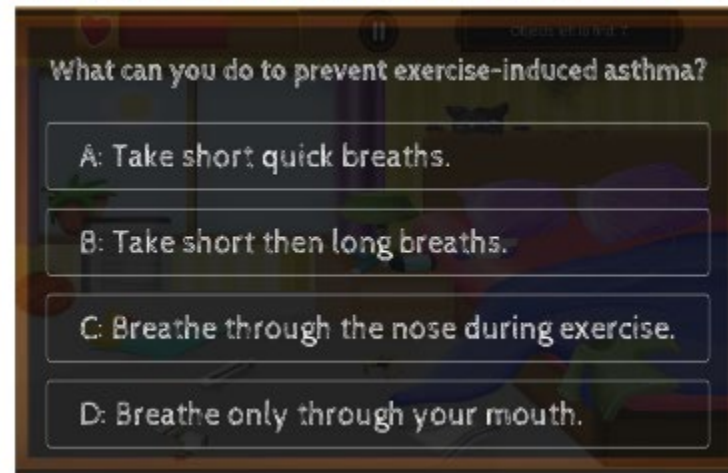
- Assess patient symptoms and quality of life concerns
- Help to assess treatment adherence
- Mobile health interventions can encourage the streamlined collection and use of PROs

The ASTHMAXcel Approach to Collecting PROs

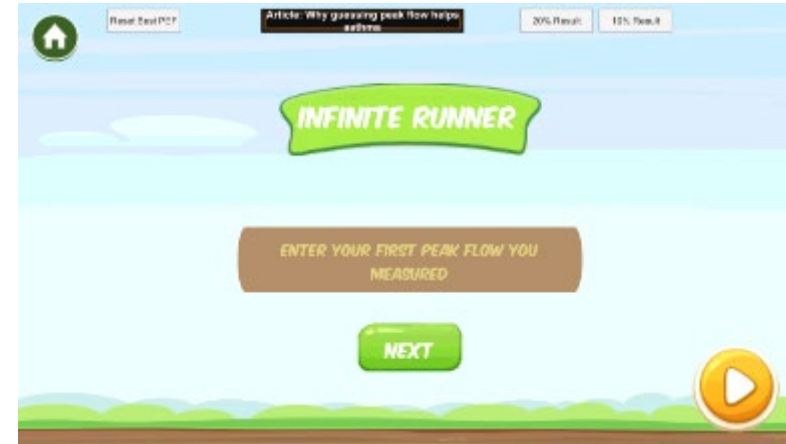
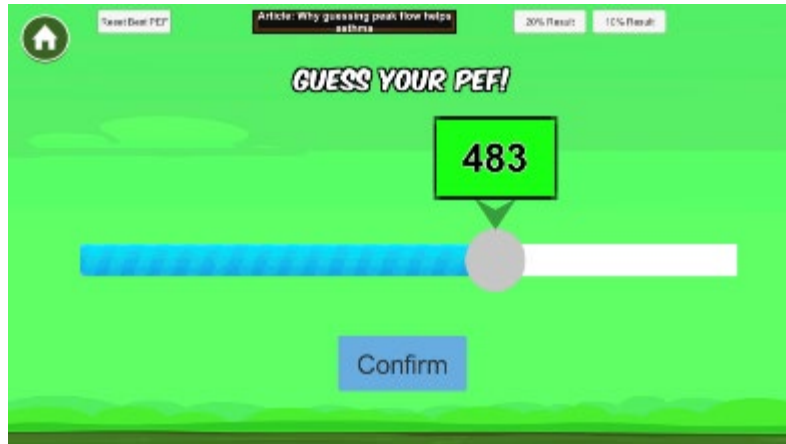


- User-centered app development process with patients and healthcare providers
- Embedding PROs within the mobile intervention
- PRO collection outside the traditional clinic setting
- App-EHR integration

