

Cerebral Palsy Research Network Meeting Minutes

Monday, December 5, 2016

via Teleconference

Attending: Amy Bailes (Cincinnati), Kristie Bjornson (Seattle), Nancy Clegg (TSRH), Paul Gross (CPRN), Susan Horn (Utah), Ed Hurvitz (Michigan), Jacob Kean (Utah), Christopher Lunsford (UVA), Tyra Mattingly (Colorado), Garey Noritz (Nationwide), Ken Rogers (Al duPont), Brandon Roque (Alabama)

Action Items:

All: Do you have a developmental pediatrician that wants to participate in our PRO study group?

Michele: Send pediatric Community Advisory Committee recommendations to investigator list.

Paul: Follow-up with Ken Rogers re: patient reported outcomes in MyChart v. interview based.

Next Call is Tuesday, January 17, 2016 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 #39

MP3 Download of the Call:

<http://www.cpresearch.net/wp-content/uploads/2016/12/20161205-CPRN-Investigator-Mtg.mp3>

Clinical Registry Update

Epic forms, based off of work by Dr. Lawson Copley at Texas Scottish Rite Hospital, have been developed by Nationwide Children's Hospital (NCH) and mapped to the Epic released SmartData Elements for CPRN. Epic rejected about 10% of the fields, e.g., Epic does not allow the use of "other" or had existing SDEs with the same or substantially similar meaning. These elements will need to be implemented as custom elements. NCH will be rolling out the non surgical forms for use in clinic imminently and reviewing the neurosurgical and orthopedic forms internally. Al duPont and Children's of Colorado are the first sites planning to receive the forms from NCH.

The draft specification for extraction of the CPRN data elements from Epic has been completed and reviewed with NCH. NCH will begin work on the extraction process in January. The hope is that a generic tool will be created by NCH for use at other Epic sites. The specification is based on PCORNET so it is based on standards that are already implemented at numerous sites.

The CPRN DCC held its first training for the CPRN Registry in REDCap with Children's of Alabama and Primary Childrens. The clinical research assistants gave us good feedback that led to minor tweaks to

the REDCap registry. Seattle Children's will be the next REDCap site. The REDCap Registry requires an IRB protocol and approval at the University of Utah that Jacob Kean is advancing. When this approval is in place, REDCap data collection will begin.

Patient Reported Outcomes (PRO) Registry

The adult study group has completed two surveys – pain and social/emotional -- and implemented them in REDCap. They will be tested by the adult community advisory committee during December with the hope to roll them out to the community in Q1.

The pediatric PRO study group met to determine what surveys would be used for an annual baseline. There was a vigorous discussion of PEDI-CAT, CP CAT and CP-CHILD/GOAL that needs further determination. This group is still hoping to engage a developmental pediatrician with an interest in patient reported outcomes.

A Pediatric Community Advisory Committee is being formed to not engage with all CPRN research but initially on the focus of the pediatric PRO registry. Michele will distribute the initial list of considerations. The hope is to have a diverse group across age, CP type, GMFCS, race and region.

Standard Operating Procedures

Work on SOPs is spinning up to try to complete our SOPs before the PCORI study might begin. Jeff Leonard, chief of neurosurgery at NCH, is leading a subcommittee on authorship that includes Ed Hurvitz, Aga Lewelt and Debbie Thorpe.

Research Priorities Conference

We plan to proceed with the CPRN research priorities planning workshop independent of any funding decision from PCORI. The planning team (Amy Bailes, Paul Gross, Ed Hurvitz, Jacob Kean, Michele Shusterman) is working on the pre-conference webinar series. The conference date would likely be late May or early June. This conference is in addition to the PCORI kickoff which, if funded, will be in late April.