

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>

US Department of Health and Human Services | National Institutes of Health



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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 data across 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, cross-cutting 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.

Example Concept: Dyspnea

Terms & Properties

National Cancer Institute U.S. National Institutes of Health | www.cancer.gov

NCI Term Browser EVS Enterprise Vocabulary Services

Terminologies Value Sets Mappings

Search: dyspnea [Search] [?]

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Dyspnea (Code C2998)

Terms & Properties Synonym Details Relationships Mappings View All

Terms & Properties

Preferred Name: Dyspnea

Definition: An uncomfortable sensation of difficulty breathing. It may present as an acute or chronic sign of an underlying respiratory or heart disorder.

CTCAE Definition: A disorder characterized by an uncomfortable sensation of difficulty breathing.

NICHD Definition: A sensation of discomfort with breathing.

NCI-GLOSS Definition: Difficult, painful breathing or shortness of breath.

CDISC Definition: Includes dyspnea on exertion, dyspnea at rest, orthopnea, and paroxysmal nocturnal dyspnea.

Display Name: Dyspnea

Label: Dyspnea

NCI Thesaurus Code: C2998 ([Search for linked caDSR metadata](#))

NCI Metathesaurus Link: C0013404 ([see NCI Metathesaurus info](#))

Synonyms & Abbreviations: ([see Synonym Details](#))

- Breathing Difficulties
- Difficulty Breathing
- Dyspnea
- DYSPNEA
- dyspnea
- Shortness of Breath

External Source Codes:

UMLS CUI	C0013404
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Example Concept: Dyspnea

Synonym Details

NCI Thesaurus

National Cancer Institute

U.S. National Institutes of Health | www.cancer.gov

NCI Term Browser

Terminologies Value Sets Mappings

NCI thesaurus

Version: 15.05d (Release date: 2015-05-26-08:00)

EVS Enterprise Vocabulary Services

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Dyspnea (Code C2998)

Terms & Properties Synonym Details Relationships Mappings View All

Synonym Details

Term	Source	Type	Code
Breathing Difficulties	FDA	SY	1816
Difficulty Breathing	FDA	SY	1816
Dyspnea			
DYSPNEA	CDISC	PT	
Dyspnea	CTCAE		
Dyspnea	FDA		
Dyspnea	NCI		
dyspnea	NCI-GLOSS	PT	
Dyspnea	NICHD	PT	CDR0000046183
Shortness of Breath	NCI	SY	

6 Different stakeholders

E13368

Example Concept: Dyspnea

Relationships

NATIONAL CANCER INSTITUTE National Cancer Institute U.S. National Institutes of Health | www.cancer.gov

NCI Term Browser EVS Enterprise Vocabulary Services

Terminologies Value Sets Mappings

dyspnea Search ?

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Dyspnea (Code C2998)

Terms & Properties Synonym Details Relationships Mappings View All

Relationships with other NCI Thesaurus Concepts

Parent Concepts: [Alteration in Respiration](#)

Child Concepts: [Dyspnea Paroxysmal Nocturnal](#)

Role Relationships pointing from the current concept to other concepts: (none)

Associations pointing from the current concept to other concepts:
(True for the current concept.)

Concept_In_Subset	CDISC SDTM Cardiovascular Findings About Results Terminology
Concept_In_Subset	CDISC SDTM Terminology
Concept_In_Subset	Clinical Data Interchange Standards Consortium Terminology
Concept_In_Subset	CTRP Terminology
Concept_In_Subset	Patient Problem Codes FDA CDRH
Concept_In_Subset	Pediatric Adverse Events Terminology
Concept_In_Subset	Pediatric Terminology
Has_CDRH_Parent	Patient Problem
Has_NICHD_Parent	Sign or Symptom

Incoming Role Relationships pointing from other concepts to the current concept:
(True for the other concept and its descendants, may be inherited from its parent(s).)

Acinar Lung Adenocarcinoma	Disease_May_Have_Finding
Advanced Pleural Malignant Mesothelioma	Disease_May_Have_Finding
Asbestos-Related Lung Carcinoma	Disease_May_Have_Finding
Basaloid Large Cell Lung Carcinoma	Disease_May_Have_Finding
Biphasic Pulmonary Blastoma	Disease_May_Have_Finding
Bronchioloalveolar Carcinoma	Disease_May_Have_Finding
Bronchogenic Carcinoma	Disease_May_Have_Finding

Example Concept: Dyspnea

NCI Metathesaurus Mappings (first 3rd)

NATIONAL CANCER INSTITUTE National Cancer Institute U.S. National Institutes of Health | www.cancer.gov

EVS Enterprise Vocabulary Services

NCI metathesaurus
Version 2.5 (using LexEVS 6.2)

Search Search ?
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 Source: ALL

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Dyspnea (CUI C0013404) [Suggest changes to this concept](#) [Add to Cart](#)

Terms & Properties **Synonym Details** Relationships By Source View All

Synonym Details:

Term	Source ^[?]	Type ^[?]	Code
Breathing Difficulties	FDA	SY	1816
BREATHING DIFFICULT	CST	GT	DYSPNEA
Breathing difficult	MDR	LT	10006338
breathlessness	CSP	ET	2596-2296
BREATHLESSNESS	DXP	SY	NOCODE
Breathlessness	MDR	LT	10006345
Breathlessness	MTH	PT	U000486
Breathlessness	SNOMEDCT_US	SY	267036007
Breathless	SNOMEDCT_US	SY	267036007
Breath Shortnesses	MSH	PM	D004417
BREATH SHORTNESS	CST	GT	DYSPNEA
Breath shortness	MDR	LT	10006332
Breath Shortness	MSH	PM	D004417
DIB - Difficulty in breathing	SNOMEDCT_US	SY	230145002
Difficulty breathing (finding)	SNOMEDCT_US	FN	230145002
DIFFICULTY BREATHING	DXP	SY	NOCODE
Difficulty Breathing	FDA	SY	1816
Difficulty breathing	MDR	LT	10012791
Difficulty breathing	SNOMEDCT_US	PT	230145002
Dyspnea, unspecified	ICD10CM	AB	R06.00
Dyspnea, unspecified	ICD10CM	PT	R06.00
Dyspneas	MSH	PM	D004417
Dyspnea (finding)	SNOMEDCT_US	FN	267036007
Dyspnea [Disease/Finding]	NDFRT	FN	N0000001030
Dyspnea NOS	MDR	MTH_LT	10013972
dyspnea	AOD	DE	0000005442
DYSPNEA	CDISC	PT	C2998