Gamification and Asthma Knowledge




Gamification and Symptom Perception




Motivational Features

[Back](#) **PRO Trophy Room**


App Achievements




Bronze Trophy
10 coins




Silver Trophy
25 coins




Gold Trophy
50 coins




Platinum Trophy
100 coins




Emerald Badge
250 coins




Ruby
500 coins




Platinum Badge
1000 coins




Sapphire Badge
2000 coins




Diamond Badge
3000 coins



Magic Pearl Badge
5000 coins



Opal Badge
7500 coins



Topaz Badge
10000 coins

[Back](#) **PRO Rank**

Order By PRO Score ▾

Rank	Name	PROs	Coins
6	sunitj19	440	1773
1	Queenjill1031	697	3831
2	June.mora19	672	3520
3	esmeraldatirado59	663	3907
4	saurabhs0906	548	2385
5	sindhu.saurabh7	482	1290
7	ss3963471	357	1377
8	dboogie9653	242	2049
9	carolmagee79	171	1487
10	lindahiggins322	171	930
11	Anjani.singh	105	267
12	Eminecosar7540	105	307
13	chussame.pizza	91	

[Back](#) **Medication self-report**


Mon Tue Wed Thu Fri Sat Sun

Did you take your medications today?


Yes ✓

No

[Back](#) **Your Awards**

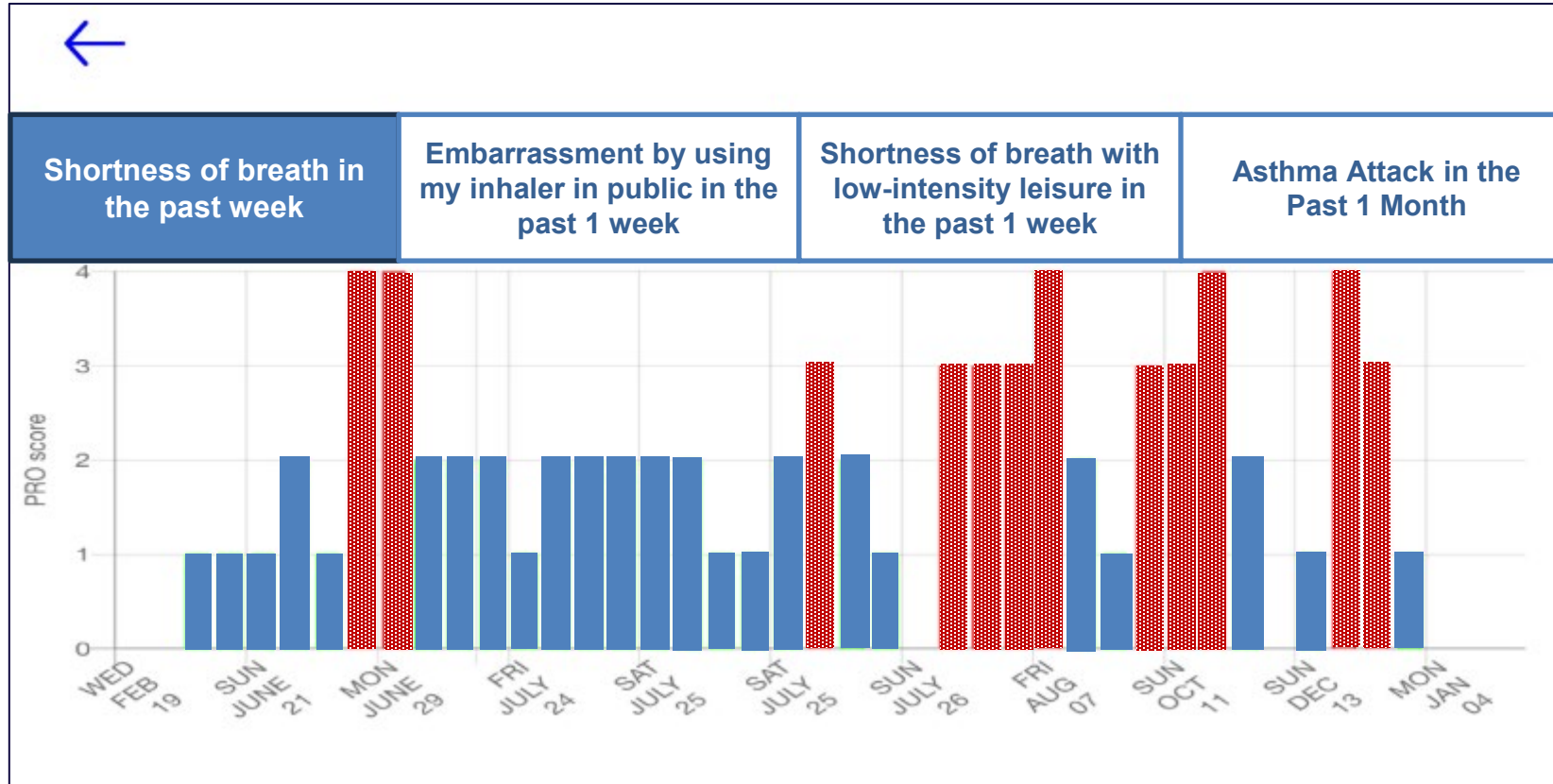


31 Hearts



0 Stars

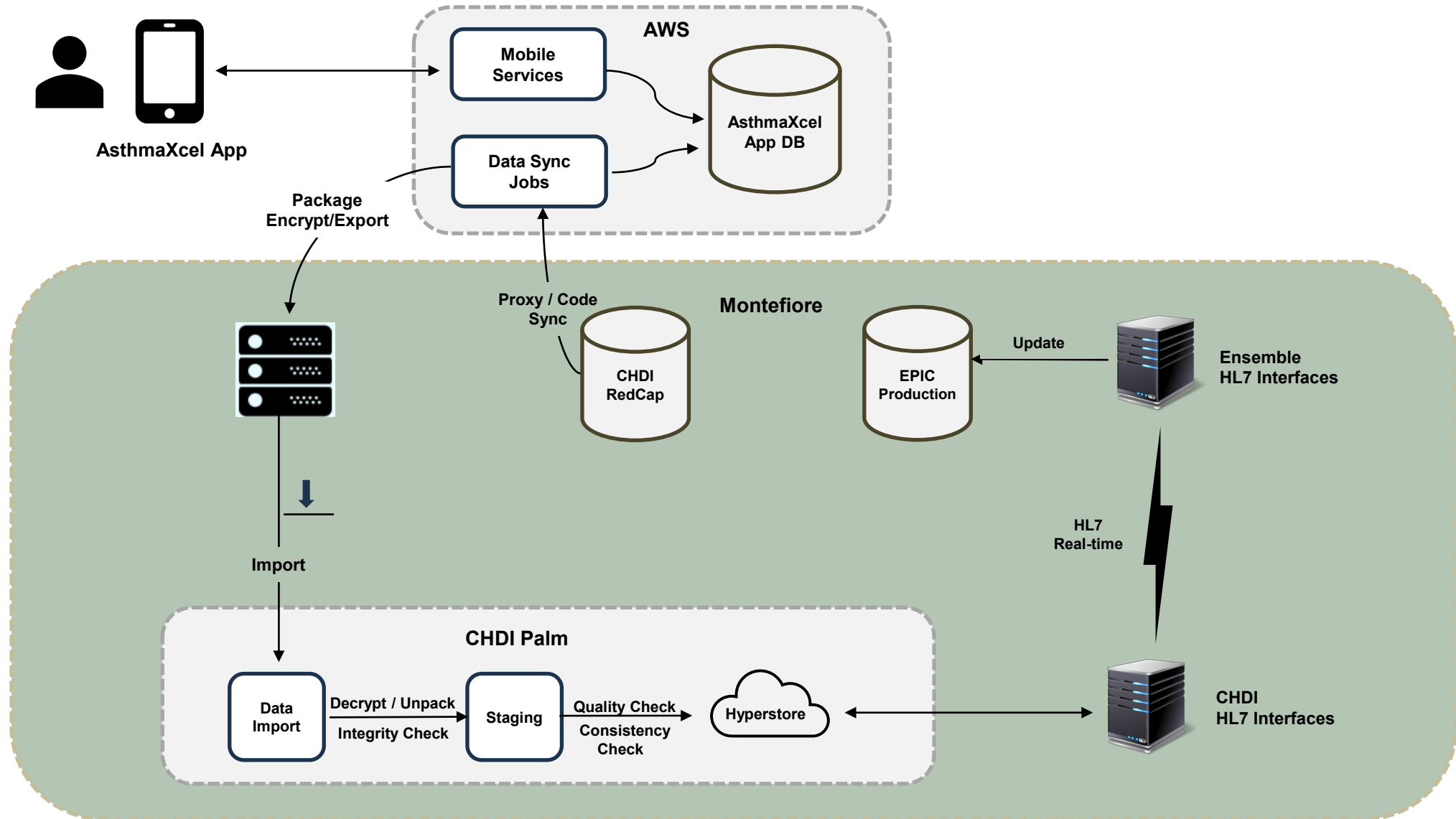
Self-Tracking and Shared Decision Making



