

LEC 2015

Thursday October 1, 2015 1:00 PM – 3:00 PM

Collaborator Identification Process / Collaborator Database

Gary Rosenthal & Russ Waitman

- Who: Site PIs
- What: The PIs are going to discuss how to track and review the data integration and collaboration from current and future institutions interested in the GPC.

Mary Ann, Russ, Gyore, Bhargav, Brittany, Sarah Esmond

Sustainability - Engagement of stakeholders, research structures. Networks within the GPC

Intros;

Support of wide range of research. One of the challenges is the breadth and width of PCORnet

How do we find people??? We know who our CTSA researchers are. Use EHR too.

The CTSA began slowly within each Institution. These Networks take time to build.

eagleEye – CTSA using. SciVal. Frontiers Pilot reviewer system

Communication. ADAPTABLE was a good test on this aspect. How to best nurture a group of investigators that work well together.

Intellectual v “Local collaborator specialist”. Those people closer to the pts.

How does a clinician view the network’s work? Does it make him look better to his pts or better to his scientific collaborators?

Need to have a Champion! For each study – Barohn as an ALS researcher.

Need to prioritize the studies/trials.

Competition between local studies v PCORnet studies. Competing for pts. An investigator-initiated study already recruiting pts will take precedence over a network trial. More beneficial for the researcher career-wise.

CTSA network – 7 or 8 hubs in the GPC – build a database – to use as a tool.

What are the things we could do?

Are there sites that won’t be as strong as others at recruiting the pts/conducting the trial?

Financial assessment for each site to vet the individual sites

Central efforts for PCORI to engage Professional Organizations? Mary Ann – PCORI are trying to figure this out as a network. The conclusion that they keep coming back to is that it would be best as a central role.

If we as a network could figure out how to do this, then PCORI could get it done at a high level.

CTSA Pilot grants seem to work. Align the program along what you are trying to nurture most. Need to incentivize the researcher to do what you need them to do.

Find or define a topic that you are focused on. Have a specific goal. One solution for all won't work. Need the researcher to be in the game "a little bit" to begin with. Then build from there.

Pick a group or cohort of researchers that we could Pilot fund to do this PCORnet GPC build. For example – all (?) sites in the GPC have over 60% response rates for the BC survey. Over 70% of respondents gave permission to link their EHR data.

Competitive Pilot program.

Another group like BC? ALS – already engaged and working.

The cardiovascular group that have come together for the ADAPTABLE study would be another group.

MU group – training for CER. Junior Faculty.

Would there be some value to defining 6 – 8 specific clusters that GPC would focus on? Might not work. Only 2 or 3 sites might be focused on a particular area.

Leverage other agencies to get involved / co-fund all of these ideas / clusters / cohorts.

For BC, getting the CCs involved – NCI interest in this work.

Gary and Betsy to discuss with Brad P.

BC GPC group still meeting as they all feel there is further work to be done and it has started well.

"Kernels of ideas".

Indiana and MU can join the groups already set up. They don't have to start from scratch.

On a wider PCORnet level, Gary described a document describing the Principles underlying proposals that would be reviewed by a PCORnet front door group. Categorizing the requests.

There is a concern about trying to line up collaborators for a study that wouldn't ever see the light of day. Waste of effort.

So Russ and Gary will have a list of principles that they can use to judge each data or collaborator request.

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PPRN engagement

Efforts in Health System Engagements

Any other issues that we want to bring on the table? No

Health System Engagement national effort – all but 1 CDRNs are involved in – Research questions and issues that the HS are involved in that PCORnet could be engaged in. Plan is that once the questions are identified, there will be a request for proposals to address these. Exciting proposal. 2 initial conf calls to get everyone up to speed on what PCORnet is trying to do. Initial discussion on what questions came up.

Health System Task Force sending out a survey for each CDRN to fill out re the various issues.

PPRN engagement – 3 representatives at the LEC from a variety of sites. Muscular Dystrophy. About.

TAPER – study of pts with Wegener's granulomatosis. Use of prednisone long term.

MAZ - How did we decide on which PPRNs to reach out to? Variety of ways – reach out to us.

Which PPRNs are ahead of the group? MAZ wasn't sure. PPRNs were expected to collaborate with CDRNs but not vice versa.

Open up to discuss collaboration and engagement?

MAZ – Tumor registries (?) clusters working thru the main coordinating center. MAZ throwing it out to us as a diverse network. Possibility of supplemental funding – outside the scope of the work that we put in for.

What would be the scope for these supplemental funds? MAZ - Would need to be generalizable across other sites.