



Neonatal Research Networks Terminology (NRNT) Project

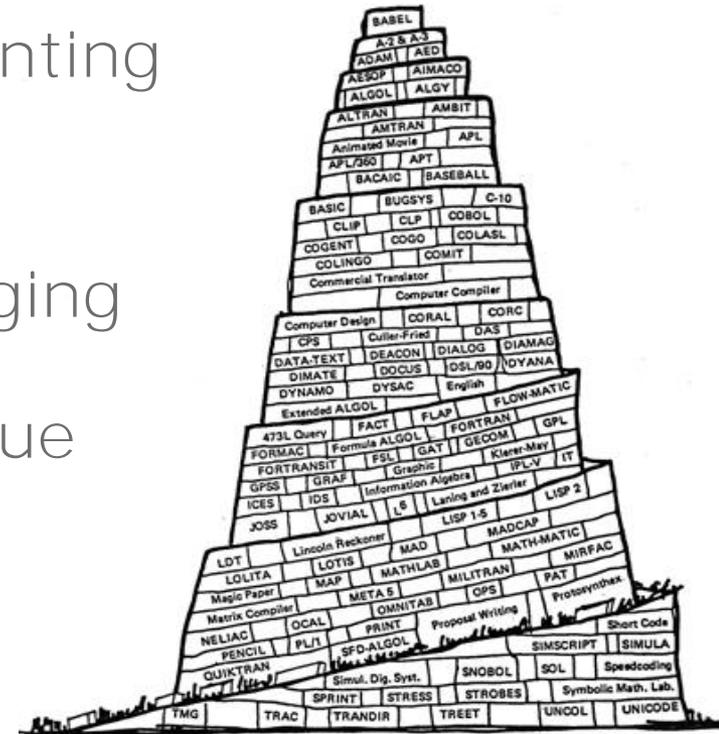
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Research Terminology: What is the problem?



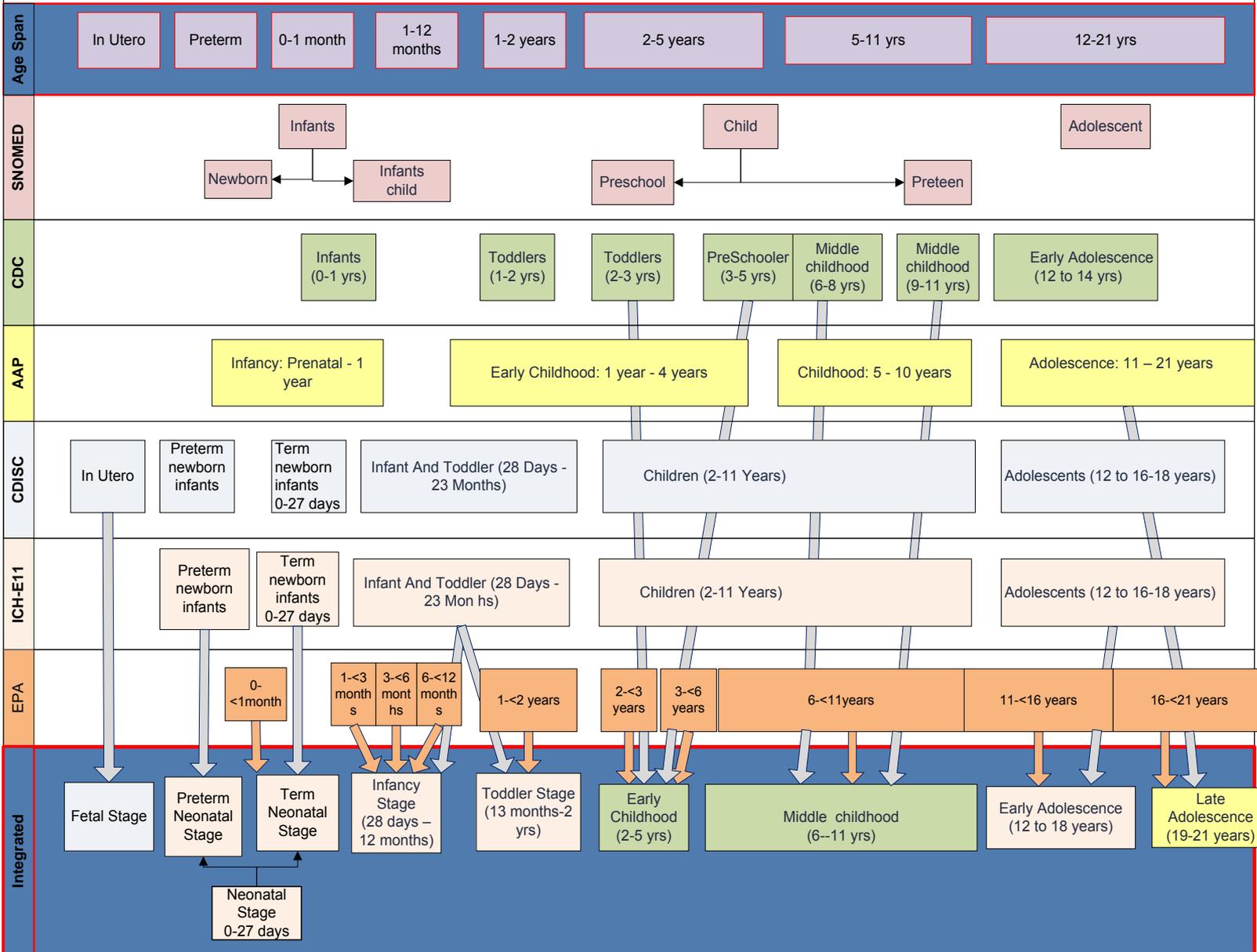
- Study-specific definitions representing complex ideas
- Outcomes research more challenging
- Pediatric research terms are unique
- Multiple systems
 - SNOMED, ICD, MedDRA