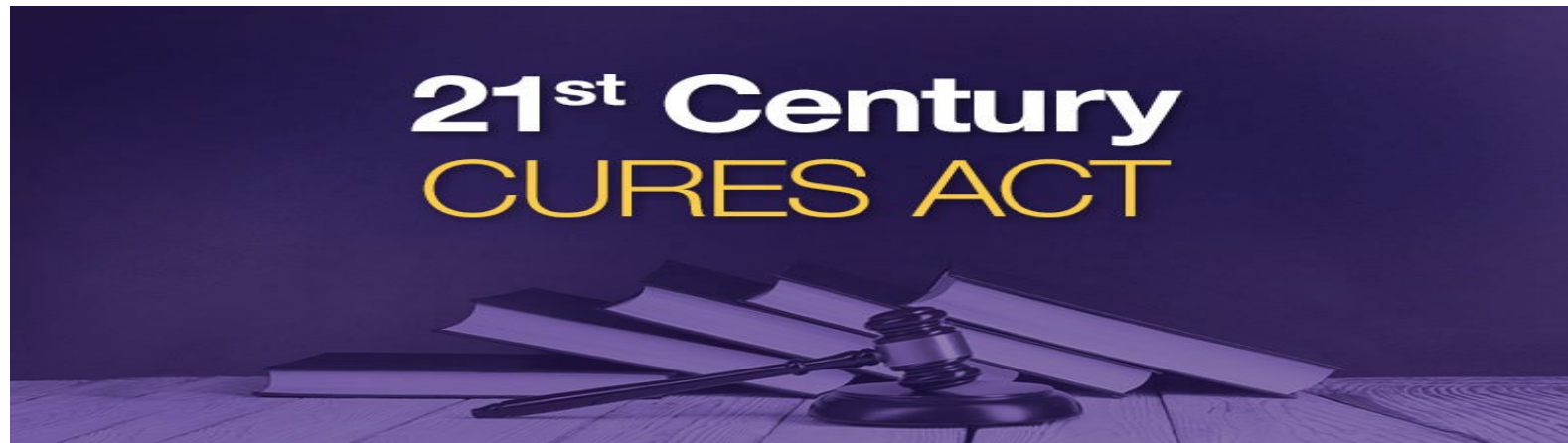
App Implementation: Other Considerations

- Regulatory
- Security Engineering and Encryption
- Data Privacy
- Funding and Sustainability

