

The following list provides a summary of a few key themes shared on the Cares and Concerns board. The verbatim transcription of the sticky notes attached is provided below. Here are my take-a-ways:

1. Patient engagement requires funding, time, compassion, understanding and lots of work from all parties! If we are going to work in this way, we have to be patient, be open to listening and learning and pace our work together.
2. Patient/participant recruitment is a very important area of concern. The process of consent is one area, but making sure participants and their families/caregivers are fully aware and invested is important, too.
3. Ask patients/patient leaders/patient researchers for help identifying strategies that matter to them and that might influence their interest in participation.

Here are the notes:

- Making a substantial difference for patients...sooner rather than later!
- What is PCORI's plan for disseminating study results?
- It is important to always include the "sooft view" or the big picture. I really appreciate that question and especially the response of the one gentleman who did a great job on tying "databases" together
- How do we get physicians/clinicians to share CTs/research studies with patients who may be eligible and/or interested?
- Need more time (Darrin Braun – ALS patient representative)
- Lots of good ideas re: consent, ways to improve intervention recruitment. How will these welcome changes be funded?? (comment surrounded by \$\$ signs)
- There is a growing body of research looking at how use of EMRs actually distracts patient/provider. Becomes "3<sup>rd</sup> party" in examination room distraction. How is PCORI considering this as it advocates for "research opportunities" becoming yet another part of the patient/provider exchange?
- Long-term sustainability / relationship given that PCORI funding is up for renewal in a few years and may go away
- "Citizen-scientist" "patient researcher" I like these terms and any others that might empower patients!
- Weather!!? The time of year that the survey is conducted is very important (summer, winter, spring)
- How/are PCOR budgets going to "press" PI/applicants to ensure how those acting as advocates – readability of consents; - liaising in community settings are compensated recognized
- Patient reported data: often asking "has anything occurred that surprised you (positive or negative) as part of being on a trial?"

- How can we incentivize and build interest? One idea is the gathering of points for each data request. So I get “2 points” for each “daily food diary” and maybe extra points for “additional comments” and when I get to “100” I get a gift card.
- Are you going to really provide adequate budget for trial budget for role that are needed for this level of engagement
- Many of the patient representatives left several hours before the event ended. This takes away the collaboration (Darrin Braun – ALS patient representative)
- Encourage look at ‘establishing trust between minorities and researchers’  
[www.buildingtrustumd.org](http://www.buildingtrustumd.org)
- As a patient I would want more environmental data collected such as chemical exposures, air samples, water samples, dirt, etc. More research needs to be done related to environmental causes. Thanks.
- Follow-up!!! Don’t do the survey and leave. Create longtime relationships and I’ll participate again.
- Make the process easy for everybody includes the family, spouse, children, etc. in the research study. Listen to what the patient has to say! Like Ann commented, Listen to your community even if you do not agree with them. Engage with them and share the results of your survey.
- Recognition, the outcome of the research: let me know what happened? The benefits of doing the research. Let me know I am doing something good.
- I loved Ann’s comment that “I listened to my neighbors, even if I didn’t agree. This is my neighborhood and it’s my job to represent them”. Doesn’t that just say it all?
- Re: identifying patients to survey...are there HIPAA and informed consent concerns? How are we addressing these? How will a patient feel/(what will they) think about getting a letter or survey they weren’t expecting and being identified as ALS/BC/obese?
- Understanding that every patient is different. Do not make assumptions.
- Give me examples “You are helping a lot of people like you.” “There are a group of people that are going through the same (experience).”