



Bridging the communication gap:

A new touchpoint for pediatric asthma education
in Emergency Departments

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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

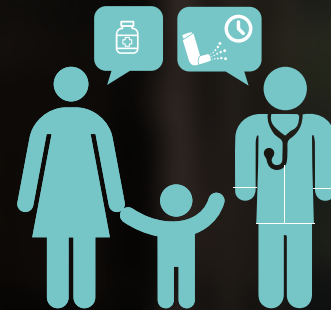


communication model

▶ 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

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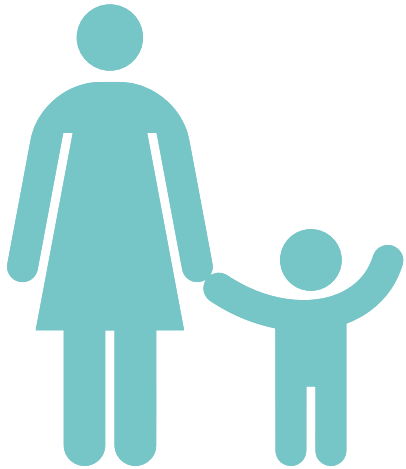


our design challenge

*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?*

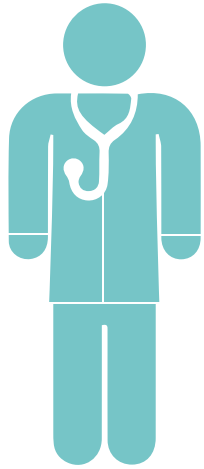
balancing needs across 4 stakeholder groups

Caregivers



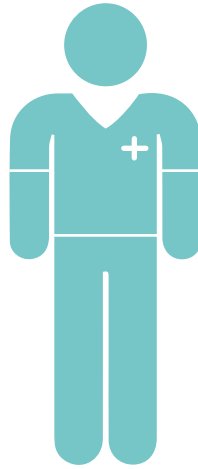
- ▶ 9 in-home interviews with caregivers of children with asthma

ER physicians



- ▶ 5 ER physician interviews conducted in the ER of their respective hospitals

ER nurses & administrators



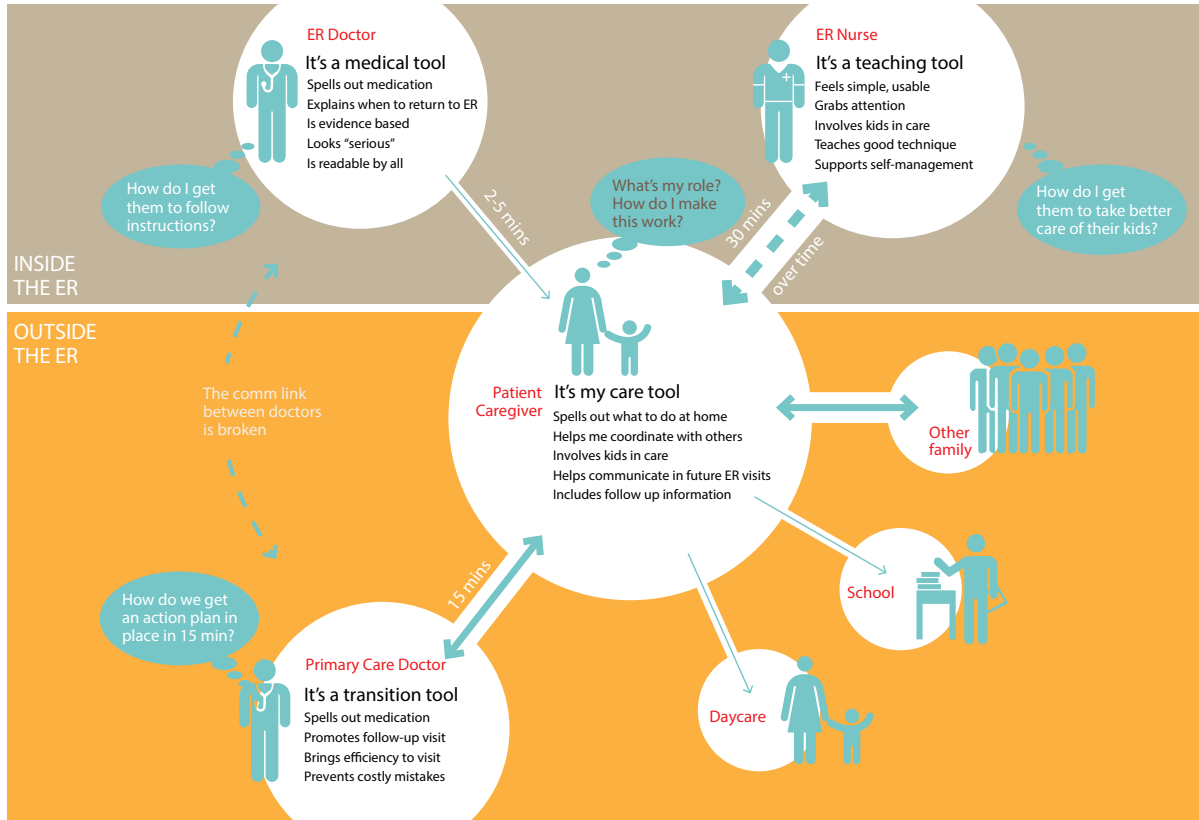
- ▶ 4 staff nurse interviews and 4 nurse administrator interviews conducted in the ER of their respective hospitals

