Bridging the communication gap: A new touchpoint for pediatric asthma education in Emergency Departments

Jaime Rivera • Paula Falco • Sarah Norell • Tara Flippin
Advised by Professors Kim Erwin and Tom MacTavish
IIT Institute of Design
Asthma is the most common chronic condition for children in America, and the burden is highest among Chicago’s minority communities.

African American are 8 times more likely to die from an asthma attack than their white counterparts.

In the Hispanic neighborhood of Humboldt Park, 41% of children suffer from asthma.
asthma is managed at home, not cured in the ER

“We put out fires. The ideal sense of the emergency room is that when kids are very sick - they have a bad asthma attack - we make them better.” - ER attending physician

Due to a number of factors, Chicago’s minority populations have limited access to healthcare and frequent the emergency department for asthma attacks. Some families even use the ER as their primary avenue for care because they will not be turned away.

The emergency department is ill-suited to address the root causes of chronic conditions. With chronic conditions such as asthma, the patient’s everyday decisions and lifestyle have a tremendous impact on their health. Better understanding of how to manage chronic conditions at home is essential to enabling patients to take control of their health.

To succeed, patients and caregivers must be proactive, informed partners in the healthcare process.
obstacles to effective ER discharge instruction

caregiver’s experience and mental model

- understanding asthma
- long exhausting process

communication model

- one way communication
- complex information
healthier kids means fewer ER visits

Many families assume that having a child with severe asthma means regular trips to the emergency room. With the correct medication and home management, their children can lead normal lives.

This is possible when families are given a new model of success and equipped with the necessary knowledge and tools.

Parents are the key to change.
Coordinated Healthcare Interventions for Childhood Asthma Gaps in Outcomes

The CHICAGO Trial is a three-year clinical trial conducted by a research consortium made up of nearly 50 members, including clinicians from six Chicago hospital systems, community health workers, city health officials and our team of designers from the IIT Institute of Design.

- funded by National Institute of Health (NIH) and the Patient Centered Outcomes Research Institute (PCORI)
- 600 families will be enrolled in the study
- comparing three ED-level interventions on the health outcomes of pediatric asthma patients
- improve the treatment outcomes for pediatric asthma patients in Chicago’s minority communities
our design challenge

How might we make complex information easier to understand and support critical conversations related to pediatric asthma education within the ER discharge process and beyond?
balancing needs across 4 stakeholder groups

- Caregivers: 9 in-home interviews with caregivers of children with asthma
- ER physicians: 5 ER physician interviews conducted in the ER of their respective hospitals
- ER nurses & administrators: 4 staff nurse interviews and 4 nurse administrator interviews conducted in the ER of their respective hospitals
- Primary care doctor: 5 primary care physician interviews conducted in their respective outpatient clinics
It's a medical tool
- Spells out medication
- Explains when to return to ER
- Is evidence based
- Looks "serious"
- Is readable by all

It's a teaching tool
- Feels simple, usable
- Grabs attention
- Involves kids in care
- Teaches good technique
- Supports self-management

It's a transition tool
- Spells out medication
- Promotes follow-up visit
- Brings efficiency to visit
- Prevents costly mistakes

How do I get them to follow instructions?

What's my role? How do I make this work?

How do I get them to take better care of their kids?

How do we get an action plan in place in 15 min?

The comm link between doctors is broken

ER Doctor

ER Nurse

Primary Care Doctor

Patient Caregiver

Other family

School

Daycare

Supporting critical conversations
The many users + expectations of an asthma ED discharge tool

INSIDE THE ER

OUTSIDE THE ER

It's my care tool
- Spells out what to do at home
- Helps me coordinate with others
- Involves kids in care
- Helps communicate in future ER visits
- Includes follow up information

Feels simple, usable
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stakeholder model
research insights

Everyone counts
To succeed in the demanding context of healthcare and emergency medicine, our solution must be stakeholder balanced, not just patient centered.

Communication is critical
The timing, complexity of content, and communication model currently used when discharging patient caregivers impedes comprehension.

Knowledge is not enough
A significant gap exists between the directions caregivers receive from the ER staff and what they can execute in the context of their real lives.

Beyond the 4 walls
Caregivers that seek follow up care are poorly equipped to communicate relevant information to their primary care doctor.

