



## ENGAGING RESEARCH

### Innovative Strategies for Patient Engagement and Research Design

#### Introduction

The mission of Indiana Children's Health Services Research (CHSR) is to improve the health and health care of children by developing and applying the best scientific evidence and methods available. CHSR examines how children get access to health care and searches for solutions to health services issues in order to find the best possible health outcomes for children. Some of CHSR's main goals are to identify the most effective ways to organize, manage, finance, and deliver high quality care to children.

In order to achieve these goals, a primary objective for health services researchers is to discover and develop research and evaluation methods that will produce the best outcomes for patients, practitioners, and populations. A recent trend in health research has been to utilize input directly from patients through a method called patient engagement.

#### Patient-Centered Outcomes Research

In 2010, as part of the Patient Protection and Affordable Care Act, the US Congress established the Patient-Centered Outcomes Research Institute (PCORI), which mandated to "improve the quality and relevance of evidence available to help patients, caregivers, clinicians, employers, insurers, and policy makers make informed health decisions."<sup>1</sup> Specifically, PCORI was authorized to fund comparative effectiveness research (CER). Patient-centered outcomes research (PCOR) and CER fit squarely into the aims of health services research, and are a fast-growing methodology when researchers consider how practitioners can deliver high quality care.

PCOR operates under the premise that research is more likely to improve the care of patients if they and other key stakeholders are involved in all aspects of the research.<sup>2</sup> For instance, if the object of a research project is to develop an effective method for pediatricians to use when treating teenage patients with diabetes, engaging teenagers, parents, and even teachers would help researchers, especially those who may not have extensive first hand interaction with kids in that age group. The researchers can use the feedback they receive from actual patients in order to develop a system that will best meet those patients' needs.

**"It's so appealing to be able to give parents tools that are easy to understand and visual instead of dense medical jargon."**

Nerissa Bauer, MD, MPH

The challenge with patient-centered outcomes research is to find a method that allows a researcher and a member of the community to communicate in a way that is mutually beneficial. Researchers are rarely trained interact effectively with community members. They also are often so immersed in their own specialties they don't know how to explain key points in a meaningful way. Meanwhile, patients and community members could come from many different backgrounds, with varying degrees of prior knowledge. Differences in cultures, education levels, communication styles, interpersonal skills, and age can create potential hurdles for researchers trying to involve patients and the community directly in research design. Thus the researcher must find an approach that will clearly communicate what he or she is looking for and garner appropriate community responses.

The idea of involving both design research experts as well as patient or community stakeholders in solving this problem emerged from a fruitful collaboration between Dr. Sarah Wiehe, CHSR faculty, and her visual communications colleague from Herron School of Art & Design, Helen Sanematsu, MFA. Ms. Sanematsu's approach employing strategies from human- (or user-) centered design research and service design was a novel idea in health research and it resulted in tangible solutions to Dr. Wiehe's research problems at the time. What emerged was a very productive and innovative partnership between Indiana University School of Medicine and Herron School of Art and Design, working together to communicate medical or health services concepts in a way that would be accessible to community members through visual media.

## The Service Design Technique

The Patient Engagement Core (PEC) was born out of a 5-year, multi-project federal grant funded by the Agency for Healthcare Research and Quality (PI: Dr. Aaron Carroll). The core utilizes designers to bridge the communication gap between patients and researchers. Members of the core work to instill patient-centeredness into health services research using design techniques. They collaborate with patients and other invested laypersons in order to adapt study methods and protocols in a way that maintains the integrity of the research but makes them more relevant to the specific study population.<sup>3</sup> The PEC aims to engage patients at every step of the research process: study design, research methods, implementation, and post-implementation, where they focus on providing information to the entire patient population.

**How does the study work?**

- You get a little bit of blood drawn.
- Some of this blood goes to the Indiana Biobank.
- The rest goes to a lab and your DNA is read.
- Just like how your DNA controls the color of your eyes, it also controls how your body works with medicines.
- The lab looks for clues in your DNA that show how your body works with medicines.
- The clues from your DNA are added to your electronic medical record.
- Your doctor can look at the clues in your electronic medical record to help pick what medicine is best to give you.

**Okay, so what might I get out of this?**

Your doctor will be able to see some parts of your DNA and **hopefully** choose better medicines or doses for you.