Primary care doctor



- ▶ 5 primary care physician interviews conducted in their respective outpatient clinics

stakeholder model



research insights

1

Everyone counts

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

2

Communication is critical

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

3

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.

4

Beyond the 4 walls

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

5

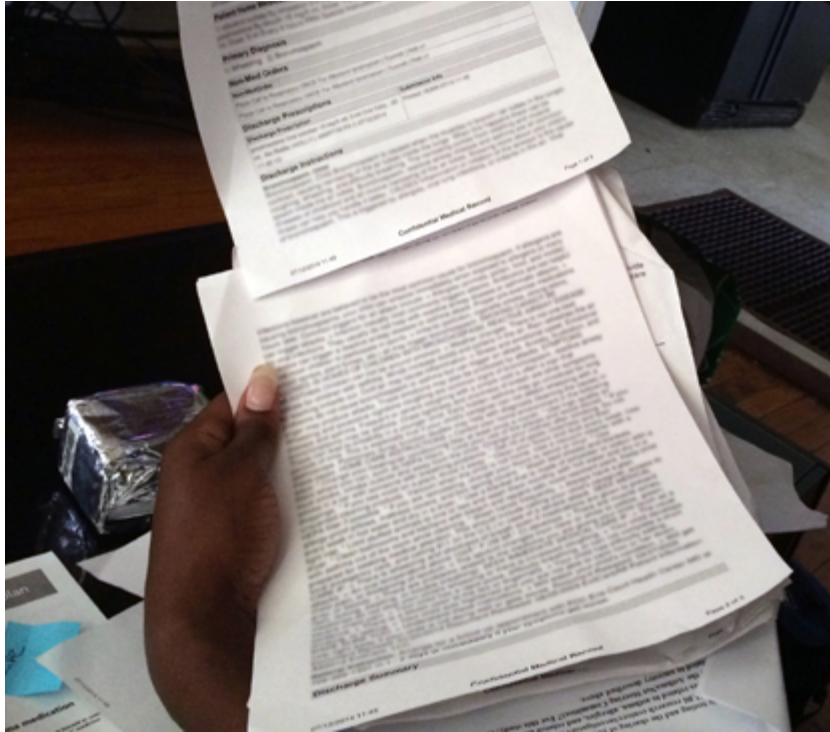
Asthma is complex

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

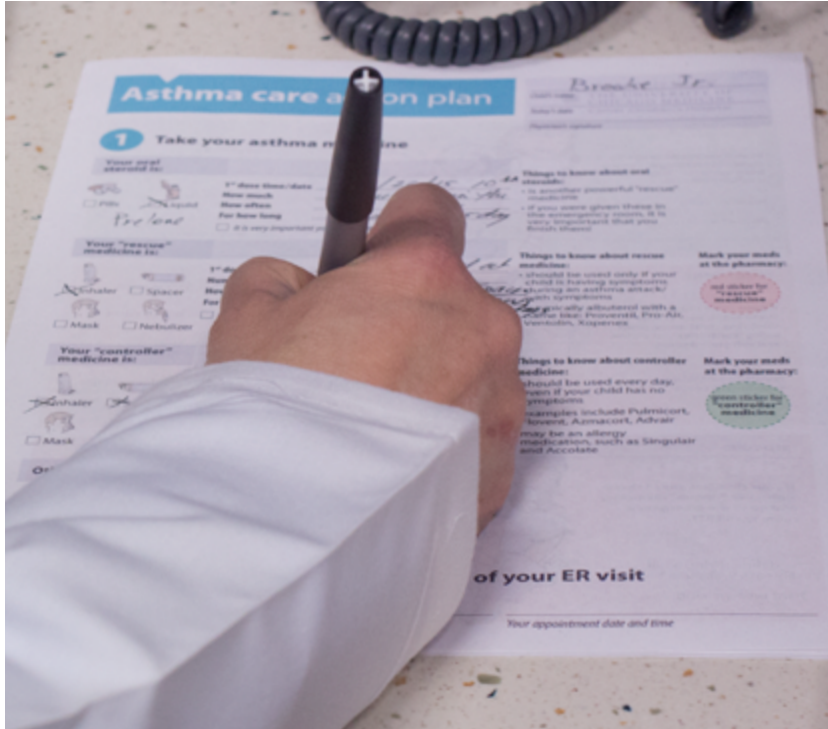


ED context level

Desired discharge protocol
Drivers of practice variation
