GPC Learning Engagement Conference
Day 2 October 26, 2021

9:10 am – 9:55 am Breakout Room #3

- PI - Priority capabilities/decisions to drive GPC/PCORnet adoption/competitiveness that scales relative to sites' aspirations
    - **Lead Facilitator: Russ Waitman, PhD (University of Missouri)**

Take Aways

1. Developed a good list of priorities for GPC
2. Will create a dedicated session to see what and who may want to collaborate
3. Considerable discussion time spent on health care system engagement and the need to clarify our ask of them and look for ways to align with system priorities rather than compete for attention in other areas

Identified Priority Areas from last Thursday (besides Proposal milestones)

- Deeper health system engagement
- Build upon NET-PRO rare cancer trial (ancillary studies)
    - Learning on frustration by site PIs and research project lead PIs
- Address NAACCR file format changes
- Genomic integration (VCF, BAM)
    - Now that we are getting data, look at different site's abilities, interests, and possible collaborations
- Mom/baby linkage and maternal health
- Blood pressure control pragmatic trial, Utah's weight loss retention also home devices
- Data quality and push every site's ability to recruit to prospective trials
    - We can distinguish ourselves here
- Leverage GROUSE platform and data linkage and subscription model is intriguing
- Infectious disease, build on public health
- Health equity, broad phenotyping
- Neuromuscular trials (CPSN)
- Other items outside milestones
    - Front Door refresh
    - TRAC/Google docs improvements/platform?
    - PASC likely to prioritize some data domains
    - Have an AWS/Snowflake follow up socialization with some sites

What are we missing or thoughts?

- Cancer opportunity – There is a Cancer call this afternoon with Pittsburgh team, Betsy and Russ joining
- Blood Pressure trials and opportunity to build on work in this space
- With the weight loss retention study there is a component on how to generate data from home
- Home Meds, this would improve recruitment and retrospective studies. Like BESTMED and Preventable. Distinction needs to be made on what this means, it is Dispensed Meds (from SureScripts or CareEverywhere) or actually the Med Reconciliation that is done. It is the latter and that is what your IT folks need to know so they can find where it is in the electronic health system.
- EDI, Equity Diversity and Inclusion is getting big nationally in research and for Health Systems. Good overlap where we can participate.

- Discussion on Health System Engagement –
    - How can we better integrate? How can we get them engaged? Like Preventable, if we had a health system-oriented way to communicate with patients, it could be very effective in reducing recruitment barriers.
    - Different sites have more or less integration with their health system and more or less support from the health system including different kinds of support.
        - Sometimes the healthy system support needed for EHR data is at the bottom of the list of the hospital's priorities.
        - Some sites are hoping for more support, to be clearly defined as to what this means, and other sites feel supported enough, but would like to have more active engagement and collaboration with the leaders, specifically CSuite, with PCORI work.
    - For more engagement, consider what can we bring that is of value to the health system?
        - Like data quality checking and helpful calculations. Example, found what looked like hand typed notes for results of quick pregnancy tests, discovered that pregnancy tests run in the Emergency Dept staff was hand entering results. From a quality standpoint this doesn't allow the clinical decision support system in EPIC to take that into account.
        - Another example is where a site discovered the health system does geocoding and are willing to share that so we can use it for Social Determinants of Health work and in turn are providing the SDOH info back to help inform patient care.
    - Other sites felt that the health system does value PCORnet research, and they don't get pushback on requested support, but for future projects it would be good to incorporate into the lead of projects, not just the clinician, but the hospital system CSuite as well and make sure everyone is engaged. Rick will be working on this in the new PCORnet phase. We can breakout this particular stakeholder group and focus on them like we do patients, and we will be doing this with the new contract in creating an Advisory Group and Rick speaking to health care systems about PCORnet to generate excitement.
        - We might not need more support from the health system, but we can do more to support their priorities or mission.
        - There may be an appreciation by the health system to support research and participation as a needed activity to maintain reputation and credibility, but perhaps not more direct value to the care of patients and or mission of value (economic) based patient care.
        - Bringing clear evidence of value (perceived by the health care system) that links improving faculty health to reputation to community engagement to patient care is a win for all.
    - Others said they also see where the health system doesn't really value research other than participation is important for reputation and a good thing to do.
    - Volume of studies is another way that could make PCORnet look more attractive.
    - Also need more researchers from University getting involved. Getting better, but still relatively small number of researchers involved in PCORnet.
    - Can be tension around profit and nonprofit studies with pros and cons around each, but still push for volume of studies.
    - We should be aware of their (system's) strategic priorities and look at how we can ALIGN and add value to those rather than try to compete for attention in non-priority areas for the health system. Like EDI which is becoming more prominent everywhere across all types of stakeholders.
    - Look at your system's strategic roadmap of priorities. There is likely to be good overlap.
    - Especially with COVID, there is just not enough bandwidth, people are being pulled in multiple directions.
    - With regards to patients being at the center, health care systems preach patient centered but are really health centered with economical ways to take care of patients or value-based care. Goals don't have to

be in competition with each other, if we can provide good quality at a good price good for all. EDI is example of area that will get their attention and that is patient centric.
    - There is value in bringing in satellite locations into the research area. We (Intermountain) still have potential we have not fully explored yet; we have traditional care sites and a Las Vegas footprint as well as another system that covers patients in CO, MT, KS and few other states and we also have a LOI with them which is a substantial amount.
    - What do we mean by engagement? We should be careful how we characterize/communicate on this. At Utah, our system is relatively engaged as they see research is important and support gaps of money, support staff and the back end to do the ETL, so we have access to the entire health systems' informatics team and although it may not be a top priority, they do support us. PCORnet is a small part of our research efforts. We need to think about what we mean by health system engagement – ours supports our research and we wouldn't want to say they *are not engaged*.
    - Do we have a data ask, clinical operation ask or both? The latter will be more challenging.
    - Be sure to consider that just because there are not challenges right now, we will face pressure as to why should we support PCORnet verses something else?
- We have a strong neuromuscular and cancer collaborative across GPC. Are there other embedded networks to collaborate on? Like BP created the BP laboratory. Could imagine a diabetic lab or other area. Often this is propelled by proposals.
    - As we relaunch, PCORI's master contract may allow space for us to propose these and including another CRN can increase the chance for funding. For example, claims integration benefits all these topics and Florida has this capability. We could look at interests across other CRNs and what their interests and capabilities are.
- With all the work done on COVID, we should look at a registry or something to piggy back. There may be good overlap with PASC, and those sites involved in this, like prospective cohort development. Lindsay, especially interested in locally sequenced genome data, COVID strains and long COVID. Utah would be interested. N3C also funded work in this area. Also interest in autoimmune disease as a part of post COVID, working to develop computable phenotypes to allow us to perform queries when autoimmune appears. May also be interested in identifying variants. Lindsay could be interested to be the lead for this type of work.
- We should have a dedicated session to see who is interested in these different areas like Cancer, COVID, genomic…

END