

## Closing session notes

### Sustainability – Brad Taylor

Spirited discussion – current funding models of other institutions, which are applicable, how to engage with commercial partners. Identify low-hanging fruit project to engage with commercial partner with low barrier to entry and low risk. Start to learn how to protect patients and institutions in such an effort, ID risks.

How do we charge for data requests? Will send out a survey about effort involved for such activities, what each would charge.

### Record Linkage – Mei Liu

How technically we can share and link data. Pilot project for specific cohorts. Long term, larger question - would we be able to create a named, integrated repository with claims data, medicare data, and EHR data that could be used for queries. Will work with Russ on this in the future.

Technical needs for software with Northwestern are clear. Next issue is testing.

Patient perspective: Why should patients be activated about linking data? How is all this not linked already?!

Russ: sometimes patients get care at different places. It's helpful to know about follow-up care that might take place elsewhere. We want to prove that we can paint a full picture with medicare data and then we can try to link with other insurers. What we learn about our ALS, breast cancer, and obesity cohorts with a full picture of data can be compared to other populations.

### IRB – Karen Blackwell

#### Next Steps:

- 1) identify duties of new reliance coordinator (30% effort) and how he/she will work with lead PIs early in process to coordinate info for reviewing IRB, help lead PI understand variability across sites, help lead PI navigate submission. Wisconsin taking lead
- 2) education to PIs and study teams about what IRB reliance is, how to work with reviewing IRB, what it means if you are relying, what it means to be a lead PI.
- 3) really want a session with all PIs and all IRBs at a future meeting. Would also like a PI who might be a consumer of the GPC

### Project Management – Brittany Zschoche

Project managers across sites have a bi-weekly call to catch up on milestones, issues, etc. Discussed Phase 2 milestones – still under discussion by Phase 2. Concerns about cohorts have been

communicated to Russ and we will figure out where each is going moving forward. Brainstormed how to improve this as a working group and centralizing information.

Dan H: There will need to be a decision about closing the data set and moving on though some sites may not be finished with their data collection. A decision among PIs and cohort leads.

#### Data Request Oversight Committee (DROC) – Tamara McMahon

Members from each institution review requests for data. Reviewed processes in place. Discussed timeline as to how fast reviews can get done. Planning a call between IRB and DROC

#### Fishing Trip – Tamara McMahon

Discussed types of data available, how to get data. Had many perspectives in the room. Interesting to hear how researchers want their data. Was more of a conversation session whereas it was planned to be a hands-on session.

Patient-Powered Research Networks: “The session was valuable, learned a lot about how the GPC works, looking forward to working together.” “Good to see how patients can work together and have similar goals for Phase 2.”

AN idea that came out was a follow-up between the ABOUT PPRN and breast cancer/B Chrischilles- could start with some survey work. [\[To do: Connect Bryan Gryzlak and ABOUT rep\]](#)

Alex Bokov interacted with rep from the MS PPRN.

#### Cohorts – Dan Hale

Working on wrapping up survey, examining data, figure how representative the data is, look at funding opportunities and manuscripts. Obesity had low response rate, breast cancer had high response rate, ALS rate was in between. ALS was focused on developing studies out of this, breast cancer was focused on getting solid data out of this, obesity has two funded studies through PCORI in the GPC and will be exploring more funding activity.

All lessons learned and notes will be collated and made available.

It’s not just one team at each site, but it’s 4-5 teams at each site who speak different languages. Need to understand the true picture of the resources that went into this project.

#### Patient Engagement – Kim Kimminau

How do our parts fit together? Patients, informaticians, patient engagement officers, investigators. Identified ways to improve – especially in the mock GPC Project Orchestration. Would like to work more

closely with the DROC. Want to more authentically engage patients and officers, and define roles & responsibilities. Session with PPRN partners illustrated opportunities for patient voices and priorities – helped us all learn what computational phenotypes are.

Discovered things we can do at each site:

- take into on ABOUT to their site
- identify what is going on already re: patient engagement – how to leverage and build, plus share across GPC
- work on getting study results shared back to patients in a plain language summary – enforcement mechanism for making this happen.

GPC website is an effort at transparency about what is going on with GPC – current initiatives. Need this in plain language.

[GPC-all@listserv.kumc.edu](mailto:GPC-all@listserv.kumc.edu) email with concerns! Check website for past events.

GPC Central will have a debrief on the LEC and set a plan to address concerns. Planned technical meeting in Winter.

A Russ vignette on Fozzie the bear and Jay Leno...