Fit with clinician/
caregiver conversations



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.

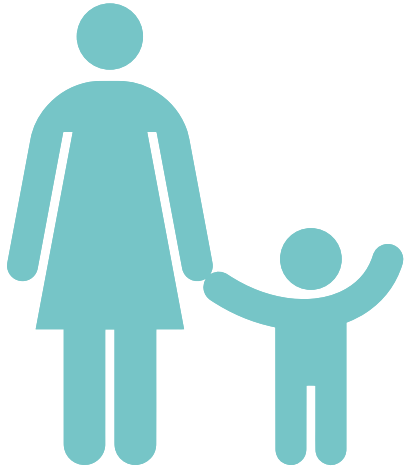
Document Metrics:

526 word count

5th grade Flesh-Kincaid reading level

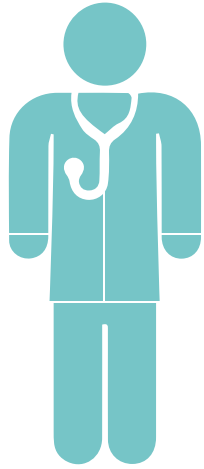
value for stakeholders

Caregivers



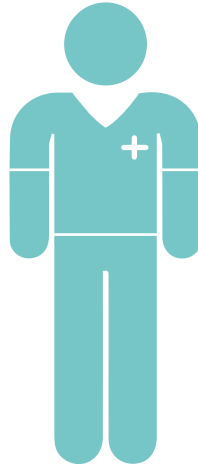
- ▶ designed to fit into complicated lives
- ▶ simple language and action items make it easy to share with care circle
- ▶ easy to engage with clinicians in conversation

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

Methods In situ interviews
Experiential walkthrough
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

