

Listening to Patients and Talking to Doctors: A Case for Design in Medicine, & A Call to Action

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This paper describes how design can work at a fundamental level to improve health in the United States. It argues for a design application that levels the playing field between the doctor and the patient in a way that re-establishes the person as the center of medical advancement. It uses the inclusion of a design research oriented Patient Engagement Core within a current study at the Indiana University School of Medicine as a way to demonstrate the relevance of design to health research. We touch upon the research environment established by the National Institutes of Health as a driver for the relevance of design in medicine, and finally, we suggest that designers use their visual communication and design research skills within health research to increase its relevancy to patients and the population, and 'make the science stick' through better understanding of patient perspectives. We assert that by entering discourse in health at this foundational stage we contribute to a new understanding of what health is, who might contribute to its improvement, who determines the relevancy of research, and how such research is used.

Keywords: Design Research, User Centered Design, Patient Centered Research, Graphic Design, Messaging, Service Design

DESIGN RESEARCH IN THE HEART OF AN FEDERAL GRANT

Design has a role to play in health related research in the United States. Our team of five—two designers, one design researcher, one doctor/scientist and one program coordinator—operates as design research center within a large study funded by the Agency for Healthcare Research and Quality (AHRQ) (Department of Health and Human Services). The purpose of our team, the Patient Engagement Core (PEC), is to instill patient centeredness *through design* into health services research. We are a resource shared by four separate projects on a five-year, \$5 million dollar grant in pediatric medicine, which compares the value of different health interventions on pediatric patients. Our task is to work with the Principal Investigators of each of the four studies to review their projects and make recommendations based on patient perspectives. Our aim is to bring to the study the voice of the patient as the voice of a person, so that studies address not only the illness but also the person who lives with it. We review study aims and data collection methods with the PI, identify areas of relevance to patient participation, and then work with patients themselves to develop ways to improve them using methods from design research. The result is a modified study that maintains its scientific rigor while being more people centered and sensitive to patients' lives.

Background: Design Research, Patient Centeredness, and CBPR

Patient Centered Outcomes Research and Community Based Participatory Research (CBPR), both prevalent research approaches in medicine, have well established principles but lack clear methodology. The Patient Engagement Core uses design research to fill the gap.

Design research aims to produce better design solutions by re-directing the focus of activity from the designer to the user. (Lidwell, 2010) Design research emerged as a field in the early 1970s, partially in response to rapidly advancing computing technologies. Its core principle of user centeredness has become fundamental to many areas of design, including the design of services, or service design. (Stickdorn 2010, 24-37) In the Patient Engagement Core, we use the service design concept of 'touch points' to help us focus on the points of interaction between a patient and his or her treatment. To do so we use a range of face-to-face, group activities to uncover clues that may help us improve the studies themselves and increase their relevance. In our previous work we have asked participants to sort word cards to identify priorities; write magazine cover headlines to help imagine desired futures, and play carnival games to learn about child safety practices. One of the studies in this grant aims to learn about relevant measures for ADHD patients from the perspective of their main caregivers (parents, grandparents, etc.). In our

Patient Discovery Session, we asked participants to draw floor plans of their homes to help them describe how they help their children get ready to go to school. With this activity we learned about specific places, times, and tasks (contexts) for 1) design to assist the parent, child and family, and 2) measures/metrics for assessing the effectiveness of health interventions.

Design research methods can be structured to facilitate increased engagement in all phases of research. We have used innumerable sheets of sticky note paper to help participants express their thoughts and experiences, and then arrange them in order of priority, prevalence, or importance, turning sticky notes into data points that facilitate shared analysis by researchers and nascent patient experts.

Patient Centered Outcomes Research (PCOR)

The aim of Patient Centered Outcomes Research is to help people make informed healthcare decisions and improve the quality of healthcare. The Patient Centered Outcomes Research Institute, established in 2010 as part of the Affordable Care Act, is the primary source of support for this area of research in the United States (pcori.org). PCOR methodology standards were drafted for the first time in late 2012, and published in November 2013, after the award of our grant. (PCORI 2013) While methodological innovation is central to discourse in design research, research methods in patient centered outcomes research are far from established.

Community Based Participatory Research (CBPR)

Community Based Participatory Research (CBPR) aims to make research more impactful through intense and long-standing collaboration between researchers and communities. In CBPR, communities are engaged in research from the initial formulation of research questions through all stages of the research process through to dissemination. CBPR measures the quality of research in the community using 12 well-established measures ranging from “Recognizing community as a unit of identity” to “Involving systems development using a cyclical and iterative process.” (Minkler 2012) It has been an area of health science research since the mid-1990s, yet its literature also de-prioritizes methodological approaches in favor of better articulation of the goals and actions of CBPR and its impact in data collection.

