The Role of the NLM in Fostering Interoperability

17th General Meeting of HSPC Joint with CIIC

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National Library of Medicine

U.S. National Library of Medicine

Transforming Data into Knowledge

and knowledge into health

Strategic Plan 2017-2027

Patricia Flatley Brennan, RN, PhD
NLM Director

NLM Strategic Plan
Transforming Data into Knowledge

Accelerate discovery and advance health through data-driven research

Reach more people in more ways through enhanced dissemination and engagement

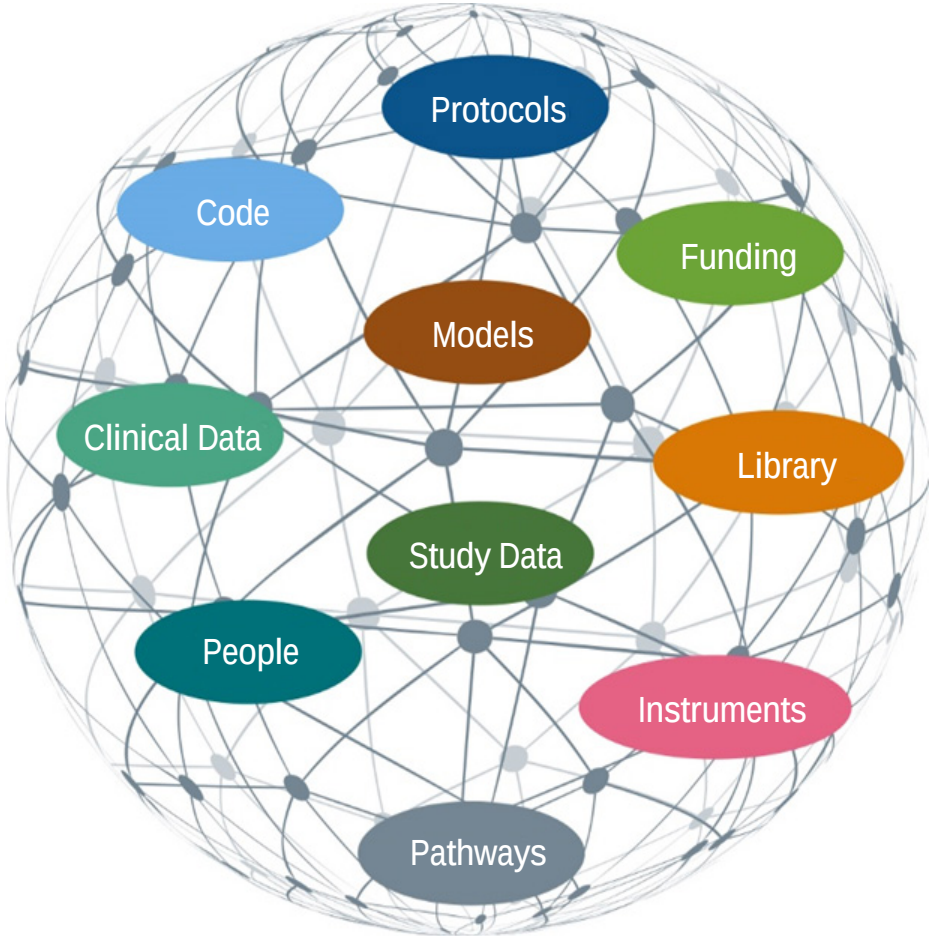
Build a workforce for data-driven research and health

Accelerate discovery and advance health through data-driven research

NIH NLM

Fostering a ecosphere of discovery

digital research objects



RRIDs characterize Methods

- identify the model organisms, cells lines, antibodies, and tools (such as software or databases) you have used
- Blogs, software took kits, algorithm implementation
- include Research Resource Identifiers (RRIDs) within the materials and methods section of their papers

doi's characterize objects

- Complete declarations (objects, articles, books)
- ISO standard, computational registry