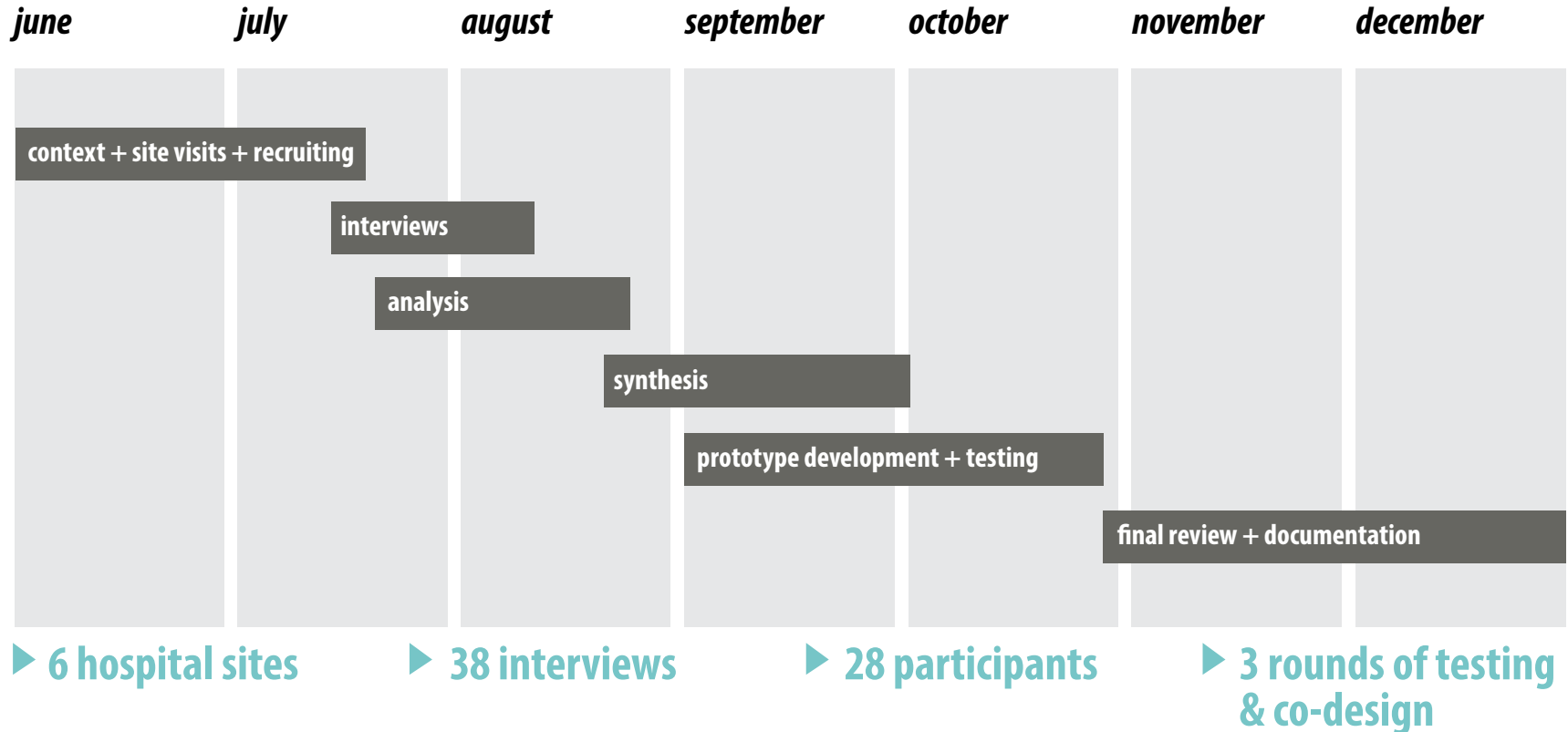
Compliance barriers
Modes of use
Communication

PROTOTYPE

Imagine, build and evaluate solutions

Concept prototypes
Iterative testing and refinement

process timeline



design methods

Analysis

- Observations clustering matrix
- Immersive analysis workshop
- User journey map
- Grounded theory analysis
- Insight sorting
- Design principle generation

Count of Comments	Family	Lifestyle	Asthma Journey	Asthma Management	ED Experience	Follow up	Prototype
Column Labels	Family Structure	Family Health	Family Support	Child's Routine	Child's Environment	Child's Education	Child's Activities
People	15	14	11	6	2	2	2
Objects	3	4	3	2	2	2	2
Environments	2	2	2	2	2	2	2
Messages	2	2	2	2	2	2	2
Services	2	2	2	2	2	2	2
Info	2	2	2	2	2	2	2
Grand Total	18	15	14	11	6	2	2