Thus, while we know the aims of Patient Centered Outcomes Research and Community Based Participatory Research, it is unclear how to *do* it. As methodologists, the design team/Patient Engagement Core is using design research methods, based on service design principles, to achieve these ends.

How It Works: Doctors as Clients, Patients as Experts

We engage in a conventional client relationship with doctors, but our primary deliverable is two-fold: in addition to creating patient-centered designed artifacts and services, we aim to nurture and develop an engaged ‘Patient Expert’ who interacts with doctors on equal footing in research to help establish and maintain the relevancy of study measures, study findings, and subsequent applications to patient lives.

Involving people in research as research subjects is difficult to initiate and sustain. Researchers who specialize in the science of discovery often lack the resources and capacity to fully address issues relating to research recruitment, such as communicating with a patient community and maintaining patient involvement throughout the course of a research project. The task of the Patient Engagement Core is to serve each of the four Principal Investigators as we would a design client. Our stated role addresses study recruitment (increasing study awareness and enrollment), study adherence (improving patient engagement and participation), project acceptability, ongoing troubleshooting, creation of patient measures, and dissemination to the patient community / community at large.

The discovery and validation of new and relevant patient measures is a fundamental aim of Patient Centered Outcomes Research, and one in which design research can make a significant impact. By initiating interaction with patients using design research methods that encourage conversation and storytelling, we hope to surface information that will help us understand what “good health” means to people in their daily lives. By articulating these definitions, we hope to incorporate them into a shared understanding of health in relation to overall quality of life.

Our work thus far has followed a process similar to that of a conventional designer /client relationship, with some additional complexities in the approval process due to the necessity of submission to the Institutional Review Board. See Table 1.1

Table 1.1 : Comparing the Patient Engagement Core Process to Conventional Design

<i>Steps</i>	<i>Activity</i>	<i>Reflection</i>
1.	The Patient Engagement Core (full team) receives the study protocol and other related materials, and meets internally to reach a broad understanding of the study aims and methods	Far from a design brief, the protocol was written for the NIH to support funding, not identify and contextualize a design problem. As such, it was necessarily short on methodology, our main area of patient centeredness. The protocol as defined in the grant gave us insufficient information to move forward
2.	Initial meeting with study PI to introduce our services and learn about the study	This was positioned to be a ‘kick-off’ meeting for the project, but it quickly became a basic client education session. A formal presentation would educate the PIs and introduce not only the team’s capacities and its relevance to their research, but provide rationales for the application of design in this area. Similarly, the PEC would have benefitted greatly from PI presentations, for which we could provide a template to ensure we receive the information we need
3.	The PEC project coordinator meets with PI to identify potential patient experts to participate in our design research, and starts contacting them to set up meeting times for our ‘Patient Discovery Session’	The PEC Project Coordinator is the main contact for patients engaged in the four studies, and needs to maintain clear communication with study PIs and their own research assistants. Our Project Coordinator is exceptional at her job; she sees all the ‘moving parts’ of each study from all perspectives and her attention to detail is critical to the success of our work
4.	The PEC design team (design researcher + designers) develops activities and an agenda for a 2-4 hour ‘Patient Discovery Session’	In a conventional design process, a formal contract would have been signed after step 2 to insure that our non-academic partners were using their budgeted amounts judiciously. Moreover, the University affiliated members of the PEC, accustomed to a model of inquiry, was guilty of scope-creep. Thus one of the recurring issues in the PEC is the difference between the expectations for work between that of the external design studio and the internal academic faculty and staff. In grant years 2 and 3 we intend to work on a contract model
5.	Discovery session activities are	As the sessions can be elaborately choreographed, a

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	sent to the whole PEC for review	week at least needs to be budgeted for review
6..	Approved discovery session activities are sent to and approved by the PI with revisions	The main PEC contact for these revisions has been our doctor/scientist. Both our doctor/scientist and design researcher need to be consulted
7.	Discovery session is conducted by PEC (full team)	The tendency is to focus on data collection over making people as comfortable as possible in a new setting: the model for a Discovery Session is perhaps less a focus group run by a facilitator and more an exercise in ‘engaged hospitality’ (along the lines of a coffee break, but hosted by a peer)
8.	PEC design team does initial data analysis and forwards the to the full PEC for validation	Potentially more efficiently done with a group analysis session as all of the data was captured on flip chart paper
9.	Designers create solutions to address issues found in the ‘Discovery Session’	Optimally, all PEC would participate in the design development phase
10.	Revised findings, report, and proposal submitted to PI	We have been submitting these via PDF but we would benefit if they were hardcopy, working documents
11.	PEC health researcher meets with PI to discuss report and design proposal	It would be beneficial for both medical and design PIs to be in attendance
12.	PI adds approved designs to the study protocol	Note: PIs are not required to follow our recommendations, however the PIs we have worked with so far have been pleased with our initial work
13.	Pediatric Protocol Development Team reviews protocol	Note: This step insures that the original study intent is maintained and that scientific rigor is not compromised
14.	Institutional Review Board approves protocol	Note: The IRB’s role is to protect study participants (‘human subjects’) from abuses in research
15.	PI proceeds with study including PEC revisions	We will be implementing methods to help us track the study and the impacts of our design work, however neither of the two studies we’ve worked on so far have reached this stage