The first time.

Without nasty side affects.

**Why just hopefully?**

Researchers believe that if your doctor could see parts of your DNA, it would be easier to choose the medicine or dose that will work best for you. Dr. Flockhart and Dr. Dexter are doing a study to test this idea. If you choose to be part of the study, you will be helping them prove that this idea is correct.

**More questions about the study?**  
Call (317) 274-2810.

**What's the Biobank?**

The Indiana Biobank is like a big lock box full of folders where each folder holds a different person's DNA and health story. Researchers can ask the Biobank to send information from these folders to help with learning about how to help people stay healthy. There are never any names shared. If you agree to give your information to the Biobank, they will keep it until you call and tell them you don't want them to anymore.

**More questions about the Biobank?**  
Call (317) 274-5688.

The design team worked with patients to craft a visual explanation of a study on pharmacogenetics that would be easy for participants to understand.



The Patient Engagement Core's visual design team crafted a set of pamphlets that would attract the attention of parents of children with ADHD for Dr. Bauer's ADHD Group Visits Program.

Specifically, the design team works directly with actual patients and community members to help health services researchers design effective research tools, as well as useful, patient-friendly “products” for practitioners. They have worked with a variety of clients in CHSR and our sister organization Pediatric and Adolescent Comparative Effectiveness Research (PACER), on topics including diabetes, ADHD, and pharmacogenetics.

## How It Works

When a principle investigator (PI) has a study, and is interested in making it community-based participatory research, he or she will contact the Patient Engagement Core (PEC). The PEC team then invites community members, often patients or parents of patients relevant to the field of the PI's research, for a “generative session.” These sessions are similar to a focus group, in that they request input from the community members present, but they are more collaborative and substantive. Everyone present is encouraged to provide honest input, participating in a back-and-forth with the leaders of the design team who run the sessions. The goal of these sessions is to generate strategies on how to make aspects of the PI's research more relevant to the people he or she is targeting in the study.

After the generative sessions, the design team presents the client PI with one or more deliverables. These deliverables are often tools the he or she may use to conduct human subjects' research, such as a visual aid research technicians can use to help conduct interviews with study participants. The design team's deliverables have proven extremely effective for study teams because rather than simply instructing researchers to improve peer recruitment skills, they provide tools that will help them accomplish these tasks.

Tools like these are successful because engaging patients in generative sessions allows those who will benefit from the deliverables to provide input into what information is communicated clearly and what is not. Visual design research specialist Dustin Lynch explains, “There is a disconnect between research and the community... We want grass roots research, we want people to invite science to solve problems that are important to them. We're able to

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do that by introducing the community to the process of research by involving them, reminding them that they are the experts of their lives and they have information that makes them not subjects of research but partners in it.”

CHSR faculty member Dr. Nerissa Bauer, recently appointed as associate director of the PEC, has seen great success as a client. Dr. Bauer says she has been impressed with the visual design team's ability to take an idea and translate it into a product that is understandable to both families and providers. “It's so appealing to be able to give parents tools that are easy to understand and visual instead of dense medical jargon,” she says. In fact, after working with the PEC, she finds it difficult to conduct research without the use of visual communications, because it has proven so effective.

Utilizing visual design and communication is especially beneficial in the field of health services research, where patient-centered outcomes are an inherent goal. To date, the Patient Engagement Core has five fully completed projects and seventeen in progress, but that is only the beginning. The visual design team has expanded from two to four designers, and currently they have three funded grants, eight grants under review, and five more in development. When Dr. Wiehe began the PEC two years ago, her goal was to assist up to ten investigators per year. However, the unique methods and positive results have made the core very popular, and Dr. Wiehe speculates they will serve nearly double the number of projects as the original goal. She says the tremendous demand results from investigators appreciating the value of engaging patients in a tangible way to address research challenges, a service they are often unable to provide for themselves.

#### References:

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2. Selby JV, Forsythe L, Sox HC. Stakeholder Driven Comparative Effectiveness Research: An Update from PCORI. *JAMA*. 2014;312(15):1513-1514.
3. Sanematsu H, Wiehe S. Learning to Look: Design in Health Services Research. *Touchpoint*. 2014; 6(2): 84-87.