Title of Design Lab:
Data Systems Design

Topic Champions:
- Reginauld Jackson, Public Health Institute (PHI) (CA)
- Sarah Pallin and Lindsay Hendrix, Louisiana Public Health Institute (LPHI)

Short Summary of session
LPHI & PHI are developing infrastructure for data systems for the use of collaboration and patient /community engagement. Both projects are very different in scope.

With the Public Health Institute (PHI), they are taking snapshot of data from non-profit hospitals, health departments, and United Ways, collected from the community health needs assessments (CHNAs), which is required as part of tax-exempt requirements. The data is made readily available publicly. PHI created a tool to provide these organizations as a way to collaborate with one another to define the community needs and services that they are providing to the community. Cross-referencing it with the CHNA.org needs maps and what the CHNA data and services provision from these hospitals to see if they are actually meeting the needs of the community. The goal is to find the best practices of CHNA and also for collaboration amongst community providers. Currently, PHI is facing issues of where the tool will live and funding. It's is very politically fueled, since many hospitals find it to be a policing tool.

With the Louisiana Public Health Institute, they are developing a clinical data research network (CDRN) as part of PCORI funding, which looks at developing data systems infrastructure for research and patient engagement for research. The LACDRN has 3 components:
1. Data infrastructure: Developing relationship with data partners to feed specified data elements into a data warehouse, which is managed by LPHI. Data is collected in a central repository and connected to the national PCORI database.
2. Research: Research is the ultimate goal for the PCORI network . The goal is to increase ease for patient centered research. Potential researchers can query PCORnet around specific data, or specific group of subjects.
3. Patient Engagement: Ultimately, a registry of potential research subjects can be developed. Developing an active cohort to be able to participate in research (with consent). This is a major challenge, but also a major component of the LA CDRN. Currently, LPHI is looking into using SMS or web components to engage patients in other care coordination or research things. Boards for CDRN which includes patients to inform, review and advising research agenda; an administrative board that will approve the business of the LACDRN; and advisory groups based on different areas (HIV/aids, diabetes, etc.) to provide ideas on the type of data to collect and the research to collect.

Key Takeaway points:
1. Main goal of PHI(CA) project is to identify best practices of the Community Health Improvement process and collaboration amongst community services providers
2. Patient and community engagement is a key challenge from both LPHI and PHI projects
3. Developing collaboration amongst different groups is also a common challenge in both projects

Action Steps: No action steps were discussed.