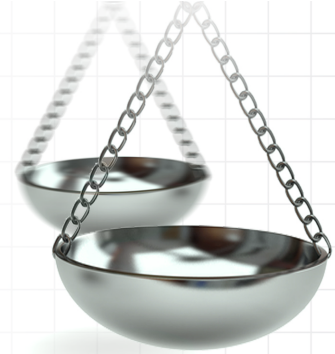

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Using design methods to provide the care that people want and need

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Kim Erwin is an Assistant Professor at IIT Institute of Design and trained in user-centered design methods, which put people at the center of any problem space so as to develop solutions that better fit their everyday lives, activities and context. Her expertise is in making complex information easier to understand and use. Her research targets communication tools and methods for collaborative knowledge construction built through shared experiences. Her book, Communicating the New: Methods to shape and accelerate innovation focuses on helping teams explore, build and diffuse critical knowledge inside organizations.

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Q What prevents current written instructions/action plans to aid asthma management from being utilized effectively after discharge from the emergency department?

We identified three classes of problems. First, asthma discharge documents are long, complex, hard to read and discourage careful reading. The action items are hard to find. Second, the kinds of content and the presentation of that content are out of step with the needs and abilities of our caregivers; medication instructions, for example, contain technical language and specify complex routines that are hard to understand and follow. Third, and as a result of the first two issues, these documents fail to support the many conversations that caregivers need to have to coordinate with others who care for their child, including aftercare, daycare, neighbors, extended family, schools and the patient's doctor. Many nurses and doctors in the emergency department (ED) also noted that the current asthma discharge documents are hard to use and do not fit their workflows. Designing the content, structure and form factor to support critical conversations became paramount [1].

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Q What was the reason for the CHICAGO Plan focusing on African–American & Latino children?

In Chicago, African–American and Latino children bear a disproportionate share of the burden from asthma. Asthma is more common in these communities and leads to missed school for children and work for their parents and other caregivers. The City of Chicago Department of Public Health, a critical partner in the study, helped assemble a broad coalition of health systems, advocacy groups and researchers to tackle asthma in this patient population.

Q How were stakeholders identified & recruited?

The CHICAGO Plan design benefited from early and continuous stakeholder engagement, many of whom are part of the research team and serve on its Steering Committee. The CHICAGO Plan Steering Committee includes clinicians and investigators from all six ED Clinical Centers, leaders of asthma advocacy organizations in CHICAGO (Chicago Asthma Consortium and the Respiratory Health Association), design experts, a representative of the Illinois Emergency Department Asthma Surveillance Project and a representative of the Chicago Department of Public Health. This broad base of stakeholders who are collaborating in the CHICAGO Plan provides direct access to children, caregivers, nurses, doctors, administrators and other end-user stakeholders.

Q In Phase I, you looked at defining design requirements; what form did this take?

We applied user-centered methods taken from the field of design to engage a diverse group of stakeholders. Design methods are not familiar to healthcare researchers but are particularly productive for healthcare investigations for two reasons. First, they seek to understand what stakeholders actually do, rather than what they say they do or think they do. This is important because human beings are highly adaptive and so often fail to notice or report behaviors, problems or workarounds that should be addressed. For the CHICAGO plan, we engaged all clinical stakeholders in the EDs where they worked and used techniques such as role play to understand the interaction model at work between caregiver and clinician, and to demonstrate the role of target materials in that interaction. Similarly, we engaged caregivers in their homes using techniques to help surface their behaviors and beliefs about asthma and its management. A second strength of design methods is that they target action as the outcome, and so bring tools such as prototypes and probes to engage stakeholders in ways that move conversations past generalities to promote detailed discoveries that guide design.

Q What were the key points you wanted to achieve during Phase II, prototype and refine?

There is a substantial gap between a strong concept informed by research and a final product that works effectively across user groups. Phase II targeted this gap. We started Phase II with three concepts, each optimized to address a different usability theme that emerged from the formative research. The goal was to emerge with a single concept that contained the strongest elements from the three. In addition to ranking, the desirability of the concepts, Phase II targeted testing and refinement of language choice, clarity and sequence of instruction, clarity and perceived benefits of illustrations, comfort and agreement (for ED staff) with treatment recommendations, as well as perceived fit with and support for critical conversations across stakeholders.

Q In Phase III, you evaluated stakeholder preferences; did any of these take you by surprise?

A significant surprise, reinforced in evaluation, is how much doctors, nurses and patients dislike their discharge documents but continue to use them. Even the patient/caregivers who took their discharge documents home stored them in bags and boxes, out of sight and reach. Essentially both caregivers and clinicians know that discharge documents are not achieving their intended purpose. The field of design, with its focus on users and methods that fit important information to the people who need to use it, is a strong partner in these kinds of situation. Given that, there is a surprising lack of design involvement in healthcare.

Q What were the key requirements identified for a discharge tool? How do these differ from existing tools?

Current discharge documents pack diverse kinds of information into a tight space with little regard for the cognitive limitations and everyday reading strategies of average people. They also demonstrate little to no situational awareness of how and under what circumstances that tool is likely to be used. To produce a tool 'fit to purpose', a discharge tool should provide clear action steps, a simple structure that creates a protocol for conversation, use writing strategies that communicate at 5th grade level or lower so that many people can use it, and employ principles of communication design to present complex information in ways that are easier to understand and use. A careful mix of text and illustration can also provide stakeholders with opportunities to identify and point to key concepts so that they can formulate questions in real time.

Q How did clinical staff and caregivers react to the final CHICAGO Action Plan after ED discharge (CAPE) document? Were there any key differences in how the document was received?

Clinicians were quick to call out the broad potential impact of the CHICAGO Action Plan after ED discharge (CAPE). They noted, it would be more worth their time to use in the ED, that it would be a more effective education tool that fits their target population and would open up the conversation better than current discharge documents. Several pointed out the value of the visuals to communicate with patients, noting the illustrations would help patients ask questions. One asked if we could design one for heart failure next.

Caregivers also expressed enthusiasm, but the most common reaction was surprise as they learned something new, typically from the trigger illustrations. Caregivers were also quick to spot the utility of the CAPE as a tool to talk with others, especially children, family and school. One caregiver said she would like to give a CAPE to her child to use with her friends to help explain her need for an inhaler.

What can be taken from the design of CAPE for future comparative effectiveness research?

The formative process presented here demonstrates a new multistakeholder driven methodology to inform the development of interventions suitable for comparative effectiveness research. This method is novel because it shifts the design process from one that relies exclusively on teams of medical experts who focus on content to multidisciplinary teams with expertise in uncovering the context of use to inform content requirements, which may also help to overcome barriers to implementation in real-world clinical and nonclinical settings.

What are the next steps for this study?

Through the Patient Centered Outcomes Research Institute (PCORI)-funded CHICAGO Plan, we are testing the clinical effectiveness of CAPE with and without a community health worker in six EDs in the south and west sides of Chicago. The opportunity to evaluate the CAPE instrument in a clinical effectiveness trial will provide definitive evidence about its effects on the quality of care and clinical outcomes in children presenting with uncontrolled asthma in the ED.

Disclaimer

The opinions expressed in this interview are those of the interviewees and do not necessarily reflect the views of Future Medicine.

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The authors have no relevant affiliations or financial involvement with any organization orentity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grantsor patents received or pending, or royalties.

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