

# User Profiles - NIH

NCI EVS works closely with other members of the NIH community to develop shared terminology resources and standards, improving the quality and efficiency of our shared research mission as well as the exchange and reuse of data. These noteworthy examples of collaboration and reuse within NIH are included in the following sections:

- [National Heart, Lung, and Blood Institute \(NHLBI\)](#)
- [National Human Genome Research Institute \(NHGRI\)](#)
- [National Institute of Allergy and Infectious Diseases \(NIAID\)](#)
- [National Institute of Child Health and Human Development \(NICHD\)](#)
- [National Institute of Dental and Craniofacial Research \(NIDCR\)](#)
- [National Library of Medicine \(NLM\)](#)
- [NIH Biomedical Translational Research Information System \(BTRIS\)](#)
- [NIH Grants](#)

## National Heart, Lung, and Blood Institute (NHLBI)


Since 2005, NHLBI and EVS have jointly developed terminology in NCI for various projects including bone marrow transplant clinical trials and the Family Blood Pressure Program. Duke, through an NIH Roadmap project, the American College of Cardiology, and CDISC, have also collaborated with EVS to produce several cardiovascular data standard sets now in use at NHLBI, with a portion incorporated into CDISC SDTM.

### EVS Related References

1. Hicks KA, Tcheng JE, Bozkurt B, Chaitman BR, Cutlip DE, Farb A, Fonarow GC, Jacobs JP, Jaff MR, Lichtman JH, Limacher MC, Mahaffey KW, Mehran R, Nissen SE, Smith EE, Targum SL.  
**2014 ACC/AHA Key Data Elements and Definitions for Cardiovascular Endpoint Events in Clinical Trials: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Data Standards (Writing Committee to Develop Cardiovascular Endpoints Data Standards).**  
*J Am Coll Cardiol.* 2015. doi: 10.1016/j.jacc.2014.12.018. [Epub ahead of print] PubMed PMID: 25553722. [[PubMed](#)]
2. Anderson HV, Weintraub WS, Radford MJ, Kremers MS, Roe MT, Shaw RE, Pinchotti DM, Tcheng JE.  
**Standardized Cardiovascular Data for Clinical Research, Registries, and Patient Care: A Report from the Data Standards Workgroup of the National Cardiovascular Research Infrastructure Project.**  
*J Am Coll Cardiol.* 2013 May 7;61(18):1835-46. doi: 10.1016/j.jacc.2012.12.047. Epub 2013 Mar 6. PubMed PMID: 23500238. [[PubMed](#)]

## National Human Genome Research Institute (NHGRI)

**The Cancer Genome Atlas (TCGA)** is a joint effort between NCI and NHGRI, developing a database of the changes that occur in the genome, associated with a specific cancer type. TCGA creates a national network of research and technology teams, and provides a mechanism for pooling results; data are publicly available. 25 Studies are associated with this data, and data are being actively submitted or used by 16 academic and research organizations, 27 commercial organizations, and 17 non-profit organizations. EVS supports terminology for annotating the CDEs for tagging information and samples, mainly cell and specimen type, with information about tumor size, anatomic location, sample preparation, and patient demographics.

**PhenX**  was initiated by NHGRI in 2007 and has broad participation by other NIH institutes and the research community. PhenX initially prioritized 21 research domains relevant to genomics research and public health; EVS provides ongoing terminology support for these domains and related PhenX efforts. For more information, see the [in the community profiles](#).

### EVS Related References

1. Deus HF, Veiga DF, Freire PR, Weinstein JN, Mills GB, Almeida JS.  
**Exposing the cancer genome atlas as a SPARQL endpoint.**  
*J Biomed Inform.* 2010 Dec;43(6):998-1008. PubMed PMID: 20851208; PubMed Central PMCID: PMC3071752. [[PubMed](#)]

## National Institute of Allergy and Infectious Diseases (NIAID)

The NIAID Division of Allergy, Immunology, and Transplantation (DAIT) Immunology and Data Analysis Portal (ImmPort) (see <https://import.niaid.nih.gov/>) is a long-term, sustainable data warehouse promoting reuse of immunological data generated by NIAID and NIAID-funded investigators. ImmPort uses NCI terminology and NCI Term Browser to define data concepts and data concept attributes with standard terms to make the ImmPort data model semantically interoperable with other data repositories..

## National Institute of Child Health and Human Development (NICHD)

Starting in 2008, NICHD initiated an ongoing effort in collaboration with EVS to establish a core library of harmonized pediatric terminology in NCI through the **Pediatric Terminology Harmonization Initiative** ([detailed description](#)). In 2013, several new expert working groups were established to extend coverage. This terminology is being developed by international teams of experts to support the acquisition, exchange, submission and archiving of clinical research data by pediatric clinical researchers and caregivers. Terminology developed through the Initiative is associated with 848 NICHD Clinical Trials, and is being used by 52 different academic and research organizations.

More than 6,500 NCI concepts are used to specify coding standards for neonatal and perinatal research, neurological development, newborn screening, and pediatric adverse events, endocrinology, immunization, infectious disease, medical devices, nephrology, oncology, and rheumatology.