ASTHMAXcel EHR Integration



App-EHR Interoperability



App-EHR Integration Challenges

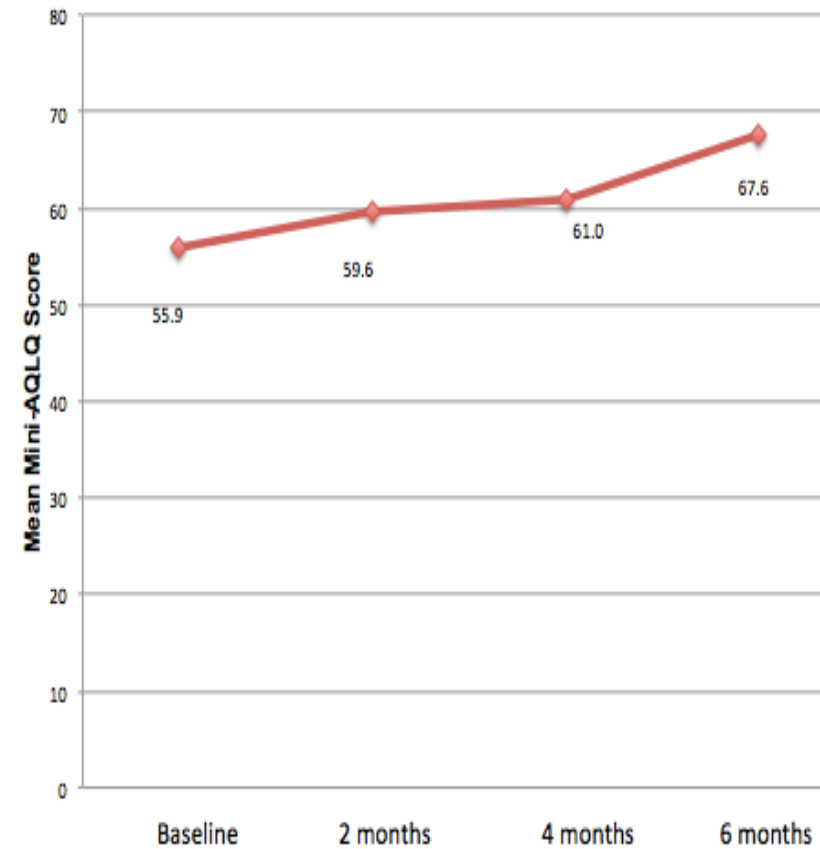
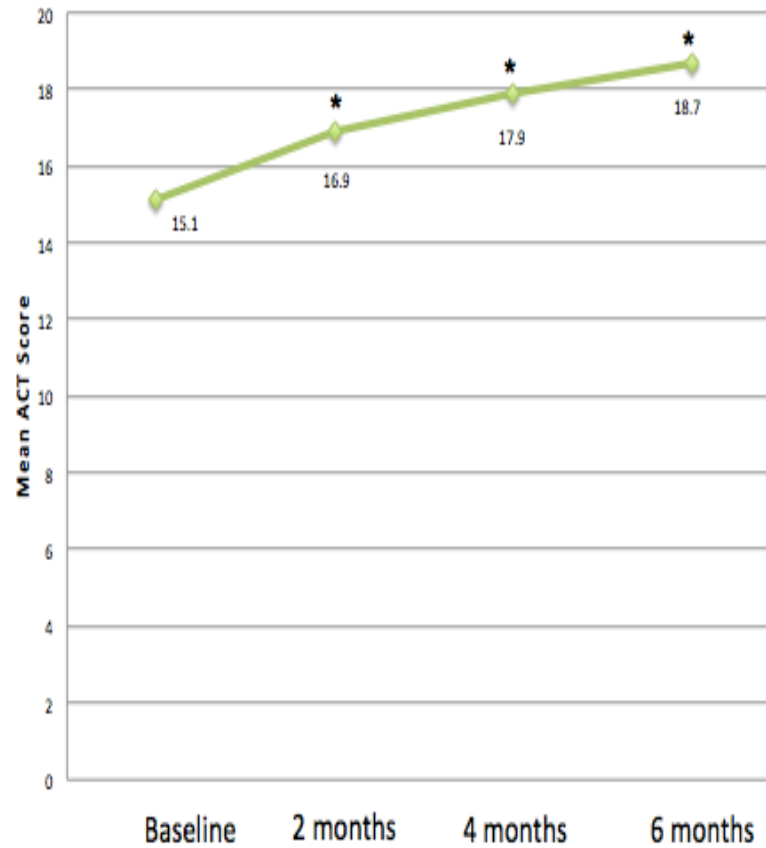
- Complicated integration process
- Integration process can be time-intensive and expensive
- Data must fit in with clinician workflows
- Where is the app-collected data displayed in the EHR?
- Regulatory and data privacy

