

2016 Learning Engagement Conference

Thursday, October 13th, 2016

Patient Engagement Bootcamp I – Orientation and Sharing

Kim Kimminau & Cheryl Jernigan – Present
Brittany Zschoche – Notes

1. Introductions and roles
2. This orientation will level the playing field
 - a. PCORI insisted that engagement be a pillar of the GPC grant application
 - b. Three disease cohorts:
 - i. Obesity (all networks had to study this one)
 - ii. Common disease: Breast Cancer
 - iii. Rare disease: ALS
3. Data alignment
 - a. Lots of work to get the data aligned
 - b. Example: What do you call a flavored, carbonated beverage that sometimes comes in an aluminum can? Regional differences: soda, pop, coke.
 - c. Q: which data? A: all the data so we get a very comprehensive profile
 - i. Ex: purchasing CMS data – to get the bigger picture, also to fix errors (misspellings, dates, incomplete info, etc.)
4. Q: how can collective patient voice help influence the changes that need to be brought to the table?
 - a. Challenges:
 - i. EHRs are private industry
 - ii. Pharmaceuticals
 - iii. Rural distance, referrals
 - iv. Inaccuracies in EHR – virtually impossible to fix mistakes
 - v. Data Privacy, trust – why should the entire GPC have access to my data?
 - b. Other issues
 - i. Standards of care have never been evaluated on a larger scale
 - ii. Security breaches are a huge concern – how do you address this?
 - iii. Coercion – patients are desperate for care; patients don't feel empowered for data
 - iv. Assumptions
 1. Doctors who have evidence-based research for everything
 2. Access to all patient data
5. Concerns, Approaches
 - a. Data security, technical aspects
 - i. Difficult to prove a negative (e.g. breaches, or lack of evidence-based care)
 - b. Delivery of health care
 - i. We live in a society of “fast food medicine” – they want it quick and efficiently
 - c. Why should I be involved in research when I have more immediate needs?
 - i. Patients can choose to participate in care only, or also care and research
 - ii. Direct benefits
 - d. How to bridge the gaps?
 - i. Iowa: science cafes

- ii. PMI: Precision Medicine Initiative
- e. How to change public perception?
 - i. Lack of communication b/t PCP and specialists is a chronic problem
 - ii. Patients and families listen better to one another as opposed to directives from researchers; peer-to-peer education
 - iii. Approach needs to be holistic and generalizable, not incremental or individualistic
- f. Education
 - i. Benefit to the patients
 - ii. Lack of education is also a chronic problem
- g. Social Media
 - i. Don't underestimate the power of social media, viral effects
 - ii. Increased access to information
 - iii. Use facetime for meetings