

Cerebral Palsy Research Network Meeting Minutes

Tuesday, April 18, 2017

via Teleconference

Attending: Anastasia Arynchyna (Alabama), Kristie Bjornson (Seattle), Pritha Dalal (UCSD), Marcia Greenberg (UCLA), Paul Gross (CPRN), Susan Horn (Utah), Michael Kruer (Phoenix), Jeffrey Leonard (Nationwide), Allison Oki (Utah), Ken Rogers (Al duPont), Angela Sinner (Gillette)

Action Items:

All Epic Sites: Please send paul@cprn.net an email with your Epic TS email address and your internal Epic contact. Please also encourage your Epic TS to reach out to Patrick Chounet (pchounet@epic.com) to request the CPRN forms.

Kristie: Send Seattle Children's Manual of Operations for registry to Paul.
Connect new clinical research assistant with Paul when hired.

Paul: [Send link to Research CP webinar #1.](#)
Request Manual of Operations from HCRN. Build CPRN equivalent.

Next Call is Monday, May 1, 2017 at noon 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 #57
or [Download the Audio File.](#)

Meeting Notes

Registry Update

Epic forms – we have achieved a major milestone with the Epic forms. The Nationwide Children's Hospital (NCH) non-surgical forms connected to the Epic Smart Data Elements (SDEs) for CPRN have been completed and made available through Epic. Contrary to our original assumption that these would be available through the Epic Community Library, they must be requested by your Epic Technical Specialist representative from Epic from the NCH Epic TS Patrick Chounet. These forms contain references to predominantly Epic Foundation SDEs but also local custom SDEs that are not currently "built-in" to your implementation of Epic. Jeff Leonard confirmed that surgical forms are still in development at NCH and will be tested initially by neurosurgery

Please send paul@cprn.net an email with your Epic TS email address and your internal Epic contact. Please also encourage your Epic TS to reach out to Patrick Chounet (pchounet@epic.com) to request the CPRN forms. Paul is establishing a Google Group for communication among the Epic sites to coordinate the installation and implementation of Epic forms for CPRN.

IRB Approvals – We have reached a total of 13 IRB approvals for the CPRN Registry including the DCC approval at the University of Utah which enables the REDCap sites with IRB approval to begin enrolling patients. The DCC will plan a training for Seattle and Gillette as soon as Seattle has onboarded a clinical research assistant (CRA). Anastasia, the CRA at Alabama, has enrolled their first patient who received an SDR this week! Anastasia requested a Manual Of Operations (MOO) as is used in HCRN and other registries. Kristie has developed a MOO for the registry at Seattle Children’s Hospital and will provide it to Paul. Paul will reach out to the HCRN network for a copy of their MOO and work to create a similar document for CPRN.

Marcia asked about generalities in the IRB protocol around site specific data transfer and asked if other sites had difficulties. All sites but UCSD had been able to get approval without additional details of transfer implementation. Paul and Jacob will continue to support Marcia with addressing issues.

Business Associate’s Agreements – two sites (UCLA and UMich) have had challenges completing BAAs without a “Letter of Participation” from CPRN. We are encouraging sites to use the invitation and acceptance letters for CPRN as a proxy for such an agreement. If these are insufficient, we will develop a letter as needed.

Community Registry – Adult surveys developed by Mary Gannotti, Debbie Thorpe and the adult study group have been loaded into the University of Utah REDCap that houses the CPRN Community Registry. Jacob is working on an IRB approval but has run into issues with capacity to consent. UofU has developed additional questions to determine capacity. The pediatric community registry instrument, CP PRO, is being discussed with Boston University to integrate their web implementation of the Computer Adaptive Test. No further status is available at this time.

Research CP -- 16 clinicians and researchers have been invited to participate in the face to face workshop in Chicago including several from CPRN including: Unni Narayanan, Kristie Bjornson, Michael Partington, Michael Kruer plus planning team members Amy Bailes, Susan Horn, Ed Hurvitz and Jacob Kean. PCORI study team members Rich Stevenson and Diane Damiano are also included. We also have invited 20 members of the community including 7 adults, 4 adult caregivers, 9 parents of children. The community members are a diverse group from across the age, race and GMFCS spectrum.

The research agenda planning process has generated more than 300 ideas to date but was paused in late March. The next phase will be a synthesis effort. Those of you who have not engaged can [watch the first webinar](#) and be invited to participate in the additional online synthesis of the original idea set.

PCORI follow-up – We have our follow-up call with PCORI regarding feedback on our application next week. We will use feedback from that to determine how to proceed with this study idea (revise for PCORI, revise for NIH, or change question, design and approach).