

## Cerebral Palsy Research Network Meeting Minutes

Monday, March 6, 2017

via Teleconference

**Attending:** Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (Michigan), Jacob Kean (Utah), Michael Kruer (Phoenix), Jeffrey Leonard (Nationwide), Christopher Lunsford (UVA), Dennis Matthews (Colorado), Tyra Mattingly (Colorado), Garey Noritz (Nationwide), Jerry Oakes (Alabama), Michael Partington (Gillette), Brandon Roque (Alabama)

### Action Items:

**All:** If you haven't registered for Research CP, please do so [here](#).

**Dennis:** (old) Check on status of Epic form / SDE comparison with Colorado's existing usage.

**Paul:** (old) Send mail to Jerry Oakes, Rob Bollo and Jeff Leonard to clarify neurosurgery element issue raised as a result of the Epic form creation.

Remember to include SOP for PIs that transfer to other institutions.

**Next Call is Tuesday, March 21, 2017 at 2 pm ET**

**Dial-in: (515) 739-1030 Access Code: 881-975-274#**

### Agenda/Notes:

**Call Playback:** Playback Number: (515) 739-1039 Access Code: 881-975-274# Reference #53

MP3 Download of the Call: <http://www.cpresearch.net/wp-content/uploads/2017/03/20170306-CPRN-Investigator-Mtg.mp3>

Forms -- Epic forms have been in a holding pattern as the key programmer, Dr. Jim Menke, has been out of office for several weeks. He returns this week. Garey Noritz will meet with him to discuss the (relatively minor) changes and get them redeployed before being made available. Garey noted that there is a tension between the clinical note and the clinical database that might take trial and error to strike the right balance. Right now it appears that for an existing patient, there is too much medical history. There are also some terms that will need more definition or additional options. Paul suggested we plan a meeting following several months of pilot to revise the CDM.

Paul is meeting with the CIO of Gillette next week to get a status on the Cerner forms and will report back. Michael Partington confirmed that the CPRN forms are not yet being used in clinic.

Michael Kruer, the PI at Phoenix Children's Hospital, our latest entrant into the network, is working on CPRN forms for Allscripts. Michael said that they are still at the early stages.

Research CP -- We kickoff our webinar series for Research CP -- setting a patient-centered research agenda for cerebral palsy -- this week on Wednesday at 8 pm ET. If you haven't already, you should register so that you receive the webinar details (including how to access the recording). If you

haven't promoted this to your clinic population and have an electronic mechanism (email, social media or webpage, please share this asap!)

IRB Progress and Challenges -- We continue to make progress with IRB approvals for the registry with two more this week (Seattle Childrens and Texas Scottish Rite -- both through the reliance process at Nationwide) and two more advancing toward submission. Unfortunately, we still do not have an approval from UU to start our REDCap based data collection. Jacob said that the protocol has been submitted and the IRB chair said that it would be expedited.

Registry extraction – The Research Institute at Nationwide Children’s Hospital (RINCH) has developed an initial extraction engine using the platform (I2B2) to pull the CPRN data from Epic. This software process will be critical to moving the captured clinical data to the registry at the University of Utah. This is being developed to work with other Epic sites to simplify and automate the extraction process.

Business Associates Agreement Nuances – A few sites’ legal teams have objected to the use of a BAA and insisted that a Data Use Agreement (DUA) is the right agreement for this research. In talking to the other DCC at the University of Utah, we learned a key to how they have convinced sites to use a BAA. BAAs are used when a 3<sup>rd</sup> party provider prepares a HIPAA protected data set for research. Since the registry represents a post processing of the EMR data, this description fits the role that the CPRN DCC plays and hence this is a key argument in why we lead with a BAA. There are other benefits like its support for future studies without an additional agreement.

PCORI study – We will have summary statement information for the big PCORI application at our next meeting.

Pediatric Community Registry – The Pediatric Patient Reported Outcomes (PRO) Registry, renamed the Community Registry, finalized a decision for its first annualized PRO – the CP PRO computer adaptive test. We will use this for the mobility domain. The study team will engage the newly formed Pediatric Community Advisory Committee to determine which other domains are most important to capture annually and then seek appropriate measures for those domains.

Standard Operating Procedures (SOPs)/Governance status – Our first draft of SOPs are coming along and in review with the executive committee. After an editing round we will share them with the investigator committee.

Next meeting -- Our next meeting will be Tuesday, March 21 at 2 pm ET in which Dr. Rob Bollo, a pediatric neurosurgeon and CPRN PI from Primary Children's in Salt Lake City, will present some preliminary findings from his intrathecal Baclofen pump infection protocol as a backdrop for our first effort in quality improvement.