

Cerebral Palsy Research Network Meeting Minutes

Monday, March 14, 2016

via Teleconference

Attending: Kristie Bjornson (Seattle Childrens), Mary Gannotti (Hartford), Paul Gross (CPRN), Ed Hurvitz (UMich), Jacob Kean (Utah), Jeff Leonard (Nationwide), Christopher Lunsford (UVA), Dennis Matthews (Colorado Children's), Tyra Mattingly Matthews (Colorado Children's), Freeman Miller (AI duPont), Bill Oppenheim, Ken Rogers (AI duPont), Brandon Roque (Children's Alabama), Ben Shore (Boston Children's), Brian Snyder (Boston Children's), Debbie Thorpe (UNC—Chapel Hill), Yvonne Wu (UCSF)

Action Items:

All: Please review the IRB protocol and provide changes through inline comments or track changes. Please email paul if you are interested in reviewing/testing the REDCap forms on a test server.

Paul: Email instructions for garnering live access to REDCap forms and how to provide feedback. Connect Nationwide Epic effort with Epic Corporate and Lawson Copley (continued)

Brian: Email introduction of Rich Finkel to Paul regarding the SMA research agenda planning process.

Agenda/Notes:

Call Playback: Playback Number: (605) 562-0029 Access Code: 881-975-274# Reference #17

Playback Download MP3: <https://www.dropbox.com/s/pdhvebl32on1lb0/CPRN-Investigator-Call-20160314.mp3?dl=0>

Disclaimer:

- REDCap forms
 - Review is planned through live forms on a test server -- paper was only for viewing "pleasure" before it was set up. Email to come with instructions.
 - Without scripting, REDCap forms appear HUGE because every possible joint measure, with every supported scale, and every other potential option is expanded. The expanded view is 10-50X what will be used per patient.
 - PROs and Patient Reported Medical History were included (and these expand too). Only one of the two PROs are presented to the patient.
 - **First name and Last name are not part of the registry!!!** We have been so focused on the different discipline forms that we have not yet removed this.

Highlights from the Executive Committee retreat

- All day meeting in Chicago on Sunday, March 13, 2016
- Everyone was there but Susan Horn (Michele by video conference)
- We created a mission, vision, shared values and strategic plan with goals and metrics (we will share them shortly – there is some necessary editing and review to confirm that it was captured accurately).
- Having our two surgical leaders in the room, Jerry Oakes and Unni Narayanan, we discussed revisions to the PCORI grant.

- We plan to narrow the study to a smaller set of surgical interventions and a more specific point in time and narrowed set of inclusion criteria for patients to limit the comparators.
 - We will have a survey soon that will be critical to determining the feasibility of this study.
 - We will need you to list the indications for certain surgeries/treatments and find historical volume for these.
 - We discussed important SOP areas and a process for developing them.
 - Data access
 - Research prioritization
 - Develop a research agenda
 - Clinical research and quality questions
 - Patient questions
 - Consider how study opportunities will be considered (by CPRN investigators, outside investigators)
- (Brian Synder shared a similar experience with Spinal Muscular Atrophy and will connect his colleague with Paul to gather further information.)

IRB Protocol

- The leadership team decided that we would write the IRB Protocol with waived consent with support for informed consent for those sites for which their IRB would not approve waived consent.
- Brian Synder mentioned efforts to legislate the use of master IRB protocols. He has participated in an NIH effort to accomplish this (as it is required for certain multi-center studies). He pointed to legislation that has passed the House and will be before the Senate but not likely until next year.
- Please review the IRB protocol and provide any feedback in comments or with track changes on the document itself.
- The final IRB protocol should be complete in a few weeks.

Other updates

Epic – Paul traveled to Columbus and met with the Jim Menke who is developing the Epic forms at Nationwide. The non surgical fields are nearly complete and will be ready for test by Garey Noritz the week of March 21st or the following week. Paul has also discussed the Epic forms development in process at Texas Scottish Rite with both the implementer (Lawson Copley) and Epic staff. He is trying to arrange a conference call with Epic, Nationwide and TSRH.

Quality Initiatives – Paul, Amy Bailes and Jim McCarthy met with Peter Margolis, KT Overbey and Keith Marsolo from the Anderson Center at Cincinnati Children’s to discuss their programs for developing quality initiatives (they run five quality improvement networks and are developing five additional ones across a variety of medical conditions and hospital processes). CPRN is exploring models to engage them to help develop our quality initiatives.

REDCap – If you are interested in experimenting with the live versions of the REDCap forms, please send mail to Paul to indicate so. We will be issuing test accounts. The benefit of this method is that the forms are not expanded and you can test what it is like to enter data albeit in REDCap and not in your EMR. We will also provide an opportunity for you to review when the data should be collected in the continuum of care.

CPRN Registry Data Environment – The technical specification for the transfer of data from sites to the Data Coordinating Center is ready and will be distributed shortly for you to share with your IT and research staff.