Reach more people in more ways through enhanced dissemination and engagement

Foster distinctiveness of NLM as a

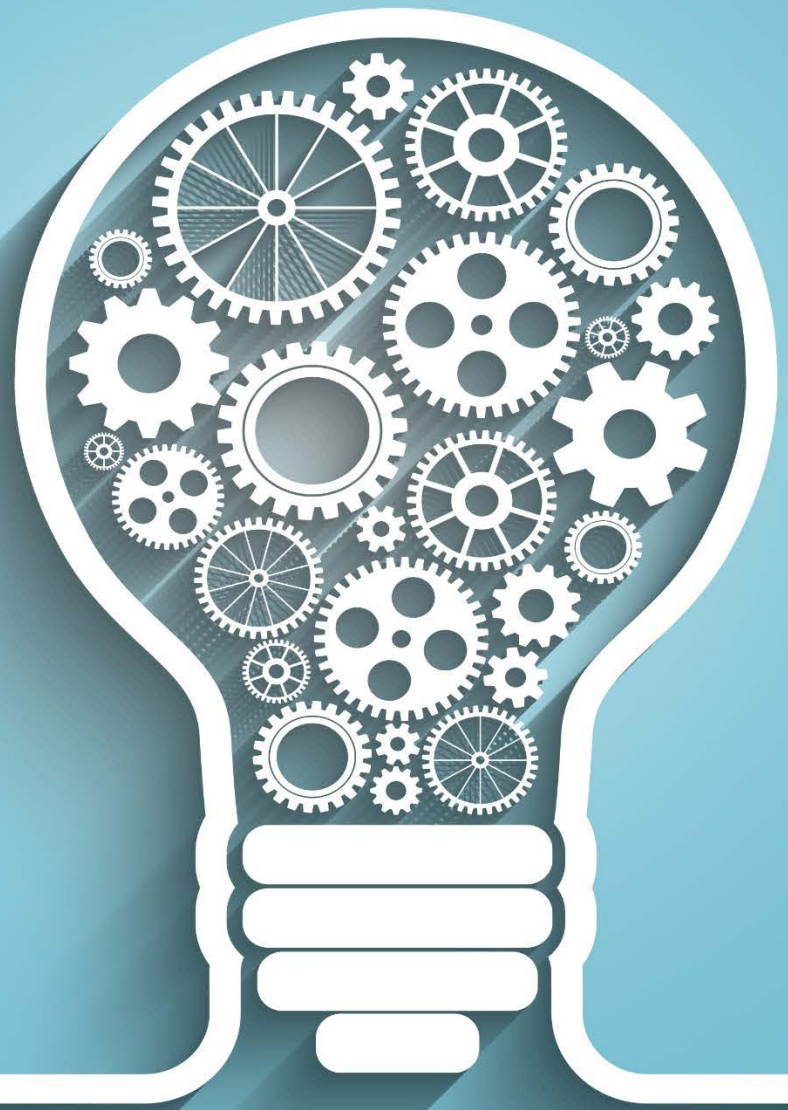
reliable, trustable source

of health information & biomedical data

The 21st Century Collection

- Innovative attribution
- Automated indexing
- Personalized presentation & delivery
- Interim products of research