App-EHR Integration Opportunities



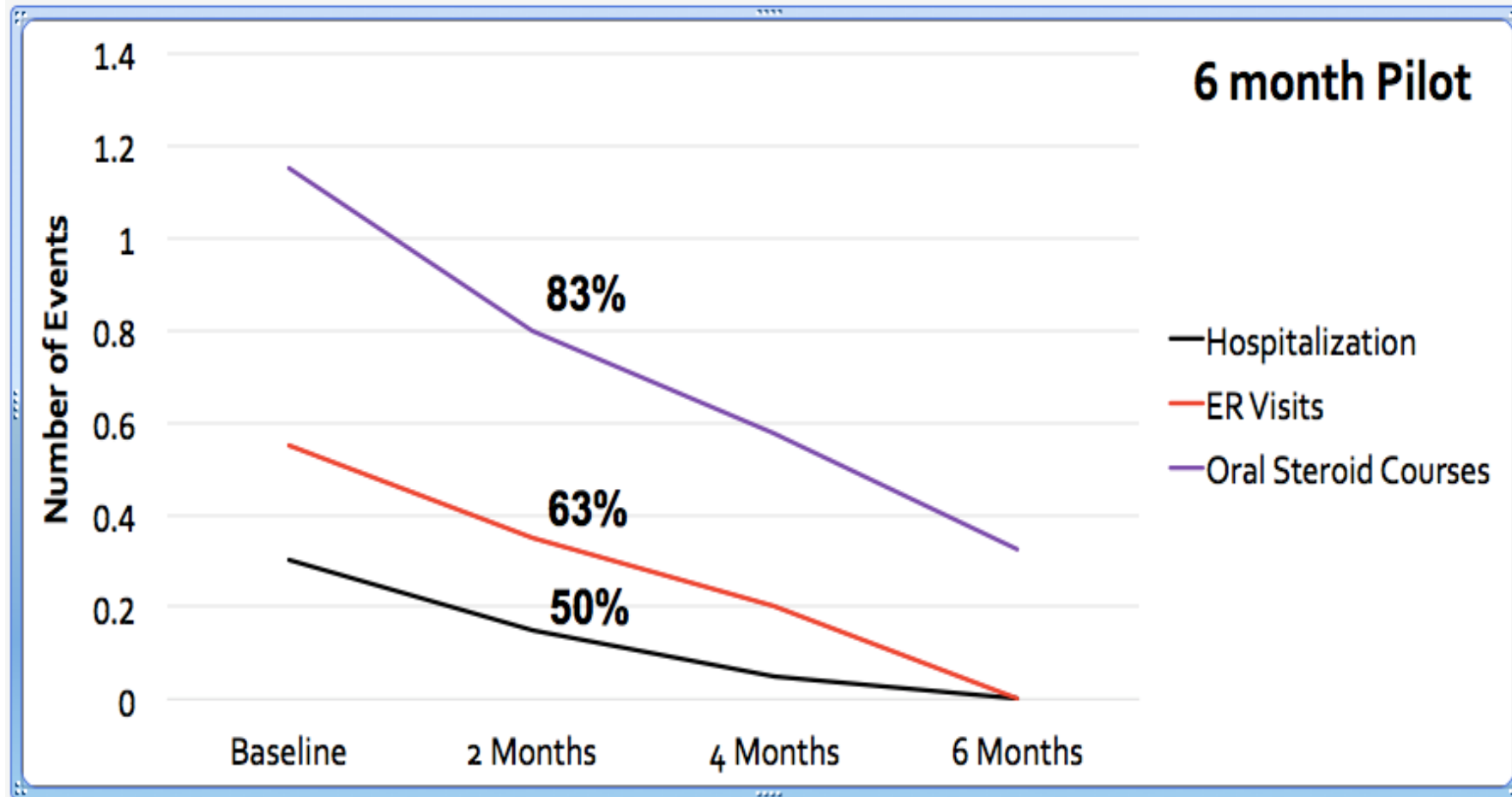
- Patient-generated health data
 - PROs
 - Medication Use
 - Healthcare utilization
- Digital care pathway via EHR app ‘order’

Improvements in Asthma Clinical Outcomes



Hsia B, et al. *Respiratory Care*.

Reduced Asthma Morbidity in Adults and Children

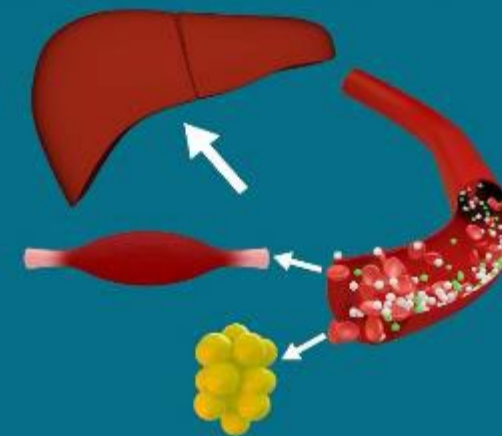


Hsia B, et al. *Journal of Asthma*.

