

Hi all,

I just wanted to highlight some of the major take-aways from our GPC site visit/engagement conference:

1. Graphic facilitator: If you don't know what this is, basically picture the collective comments, suggestions, questions, themes, etc of the group all translated into a graphic with only choice words or phrases and pictures that tell a thousand words. This was something I would like to see more of during the network partner conferences and shared with the public. These nuggets of information could be shared as a visual to amplify the "voices" of patients via our communications firm. This falls in nicely with the voices to a chorus metaphor.

2. There is no replacement for the acceleration of action and shared ideas than an in-person event like this where we can FINALLY see the faces of all the people we work with on a daily basis. Moreover, the trust increases 10-fold when we are able to convey our enthusiasm for their enormous effort up to now.

3. Russ showed what was referred to as a Lifetime Data Density Chart. This initially sent the patients into a frenzy, but when explained, was, dare I say, one of the best graphics I've seen to illustrate completeness of data. Even one of the CTSA/ALS Leads said, "Russ, is this what you have been asking me to prove to you, but I have not understood until this very moment?" I hope to share on our next team meeting if you all are interested.

4. Retention strategies: Dan Masys talked about the very strong return on investment if we focus on retention with the engagement of patients, clinicians, and health systems while we are holding their attention in forums of this nature. The thought is that the patients become our salesforce because they will ultimately recruit for us and will have stake/ownership in keeping those recruited invested for the long haul. Dan also went on to explain how retention is a major issue that has since fallen by the way side and we are in a wonderful position to make great strides in this area.

5. Marshfield via Murray Brilliant shared wonderful accomplishments in the area of Biospecimen work re: returning collective results to his community. Definitely something to catalogue and share PCORnet-wide as many sites are struggling with this.

6. During the data sharing agreement breakout, with patients included, Russ found that actually taking them into the portal where they could see how the data was characterized in the data model, how researchers searched the warehouse for potential study options, what a patient in the system looked like in those views, and how we might 'allow' investigators to be given access to this system was extremely helpful. It took "data sharing" out of the abstract.

7. There was a full day and a half of discussion about how, when and where PCORnet wants patient involvement, engagement, ideas, input, etc. However, there was still one individual who had to bring it to our attention that the words: "patient generated hypothesis testing to inform

the research" was not clearly articulated to the crowd. The crowd unanimously agreed that they didn't realize even after all the talking that we truly want their input in this way. Food for thought about semantics and what words land on what audience!

8. Jaye Bea, Joe S. and I realized that we need to find a way to get our experiences in events such as this back to the CC. They need to be able to, at the very least, live vicariously through us to see how all of their hard work in offering technical assistance has paid off. Not to mention, the opportunity to have anecdotal information of where their help is still needed so that they don't have to be reactive to the network partners. I would like to put this up for discussion on one of our team meetings as well.

I'll stop there, but I could go on and on. I'm sure Jaye Bea and Joe (although I know he already sent out a wonderful synopsis of his perceptions from the first day) will join in to contribute their pearls from the meeting, but I just want to begin the discussion and give us a place to download and share at the same time.

Maryan Zirkle MD, MS, MA

Program Officer, CER Methods and Infrastructure Program

Patient Centered Outcomes Research Institute (PCORI)

1828 L Street, NW, 9th Floor, Washington DC 20036

O: **202.827.7735** | C: **202.744.6190** | F: 202.355.9558

mzirkle@pcori.org | www.pcori.org