

Cerebral Palsy Research Network
Pediatric Patient Reported Outcomes Registry Committee
Via Teleconference
Monday, November 27, 2016

Attending: Amy Bailes (Cincinnati), Mary Gannotti (Hartford), Paul Gross, Susan Horn (Utah), Jacob Kean (Utah), Aga Lewelt (Jacksonville), Brandon Roque (Alabama), Ben Shore (Boston), Jilda Vargus-Adams (Cincinnati)

Action Items:

All: Think about which survey/measure(s) we should do annually.
Consider the concept of a question of the week (creating a bank of 52) to keep people engaged.

Michele: Please send the proposed pediatric panel names to the study group.

Paul: Research the reporting limitations of REDCap (per question or per survey). If the reporting is per question, will it create a bias in futures surveys/questions.

Next meeting: Wednesday, December 19, 9 pm ET

- Recording Playback: (712) 775-7029 Access Code: 417284# Ref# 23
- [Download as an MP3](#)

Meeting Notes:

Vision and Status

Paul reviewed the vision and status of the patient powered registry. Since its founding, CPRN has envisioned a registry for collecting patient reported outcomes (PROs) over the long term. While this registry will be linked to the clinical registry, it is also viewed as a registry for the community to be used not only for PROs but as a contact registry for research. It also provides the benefit of long term follow-up after peds have “graduated” from a pediatric hospital if they do not move to another CPRN site that does lifespan care. We originally planned to leverage a free service for this but its sales pitch did not match the product so we looked for alternatives. So we are moving forward with REDCap to manage the surveys and the registry database and a portal that manages the login for participants. This is required because REDCap doesn’t allow user logins and this provides participants a way to access surveys and reports from surveys. The portal is called mycerebralpalsy.org and is currently very bare bones. We plan to finish mycerebralpalsy.org after we get the handshake with REDCap finalized and it is close. People will log in and see what surveys they have taken, get reports from those surveys and be able to review and/or revoke their consent. MyCerebralPalsy will collect some demographic data

under the privacy policy of CPRN. That policy will give CPRN the right to share this demographic data with the registry but then they will explicitly approve sharing this data with the initial consent for the first survey.

Right now, we have GOAL and CP-Child loaded in REDCap. We will shortly be adding the adult surveys which are under development. Mary summarized that the surveys for adults developed to date are for demographics, pain and social and emotional questions. They have reviewed these (and prioritized them) based on the feedback from the adult study panel which was assembled from the community to be representative and to help guide our research efforts to be patient-centric. They plan to pilot these surveys with this group imminently and then launch them to the community in Q1. Paul explained that we are developing a similar group for pediatrics and Michele will share the list of patients/caregivers for your feedback.

Mary asked about the involvement of corporations that support large numbers of people with CP. Paul asked to defer this until later but noted that we want to be very careful with industry involvement in our early stages.

Reports to participants

Paul asked what the N should be for providing reporting back to participants in a given survey to see where their answers fit versus the community of participants. A discussion ensued about whether this had to be in real time or could it be quarterly, was it per question, and how users would find it usable and could they slice and dice based on answers (show me all the answers for people with GMFCS 3). This reporting is considered state of the art for engagement which is a key to the success of a patient powered registry. The best for engagement is in real time but we need to set what number is good enough. REDCap's default is 10.

Jacob asked whether reporting would create a bias in future answers. Paul hoped that this issue would not be an concern because reporting was on whole surveys and not by questions. We will need to consider this further. Mary asked if it could be feedback on certain questions but Paul was concerned that that would take custom programming. We could do this by breaking the surveys into smaller chunks.

Short surveys are another key aspect of engagement. We have access to a survey methodologist at the University of Utah that will review surveys for best practices in forming of questions and keeping the engagement high.

Extemporaneous and non validated surveys or validated outcome measures

Goal is to have standing validated outcome measures like an annual measure. Should it be CP-Child and GOAL or CP CAT or CP CAT (but that doesn't run in REDCap)? Amy asked if it could be MPOCH. Jilda thought the primary interest was understanding outcomes of intervention. PEDI-CAT would be ideal but it has been difficult to incorporate a CAT into these structures. Jacob pointed out the REDCap can deliver CATs and if not, we administer any measure that has been developed as a CAT as a short form. So this shouldn't be an issue. Using the mycerebralpalsy

platform has the potential to exceed any other validation level for existing measures. Mary concurred with the value of the PEDI-CAT.

What is the appropriate period? We need to think of this in the context of longitudinal studies in REDCap and the event grid. Aga asked if we can capture the interventions and key surveys off of interventions. Should we do four annual measures annualized each quarter? Ben raised the challenge that the kids are dynamic and if you are different each quarter and it will be hard to compare. Nice thing about PEDI-CAT could be the linking tool and because it is CAT it is quite quick versus the respondent burden of GOAL and CP-CHILD. PEDI-CAT could be your constant measure because the burden is low. Could the other measures be guided by age and type of CP (like GOAL for ambulant and CP-CHILD for non ambulant).

PEDI-CAT v. CP-CAT – PEDI-CAT has much broader domains. Ben has worked with Steve on both and it has a responsibility domain which can be followed for up to 20 years and follow kids through transition. Mary concurred.

Key question is to resolve our core annual offering. Jacob noted that having compared CP CAT to GOAL and CP-CHILD, it appears this to be superior in every respect. Jilda has not used the CP CAT but agrees with Ben and Mary from what she has read. Do GOAL/CP-CHILD make sense in the face of PEDI-CAT? Yes, because they are different. CP-CHILD is quality of life versus function. There is some domain overlap but PEDI-CAT is more related to function and participation.

Which do we want to do first? We should ask our stakeholders. Paul recommends that we give them something to shoot at rather than a blank piece of paper. What are the long term questions we want to answer – quality of life and long term outcomes from interventions. Aga asked if we can ask the engagement people or the stakeholders how long can you ask people to take every year.

Finally, on the extemporaneous front, we should consider a “question of the week” as a way to maximize engagement. T1D does this with their patient powered registry with a question of the day. We could create a bank of 52 questions for the question of the week and get them engaged for example 20 of the 52 and they can see immediately where their answer stands. And then they are more likely to do the annual survey.