Harmonized terminology is the infrastructure that researchers need to accurately compare and aggregate data for multiple analyses



Integrated child-life stages for NICHD Pediatric Terminology as mapped to existing medical terminologies



AAP: American Academy of Pediatrics

CDC: Centers for Disease Control and Prevention

CDISC: Clinical Data Interchange Standards Consortium

EPA: Environmental Protection Agency

ICH-E11: International Conference on Harmonisation

SNOMED: Systematized Nomenclature of Medicine

NRNT: Goals & Objectives



- Create a harmonized neonatal terminology that:
 - Builds upon accepted neonatal research data collection needs
 - Harmonizes across the stakeholders to provide a common data view
 - Aligns with an accepted international terminology standard
 - Does not require participating networks to change current data collection and analysis practices
- Develop a set of terminology harmonization procedures, methods, and tools that can be reused in other areas of pediatrics research



NRNT Participants



- Neonatal networks
 - Vermont-Oxford
 - **Children's Hospital Neonatal Consortium**
 - NICHD Neonatal Research Network
- Domain experts
 - **CCHMC, CHOP, Texas Children's, NICHD, UC-Denver, VON**
- Terminology technologies experts
 - Apelon, Booz Allen Hamilton
- International participation
 - GRIP Network (Adolf Valls i Soler)
 - Canadian Neonatal Network (Prakesh Shah)



NRNT Project Execution Content Development Overview



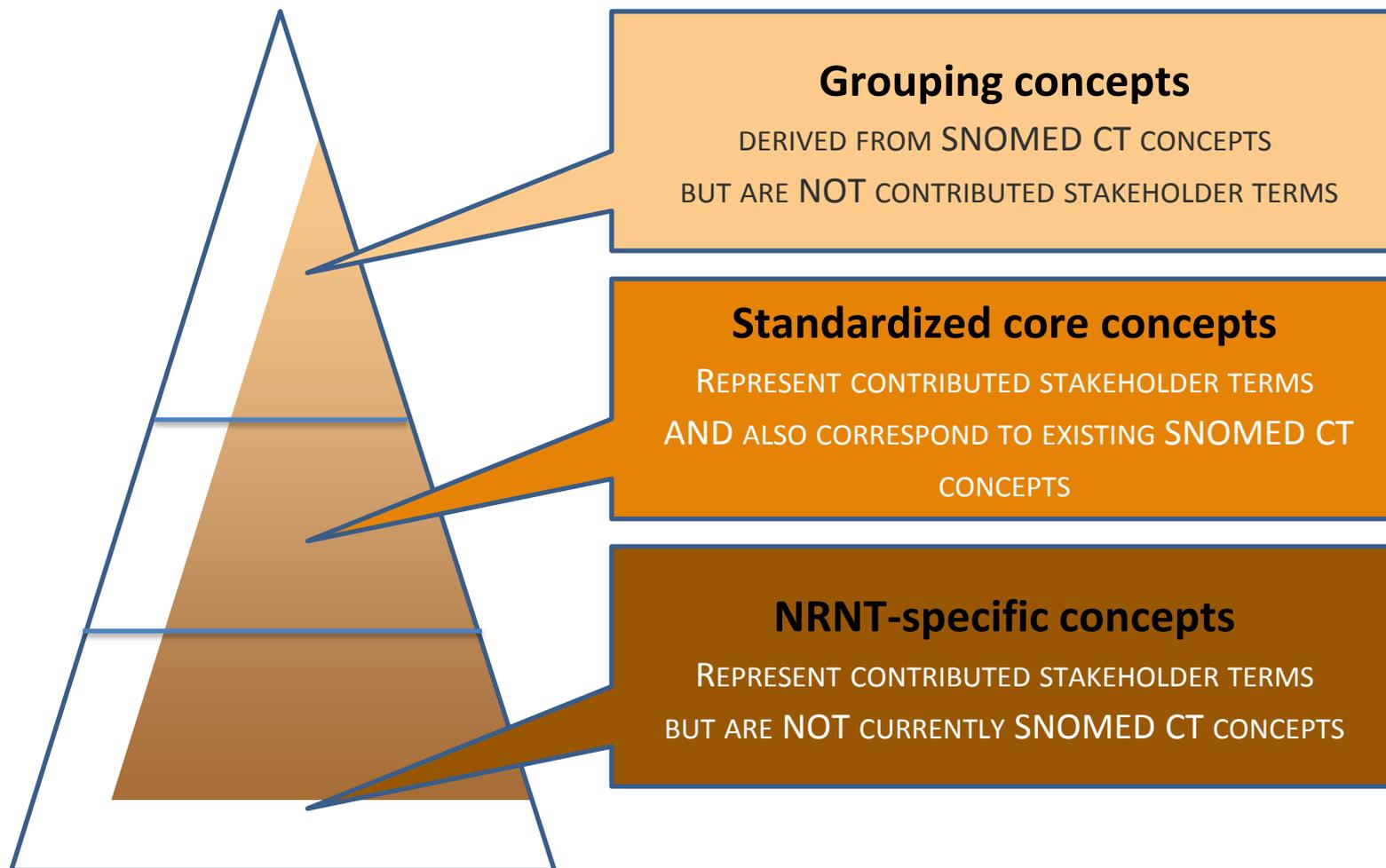
Gather terminologies from existing neonatal research networks