ASTHMAXcel Extensions: DiabetesXcel



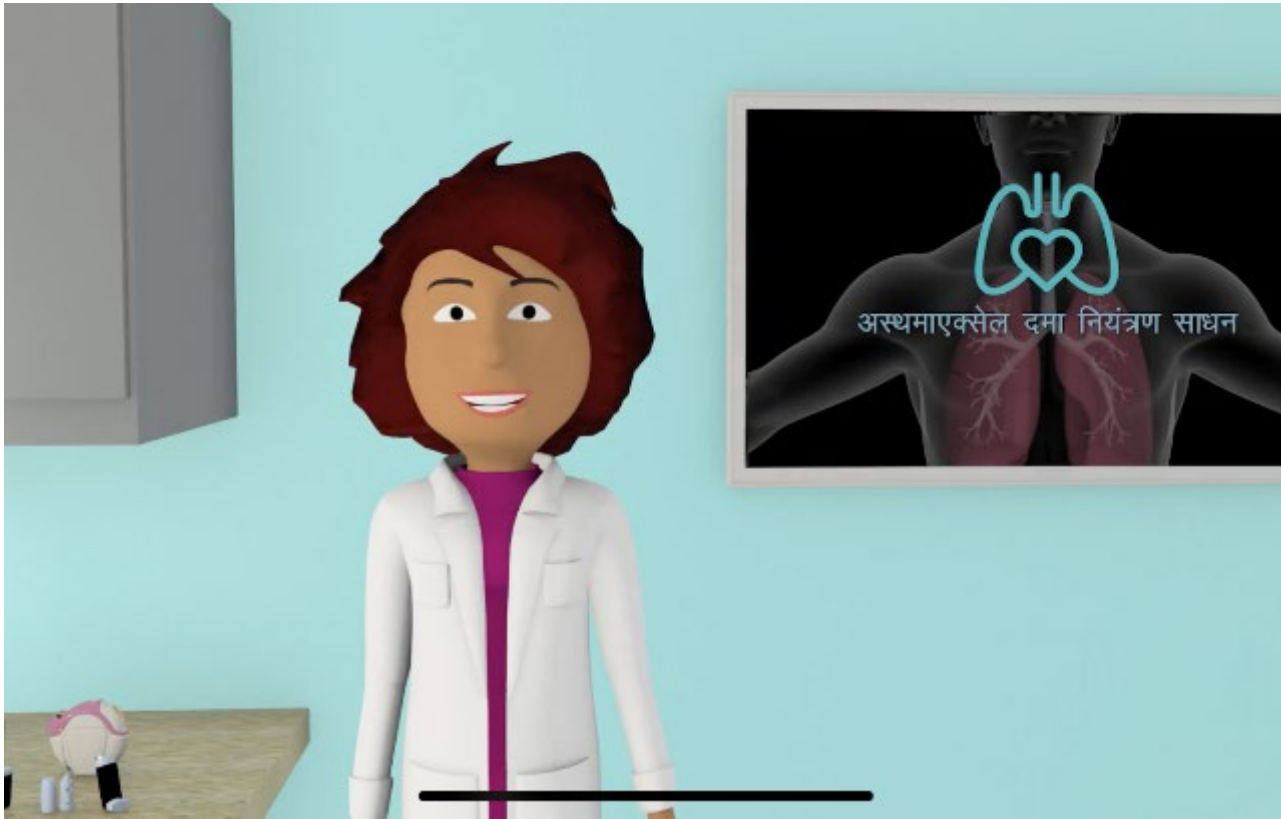
How does Insulin work?



DiabetesXcel



ASTHMAXcel in India











Mobile Platform Extensions



 BeWellXcel	 ASTHMAXcel PRO	 ASTHMAXcel ED
 MedProtocols	 ASTHMAXcel	 ASTHMAXcel Adventures
 DiabetesXcel	 ASTHMAXcel Perception	 ASTHMAXcel - दमा नियंत्रण साधन



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Teamwork Makes the Dream Work

Health IT
Programmer
Usability
Testing
UI/UX
IT Security



Clinical Eval
Project Managers
Statistician
Epidemiologist



Content Developers
Physicians
Behavioral Scientist
Animation Studio



Advisors



Current Work: Digital Biomarkers and Phenotyping

- Voice biomarkers
- Social and environmental stressors
- Lifestyle biomarkers
- Laboratory biomarkers
- App usage patterns

Research Impact



By implementing user-centered design strategies involving patients and healthcare providers, ASTHMAXcel and other asthma mobile health interventions can improve clinical outcomes and reduce health disparities.

Summary



Asthma mobile apps must be guideline-based, user-centered, and validated



Apps represent wonderful opportunities for personalized medicine



Teamwork makes the dream work

Contact Information



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