

### TRANSFORMING THE CLINICAL ENTERPRISE

Bridging the Gap between Evidence and Care: Using Human Centered Design to improve pediatric asthma care in high-risk communities

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#### KEY POINTS

- ✓ The CHICAGO Plan is a multisite, 3-arm comparative effectiveness trial with the goal of reducing ED repeat visits, which features the inclusion of *Human Centered Design (HCD)* to adapt study interventions to fit stakeholders and contexts of use.
- ✓ In the ED, effective care transition communication between providers and caregivers of minority children presenting with asthma exacerbations has not been well-supported, especially due to ill-suited patient education materials.
- ✓ The design team worked with researchers, asthma experts, families of children with asthma, ED physicians, nurses, and outpatient providers to develop a new, guideline-based asthma action tool for children, their caregivers and clinicians providing medical care in six Chicago Emergency Departments.
- ✓ The CHICAGO Plan demonstrates how a design-informed process can create “fit to purpose” solutions based on the likelihood of use.
- ✓ The CHICAGO Plan discharge tool organizes discharge communication around four key action items, is written at a 4th grade reading level, and employs best practice communication design techniques to create a document everyone, including children, can use.
- ✓ The tool was designed to shift the communication model in the ED from “delivery of information” to “collaborative conversation” between patients and providers.
- ✓ Results suggest the potential for a beneficial partnership of design and healthcare professionals to bridge evidence-based care to the people who need it.

#### ISSUES AND CHALLENGES

**Developing an effectual tool that addresses the disproportionate burden of asthma for minority children, high-repeat emergency department visits, and ineffective discharge tools and communication techniques for care guidelines**

Minority children in Chicago disproportionately bear the burden of asthma. African-American children are about three and four times more likely to have an

asthma-related emergency department (ED) visit and to die from asthma, respectively, compared to white children. Gaps in implementation at provider- and patient-levels contribute to these asthma disparities, with studies suggesting that minority children are less likely than white children to be prescribed and use guideline-recommended asthma care.

In the ED, effective care transition communication between providers and caregivers of minority children presenting with asthma exacerbations is not well-supported. Research consistently identifies

discharge tools and patient education materials as ill-suited to the needs of both clinicians and caregivers, leading to poor preparation for self-management at home and return visits to the ED. These materials are particularly challenging for low-literacy populations.

### THE CHICAGO PLAN APPROACH

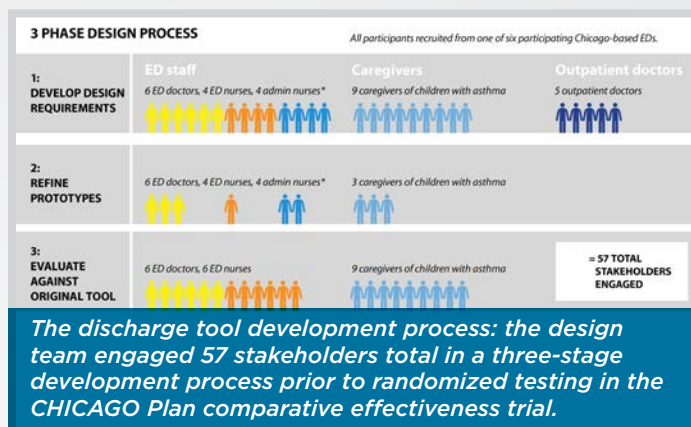
**Applying *Human Centered Design* to produce “fit to purpose” tools that support clinicians in consistently delivering the care patients need at discharge, and that subsequently help patients and family carry out that care in the complex settings of home, work, and school**

Today’s discharge tools are long, complicated, and difficult to read and use in situ. Designing new tools that are not just easier to understand, but also crafted to promote effective interactions between providers and patient/caregivers in specific settings is possible. The CHICAGO Plan provides such an example.

