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
African American children in Chicago 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 the most common chronic condition for children in America, and the burden is highest among Chicago’s minority communities. African Americans are 8x more likely to die from an asthma than others with the condition.

Due to a number of factors, these 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.
“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

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 communication in ER

caregiver’s experience and mental model

- stressful noisy environment
- long exhausting process

communication model

- one way communication
- complex information
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 taught a new model of success and equipped with the necessary knowledge and tools.
coordinated healthcare interventions for childhood asthma gaps in outcomes

The CHICAGO Trial is a three-year clinical trial in collaboration with six Chicago hospitals. The research consortium is a team made up of nearly 50 members, including clinicians, 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
- testing the effectiveness of a new touchpoint in asthma education used at discharge from the emergency department
- improve the treatment outcomes for pediatric asthma patients in Chicago’s minority communities
How might we redefine the communication model between clinicians and pediatric asthma patients in the emergency department to improve adherence to care guidelines post discharge?
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

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Inside the ER

**ED Doctor**
- It's a medical tool
  - Spells out medication
  - Explains when to return to ED
  - Is precise, complete
  - Looks "serious" is readable by all

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

**Patient Caregiver**
- 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 ED visits
  - Includes follow-up information

Outside the ER

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

**How do I get them to follow instructions?**
- 2-5 mins

**How do I get them to take better care of their kids?**
- Over time

**What's my role? How do I make this work?**
- 30 mins

**Outpatient Doctor**
- 15 mins

**Other family**
- School
- Daycare

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

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

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

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.

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

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
+ preparing caregivers for at-home asthma management

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

- This new touchpoint 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 as a new way to manage the post-discharge care of their child.
weakness of the ER discharge touchpoint

- 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
- handed to patient for future reading, but rarely reviewed with patients

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

**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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- 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 multiple stakeholder groups in the ER

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

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design-driven contextual inquiry

Understanding the ED discharge experience + tools for pediatric asthma caregivers

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

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

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

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

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

**COMPLIANCE BARRIERS**
Modes of use
Communication

**PROTOTYPE**
Imagine, build and evaluate solutions

**CONCEPT PROTOTYPES**
Iterative testing and refinement
process timeline

- June: Context + site visits + recruiting
- July: Interviews
- August: Analysis
- September: Synthesis
- October: Prototype development + testing
- November: Final review + documentation
- December: 6 hospital sites, 38 interviews, 28 participants, 3 rounds of testing & co-design
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**设计方法**

**分析**
- 观察聚类矩阵
- 全身沉浸式分析工作坊
- 用户旅程地图
- 深度理论分析
- 设计原则生成
- 观察聚类
- 离散分析
- 观点生成

**合成**
- 观点生成会
- 角色扮演创意
- 测试AB选项

**研究**
- 文献研究
- 专家访谈
- 田野作业
- 田野访问

**原型**
- 概念评估
- 解决方案原型
- 将来：试点开发和测试
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 medical community, 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.
divergent thinking vs. convergent thinking

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

- 3 rounds of iterative testing + refinement with stakeholders
- field test of prototypes to elicit how participants would use tools in situ
- providing tools to give participants license to be partners in the design process
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A shared, empowering communication model

- Expanding the care circle
- Engaging kids
- Connecting to digital content
- Promoting a collaborative conversation
- Structuring complex information
- Enabling hard conversations

Asthma care action plan

Child’s name

Today’s date

Physician’s signature

Take your asthma medicine

Your oral steroid is:

Things to know:

is another powerful “rescue” medicine if you were given these in the emergency room, it is very important that you

Things to know:

should be used only if your child is having symptoms during an asthma attack/

is typically albuterol with a name like: Proventil, Pro-Air, Ventolin, Xopenex

Your “rescue” medicine is:

Pills / Liquid

1st dose time / date

How much

How often

For how long

After that, use ONLY when symptoms occur

Mark your meds at the pharmacy:

red sticker for “rescue” medicine

Your appointment date and time

Doctor’s name

Clinic telephone number

See your doctor or clinic within 3 days of your emergency visit

1st dose time / date

How much

How often

For how long

Other medicine to use:

Things to know:

It is very important you complete the dosage

Inhaler

Spacer

Mask

Nebulizer

Your “controller” medicine is:

Take every day EVEN IF no visible symptoms

Mark your meds at the pharmacy:

green sticker for “controller” medicine

Inhaler

Spacer

Mask

Nebulizer

promoting a collaborative conversation

connecting to digital content

expanding the care circle

engaging kids

structuring complex information

enabling hard conversations

contexts
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
Stay on top of asthma

- Don’t wait! Call with questions
- Identify your child’s asthma triggers
- Give medications as prescribed
- Take your child to the doctor regularly

Call your child’s regular doctor as soon as possible to help you understand your child’s asthma and treatment plan.

Build a trigger list of what seems to make your child’s asthma act up. Add to that list as you notice new triggers. Try to help your child avoid these!

If your child has a cold, use your child’s action plan; and help them to blow their nose and clean it with saline water, if needed.

Avoid smoking a known asthma trigger — and avoid having your child in a house where someone smokes.

Here are some examples of common asthma triggers:

- Review how to use the inhalers with your child’s doctor.
- Develop tricks to help remind you to give the medications.
- What might be useful tricks?
- Set alert on your smartphone
- Keep medicine by your coffee pot

Your child’s doctor is there to help — they want to see how well your child is doing and to review your child’s symptom control. Together you and your doctor will discuss a new Action Plan, with instructions for when your child’s asthma is under control and when it is not well-controlled.

“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
“I love the digital links. I live on my phone so those would be really helpful.”
- Mother of 11 year old boy

- 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 make copies of the instructions. It gives his school a better understanding of why I took him to the ER. I also take those instructions to his doctor when I go home.” - Mother of 6 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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Sources:

Slide 1

Slide 2
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Slide 3
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Change: Design vs. Scientific method for…. User Centered Design Methods vs. Scientific method

Slide 6