CUSTODIAN | CONNECTOR | DISCOVERER

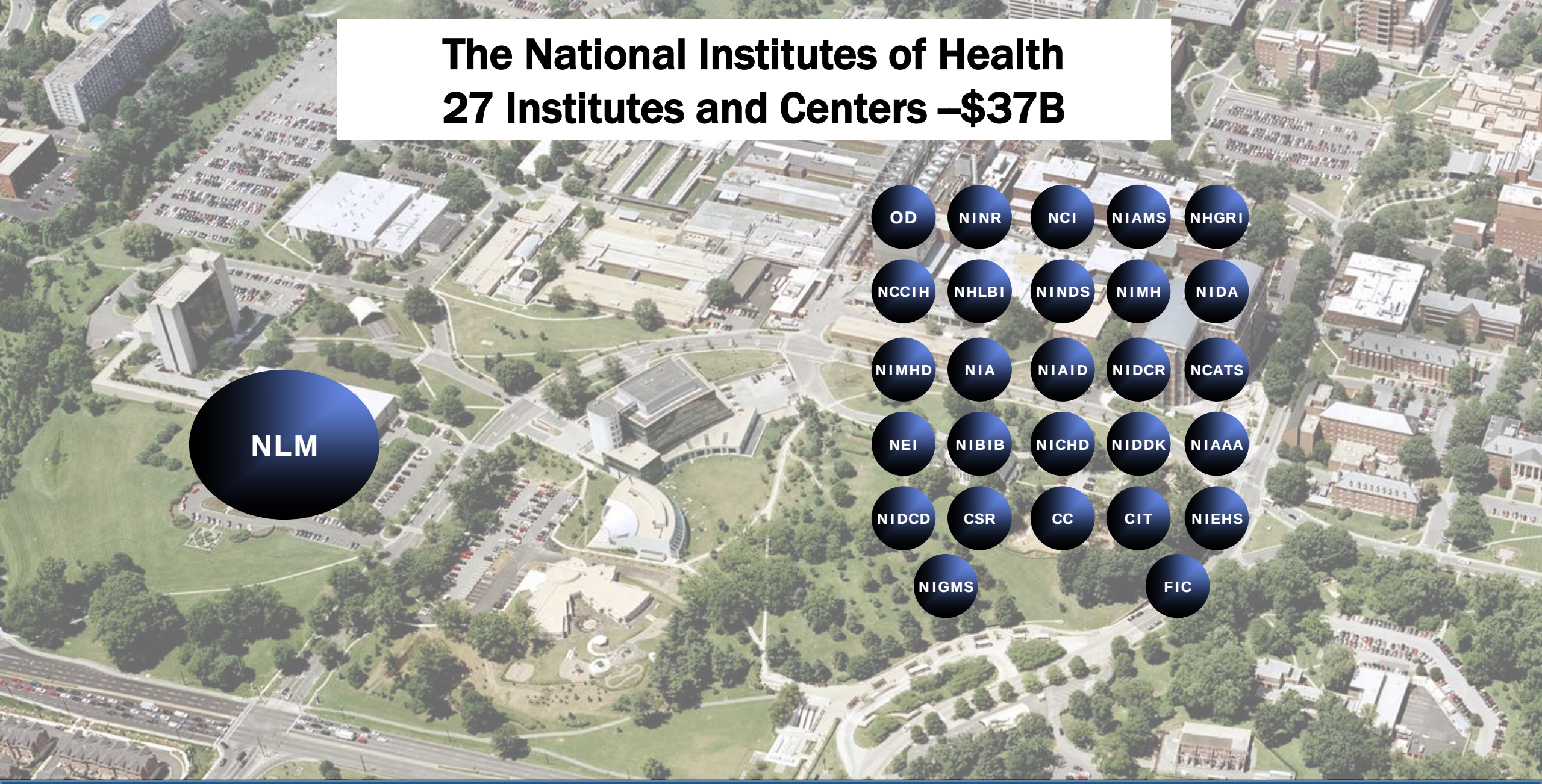


Build a workforce for data-driven research and health

Expand & enhance research training

for biomedical informatics & data science

The National Institutes of Health
27 Institutes and Centers –$37B



NIH Strategic Plan for Data Science

- **Requested by Congress**: In its fiscal year 2017 report, the Committee directed NIH to work with its external partners and stakeholders to provide the Committees on Appropriations of the House of Representatives and the Senate a detailed strategic plan **by May 5, 2018**, spelling out it how intends to make big data sustainable, interoperable, accessible, and usable.

	Data Infrastructure	Modernized Data Ecosystem	Data Mgmt, Analytics, & Tools	Workforce Development	Stewardship and Sustainability
GOALS					
OBJECTIVES	• Optimize data storage and security • Connect NIH data systems	• Modernize data repository ecosystem • Support storage and sharing of individual datasets • Better integrate clinical and observational data into biomedical data science	• Support useful, generalizable, & accessible tools and workflows • Broaden utility of and access to specialized tools • Improve discovery & cataloging resources	• Enhance the NIH data-science workforce • Expand the national research workforce • Engage a broader community	• Develop policies for a FAIR data ecosystem • Enhance stewardship

NIH Strategic Plan for Data Science:

Cross-Cutting Themes

- Support **common infrastructure and architecture** on which more specialized platforms can be built and interconnected
- **Leverage commercial tools, technologies, services, and expertise**; adopt and adapt tools and technologies from other fields
- Enhance the nation's biomedical **data-science research workforce**: improved training programs, novel partnerships
- Ensure NIH-supported data resources are **FAIR**
- Ensure **information security** of patient and participant data
- Improve the ability to capture, curate, validate, store, and analyze **clinical data** for biomedical research
- With community input, develop, promote—and refine as needed—**data standards**
- **Coordinate and collaborate** with federal, private and international funding agencies and organizations to promote **economies of scale and synergies and prevent unnecessary duplication**

