

## GPC LEC 2016 –Patient Engagement/Friday 8 am Session

1. Introductions
2. Review of draft document – Principles of Partnership Self-Assessment Tool
3. Document is from U-Mass Worcester
  - a. Regional center grant – put in KU format for CTSA work
  - b. Purpose: for investigators to take a self-assessment to see where they are with engagement
    - i. Would guide how to help investigator in their patient or community engagement
  - c. Kim Kimminau is a member of national Engagement team for PCORnet; Engagement Committee leader adopting/adapting for PCORnet
  - d. One topic is conflict resolution – need to think through how to work through it if encountered
  - e. Example: Christie Befort PCORI grant at KUMC. Had not done the level of patient engagement PCORI expected. Her grant had a significant rural component. This document helped determine how Christie was thinking about engagement. Occurred at Letter of Intent stage. Actually got the contract.
4. Paula – Has a “Parameters for Partners” document
  - a. If community has an idea, this is how they approach researchers and vice-versa
  - b. Shows capacity of community
  - c. Used for 8 years
  - d. Similar to Community Health Assessment plan
  - e. Request for Paula to send in for distribution
5. Cheryl – Suggestion of using the term “Shared Goals”
6. Paula – Have to demystify what community engagement is
7. What does “Shared Values” mean to you? How can this be operationalized?
  - a. For benefits, need to articulate
  - b. What would be metrics?
8. Cheryl – Can translate into better words for metrics?
9. This is designed for the investigator. Not designed to be community or patient facing document.
10. Can be used as an ongoing assessment tool.
11. Not sure where this will live – could be a website, etc.
12. Should these be put in the context of “ongoing” vs. past tense
13. Observation – some of these items could be in place but not adhered to; suggest different headings
  - a. Could be set up as an ongoing living document
  - b. Are you working on it or is it being adhered to.
  - c. Suggest separating vs. having “in place and being adhered to”
14. Comment box – For the interviewer (i.e. Kim), it’s a place to track thoughts about how Kim could help
15. Kim wants to spend time on the “big buckets” – are we capturing the right things
16. Kim has not used the metrics column yet
17. Cheryl P. – For metrics, suggest counts (Kim – these are process measures)
18. Jeff - Some items very passive. Need to associate action with some of the items.
  - a. What are desired outcomes
19. Cheryl J. = Experience from initial Breast Cancer meeting at LEC

- a. Survey – Wasn't fully reflecting things patients said they wanted
  - b. Started being torn apart
  - c. Investigator started arguing the points
  - d. She did listen – had better organization, flow
  - e. Example – Other investigator suggested taking comment box out, patients suggested leaving it in. It was left in and resulted in rich comments
  - f. Original plan was to come from Iowa. Changed to survey coming for where patient got treatment. Took longer but got 60+% response rate
  - g. Getting patients engaged in writing papers
  - h. Patients should be participants at conferences, etc.
20. Need to outline guiding principals
21. Key point: "This is a process". Continues to be a learning journey for both investigators and patients.
22. Investigators within GPC should present impact of patient engagement to other investigators
- a. Good topic for next LEC
  - b. Ht./Weight cohort survey got very low results – could have potentially gotten much better results with engagement
23. Danielle – Survey would benefit from examples
- a. Pop up box with clarification of what they are looking for
24. Will send out survey electronically and please send feedback
- a. Please send any examples from you current efforts
    - i. Cheryl suggests providing stories if you have them regarding things that worked
  - b. Seek feedback from colleagues also
  - c. Will put on a timeline
  - d. Will help set course to national discussion
25. SHIFTING GEARS/NEW TOPIC – **REFLECTIONS!**
- a. Kim reviewed questions from agenda
    - i. What excited you most?
    - ii. What "best practices" could be shared throughout the GPC network?
    - iii. How do you think "we" could spur and support greater patient interest and involvement in the GPC's research and research decision making process (at the researcher, site and overall network levels)? What are the barriers? What are the opportunities
    - iv. Communications – ideas on ways to improve upon our information sharing with each other?
26. Great group but nobody knocking on our door
- a. Cheryl's story regarding BC survey input – share success story of 63% response rate
  - b. Paper not yet planned for BC survey PE – Could be a suggestion
    - i. Cheryl suggests it be an article
    - ii. Should write it up; needs co-authoring
  - c. Patients could do a poster of the experience/have patients lead it
  - d. Have patients talk at the LEC next year
  - e. "How can engaged group of patients improve....."
  - f. Or lessons learns – Do's and Don'ts
27. Enjoyed Charlie Thompson's talk
- a. Growth represents pent up demand
  - b. Groups go to where physicians and researchers are – need to proactively get in front of them

- c. Need to find where Patient Engagement is not on researchers radar and go there
  - d. Take to other professional organizations (outside of PCORI)
- 28. Thoughts regarding of holding a workshop (representing GPC)
  - a. Need actual success stories
  - b. Need to involve researchers
- 29. Focus on education
  - a. It is the stories that speak
  - b. Patient stories are compelling
  - c. Impressed by teen panel and their knowledge
- 30. Mentor network for Patient Engagement Officers
- 31. Working with community health workers – more prone to listen to patients
  - a. Builds trust
- 32. Should talk more about sustainability of PCORnet
- 33. For ADAPTABLE calls, should have patient engagement
  - a. Inquire with Lena
  - b. Work with Nancy and Betsy at Iowa
  - c. Can be framed as more sites coming in
  - d. Observation is it's not very interactive
  - e. Sites have latitude on recruitment strategies
  - f. Important opportunity – Patient group can influence
- 34. Paula – Really likes the ideas of metrics; her communities look at this as a movement; how do we impact both researchers/communities-patients
- 35. Need more education on research – patients and clinical team aren't experts
- 36. Lucy – Very happy to have attended. Blessed that she was able to come. Happy to be going home. Part of Froedert's volunteer program, talks to transplant patients
- 37. Jeff – Nice to get ideas on how he can be more effective as a Patient Advisor, has appreciated hearing from others and seeing examples. Idea of a blog would be a really cool idea.
- 38. Deb – Exploring a continuum of involvement and participation. Looking at opportunities for just episodic involvement. Would welcome feedback from others.
- 39. Bill – Lot of good here but when go back run into a wall with the medical school. Not perceived as adding value. Pretty frustrating.
  - a. Function of being fairly new
  - b. A major culture shift
- 40. Was excited to hear teen panel
- 41. Appreciate seeing same faces as last year (at LEC) and get inspired by stories
- 42. "Science Café" is a great idea good mechanism for UNMC
  - a. Need to talk about GPC in our community
- 43. From a Project Manager perspective, need to be involved from initial meetings. Need continuity.
- 44. Good feedback for Kim – she brings a lot of energy
- 45. For Front Door requests, PEO's should have visibility
  - a. Should these be agenda items on regular meetings? YES
- 46. Cheryl J. – Feels group is jelling as a team and support group.
  - a. Up to us to ensure our voices keep being heard.