#### Meeting the Challenges of Emergency Department Discharge Care Guidelines

In the rushed and interrupt-driven environment of the ED, doctors and nurses struggle to recall and deliver guideline-based asthma instruction at discharge. As a result, practice variation is pervasive, not only within any given ED, but within the same provider on the same shift. Theoretically, discharge tools are intended to fill this experience gap and to explain, support, and reinforce post-ED care practices. However, direct observations in Chicago-based EDs, combined with interviews of ED clinicians and caregivers of children with asthma using those EDs, highlight that these tools are not effective in or responsive to ED realities.

A cross-site assessment of pediatric asthma discharge tools used at these EDs shows significant consistency in design: pages of undifferentiated text, written at a 7-12th grade reading level, with formats that do not adhere to cognitive human-factors and information design principles, and a dotting of pertinent care information in-between generic discharge information. This presentation is not only difficult to comprehend by patients, it’s difficult for providers to navigate in a time-pressed context. As a result, providers seeking to orient caregivers to critical instructions and to



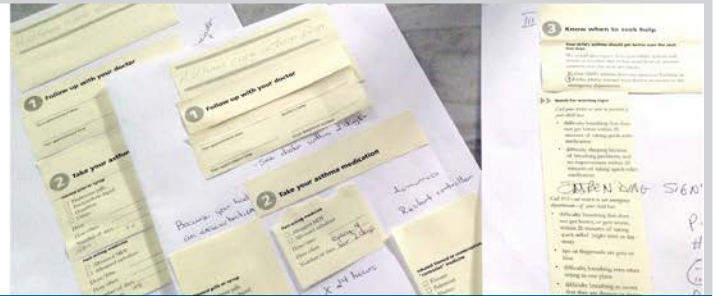
cooperatively develop a shared understanding of next steps are left unsupported in these activities. All ED providers interviewed stated dissatisfaction with their discharge tools, as did the outpatient providers interviewed at each site who are on the receiving end of these documents.

#### Developing Home Care Guidelines for Real-world Settings

The lack of fit between discharge tools and real-world settings extends to the home care context. Three-hour interviews in the homes of families with children admitted to the ED for uncontrolled asthma within the last 12 months reveal a similar lack of support for their needs, activities, and context. Discharge documents, if present in the home, were stored out of sight in bags or boxes. Caregivers reported using them as proof of a legitimate medical event with school staff, employers, and at follow-up appointments. These same caregivers also reported confusion about types of medication, medication usage, asthma triggers and self-management practices, suggesting they had not read or could not extract relevant asthma management information from their discharge documents.

Caregivers who reported successful management of their child’s asthma noted that it took years to piece together triggers and medications, and had done so largely unaided and on their own. Importantly, in the days and weeks following discharge, caregivers volunteered a strong need to explain asthma and their child’s status to other lay people in their child’s care circle, including aftercare and daycare workers, extended family, neighbors, summer camp personnel, and others. **However, the caregivers did not look to the ED discharge documents to fill knowledge gaps or for communication assistance.**





*Prototyping with stakeholders: all interviews included prototype development. Right: Outpatient providers were given guideline-based asthma care printed on sticky notes and asked to construct the discharge document they wished their patients received in the ED. Left: Sample discharge prototypes created by outpatient providers.*

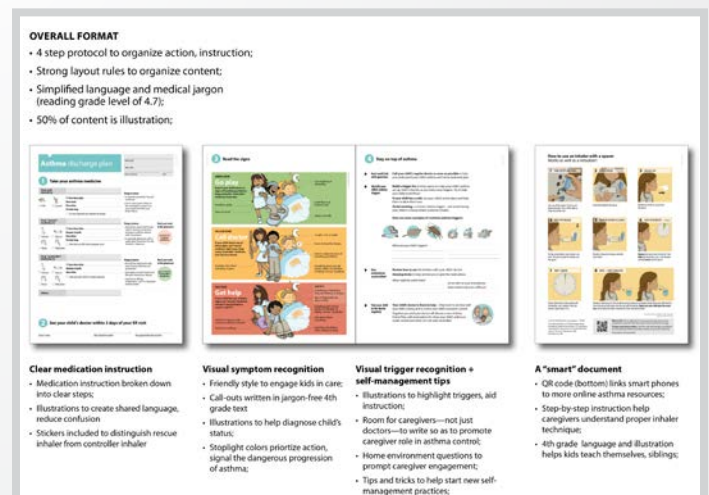
### The CHICAGO Plan: Applying *Human Centered Design* to Develop Productive Healthcare Tools