For more information, visit the [NCI website pediatric terminology page](#).

## EVS Related References

1. Bonhoeffer J, Kochhar S, Hirschfeld S, Heath PT, Jones CE, Bauwens J, Honrado Á, Heininger U, Muñoz FM, Eckert L, Steinhoff M, Black S, Padula M, Sturkenboom M, BATTERY J, Pless R, Zuber P; GAIA project participants.  
**Global alignment of immunization safety assessment in pregnancy - The GAIA project.**  
*Vaccine*. 2016 Dec 1;34(49):5993-5997. doi: 10.1016/j.vaccine.2016.07.006. PubMed PMID: 27751641. [[PubMed](#)]
2. Gipson DS, Kirkendall ES, Gumbs-Petty B, Quinn T, Steen A, Hicks A, McMahon A, Nicholas S, Zhao-Wong A, Taylor-Zapata P, Turner M, Herreshoff E, Jones C, Davis JM, Haber M, Hirschfeld S.  
**Development of a Pediatric Adverse Events Terminology.**  
*Pediatrics*. 2017 Jan;139(1). Available online Dec 27, 2016. pii: e20160985. doi: 10.1542/peds.2016-0985. [Epub ahead of print] PubMed PMID: 28028203. [[PubMed](#)]
3. Hirschfeld S, Songco D, Kramer BS, Guttmacher AE.  
**National Children's Study: update in 2010.**  
*Mt Sinai J Med*. 2011 Jan-Feb;78(1):119-25. doi: 10.1002/msj.20227. PubMed PMID: 21259268. [[PubMed](#)]
4. Kahn MG, Bailey LC, Forrest CB, Padula MA, Hirschfeld S.  
**Building a Common Pediatric Research Terminology for Accelerating Child Health Research.**  
*Pediatrics*. 2014. Available online Feb 17, 2014. DOI: 10.1542/peds.2013-1504. [[Online](#)]
5. Sward KA, Rubin S, Jenkins TL, Newth CJ, Dean JM; Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) Collaborative Pediatric Critical Care Research Network (CPCCRN).  
**Case Study: Semantic Annotation of a Pediatric Critical Care Research Study.**  
*Comput Inform Nurs*. 2016 Mar;34(3):101-4. doi: 10.1097/CIN.0000000000000236. PubMed PMID: 26958992; PubMed Central PMCID: PMC4788017. [[PubMed](#)]

## National Institute of Dental and Craniofacial Research (NIDCR)

Since 2008, NIDCR and EVS have jointly developed terminology in NCI for dental treatments and medical procedures.

## National Library of Medicine (NLM)

Since its inception, EVS has worked with NLM on a variety of terminology content and technology efforts. EVS licenses content from and harmonizes with NLM's Unified Medical Language System (UMLS), building NCI by modifying and extending a subset of the UMLS Metathesaurus and using NLM editing software.

NCI is also a contributor to the UMLS, providing monthly builds of NCI for inclusion in UMLS. (UMLS only publishes twice yearly; they pull whichever build is most current at the time they begin processing.) EVS also worked with NLM and other federal partners to develop the Federal Medication Terminologies framework for harmonized medication coding (see below). EVS staff provided start-up phrase dictionaries and search criteria for the PubMed Cancer Subset, and jointly maintains this content with NLM on an ongoing basis.

NLM's DailyMed gets over 10 million hits each month, and each of the SPL files in DailyMed uses terminology that is maintained by NCI. There are over 27,000 SPL files on DailyMed, and another 5,000 SPL files that are not on DailyMed. Each of these SPL files requires NCI codes.

NLM studies on a variety of biomedical terminology, ontology, and informatics issues have increasingly taken NCI and other EVS resources as an important focus and test case. NCI is also making an increasingly important contribution to results obtained in NLM's natural language processing work.

