Cerebral Palsy Research Network
Pediatric Patient Reported Outcomes Registry Committee
Via Teleconference
Monday, December 19, 2016

Attending: Mary Gannotti (Hartford), Paul Gross, Ben Shore (Boston), Unni Narayanan (SickKids), Kenneth Rogers (AI duPont)

Action Items:

All: Determine domain differences / CAT selection for annual survey.
Paul: Determine how to get CAT options in front of participants (REDCap?, other web service).
         Determine licensing costs of various options.
         Ask IAN folks how PROs get validated and if not, what challenge this proposes.

Next meeting: Not set. Likely January 9, at 9 pm ET.

- **Playback Number:** (515) 739-1039
- **Access Code:** 881-975-274# Ref# 42
- Or download it here: http://www.cpresearch.net/wp-content/uploads/2016/12/20161219-CPRN-Pediatric-PRO-Study-Group-Mtg.mp3

Meeting Notes:

Vision and Status
Paul reviewed the vision and status for Unni and Ken.   While the portal has made progress technically, there is no change in the end user facing status, i.e., it is not testable by you at this stage. We spent a bit of time discussing various mechanisms by which PROs can be validated or linked to clinical records.

Annual Outcome Measure
We had an extended discussion about CP PRO v. PEDI-CAT and determined that we need to get a detailed comparison of the domains that are covered by these instruments. We need to determine if we should engage Maria and MJ to determine this or if we can resolve it ourselves. Again we emphasized the importance of determining which domains were most important to measure but still got hung up in what the differences are between the PEDI-CAT and the CP-PRO.

Unni recommended that we remove the GOAL from the running for this annual measure since it is not sufficiently validated and it is intended to be used in conjunction with interventions.

For GMFCS IV-V's, we need to determine if the burden of multiple CATs to cover the domains included in CP-Child represent a reduced burden or not.