NLM Initiatives to Promote Interoperability

- Central coordinating body for clinical terminology standards in HHS in close collaboration with ONC
- Supports research in knowledge representation
- Key initiatives:
  - Terminology and data standard support (SNOMED, RxNORM, LOINC)
  - MedlinePlus Connect – 11M links a year
  - Common Data Elements
    Value Set Authority

NIH Clinical Common Data Elements

- **Formed in 2012 as CDE initiatives blossomed at NIH**
  - Foster communication, collaboration, & coordination across ICOs
  - Reduce duplication, share lessons learned, & identify opportunities
- **Members from all ICOs (100)**
  - Meet every other week (35 – 45)
- **Subgroups address specific issues**
  - Harmonizing CDE-related infrastructure across NIH
  - Defining CDE-related terms
  - Describing best practices for developing & implementing CDE initiatives
- **Web-based resources for CDE efforts**
  - NIH CDE Repository
  - NIH CDE Portal to NIH CDE initiatives & related resources

Home

NIH encourages the use of common data elements (CDEs) in clinical research, patient registries, and other human subject research in order to improve data quality and opportunities for comparison and combination of data from multiple studies and with electronic health records. This portal provides access to information about NIH-supported CDEs, as well as tools and resources to assist investigators developing protocols for data collection. What is a CDE?

Webinar: Overview of NIH CDE Initiatves (September 8, 2015) View slides / watch recording

NIH CDE Collections

Sets of CDEs that have been identified for use in particular types of research or research domains after a formal evaluation and selection process.

Summary Table | Subject Areas

NIH CDE Tools and Resources

Databases and repositories of data elements and case report forms that may assist investigators in identifying and selecting data elements for use in their projects.

Summary Table | Subject Areas

NIH CDE Repository

The Repository is a platform for identifying related data elements in use across diverse areas, for harmonizing data elements, and for linking CDEs to other existing standards and terminologies.