Asthma is complex
Families who use the ER as their primary source of healthcare are most in need of information that fits their educational level.
improving ER discharge and patient instruction + preparing caregivers for at-home asthma management

- We designed a new patient education tool that promotes the diverse needs of all stakeholder groups.

- This new discharge tool drives an improved communication model between clinicians and caregivers of children with asthma.

- The new patient education tool will be tested for the next 2 years across 6 Chicago Emergency Departments.

- In total, over 400 families will take this tool home to test it as a new way to manage the post-discharge care of their child.
Weakness of ER discharge tools and touchpoint:

- Tools do not promote effective conversation between clinician and patient.
- Handed to patient for future reading.
- Instructional language is written as a doctor would write a prescription.
- Dense content with little hierarchy makes action items hard to find.
- Caregivers retain these documents but rarely reference them post-ER.

Document Metrics:
1,100 + word count
7th grade Flesh-Kincaid reading level
assessing the current asthma discharge tool

**Document level**
- Principles of information design + readability

**User level***
- Content requirement
- Opportunity assessment
- Modes of use
* 4 user groups total

**ED context level**
- Desired discharge protocol
- Drivers of practice variation
- Fit with clinician/caregiver conversations

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**Principles of information design**

**Readability**

**Content requirement**

**Opportunity assessment**

**Modes of use**

* 4 user groups total

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**Drivers of practice variation**

**Fit with clinician/caregiver conversations**
a new touchpoint for asthma education

- designed to be used in the home and with extended family and community (school, daycare, babysitters, etc.)
- 4 clear action items
- acts as a mediating object between caregivers and ER physicians, nurses, primary care physicians, and specialists.

Document Metrics:
526 word count
5th grade Flesh-Kincaid reading level
value for stakeholders

Caregivers
- designed to fit into complicated lives
- simple language and action items make it easy to share with care circle
- easy to engage with clinicians in conversation

ER physicians
- helps clarify medication instruction for caregivers
- promotes a consistent ER asthma discharge process

ER nurses & administrators
- visuals provide a starting point for tough conversations
- helps involve pediatric patients in education and self-management

Primary care doctor
- carries the ER experience into the primary care office visit
- accelerates conversation into long term management plan instead of reconstructing the ER visit
design-driven contextual inquiry

Understanding the ED discharge experience + tools for pediatric asthma caregivers

**OBSERVE**
Create a “thick description” of the activity system

**STRUCTURE**
Apply user-centered analytic frameworks to identify patterns

**MODEL**
Integrate patterns and insights into frameworks and narratives

**PROTOTYPE**
Imagine, build and evaluate solutions

**Methods**
In situ interviews
Experiential walkthru
Photo documentary
Co-design

POEMS framework (people, objects, environments, messages, services)

Compliance barriers
Modes of use
Communication

Concept prototypes
Iterative testing and refinement

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process timeline

- june
  - context + site visits + recruiting
  - interviews
  - analysis
- july
  - synthesis
- august
  - prototype development + testing
- september
- october
- november
- december

- 6 hospital sites
- 38 interviews
- 28 participants
- 3 rounds of testing & co-design
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Analysis
- Observations clustering matrix
- Immersive analysis workshop
- User journey map
- Grounded theory analysis
- Insight sorting
- Design principle generation

Synthesis
- Ideation session
- Role play ideation
- Testing AB options

Research
- Publications research
- Subject matter experts interviews
- Ethnographic interview
- Field visits
- Field activity

Prototyping
- Concept Evaluation
- Solution Prototype
- Field visits
- Field activity
- Immersive analysis workshop
- User journey map
- Grounded theory analysis
- Insight sorting
- Design principle generation

Prototyping
- Concept Evaluation
- Solution Prototype
- Future: Pilot development and testing
**divergent thinking vs. scientific diligence**

- While design methods strive to build a rich description of participant context, medical research methods seek evidence and proof.

- These contrasting approaches created a productive tension between the design team, trained to imagine a better future, and the CHICAGO Trial consortium, trained to deliver thorough, evidence-based care.