## EVS Related References

1. Bodenreider O.  
**Comparing SNOMED CT and the NCI Thesaurus through Semantic Web technologies.**  
*Proceedings of the Third International Conference on Knowledge Representation in Medicine (KR-MED 2008)*, 2008: p. 37-43. [[PDF \(CEUR Workshop Procs. v.410\)](#)]
2. Bodenreider O.  
**Biomedical ontologies in action: role in knowledge management, data integration and decision support.**  
*Yearbook of Medical Informatics* (2008) pp.67-79.
3. Bodenreider O, Hayamizu TF, Ringwald M, De Coronado S, Zhang S.  
**Of mice and men: aligning mouse and human anatomies.**  
*AMIA Annu Symp Proc*. 2005:61-5. PubMed PMID: 16779002; PubMed Central PMCID: PMC1560846. [[PubMed](#)]
4. Burgun A, Bodenreider O.  
**Issues in integrating epidemiology and research information in oncology: experience with ICD-O3 and the NCI Thesaurus.**  
*AMIA Annu Symp Proc*. 2007 Oct 11:85-9. PubMed PMID: 18693803. [[PubMed](#)]
5. Cimino JJ, Hayamizu TF, Bodenreider O, Davis B, Stafford GA, Ringwald M.  
**The caBIG terminology review process.**  
*J Biomed Inform*. 2009 Jun;42(3):571-80. Epub 2008 Dec 25. PubMed PMID: 19154797; PubMed Central PMCID: PMC2729758. [[PubMed](#)]
6. Fung KW, Bodenreider O.  
**Knowledge Representation and Ontologies.**  
In: Richesson RL, Andrews JE, editors. *Clinical research informatics*. New York: Springer; 2012. Chapter 14, pp.255-275. [[Springer](#)] [[PDF](#)]
7. Luciano JS, Andersson B, Batchelor C, Bodenreider O, Clark T, Denney CK, Domarew C, Gambet T, Harland L, Jentzsch A, Kashyap V, Kos P, Kozlovsky J, Lebo T, Marshall SM, McCusker JP, McGuinness DL, Ogbuji C, Pichler E, Powers RL, Prud'hommeaux E, Samwald M, Schriml L, Tonellato PJ, Whetzel PL, Zhao J, Stephens S, Dumontier M.  
**The Translational Medicine Ontology and Knowledge Base: driving personalized medicine by bridging the gap between bench and bedside.**  
*J Biomed Semantics*. 2011 May 17;2 Suppl 2:S1. PubMed PMID: 21624155; PubMed Central PMCID: PMC3102889. [[PubMed](#)] [[Free PMC Article](#)]
8. Mougin F, Bodenreider O.  
**Auditing the NCI thesaurus with semantic web technologies.**  
*AMIA Annu Symp Proc*. 2008 Nov 6:500-4. PubMed PMID: 18999265; PubMed Central PMCID: PMC2655981. [[PubMed](#)]

9. Pathak J, Peters L, Chute CG, Bodenreider O.  
**Comparing and evaluating terminology services application programming interfaces: RxNav, UMLS and LexBIG.**  
*J Am Med Inform Assoc.* 2010 Nov-Dec;17(6):714-9. PubMed PMID: 20962136; PubMed Central PMCID: PMC3000749. [[PubMed](#)]
10. Zhang S, Bodenreider O.  
**Alignment of multiple ontologies of anatomy: deriving indirect mappings from direct mappings to a reference.**  
*AMIA Annu Symp Proc.* 2005:864-8. PubMed PMID: 16779163; PubMed Central PMCID: PMC1560629. [[PubMed](#)]
11. Zhang S, Bodenreider O.  
**Experience in Aligning Anatomical Ontologies.**  
*Int J Semant Web Inf Syst.* 2007;3(2):1-26. PubMed PMID: 18974854; PubMed Central PMCID: PMC2575410. [[PubMed](#)]

## NIH Biomedical Translational Research Information System (BTRIS)

The NIH Clinical Center's trans-NIH Biomedical Translational Research Information System ([BTRIS](#)) was started in 2008 to help investigators from the NIH Clinical Center, Institutes and Centers access clinical and research data, improve protocol reporting and data analysis, and reuse data to support new hypotheses and collaborations. EVS and BTRIS share the common goals of providing tools to enable data aggregation and query, cross-study comparisons, and translation research. EVS has provided both the software editing tools and initial NCI content to launch the Research Entities Dictionary (RED), which combines the terminologies from the systems that contribute data to BTRIS. Both programs continue to collaborate on shared clinical content standards, best practices and systems, in order to better coordinate research information across NIH.

BTRIS provides clinical investigators with access to identifiable data for the subjects on their own active protocols, while providing all NIH investigators with access to de-identified data across all protocols. BTRIS provides users with advanced search, filtering, and aggregation methods to create data sets to support ongoing studies and stimulate ideas for new research. BTRIS contains subject data from CRIS/MIS (the Clinical Center Medical Information Systems) and research data from NIAID (Crimson), NIAAA, and NCI. Data are available from 1976 to the present.

BTRIS Data Access is the data repository where principal investigators or their designees create reports on their active protocols with identified subject data. Multiple reports are available in BTRIS and can easily be run by researchers through a series of prompts. Reports include the IRB Inclusion Enrollment Report, demographics, patient lists, laboratory and microbiology results, vital signs, medication orders and administration, diagnoses, and radiology reports (with links to images in the CC PACS system). BTRIS provides researchers with tools to generate reports for their protocols. Reports are customizable for the requirements of specific reporting agencies, etc.

BTRIS creates and uses a Research Entities Dictionary (RED) to standardize data formats and terminologies between data sources. With the use of RED codes, researchers can extract a comprehensive set of like data from disparate sources, and BTRIS tools support construction of comprehensive queries. Use of the RED also allows researchers to identify patients that meet multiple criteria relevant to the researcher's interests. Work is ongoing to publish RED through EVS terminology servers and browsers.

For more information, visit the [BTRIS website](#).

## NIH Grants

NCIt is one of four NIH-approved terminologies for grant coding, and EVS has helped develop the Research, Condition and Disease Categorization (RCDC) grant coding system.

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