Patient Advisory Board

The PEC is also responsible for extending the impact of patient centered research into the institution through the Patient Advisory Board. Comprised of two participants from each of our patient discovery sessions and six top-level administrators/scientists from the IU School of Medicine, the Board will meet twice a year to review studies proactively, to identify barriers and facilitate successes beyond the four projects supported by this grant. The Board will continue our work of introducing patient centered perspectives into University research.

Mini-grants

Mini-grants will be awarded for patients interested in extending the research project in some way or to develop ideas for disseminating study findings to patients and other stakeholders. We will encourage patients participating in the Patient Engagement Core to develop proposals that

will be reviewed by the Agency for Healthcare Research and Quality. We will assist the patients as needed in preparing the proposal, including assisting with visual communication needs.

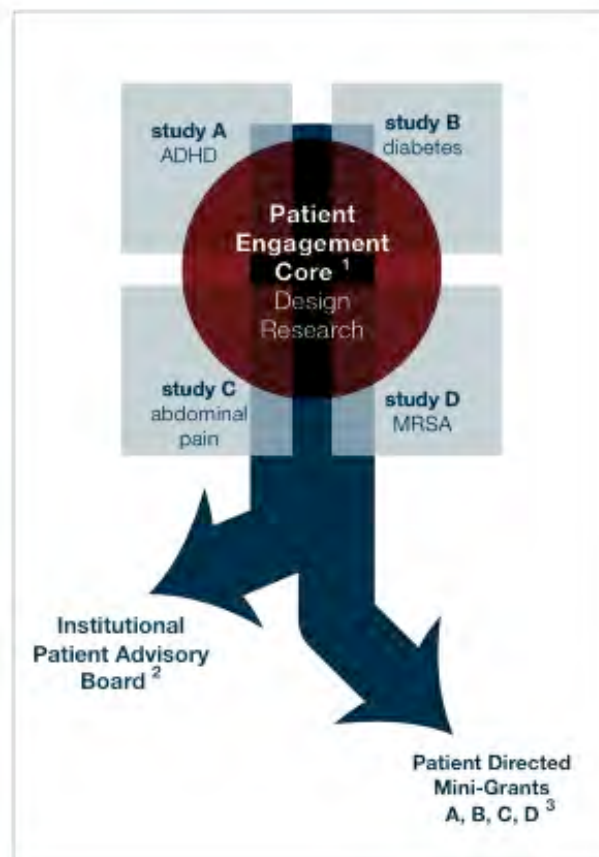


Figure 1: The Patient Engagement Core Methodology

The Patient Engagement Core (PEC). The PEC is a service that uses design to support four separate studies to improve pediatric care. 1. The Patient Engagement Core (PEC) conducts user-centered research to improve study methods. This includes designing communication and communication artifacts (messaging and graphic design) and study-to-patient touch points (service design). 2. Two patients from all four studies meet twice a year with scientists and administrators to proactively review research in the Indiana University School of Medicine (IUSM). This step introduces user centered/patient centered values throughout IUSM. 3. Mini-grants are awarded to patients to pilot their own studies with IUSM support.

RELEVANCE

Health sciences research is a viable, sustainable, and relevant area for design practice and design research.

Design in the context of national research agendas

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The Patient Engagement Core is an example of how design research fits into a large, federally funded grant in Patient Centered Outcomes Research. While the Patient Engagement Core's methods align with Patient Centered Outcomes Research and CBPR, the request for proposals did not specifically call for a design research component. The relationship between the IU School of Medicine and the Herron School of Art and Design was viewed as "strikingly novel" and as a notable strength of the proposal. As Patient Centered Outcomes Research matures and its literature expands to embrace methodology, the onus is on designers to establish themselves as co-investigators in the field, and demonstrate the relevance of design practice to quality patient centered practice.

