Cancer Collaborative Research Group (CRG) Session Notes

Overview: PCORI has announced an opportunity to create condition-specific Collaborative Research Groups (CRGs) that will support research across many CDRNs and PPRNs. This session will focus on the creation of a Cancer CRG that will provide leadership, stakeholder engagement, data science, and communication resources for collaborative cancer research.

- How would the GPC respond to a request to:
    - Recommend its 2 top patient-centered cancer research questions?
    - Populate a CDM tumor table?
- Each CDRN should identify:
    - Priority data elements
    - Follow common approaches?
    - Research interest groups

- Each CDRN has its own engagement work. How the application will reflect our recognition that we have a wide range of patient engagement options. How to assure PCORI that patients took part in developing the application (considering the limited time frame)?
- There are existing research projects in CDRNs that may involve novel and innovative approaches that we should seek to leverage - CDM isn't the endgame
- Challenges but GPC was able to pull off breast cancer data survey somehow
- Marshfield has extensive experience with cancer data as a CRN participant - this could be valuable to the CRG effort
- BOB - how should the application reflect that we have a wide range of patient engagement options and how to harness that? How to assure PCORI that the application has been well informed by patient input?
- BETSY - Sue Friedman is already in the loop and has had to work to advocate e.g., for not having 2 CDRNs leading the cancer cCRG
- CHERYL - We have a GPC patient advisory council and some have cancer - need to be sure patients involved in the top research questions. How do we identify our specialities and the most likely that we can excel at and get funded? How do these mesh up? Are there questions that apply across cancers?
- BETSY - ABOUT developed a process for patient community for assessing and prioritizing research questions - so there is a process that we can use for this to bring their voice to the table. At least there is a mechanism that can be leveraged.
- CHERYL - what are the low hanging fruit? breast cancer is likely - what is the top research question? We want a quick win rather than starting from scratch - basically where are our strengths?
- BETSY - PORTAL's emphasis on on colorectal cancer - both breast cancer and colorectal have hereditary components so that might be a possibility?
- BETSY - what about other collaborations and relationships with cancer centers?

- CHERYL - there are elements not included in the oncology record that are important per ASCO
- BETSY - we can make a long list of these elements….but there are 7 cancer centers affiliated with the GPC...but so far GPC hasn't been ready for prime time….but now might be the time to proceed with this - BETSY is presenting to the cancer center at UI in December….esp with medicare claims linkages coming online….so might be time to start promoting esp. if we can leverage pilot funds….start create a list of cancer center contacts...what about other organizations at our institutions?
- BETSY - KOMAN, ACS?
- CHERYL - reaching out to researchers or patients? There are several organizations that can be reached out to but we first need to identify what the priorities are and what we need from them and why.
- BRAD - what about working with the state cancer plans?
- BETSY - good idea - yes put that down as an activity. And at some point we need to identify the most appropriate advocacy groups….
- CHERYL - at some point researchers can reach out to the groups they have worked with same for health systems or hospitals - we can leverage these
- BETSY - what can we do in the next 2 weeks?
- BOB - Kim notes that we should not forget to include patients in the process….so she is geared up to be responsive to patient voice….maybe that the ABOUT network is running an assessment in the next 2 weeks in the GPC but might be more difficult for other CDRNs
- SARA - patient advisory council meeting on 10/25 so still time to include an ask
- BETSY - the whole thing (application) is 3 pages - even a sentence or 2 that describes what GPC will do and how we are poised to so this work. Ie, how do we engage patients within GPC specifically - we should say the same thing for how we engagement other networks as well as researchers.
- CHERYL - maybe have the PAC look at the issue of how to engage patients - a guideline for how to move forward in the GPC for this kind of issue - given the many types of interests and cancers
- BETSY - ABOUT has a model for training to be a cancer research advocate….that might be one thing….also the ability to generate and assess and prioritize pati centered questions - GAP assessment tool...that works for about - but what would we do for this?
- CHERYL - Does the ABOUT training address broad questions and can we even use it? What is their training program? It'd be great for the council to see that process in action. Example of patents having input into the RFA process for another project….she described a process of patient review that engagement patients after a scientific council approval.
- BETSY - maybe we can at least have patient engagement council to review the proposal paragraph
- BOB - at least we can say that we asked the PEC to review and provide feedback on the proposal….
- BETSY - CDM tumor table….each has to support or develop tumor table ...not certain that all have to commit to populating such a table….If CRG comes up with this list in

NAACCR format some sites have their data as source data and not in i2b2; others have it in i2b2 others have populated it as a tumor table in CDM. What about doing this as a new table?

- BOB - our data folks are trying to follow common approaches as much as possible for ETL. using shared scripts etc. they'd say that if it was built into the way things work then it should be easy(er)
- Easiest if there is a common approach to this - sometimes there is difficulty with this vs optimization
- BRAD TAYLOR - MCW currently has the tumor data as source, and in i2b2. We have not translated that to the PCORI CDM. In time we will make that transition.
- BETSY - should help to know the scope of how feasible this is….
- JOAN - chemotherapy
- BETSY - we'd like to look at treatment difference across for sites and quality issues….many places use billing data cpt codes...can we do better than that?
- JOAN - perhaps that is the best we can do but there are more optimal ways and it's not trivial to do this
- BETSY - tumor table doesn't solve things alone - we need to demo that we understand the underlying data sources enough - the CRG contract implies a commitment to do this.
- JOAN - happy to explore this further at MCW
- BOB - was really talking about te the occurrence data in the cancer registry...not really infusion data ….this is only recently coming on line…..they are discovering a lot of variation historically how procedure codes change to electronic order entry codes for infusions. So to the extent to which we are working with sites that have made such transitions….the local source info and contacts will be critical….and a large undertaking….this would be a separate and more involved (infusion data) activity
- BETSY - this could be important for conditions and treatment beyond cancer too….figuring out the origins of the information would be doable in one year but also loading the data for analyses would not….
- BOB - spent a year to do this with a lot of assistance
- BETSY - KAISER is offering their assistance to do this….
- JOAN - need to be prepared for reviewers asking about this….
- BETSY - right now we say that PORTAL will be consulting to assist the sites to do this work...what about individual members in the GPC to be part of the CRG….we now have a few folks on leadership activities but what about individual investigators? Comes down to those who want to collaborate and write a proposal….
- BOB - RIGs are particularly a good venue for this. Not a great system yet for how to do this across all sites….with front door process starting up….at baseline we can reach out to site leads and tell them these are the interests groups we are thinking about….
- BETSY - we can nominate candidate RIGs…..investigators may not easily let their ideas go but if we can identify specific RIGs that they can join and lead that might be a good approach….
- BETSY - will send the proposal to the breast cancer cohort out for comments.

Adjourned.

Submitted by Brian Gryzlak/Evgenia Folts/Brad McDowell