10-10:50 BREAKOUT SESSIONS
- **Room 3: Dev/PM/PI**

  - **Lead Facilitator: Russ Waitman, PhD (University of Missouri)**

Some acronyms:
Dev/PM/PI, GROUSE, SDDMF.
Developers/ Project Manager/ Project Investigator
SDDMF: Social Security Death Master File:
Greater Plains Collaborative Reusable Observable Unified Study Environment= GROUSE

Focus emphasized
1. Heighten engagement
2. Stronger data quality and dedicated 50% GPC resource to help with that

Principles for funding (published in Jan 2021)
- New priorities (Congress) IDD & DD, Maternity and Mortality and Morbidity
- Focus on quality data metrics
- National scope
- Patient at center
- Data can be linked to patient (expand this unique element)
- Learning Health system – what is definition of that. RW not sure for PCORI, but health system implementation (adopt evidence and put it into practice)

Overview:
-A lot of what we are doing is govern by prioritizing principles
-On a high level, we reinvigorate the engagement of clinicians and payers given that we don't' have funding for VPRNs, or health plans.
-There is a greater focus on stronger data quality we have the enhanced 50% effort here to help with that.
-this slide highlights GPCs specifics which was PCORI on January are prioritizing principles on what infrastructures they are going to fund and this will help us think about where their funding aligns with helping us build a vibrant network.
-Note that they have some new priorities nationally on their authorization (the congress set these parties) and that is an increase attention to intellectual development of disability, maternal morbidity, and mortality.
-there was a document that came out last year (health 2030 parties), highlighted maternal morbidity and mortality.

-again, the focus is on quality and matrix to see how sites and work performing networking will be an area focus, these highlights are the funding characteristics that kind of give you a sense where PCORI interests in putting its dollars.

- nationally the focus on what we are doing can help support national research, putting the patient at the center.

-the opportunity for us with tools to link data so that we don't have to consolidate all the data, but going beyond PCORNet link with other data that are held by our partners such as CMS claims, or other private data.

-if you ever wondering or thinking about as we move forward with phase 3, or if additional opportunities arise, they may be grounded in these prioritizing principles.

Question 1:
PCORI focuses on the learning health system, what is the definition of that?
Looking at the institutive they announced this summer, where they collected input on a health system implementation institutive, they are interested in health systems that are looking to adopt evidence and put it into practice, but then also learn from the findings and then tailor them.

Overview of the proposal and milestones:
-PCORI has given us a document with many of the milestones from the original statements of work, many of these items are things that we already do such as how we run our governance, how we run our steering committee, how we comply with PCORnet policies.

-When we originally responded to PCORI on the funding announcement, we defined our milestones in a spreadsheet, and came back in a word document broken up into 6-month intervals, and this is easier for everyone to track. So, we mapped things we had in the initial proposal into these 6-month intervals for example:

> -are we engaged in a PCORNet designated study?
> -we should recruit people to clinical trials, or we get our data available for the study.
> -we need to make sure that don't have a highly laten data where the data is greater than 90 days old.

-Need to pay attention to these items and that is why we are having a dedicated data analyst who can help us look at the data quality and see who is in trouble. That is why we need to work a team to get things covered.

GPC area highlighted in proposal:

-GPC specific, Data Sharing Agreement, share Death Data

- In 1st 6 mos; data sharing agreement, Death indicator/SSDMF distribution
- 12/2022 Tumor Table, GROUSE refresh, NLP design/governance, Veterans/DoD linkage GPC and veterans data (shld have good basis to cover veterans)
- 2023 Tumor table refresh, GROUSE refresh, NLP at 4 sites, REDCAP/FHIR at *vanguard* sites, VA/DoD linkage, in person LEC
- 2024 Tumor table refresh, GROUSE refresh, NLP funding, REDCAP/FHIR at *majority* sites, VA/DoD linkage, LEC in person

-Datavant will be a great solution for us, we are funded so we are working on purchasing the death master file data from Datavant.

-Other item we have in our milestone are

1st adopting/working toward standardization of the Tumor table that we are working to define in the last couple of years

2nd item, as noted on the strategic priorities for PCORI infrastructure, the idea of data linkage.

Dr. King, who is part of a team called Da Vinci that centrally manages data for VA population, they did a linkage pilot with REACHnet to see the overlap between REACHnet research network and the VA population. When we look at the GPC and the sites that we have in our network, we should have very good veterans overlap. We got in our milestone record linkage in GPC and VA, from Jacob's perspective, it would be best if we centrally pull our hashes.

Comment:

Rachel Hess (Utah):

The other think that we have beside Jacob's technical capability is a woman named (Meg Eveniamin) who has been evaluating VA choice and has had all the contract to do that to look at how veterans being allowed to go to the civilian healthcare system affects the quality. I think, we are not only having the opportunity to us that from PCORI standpoint, but from individuals interested looking at VA quality. These linkages will be hugely attractive for VA researchers. And will be a way to bring others to the PCORNet environment.

-Note, we are going to work with Huaxu from Huston to develop an approach to do consistent NLP across our sites.

Question:

Jim Campbell (Nebraska)

I'm interested in the VA linkage, so exactly what is it that they are committed to from the standpoint of what view of VA record data would be available for sharing.

Answer Rus (MU):
At the lowest level, we would be our hash tokens from GPC up in the Datavant portal, private project, and we will first see what the overlaps between our population and their population.

Comments:
Rachel Hess (Utah):
Jacobs has several projects now that link VA and DoD data to look what happens to individual with mild traumatic brain injury. He has permission to link VA active duty and civilian data.

GROUSE, we have now received the Medicare data in the GROUSE environment, which is now running in AWS, as we get site level data brought no board, the snowflakes warehouse tool, will give us more flexibility in terms of how we manage the data and have better auditability.

If we want to make changes on how to look at the GPC Dev, for example if the data coordinating center people, or the study feasibility people go ahead licensed Jira or Confluence for everybody, we can partner with what they are doing. (Dr. Mosa agrees)

Long-term COVID
The NIH founded New York University to be the clinical coordinating center to define studies that look at long COVID and then they Mass General at Harvard Boston to be the data coordinating center. They were going to manage an i2b2 cohort COVID patients.

Comments:
Rachel Hess (Utah)
-We are not going to use i2b2 without re-budgeting, there are 15 sites, the i2b2 to be done under 200k which we all the sites responded No.
Russ: The work for NLP, the basic work will be complimentary.

Notes:
Jim Campbell (Nebraska)
we are participating in the NLC group, the agreement has been amended to include the funding for chest X-ray imaging, viral sequencing data. Which means they are going to find ways for additional funding for participating sites.

Russ:
The idea that we did the work around tumor, registry linking, a need a deeper molecular testing data, linking genomic results. We could possibly make consistency for GPC, for example these are the numbers of patients that have treat different cancers, here is the numbers on our

registry and these are the numbers for the sequence data. We want to see how these projects overlap and other key areas we need to focus on. On the steering committee calls, what they proposed that might be a little different.

Betsy Chrischilles
My question has to do with AWS and Snowflake, where do they fit in the milestones. I am wondering, if possible, to put set up an executive session for AWS, Snowflake, and VA linkages.

Russ:
AWS with Snowflake has better data security standards. Further meetings are needed to make the aware.