Understand

Research

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



Abstract

Synthesis

- Ideation session
- Role play ideation
- Testing AB options



Make

Prototyping

- Concept Evaluation
- Solution Prototype
- Future: Pilot development and testing



Real

divergent thinking vs. scientific diligence

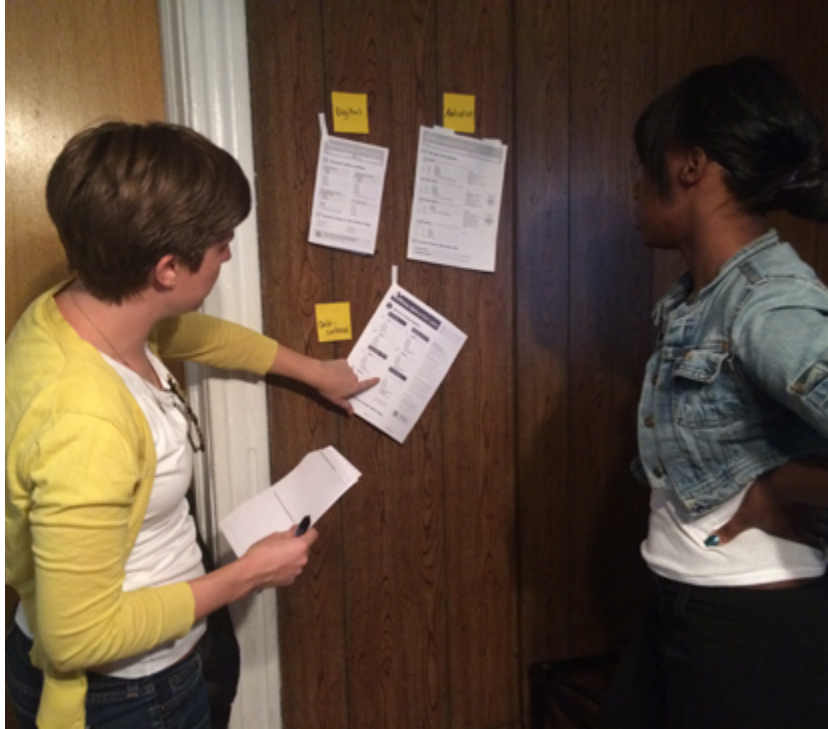
- ▶ While design methods strive to build a rich description of participant context, medical research methods seek evidence and proof.
- ▶ These contrasting approaches created a productive tension between the design team, trained to imagine a better future, and the CHICAGO Trial consortium, trained to 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



