## COMMUNITY HEALTH ENGAGEMENT PROGRAM'S PATIENT ENGAGEMENT CORE

# FRAMING PHARMACOGENETICS FROM A PATIENT PERSPECTIVE

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## BACKGROUND

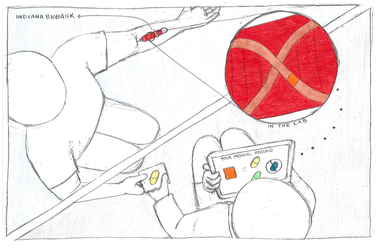
The Patient Engagement Core (PEC) uses interactive design research methods to help participants draw on their lived experiences to explore study issues and envision solutions. The team joined with Kenneth Levy, PhD, MD to improve recruitment and assess study acceptability for *A Prospective Randomized Trial to Assess Cost and Clinical Outcomes of a Clinical Pharmacogenomic Program at Eskenazi Hospital* (David A. Flockhart, PhD, MD & Paul Dexter, MD).

## METHODS

The PEC facilitated an informal group discussion guided by generative, interactive design research activities that focused on the specific objectives identified with the study team. There were ten participants who were regular users of the health care system and were recruited by the ResNet team led by Jane French. The activities were as follows:

**NOTECARD PROMPT**
Write on an anonymous notecard what you think *genetics* and *pharmacogenetics* are.

**TELEPHONE**
Explain to the person next to you what you think is going on in this image. Explain pharmacogenetics




**SIMILES**
Explain pharmacogenetics using a simile.

**RISKS AND BENEFITS**
What would concern you about this study? What would interest you? Which is the most important concern and interest for you personally?

## ANALYSIS

The content generated during the session was grouped thematically to identify key barriers to recruitment that could be addressed within the very short recruitment window available.

## KEY INSIGHTS

- **Participants showed a low baseline knowledge of pharmacogenetics** and pieced together initial definitions using similar words they already knew like *pharmacy, pharmaceutical,* and *genetics*
- **Participants described pharmacogentics as a form of personalization** using phrases like *personal genetic makeup, what's right for you, what medicine is best for you,* and *testing your blood*
- **Participants were able to use everyday concepts to create similes that explained pharmacogenetics:** *If you go to pick out an outfit and don't try on the clothes and just guess, it might not fit. So you'll just have to go right back to the store.*
- **Participants were curious about how they and their doctors could use pharmacogenetics for their care,** particularly in avoiding medication side effects and getting the benefits of proper medication more quickly
- **Participants were somewhat concerned about the procedure,** specifically fear of needles and the potential for pain
- **Participants were very concerned about future use of data by others,** especially entities perceived to be part of the government (Biobank)

## DISCUSSION

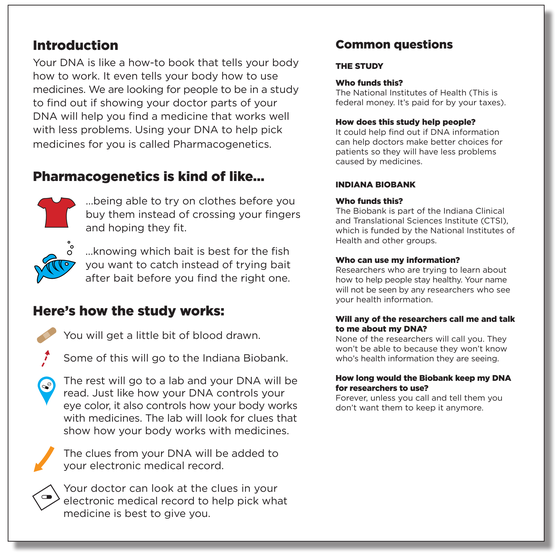
Through design research methods, the PEC worked with patients to co-design a tool to help research assistants recruit and a take-home brochure to help patients understand the study and the Biobank. The PEC's methods aim to establish a relationship between researchers and patients in which all are valued and respected, positions are well-articulated, needs are clear, and expectations are established.

## ACKNOWLEDGMENTS

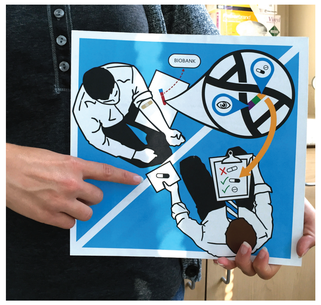
Dr. Kenneth Levy and his research team | Jane French and the ResNet team | Our awesome session participants

## DELIVERABLES

### *Research assistant tool*


**FRONT** | Tool for research assistants to show patients study process




**‹ BACK**

Includes key information for research assistants framed by patient input:

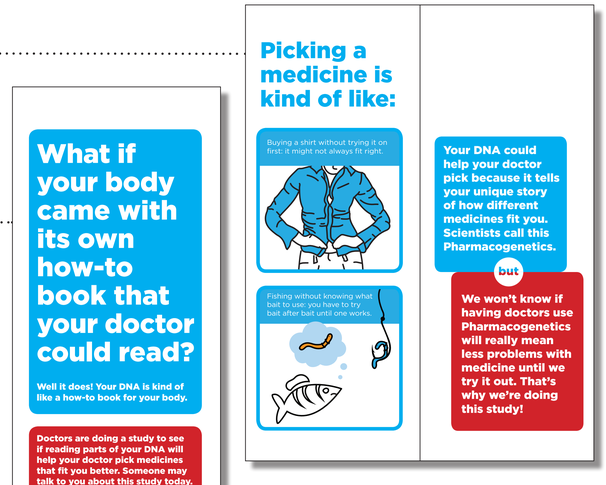
- similes from session that explain pharmacogenetics
- patient-friendly breakdown of study procedures
- answers to most frequent questions asked in session

### *Patient brochure*


Same content as research assistant tool plus:

- patient-friendly definition of DNA
- contact information for more details

Language doesn't talk down to patients and gives them what they need without being esoteric




*"For me it all goes back to understanding and knowledge and knowing the process [before trusting researchers with my blood]."*

– SESSION PARTICIPANT

INDIANACTSI
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