

# Terminology Development

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# Working Group Accomplishments (4091 + ~2450 = 6,541)

- *Neonatal Research Network Terminology (1007 concepts)*
- *Neurological Development Terminology (64 concepts)*
- *Newborn Screening Terminology (327 concepts)*
- *Pediatric Adverse Events Terminology (1371 concepts)*
- *Pediatric Endocrine Terminology (~1000 concepts)*
- *Pediatric Immunization Terminology (89 concepts)*
- *Pediatric Infectious Disease Terminology (~500 concepts)*
- *Pediatric Medical Device Terminology (31 concepts)*
- *Pediatric Nephrology Terminology (~450 concepts)*
- *Pediatric Oncology Terminology (~600 concepts)*
- *Pediatric Rheumatology Terminology (264 concepts)*
- *Perinatal Terminology (653 concepts)*
- *CDISC SDTM Anatomical Location Terminology (749 concepts)*
- *CDISC SDTM Directionality Terminology (32 concepts)*
- *CDISC SDTM Laterality Terminology (7 concepts)*

# Working Group Formation

- Relevant area in pediatrics chosen that is lacking in standard terminology to support clinical trials and research
- Working group leaders chosen by Pediatric Terminology Governance group, which is comprised of representatives from NIH, leading pediatric groups, EVS leadership
- Solicit leaders in the fields of interest to lead groups or suggest names of potential candidates
- WG members are from diverse interests related to the project topic
- Actively seek to include international participation

# Subject Matter Expert (SME) Contributions

## SMEs

- Define the scope of work
- Meet for an hour each week via phone and web conference to discuss terms
- Contribute their expertise to term and definition development
- Review material weekly, identify gaps, refine terms and definitions, and submit comments via email



# Behind the Scenes at EVS - Draft Terminology

- Sources suggested by Working Group Leads or participants
- Compile terminology from Clinical Trials, Journals, and Texts
- Organize terminology into groups that facilitate review and maximize efficiency of working group
- Declare Preferred Term and Synonyms
- Draft definitions for all terms
- Reconcile any previously reviewed terms and definitions
- Work with Governance group to promote quality and consistent terminology

