

Proposal for NEON

- Monthly data submission, through REDCap
- Aggregated de-identified counts from all sites
- Reports back to sites quarterly
 - Comparison overtime with key metrics
 - Comparison with other sites (in aggregate)
- Purpose of the data collection>>> **what needs to be improved?**

NEON Data: Participating NICUs

- # of ELBW
- # of infants with grade 3 or 4 IVH, HIE, or Cystic PVL
- # of infants with MRI
- # infants with completed GMA

NEON Data: Participating Follow-up Clinic

- Number of patients < 14 months (CA?) seen in reporting period
 - Number of new patients < 14 months
 - From above # with IVH, HIE, Cystic PVL or <1000g
- Of new patients:
 - Number with GMA from NICU
 - Number with imaging from NICU
- For all patients, in the reporting period:
 - # of GMAs
 - # 3-4month HINE
 - # with score <57
 - # 6-month HINE
 - # with score <60
 - # 9-12-month HINE
 - # with score < 63
 - # of diagnostic motor assessments completed

NEON Data: Participating Follow-up Clinic

- # of patients with a “high-risk” for CP diagnosis
 - # with prescribed therapy
- # of patients with an initial diagnosis of formal CP in reporting period
 - # of CP diagnosis to infant < 12 months
- For new formal CP diagnoses:
 - # with NICU neuroimaging available
 - # with post-discharge neuroimaging
 - # with GMA
 - # with HINE
 - # diagnostic motor assessment
 - # diagnosed through a neurologist
 - # diagnosed through another entity
- For new formal CP diagnoses, prescribed therapies
 - # ECI
 - # private therapy
 - # none