Project Introduction: Building Shared Solutions

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Project Goal

Pediatric Research Terminology Project Goal: Establish a set of harmonized pediatric terms that will help to standardize variables and datasets in pediatric clinical research, safety, and quality reporting.



Collaboration Overview

https://www.nichd.nih.gov/health/clinicalresearch/clinical-researchers/terminology/Pages/about.aspx

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Pediatric Terminology Harmonization Initiative: Overview

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In early 2009, the NICHD initiated an ongoing effort to establish a core library of harmonized pediatric terms that enables clinical investigators to more readily compare and aggregate dataacross clinical research portfolios.

This effort drew on an analysis of reference terminology and literature sources, and used modeling, annotation, and semantic integration tools to produce newly harmonized pediatric concepts and their corresponding data elements. To commence this initiative, the NICHD focused on developing the terminology and metadata for content-specific data acquisition tools for neonatal and infant examinations.

The content of the newborn examination form was developed using newborn metabolic screening submission forms as a model to conceptually outline the comprehensive examination that fully assesses the health of a newborn. This initiative identified specific concepts and terms within the neonatal and infant examination domain and used existing resources, such as the National Cancer Institute Thesaurus (NCIt) and the Systematized Nomenclature of Medicine (SNOMED), to harmonize the various fields and develop consistent terminology for these areas. The neonatal and infant examination concepts were developed as part of a broader pediatric terminology that is based on a developmental stage framework that follows a child's development through the various child life stages from pre-birth to 21 years of age.

1. Developing the terminology in NCI Thesaurus:

The terms identified from the concept outline were represented as a terminology that depicts the concepts and their attributes, and were incorporated into the NCI Thesaurus in collaboration with NCI Enterprise Vocabulary Services (EVS) curators. The neonatal and infant examination terms are organized as a subset in the existing NCI Thesaurus hierarchy. Each term is represented as a separate concept, and assigned a unique code, term definition, and synonym/abbreviation, where required. Each newborn examination concept has an association relationship "Concept in Subset: Newborn Screening," for easy retrieval of the terminology.

Pediatric Terminology Collaboration

2008 - 2010

- International collaboration harmonized life stages (6 systems)
- Agreed coding for Immunization, Neurological Development, Newborn Screening, and Pregnancy and Childbirth Terminology

2011-2012

- ➤ Neonatal Research Networks Terminology (NRNT) 3 Networks
- Includes neonatal diseases, findings, tests, and interventions

2013-2015 and beyond

- International working groups now completed: Pediatric Adverse Events, Perinatology, Pediatric Rheumatology
- Active working groups: Pediatric Endocrinology, Pediatric
 Nephrology, Pediatric Oncology, and Pediatric Infectious Disease
- Reaching 6,500 concepts from existing working groups
- Potential to expand into additional domain areas for pediatrics through additional working groups and partnerships such as PEDSNet, CARRAnet, Pediatric Endocrinologists Society, GRiP, GAIA Project, and others

NCI EVS Role

http://evs.nci.nih.gov

EVS provides expertise and services in biomedical terminology and ontology to help NCI and other stakeholders understand and share research, care, and health information:

Encode Precise, Stable Meanings:

Support **best-practice**, **science-based**, **quick-response** terminology/ontology resources to help researchers accurately collect, code, and analyze data.

Build Shared Standards:

Partner and harmonize with other ICs, agencies, SDOs, and researchers in creating and improving shared standards for increasingly international, crosscutting research.

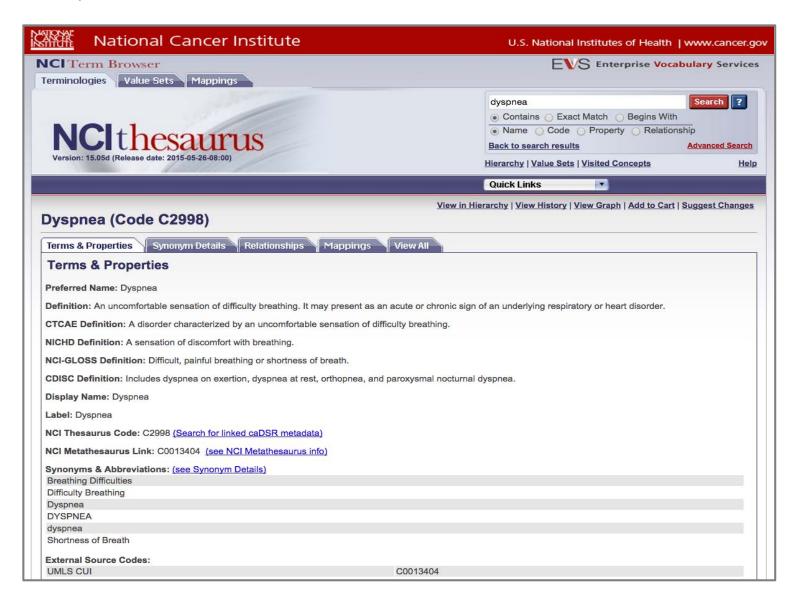
Support Semantic Infrastructures:

Support **metadata**, **models**, **value sets**, **and mappings** that provide broader, computable representations to structure meanings and make them interoperable.

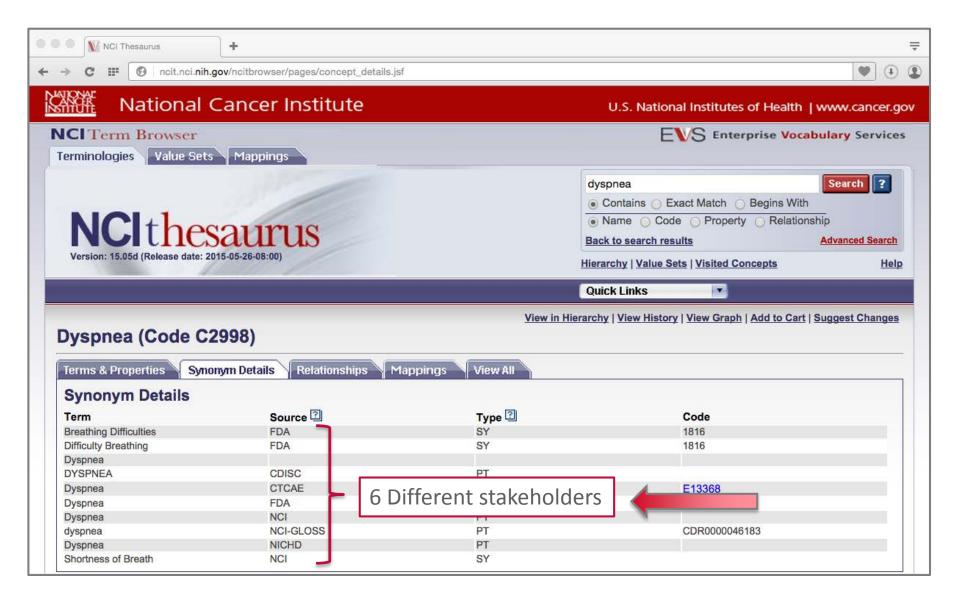
Promote Open Content and Tools:

Promote **open access**, open source content and tools to lower barriers, share burdens, and build shared resources.

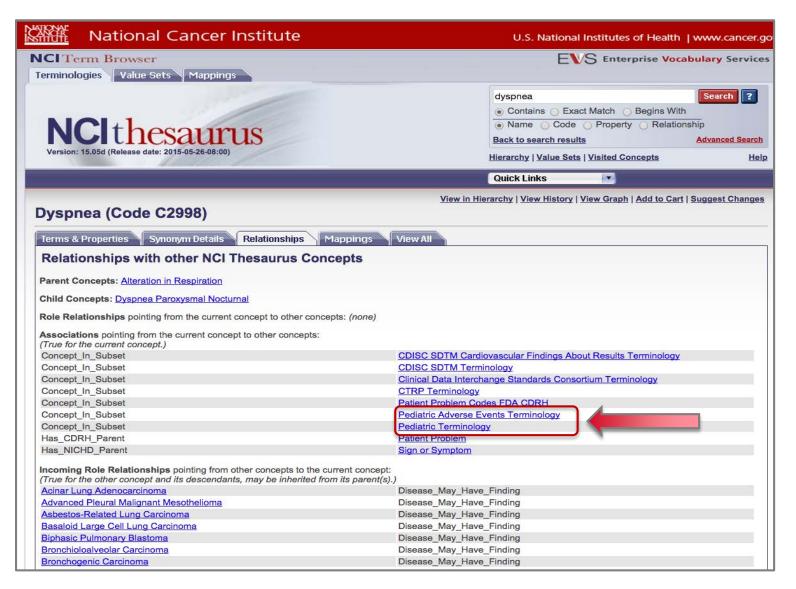
Terms & Properties



Synonym Details



Relationships



NCI Metathesaurus Mappings (first 3rd)