Create initial alignment by mapping to an external standard

Load the terminologies into a wiki for stakeholder review



Three-layer Model for Building NRNT



Example of NRNT Concept Hierarchy as Posted on Wiki



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hierCV.txt - Notepad
File Edit Format View Help
Congenital anomaly
  Congenital anomaly of cardiovascular system
    Congenital heart disease
      Cardiac septal defects
        Atrial septal defect
        Ventricular septal defect
        Single ventricle
      Complete atrioventricular canal defect
        Complete atrioventricular canal defect (balanced)
        Complete atrioventricular canal defect (unbalanced)
      Complex congenital heart disease with left ventricle only
      Complex congenital heart disease with right ventricle only
      Congenital abnormality of atria and atrial septum
        Cor triatriatum
      Congenital abnormality of ventricles and ventricular septum
        Left ventricular outflow tract abnormality, other specified
        Left ventricular outflow tract obstruction
        Tetralogy of Fallot
          Tetralogy of fallot - complete av canal defect
          Tetralogy of fallot - type unknown
          Tetralogy of fallot with pulmonary atresia
          Tetralogy of fallot with pulmonary stenosis
      Congenital anomaly of heart valve
        Aortic valve atresia
          Hypoplastic left heart syndrome with aortic atresia
        Congenital atresia of the pulmonary valve
        Congenital atresia of tricuspid valve
          Congenital atresia of tricuspid valve with pulmonary atresia
        Congenital insufficiency of aortic valve
        Congenital insufficiency of pulmonary valve
        Ebstein's anomaly
        Mitral atresia
```



Results Thus Far: Counts by Body System*



Body System	NRNT Concepts	Stakeholder Terms	SNOMED CT Mappings	NRNT Specific Concepts
CNS	249	162	197	50
Cardiovascular	209	141	155	50
Endocrinology	80	40	76	4
Genetics	163	97	153	9
Gastrointestinal	158	119	135	23
Genitourinary	89	56	79	10
Hematology	125	66	117	8
Metabolic	112	67	110	2
Musculoskeletal	70	44	66	4
Oncology	33	13	31	2
Ophthalmology	83	41	58	25
Respiratory	114	94	84	29
Skin	105	38	97	8

* The same concept will be counted in multiple rows if it is included in multiple body systems



What have we produced?



- Robust pediatric terminology that covers data collection requirement for neonatal research networks
 - Links to an international terminology standard
 - Retains grouping concepts for data reporting and aggregation
 - Supports cross-network comparison and aggregation
- An initial core pediatric terminology with known extensions to SNOMED CT
 - Extensions will be promoted to NLM and IHTSDO



Next Steps



- Finalize remaining domains
- Extend to international neonatal research networks
- Use processes and tools as foundation for additional harmonization efforts
- Submit NRNT to IHTSDO for changes to SNOMED CT



- **Identify use case that exploits harmonized terminology for extended analyses not possible w/o NRNT**





Thank you!

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