- We combined strengths: The clinician’s exacting standards and evidence-based approaches demanded deep rigor from the design team, while the creative divergent thinking of design team pushed the project into spaces not conceived of in the original research proposal.
engaging the CHICAGO Trial consortium

- creating an immersive built environment to communicate massive interview data, build user empathy and set the stage for co-analysis workshop
- establishing clear metrics, such as word count limits and reading levels, to turn medical expertise into patient-appropriate content
- socializing new tools with Steering Committee members through storytelling and prototypes
engaging with stakeholders

- 3 rounds of iterative testing + refinement with caregivers, ER physicians, ER nurses, ER nurse administrators and primary care physicians
- field tests of prototypes to elicit how clinicians would use tools in situ
- putting tools in the hands of participants to be partners in the design process
a shared, empowering communication model
clarifying medications

"Understanding and correctly using medications, that is the fire I’m trying to put out here."
- ER attending physician

- the what, how and why of multiple asthma medications all in one place—no need to search for information
- physical stickers to distinguish medications and reduce mix-ups
- filling information in by hand encourages ongoing dialog and instruction during the discharge process
- check boxes act as triggers to remind clinicians to address key points
enabling child engagement

“She knows how to take her medicine on her own. If I am not right here she says ‘Mom, I just took a treatment.’” - Mother of 9 year old girl

- illustrations and callouts put critical information within reach of individuals with low-education levels
- visual presentation clarifies the dangerous progression of asthma symptoms
- showing physical symptoms create an easy diagnostic tool for caregivers, highlights what to do at each stage
- friendly style helps nurses and caregivers include kids in education and self-management
“Cockroaches are difficult to talk about. Smoking is very obvious, but cockroaches is just...It’s a sensitive subject.” - ER staff nurse

- creates room for caregivers, not just clinicians, to write
- home environment questions for caregivers promote their role in managing their child’s care
- images of asthma triggers help nurses broach sensitive subjects, start hard conversations
- tips and tricks help caregivers start building routines to keep to medication regimens
How to use an inhaler with a spacer

*Works as well as a nebulizer!*

1. **Take cap off and shake.**
   - Take cap off the inhaler. Check for and remove any dust, lint, or other objects. Shake the inhaler well.

2. **Attach spacer.**
   - Match the inhaler to the spacer.

3. **Breath out.**
   - Breathe out all the air, away from the spacer.

4. **Press the inhaler.**
   - Press the inhaler one time. This puts one puff of medicine into the spacer.

5. **Breathe in deeply and slowly.**
   - Breathe in slowly and deeply, and hold your breath.

6. **Hold your breath — 5 secs.**
   - Remove the device from the mouth. Then hold your breath for 5 seconds. Then breathe normally away from the spacer.

7. **Wait 1 minute.**
   - If your child needs to take another puff of medicine, wait 1 minute. After 1 minute, repeat steps 3 to 6.

8. **Rinse — Don’t swallow!**
   - Rinse your child’s mouth after the last puff of medicine. Have your child rinse his or her mouth out with 1 is of water. Have your child spit the water out. Do not allow the child to swallow the water.

**QR codes help digital-savvy caregivers access online resources, such as videos for asthma care**

**Step-by-step instruction help caregivers understand key inhaler techniques, an essential part of managing asthma**

**Simple language and illustrations help kids teach themselves, care for siblings**

“I love the digital links. I live on my phone so those would be really helpful.”
- Mother of 11 year old boy
Better equips caregivers for follow up appointments with primary care physician

Helps caregiver share critical asthma information—symptoms of an attack, actions to take and triggers to avoid—with schools, daycare, babysitters and others who care for the child.
thank you

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Dr. Jerry Krishnan, for his leadership and trust
And the talent of the many CHICAGO Trial collaborators who contributed to this work

Funded by the Patient Centered Outcomes Research Institute (PCORI), the CHICAGO Trial is a collaborative effort between 13 Chicago based institutions, including the University of Illinois Hospital & Health Sciences System, Sinai Health System, Rush University Medical Center, Lurie Children’s Hospital, University of Chicago, Northwestern University, Chicago Department of Public Health, Respiratory Health Association, Chicago Asthma Consortium, NorthShore University Health System, and the Illinois Institute of Technology. This broad-based collaborative, including caregivers, patient advocacy groups, public health officers, and patient-centered outcomes researchers is dedicated to eliminating asthma health disparities. Drawing on collaborations that span nearly two decades, we propose studies testing both provider- and patient-level interventions to improve clinically meaningful outcomes in a minority pediatric ED population with uncontrolled asthma.
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Sources:
Logos - Noun Project

Slide 1

Slide 2
City of Chicago Department of Public health (CDPH)

Slide 3
Change: Design vs. Scientific method for… User Centered Design Methods vs. Scientific method

Slide 6