Digital Healthcare Innovations to Engage and Empower Patients in Their Care

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Agenda

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

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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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• At any time during the presentation, type your question into the “Q&A” section of your WebEx Q&A panel.

• 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.
Digital Healthcare Innovations: Engaging and Empowering Adolescents with ADHD

Kimberley D. Lakes, Ph.D.
Professor, Department of Psychiatry and Neuroscience, School of Medicine,
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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.
• Most prevalent childhood psychiatric condition
• Characterized by deficits in self-regulation
• High annual societal cost in the U.S.\(^1\)
  o 19.4 billion among children ($6799 per child)
  o 13.8 billion among adolescents ($8349 per adolescent)

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
  o Adolescents
  o Parents/Caregivers
  o Teachers
  o 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

Activities
- To Do
- Done
- Rewards
- Add

ToDo
- Walking the dog
- Go
- Go to bed

Cancel
- Walking the dog
- Wellness
Smartwatch Application for Children: Redeem Rewards

Activities
To Do
Done
Rewards
Add

Rewards
Total Points
70

Reward
Free Time!
30 minutes

Reward
1 FREE
50

Reward
150
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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Are Smart Displays Better than Laptops for Delivering Interventions to Older Adults?

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Who Are We?

• Center for Health Enhancement Systems Studies at the University of Wisconsin - Madison

• 50+ clinicians, scientists, and engineers working on:
  o Technologies to help people cope
  o Organizational change: quality improvement and sustainability

• Mission: No one should have to suffer twice
  o 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.
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
We Developed Elder Tree

- Home page:
  - Thought of the day
  - Search
  - What's new

- Personal:
  - To Do's
  - Health tracker
  - Bookmarks

- Conversations:
  - Private
  - 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
  o Require typing (older adults have tremors)
  o Must remember password (easy to forget)

• Is voice activation more appealing, usable, effective?
  o You just talk to it
  o It talks to you to remind
  o 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.
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

Living Well with Chronic Pain

The Real Facts About Chronic Pain

LESSON ONE:
THE REAL FACTS ABOUT CHRONIC PAIN

Resources & Activities
Transcript & Bibliography

Medications and Chronic Pain

Play
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
  o Discussion Group: most heavily used on laptop – it was the glue
  o Journaling
  o 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!!!!!!!
  o It’s a business

• Moved to Amazon Alexa Show
  o Had to start all over in programming and recruitment
  o 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:
  o 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
  o 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?
  o Could a chatbot do it?
  o 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
  o Still can’t handle accents
  o Dictation was arduous
    - Limited number of words
    - Very hard to edit
  o Forget: Discussion Group & Journaling

• But after a lot of work, Smart device is running smoothly
  o There appears to be a lot of return use of the apps
  o Very low attrition in the study
  o **Alexa: my preferred device; on it >3 times/week**
Contact Information

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

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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

- **# of Respondents**
  - Yes: 6
  - No: 5

- **Age**
  - 1 - 17: 7
  - 18 - 30: 9
  - 31 - 40: 8
  - 41 - 50: 7
  - 51 - 60: 6
  - 61 - 70: 2
  - 71 - 90: 4

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59
ASTHMAXcel Mobile Platform

- Tailored Push Notifications
- Asthma Education
- Goal Setting
- Patient-Reported Outcomes
- Patient & Provider Portal
- Electronic Health Record Integration
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
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.

1) Start button clicked/touched

2) “Environmental control strategies” fades/appears at top of screen

3a) “Preventive measures regarding cat exposure” fades/appears at top of screen as MP3 describes the video (audio file provided) and dynamic image (see list of images) appears at bottom of screen

3b) Dog algorithm (see slide 2) (“Do you have a dog…”)

4) Video box/screen appears

5) User clicks on start button for video

6) Video plays

7) Proceed button/arrow clicked/touched

Yes: 3) “Do you have cats at home or are you around cats at your workplace or friend’s house?” fades/appears at top of screen as MP3 asks the question (audio file provided) and answer choices (see PPT) appear. User can choose to use voice recognition or click/touch answer choice. As answer is selected, that text/choice appears on the screen.

No: 3b) Dog algorithm (see slide 2) (“Do you have a dog…?”)
ASTHMAXcel Minimum Viable Product
The ASTHMAXcel Journey

Evaluation and Data Collected

2014 – 2017: Proof of Concept and Launch
- Pilot Adults & Peds
- Patient & Provider Feedback Sessions

2018 – 2022: App Validation and Extension
- Randomized Controlled Trial Adults & Peds
- Patient-Reported Outcomes

2023: Personalized Medicine
- Biomarkers

Patient Satisfaction & Clinical Outcomes

Features & Platform

- iOS & Android Launch
- Adherence Push Notifications
- Electronic Health Record Integration
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)
Medications for asthma and how these work

Importance of smoking cessation

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

- No
- Yes

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

Chapter 1: How does asthma affect your airways?
Follow along with Tommy to learn about how asthma causes narrowing of the 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

App and Algorithm Flow

1. Patient Education
   - Educational Chapter Content
     - End-of-Chapter Assessment
     - Asthma Knowledge Evaluation
     - PRO Collection

2. Data Collection
   - Monthly SMS/Push Notification Check-In
   - PRO Collection

3. Data Storage and Analysis
   - Storage of PRO Data
     - EHR
     - REDCap Database
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
### Self-Tracking and Shared Decision Making

<table>
<thead>
<tr>
<th><strong>Shortness of breath in the past week</strong></th>
<th><strong>Embarrassment by using my inhaler in public in the past 1 week</strong></th>
<th><strong>Shortness of breath with low-intensity leisure in the past 1 week</strong></th>
<th><strong>Asthma Attack in the Past 1 Month</strong></th>
</tr>
</thead>
</table>

![PRO score chart showing trends over time](chart.png)
App Implementation: Other Considerations

• Regulatory

• Security Engineering and Encryption

• Data Privacy

• Funding and Sustainability
ASTHMAXcel EHR Integration

AsthmaXcel App

Package Encrypt/Export

Mobile Services

Data Sync Jobs

AsthmaXcel App DB

AWS

Import

CHDI Palm

Data Import

Decrypt / Unpack
Integrity Check

Staging

Quality Check
Consistency Check

Hyperstore

CHDI HL7 Interfaces

Ensemble HL7 Interfaces

HL7 Real-time

Update

Montefiore

CHDI RedCap

EPIC Production

Proxy / Code Sync

Encrypt / Export

Montefiore

76
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
  o PROs
  o Medication Use
  o Healthcare utilization

• Digital care pathway via EHR app ‘order’
Improvements in Asthma Clinical Outcomes

Reduced Asthma Morbidity in Adults and Children

ASTHMAXcel in India
Mobile Platform Extensions

- BeWellXcel
- MedProtocols
- DiabetesXcel
- ASTHMAxcel PRO
- ASTHMAxcel
- ASTHMAxcel Perception
- ASTHMAxcel ED
- ASTHMAxcel Adventures
- ASTHMAxcel - एक निदेशक साधन

Get it on Google Play
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
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.
Asthma mobile apps must be guideline-based, user-centered, and validated

Apps represent wonderful opportunities for personalized medicine

Teamwork makes the dream work
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