Pilot Breakout Sessions - Observational Studies - Troost Room and webinar attendees (~25 attendees)

Co-facilitators: Tamara McMahon, Brad Taylor, Betsy Chrischilles

*(Names of speaker included below when known)*

Welcome/ Purpose is to share experiences rather than presentations from specific persons.

1. Brad Taylor - In phase 1, focus was ALS, obesity, breast cancer. Review of data marts and surveys or these populations. There are some challenges wrt completeness, CDM, etc.
2. Betsy Chrischilles - All entered on a strong footing because of oncology data that was put into data warehouses. But weren’t able to get info about test orders, treatments, etc. But RCR project is situated for this. Focus on molecular test results - most data have a home in the CDM. Needs to be wrapped up in 8 months.
3. BT - Sites are not capturing in the same way. E.g., at MCW, many times docs order tests and send them off campus for assessment. Tests come back in different formats and are put in EMR in different formats.
4. Dan Hood - takes resources to build new data into data warehouse, guidance on implementation
5. Tamara McMahon (T.M.). - KUMC is trying to being in free text notes - working to make them available in de-id formats to other researchers. Integration of other path, radiology also challenging
6. BC - can we hear from Erin about her pilot experiences?
7. Erin Doren - Will be looking at dx codes to obtain complication rates. Note sure if other projects have looked at this...infections, readmissions, prolonged hospitalizations, etc. Could need free text for this?
8. BC - Mary Schroeder used NY state data for this - she may be able to share with Erin. Mostly dx codes and encounters
9. BT - need to know when admitted, data are available for this but some others elements are in unstructured notes - there are some processes for this depending on what Erin is looking for but inconsistencies across sites.
10. BC - Erin interested in reconstruction for NLP. Brad?
11. BT - not aware. Can start at one site but will be challenging across all GPC sites
12. Erin Doren - initially focus on encounters, readmissions...but would healing, satisfaction will need to consider standardization, how reported.
13. BT - PROs - how are these being recorded into the EMR
14. BC - could look to survey for such items - we did include items on complications
15. Possibly look at port infection rate for example
16. BC - could look at persons with ports and then survey them...would be useful to be able to identify cohort based on procedures or diagnoses.....the GPC infrastructure is set up for this...IRB/DSA, etc.
17. Neena Sharma - Opioids and other meds following lumbar spine surgeries and PT outcomes, e.g., time spent during stay, distance walked, mobility, transfer, etc - will need to know higher use of opioids, function, etc. - some data are available, some are not
18. TM - at KUMC PT data are structured well but not at all sites
19. BT - for MCS - captured in a flowsheet/ NLP notes - so may be complications - not sure if all sites ingested that info. So they would need to specifically look for what she needs
20. BC - how does this work?
21. BT - EPIC at most EMR - comes with a standard flowsheet implementation. But at MCW they didn’t do this and this is resource intensive.
   a. What it looks like will be different for each institution
22. TM - some are specific to sites - how they are used, etc. There is some structure but not consistent across sites....e.g.. Bp might be consistent across sites.
23. DH - they have a good way to review NLP - wide array for path reports, echocardiograms, etc. but would need a lot of individual site work
24. Carol Greary - at UNMC flowsheets may change over time but you might not know how or why they are changed. So need to realize that this is a variable.
   a. E.g., distress scales for cancer change annually....renders data unusable over time. Differentially documented---need local experts on this.
25. BC - for pilots just learning about this is useful
26. TM. - e.g., living status, level of education - not captured consistently
27. CR - cleaning the data is a different exercise vs reviewing data that are more static
28. Who maintains the flowsheets?
29. CR - setup for clinical care without a nod to research - not intended to be used for research
30. NS - she will need to get info on pain intensity- where are these data? How to calculate averages...
31. In multiple places and varies by site and over time
32. CR - method used to assess pain will also vary over time; need to identify meds vs when pain was asked
33. Cherie Binns - timing of pain ratings are important
34. BC - sometimes it is important to have a local expert review data
35. Cherie Binns - agreed sometimes this is quicker
36. BC - for important data elements are good for comparing sources/methods
37. TM. - true for small numbers of patients/ some things cannot be standardized though.
   E.g., dispensed/prescribed.
38. BT - Meds are be a challenging issue e.g., dose/form, strength - nuances multiplied across sites
39. BC - likes billing data because they are curated and standardized to some extent. Won’t work for everything....procedures, diagnoses, etc.
40. CB - billing isn’t always accurate approach - billing almost always overestimates meds for example
41. TM. - a lot has been done wrt IRB for data sharing.
42. CG - need to be very specific about data needed - data are always there
43. T.M. - even encounters can be difficult to define - think through each data element and define it.
44. BC - worth mentioning CDM - e.g., encounters table, allowable field types - suggests reading through documentation for CDM
45. BT - GPC will have NAACCR in i2b2 - but not all PCORnet sites
46. T.M. - Review of pcori CDM and i2b2 to group
47. DH - CDM is useful for standardizing across 90 site in PCORI
48. BT - i2b2 helps us do this within the GPC
49. BC - PRO table in CDM - captures origin/scale - but no guidance as to when instrument should be used - possible project - capture pain for example prospectively - this could be the home. Might be able to better leverage the CDM
50. BT - There is a version CDM version 4.0 in development in June 2018. Then there will be a new EDC to see how well we have been populating the new variables
   a. Julie - sickle cells - wants to know the prevalence of these codes -
      i. **ACTION ITEM FOR ALL SITES** - check into prevalence for these CPT codes 93888, 93886
51. PROs - what are these?
52. BC - in early version of the table, the focus was on the **PROMIS** surveys. Next meaningful use is to get some of these into EMR - e.g., pain, fatigue, upper extremity disability, anxiety, etc. Might be able to know that a patient took the fatigue scale 1 day after chemo…..not populated right now.
53. CB - PROs used at PPRN - these drive their research - took 16 symptoms of MS e.g., asked how much these impact daily living - fatigue/sleep disturbance were highest - thus, they need to reshift according to priorities for the patient
54. Why not more patients involved?
55. BT - shift from patient to community engagement. Sees a shift back to patient engagement in design of studies too. May see more of this moving ahead.
56. BC - at least PCORI has helped put this on the front burner.
57. Patient - include patients for each poster topic.
58. BC - is the patient engagement committee going to help involve patients in the pilot research?
59. T.M. - at least there was a patient who reviewed the proposals.
60. Jeff Ordman - The patient advisory council meets once a month - would be useful for researchers to engage with patients on their calls….interesting to read the range of patient involvement in pilot applications….might not necessarily need patients with specific conditions represented. Would be good to incorporate pilot review / updates in their calls.
61. A lot of interest in what KUMC is doing - facilitators are important to the group.
62. CB - researchers can approach PCORI who can stand up advisory council to help them - or ad-hoc committees to help researchers better define research question - many CDRNs and PPRNs that can assist researchers.
63. JO - Lack of visibility. They have to consistently advertise for consultations. How is each site advertising? Need to find a way to collectively promote themselves.
64. BC - apply for patient engagement award via PCORI
65. CB- make sure Kim or Cherie knows about your engagement group.
66. The engagement awards are up to $250 K for 2 years. LOI due 2/1/18 and 6/1/18.
   Every project should ideally have a marketing budget and dissemination budget.
67. How is this maintained over time?
68. BC - there are projects specifically about disseminating findings. Potentially put in an
   application for this given that GPC now has findings to proffer.

Adjourned ~ 11:50am.

Notes submitted by Brian Gryzolk