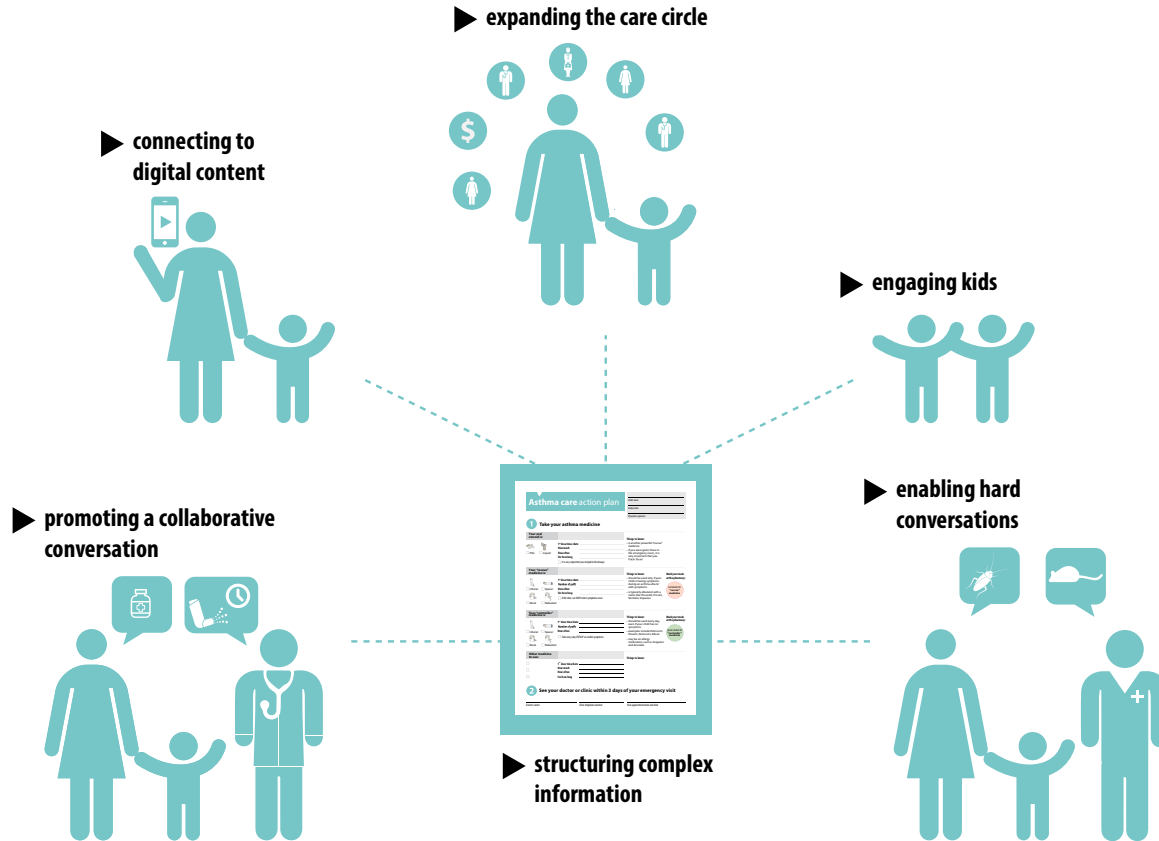
- ▶ creating an immersive built environment to communicate massive interview data, build user empathy and set the stage for co-analysis workshop
- ▶ establishing clear metrics , such as word count limits and reading levels, to turn medical expertise into patient-appropriate content
- ▶ socializing new 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

Asthma care action plan

1 Take your asthma medicine

Your oral steroid is:

Pills Liquid

1st dose time/date _____
 How much _____
 How often _____
 For how long _____
 It is very important you complete the dosage

Things to know:
 • is another powerful "rescue" medicine
 • if you were given these in the emergency room, it is very important that you finish them!

Your "rescue" medicine is:

Inhaler Spacer

Mask Nebulizer

1st dose time/date _____
 Number of puffs _____
 How often _____
 For how long _____
 After that, use ONLY when symptoms occur

Things to know:
 • should be used only if your child is having symptoms during an asthma attack/with symptoms
 • is typically albuterol with a name like: Proventil, Pro-Air, Ventolin, Xopenex

Mark your meds at the pharmacy:

Your "controller" medicine is:

Inhaler Spacer

Mask Nebulizer

1st dose time/date _____
 Number of puffs _____
 How often _____
 Take every day EVEN if no visible symptoms

Things to know:
 • should be used every day, even if your child has no symptoms
 • examples include Pulmicort, Flovent, Azmacort, Advair
 • may be an allergy medication, such as Singulair and Accolate

Mark your meds at the pharmacy:

Other:

Child's name _____

Today's date _____

Physician's signature _____

2 See your child's doctor within 3 days of your ER visit

Doctor's name _____

Clinic telephone number _____

Your appointment date and time _____

“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

3 Read the signs

GREEN ZONE
Go play
Even if your child shows no signs of breathing problems, keep using the "controller" medicine every day.

- no coughing or wheezing
- peak flow is at normal level
- sleeps soundly
- breathes easily
- plays as usual

YELLOW ZONE
Call doctor
If your child shows any of these signs, use "rescue" medicine right away, keep using "controller" medicine, and call your doctor.