Human centered design (HCD) is a field that has methods and tools optimized to create products, technologies, and services that fit the everyday activities and needs of consumers, and has been doing so in industry for decades. Expertly applied, HCD methods generate a rich description of the context and needs of all relevant stakeholders, accelerate the development of solutions in collaboration with those stakeholders, and produce a risk-reduced, novel product that works effectively across multiple stakeholder groups. These same approaches can be productively applied to design tools and services for providers and patients in healthcare.

The CHICAGO Plan is a demonstration of how a design-informed process can create “fit to purpose” solutions that demonstrate situational awareness of how and under what circumstances that tool is likely to be used. The CHICAGO Plan discharge tool organizes discharge communication around four key action items, is written at a 4th grade reading level, and employs best practice communication design techniques to create a document everyone, including children, can use. Importantly, it was designed to shift the communication model in the ED, from “delivery of information” to “collaborative conversation” between patients and providers.

The extensive design-led development process is documented in multiple peer-reviewed publications (see below). The resulting tool was tested for effectiveness in a PCORI-funded randomized clinical trial involving 370 families and six EDs, and generated measurable process improvements

across all sites. In separate preference-based testing, clinicians reported this was a tool that was “worth their time,” would open up more effective communication with patients and reflected the care that they as doctors seek to provide. These results suggest the potential partnership of design and healthcare professionals to bridge evidence-based care to the people who need it.



*The final discharge tool: Guideline-based asthma care is translated into text and visuals, and clustered into 4 action items to guide discharge conversations and caregiver home care.*

### RESULTS/OUTCOMES

A design-led development process involving 56 stakeholders across six EDs, five outpatient, and nine home settings resulted in:

- 247 families, who were randomized to receive either the new discharge tool in their ED (versus “usual care”) or the new discharge tool in combination with home visits by community health workers, received significantly higher levels of guideline-based asthma care (prescriptions for both rescue and controller medications and a follow-up appointment).
- A novel, culturally-tailored ED discharge support tool that combines visual language and 4th grade writing strategies to make complex medication instructions, asthma symptom identification, and home-management advice easier to understand and use by lay people post-ED. The tool was intentionally designed to support care coordination conversations between caregivers and the extended family, schools, childcare, and outpatient clinics that are part of a child’s care circle.
- A discharge tool intentionally designed to engage children in care, reflecting research findings that children as young as 9 years old are in charge of their own asthma care.
- A discharge support that is also tailored to the complex environment of the ED and its time-pressed clinical workflows: it promotes a 4-step asthma discharge protocol to standardize and simplify discharge activities and communication between providers and caregivers.
- Significant process improvements during the 30 month RCT at the six Chicago Emergency Departments: 99% of patients who received the discharge document left with a prescription for systemic corticosteroids (versus 61% usual care group); 63% left with a prescription for a controller medicine (v. 41% usual care group); 99% left with a prescription for rescue medication (v. 85% usual care group); 49% left with a follow-up appointment (v. 8% usual care group).
- Strong multi-stakeholder preference for the new discharge document as compared to current discharge documents in a side-by-side evaluation with 20 ED doctors, nurses and caregivers at two of the six CHICAGO Plan study sites; this tool also won first place in the 2015 Core77 Design Awards in the Service Design category.
- Online Education (532 healthcare professional learning modules and 86 patient learning modules total).

### FOR MORE INFORMATION AND RELATED MATERIALS ABOUT THE PROGRAM

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