Translational Science

The 60 Clinical and Translational Sciences Institutes (CTSI) across the country are another recently established area of study that benefits from the application of design. (ncats.nih.gov/files/factsheet-ctsa.pdf) (indianactsi.org) Charged accelerating the pace at which medical discovery moves from the Ivory Tower to application in the 'real world,' the Institutes were established in 2006 and explicitly call for increased community engagement in research. We have been working on community research projects with the Indiana CTSI since 2011 and our work is now a core service of their Community Health Engagement Program, where our work is seen as both a way to communicate with people, and as a research method to learn more about them. As in the Patient Engagement Core, our work with CHEP and the Indiana Clinical and Translational Sciences Institute is also to make "community investigators" one of the outcomes of our work, consistent with the principles of CBPR and in alignment with the mandates of the grant.

Health science research in academic design settings

As designers in the academy, we are especially well positioned to work with academic researchers in health. The shared culture of the University forms a unifying backdrop for our collaboration, and while our research and service responsibilities may differ, this commonality is, we believe, fundamental to establishing the credibility and validity of the design discipline in this context. Academic designers also have at their ready shared information systems, research tools, and a financial infrastructure that makes long-term engagements such as those in the Schools of Medicine and Public Health possible.

Design pedagogy

Student learning stands to be impacted significantly from collaborative research with the health sciences. The two designers who work with us in the Patient Engagement Core are former Herron students who started their own studio, and over the years over 30 students have been engaged, both inside and outside of class, on design and design research projects for the IU School of Medicine, the Fairbanks School of Public Health, and IU Health, Indiana's largest healthcare provider. Various combinations of them form a growing pool of health-engaged, design researchers in central Indiana. Significant to their development have been courses in that emphasize design thinking, service design, and design research methods. Well-trained graphic design students who look to define problems as much as they look to solve them, who bring a people centered approach to their work, and who take seriously the impact of visual and verbal language, already possess the skills needed to engage in a large part of the work we do.

In terms of student learning, the advantages of applying your skills and acquiring new ones in settings outside the classroom are widely discussed, as is the significance of gaining 'content' knowledge in medicine and the health sciences. However I might argue that in community health

research—in which we consider the overall population in addition to the patient in the clinic—the most valuable lesson is that of health as less of a science are more of a matter of social justice. Engaging with the dominant issues of health in the U.S. today such as obesity and diabetes puts one at the center of complex systems of economics, governance, societal structure, and culture. An ant’s eye view of the working of such forces can be a powerful lesson in the realities of the world that students will be entering as designers. As purveyors of image and type, it is important to bear in mind whom you might be serving with those skills, and to what ends.

CONCLUSION

With the establishment of the Patient Centered Outcomes Research Institute and the Clinical and Translational Research Award, it is clear that medical research in this country is shifting its focus to patient centered approaches that necessitate community engagement and involvement. While many doctors conduct research with human subjects, this substantial push by the NIH toward better *patient* outcomes underscores the necessity of a patient perspective in *research* outcomes. Visual communication designers and design researchers need to be willing and ready to fill this need as ‘graphic designers’ who impact research awareness; as methodologists who create data collection methods; and as design researchers who improve the quality of health improvement interventions. Our greatest challenge is the pioneering nature of the work: doctors typically do not interface professionally with designers, and introducing the relevance of a practice conventionally viewed as decorative within a discipline as empirically grounded, rigorous and institutionalized as medicine can be difficult. However, once our work is understood as patient driven rather than style driven, it is readily seen for its problem solving potential by researchers who are challenged by study recruitment, patient adherence to research protocols, and the determination of patient centered measures. Informed by a progressive national research agenda, and backed by the mandates of federal grants, design is positioned, right now, to play a key role in improving health in the United States. Designers bring out the expertise of patients and regular people. We as designers need to get in there and do our part.

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REFERENCES

- Lidwell W, Holden K, Butler J. 2010. *Universal Principles of Design, Revised and Updated: 125 Ways to Enhance Usability, Influence Perception, Increase Appeal, Make Better Design Decisions*. Gloucester, Mass: Rockport Publishers
- Stickdorn M, Schneider J. 2010. *This is Service Design Thinking*. Amsterdam: BIS Publishers
- PCORI (Patient-Centered Outcomes Research Institute) Methodology Committee. 2013. *The PCORI Methodology Report*. pcori.org/research-we-support/research-methodology-standards
- Minkler M, Garcia A, Rubin V, & Wallerstein N. 2012. *Community-Based Participatory Research: A Strategy for Building Healthy Communities and Promoting Health Through Policy Change*. Berkeley, California: University of California PolicyLink, School of Public Health, UC Berkeley