

End of conference feedback & wrap up (Waitman)

Survey will go out next week to get attendee input on LEC 2016

Thanks to Kauffman Foundation for hosting our event

Key items/next steps to summarize sessions:

1. Breast Cancer
 - a. Cancer CRG – work with PAC to get input on submission due end of October
 - b. Enhance CDM with specifics unique to institutions
 - c. Value added – making treatment (infusion) data available, but this is challenging – need to improve our ability to do this
2. GROUSE
 - a. Keep GPC dev group appraised
 - b. Will update cohort leads to prioritize analyses
 - c. User group for our claims data experts
3. Front Door/Maximizing GPC value discussions
 - a. How to trickle down opportunities to investigators
 - b. Create newsletter to celebrate our GPC/PCORnet successes with health systems leaders
4. IRB team
 - a. Progress made on updating standard operating procedures
 - b. Face to face time with site PI's – communicate what study PI's need to do, what relying site PI's need to do
 - c. SMART IRB – name of overall process to be adopted by GPC (sponsored by NCATS)
5. Patient Engagement
 - a. Face to face meetings valuable
 - b. Turning point: engagement needs to be at the front door (PEO, patient advisors) – send front door requests to PEO's and site PI's; find out if PCORI has patients vetting requests
 - c. Turning point: engagement must happen at the beginning; no one is knocking on their door right now
 - d. How to better use patient stories in engagement process
 - e. Researchers & patient advocates are not used to working together – keep asking how/are we engaging patients? How did it change the outcome? Site leaders - help get other researchers on the bandwagon
6. ALS presentation
 - a. Very clear that patient engagement had an impact on the survey – patients tweaked questions, and suggested other questions to ask
 - b. Amended survey instrument resulted

Next event: GPC Hackathon, January 17-18, 2017 in Kansas City