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 NCIt 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.

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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.

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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://immport.niaid.nih.gov/) is a long-term, sustainable data warehouse promoting reuse of immunological data generated by NIAID and NIAID-funded investigators. ImmPort uses NCIt 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 NCIt 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 NCIt 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.

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National Institute of Dental and Craniofacial Research (NIDCR)

Since 2008, NIDCR and EVS have jointly developed terminology in NCIt 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 NCIm 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 NCIt 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 NCIt codes.

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

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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 NCIt 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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