Cognitive Neurodevelopment Milestones

• Definition
  – Cognitive functions encompass reasoning, memory, attention, and language and lead directly to the attainment of information and, thus, knowledge.
  – Developmental milestones are behaviors or physical skills seen in infants and children as they grow and develop.

• Concepts
  – Cognition and behavior are distinct, but interacting concepts.
  – Cognition is difficult to assess in young children; attainment of developmental milestones “on time” is an often-used serogate.
• Special Considerations
  – Pros and Cons:
    • Direct assessment: more “objective”, point-in-time snapshot (susceptible to mood, illness, fatigue, shyness), time consuming and therefore costly, require special training
    • Parent/caregiver/teacher questionnaire: faster and less expensive, may be completed outside a clinic visit (remotely), allows consideration of child general function over time, generally do not require special training, may be more subjective/biased
Existing measurement protocols in PhenX Toolkit

• Measure #1
  – Executive Function – Questionnaire – Children or Preschool Children
    • Behavior Rating Inventory of Executive Function (BRIEF) ages 2-5 / 5-18 years

• Measure #2
  – Executive Function - Direct Assessment – Adolescent
    • Trail Making Test (TMT) for Children (ages 9-14 years)

• Measure #3
  – Scale of Developmental Domains of Early Childhood
    • Mullen Scales of Early Learning (ages birth to 68 months)
Existing measurement protocols in PhenX Toolkit

• Measure #4
  – Intelligence Scale – 2.5 to 7.6 / 6 to 16.9 / 16 to 90 years
    • Age-appropriate Wechsler Intelligence Scales® (WPPSI, WISC, WAIS-IV)

• Measure #5
  – Pediatric School Performance
    • 4 questions from the Education - School Questionnaire from the Pediatric Hydroxyurea Phase III Clinical Trial (BABY HUG) that capture current grade and age, whether and details if the child has ever been held back, and whether the child receives special accommodations for education.

• Measure #6
  – Early Childhood Speech and Language Assessment
    • Ages and Stages Questionnaire (ASQ-3) (1 to 66 mo)
Description of measurement protocols in PhenX Toolkit

• Executive function is well-covered
  – BRIEF
  – TNT

• Cognitive function is well-covered for certain age groups
  – Mullen for young children
  – WPPSI, WISC, WAIS for preschool through adults

• Developmental milestones are covered for young children
  – Ages and Stages
Missing elements

- Not much is missing, although there are other commonly used tools
  - Capute Scales (CAT/CLAMS)
  - Stanford Binet Intelligence Scales
  - Bayley Scales of Infant and Toddler Development
  - Bayley Infant Neurodevelopmental Screener
  - NIH Toolbox (age 3 and up)
  - Many more
Recommendations to the WG

• Could leave as-is; i.e., do not add additional measures
• Discuss whether there is utility in adding additional scales