- coughs a lot at night
- hurts to breathe deeply
- hard to sleep because of breathing problems
- breathing does not get better within 20 minutes of taking "rescue" medicine
- breathes fast when standing in place

RED ZONE
Get help
If your child has any of these signs, use "rescue" medicine, and go to the emergency room or call 911.

- Call 911
- breathing so hard that they are drowsy or sleepy
- lips or fingernails are grey or blue
- breathing gets worse within 20 minutes of taking "rescue" medicine
- ribs show when breathing
- hard time breathing when sitting in place
- hard time saying a full sentence without a breath
- hard time walking

"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

a tool for everyone, not just the doctor

4 Stay on top of asthma

▶ **Don't wait! Call with questions** Call your child's regular doctor as soon as possible to help you understand your child's asthma and treatment plan.

▶ **Identify your child's asthma triggers** 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:



What are your child's triggers?

_____	_____
_____	_____
_____	_____

▶ **Give medications as prescribed** 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 an alert on your smartphone
keep medicine by your coffee pot

▶ **Take your child to the doctor regularly** 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

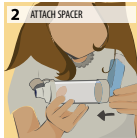
- ▶ creates room for caregivers, not just clinicians, to write
- ▶ home environment questions for caregivers promote their role in managing their child's care
- ▶ images of asthma triggers help nurses broach sensitive subjects, start hard conversations
- ▶ tips and tricks help caregivers start building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

a “smart” document

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
Attach the inhaler to the spacer.



3 BREATHE OUT
Breathe out all the air, away from the spacer.



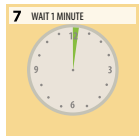
4 PRESS THE INHALER
Put lips around device, press inhaler one time. This puts one puff of medicine into the spacer.



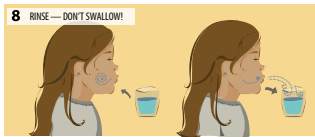
5 BREATHE IN DEEPLY & SLOWLY
Breathe in deeply and slowly, and hold your breath.



6 HOLD YOUR BREATH — 5 SECS.
Remove the device from the mouth. Then hold your breath for 5 secs. 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 one minute, repeat steps 3 to 6.



8 RINSE — DON'T SWALLOW!
Rinsing is only necessary if the medicine you just took was an inhaled steroid. Have your child rinse his or her mouth out with water after the last puff of medicine. **Make sure your child spits the water out.** Do not allow the child to swallow the water. Recap the inhaler.

From the American College of Chest Physicians
Illustrations by Paula Falco



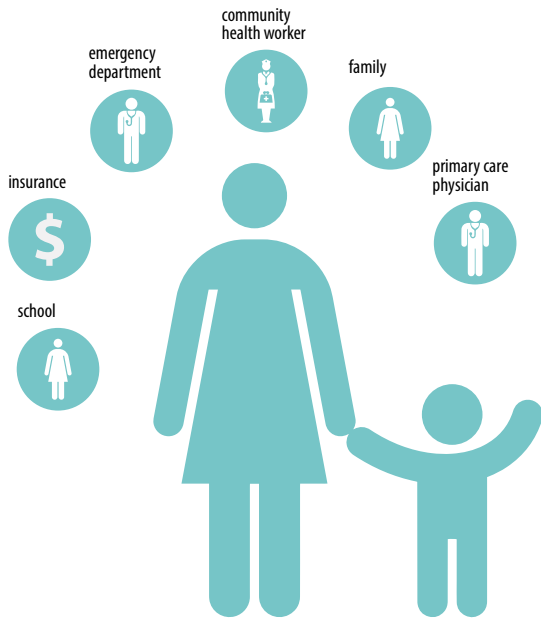
What is this? This is a QR code. To use it, go to the app store on your smartphone, search for “QR code readers” and download the free app.
To learn more about asthma, scan this code with the app to go directly to the Respiratory Health Association website. Or go to the link below:

www.tinyurl.com/asthma1b

“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

sharing with care circles



“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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IIT Institute of Design

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.

Sources:

Logos - Noun Project

Slide 1

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Slide 2

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Change: Design vs. Scientific method for... User Centered Design Methods vs. Scientific method

Slide 6

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