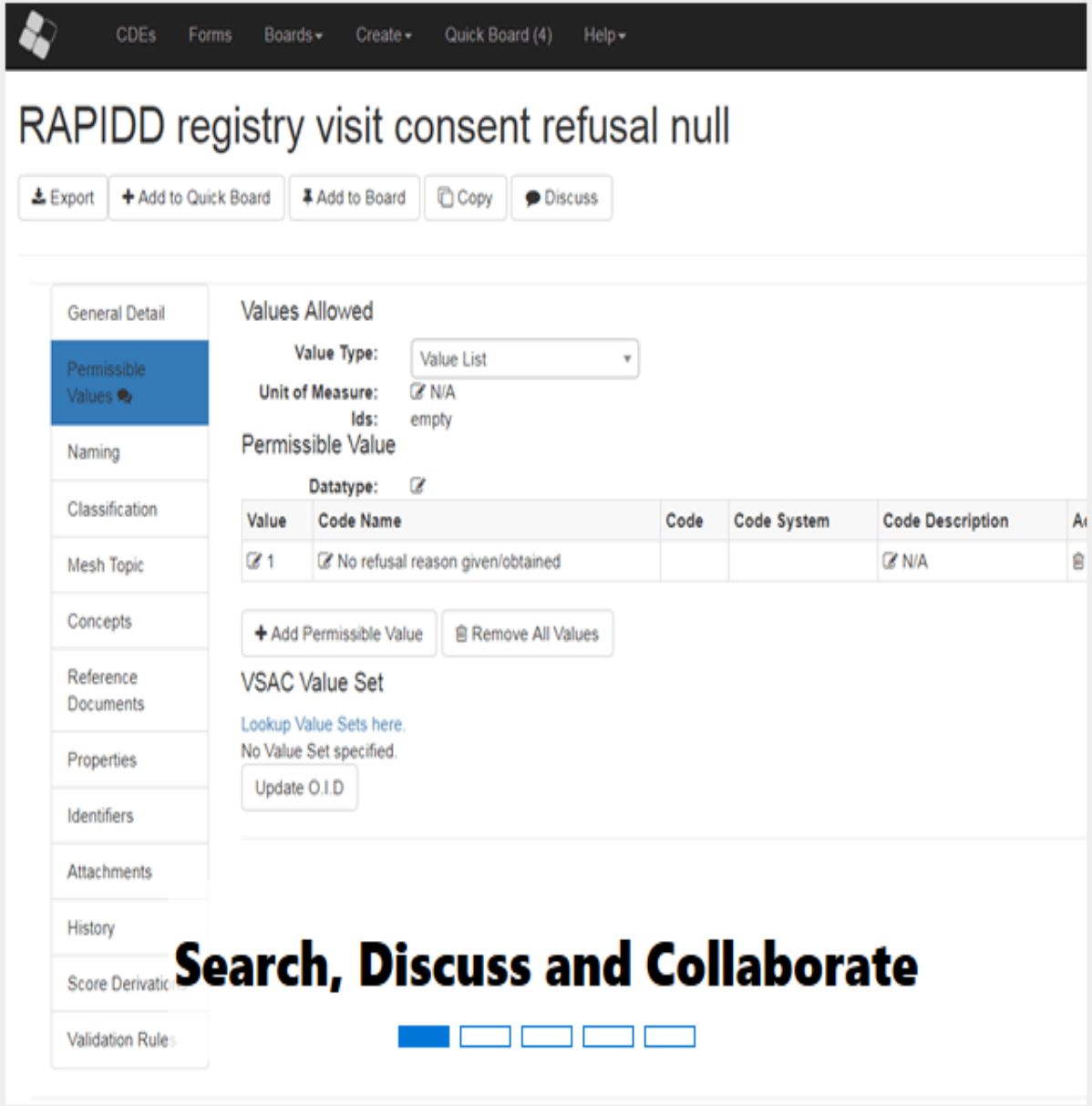
CDE Repository

Some NIH programs have issued specific guidance for using CDEs in funded research.

NIH CDE Repository

The NIH Common Data Elements (CDE) Repository has been designed to provide access to structured human and machine-readable definitions of data elements that have been recommended or required by NIH Institutes and Centers and other organizations for use in research and for other purposes.

Visit the NIH CDE Resource Portal for contextual information about the repository.



Browse CDEs

Browse Forms

Interactive Tour

Report a problem!

Summary Table for NIH CDE Initiatives

This table lists summary information for NIH CDE Initiatives. More information on NIH CDE Initiatives: Subject Areas, Detailed Summaries.

Show 50 entries

Search:

Link to Homepage	Link to CDEs	Brief Summary	Number of Elements	Studies and Publications	CDE Resource Contact
Standardized Asthma Outcomes for Clinical Research	Asthma CDEs	The standardized asthma outcomes for clinical research represent recommendations for core (required in future studies), supplemental (to be used according to study aims), and emerging (requiring validation and standardization) outcomes for 7 domains of asthma clinical research outcome measures. Subject Areas | More...	10 (adults), 25 (children)	–	NHLBI, NIAID
Chronic Low Back Pain CDEs	cLBP	Recommended minimum dataset for research on chronic low back pain. Subject Areas | More...	40	–	NCCAM
Early Detection Research Program	EDRN	CDEs for use in describing samples and data collected as part of cancer biomarker research. Subject Areas | More...	1,600	Publications	NCI
eyeGENE	eyeGENE	As part of eyeGENE, common data elements have been developed for collecting phenotypic data associated with more than 30 inherited ophthalmic diseases. Subject Areas | More...	200	Studies Publications	NEI
Rare Diseases Registry Program (RaDaR)	GRDR	CDEs to facilitate standardized data collection into the GRDR and to assist organizations in establishing rare disease registries that contribute information to GRDR. Subject Areas | More...	75	Publications	GRDR
Quality of Life Outcomes in Neurological Disorders	Neuro-QOL	A core set of quality-of-life questions that address chronic neurologic disorders, plus sets of supplemental questions specific to targeted diseases or subgroups of patients. Subject Areas | More...	500	Publications	NINDS
NIDA Substance Abuse Electronic Health Record Data Elements	NIDA EHR	A set of brief screening and initial assessment tools for substance use disorders (SUDs) for use in general medical settings. Subject Areas | More...	80+	–	NIDA
NIH Toolbox for Assessment of Neurological and Behavioral Function	NIH Toolbox	An integrated set of tools for measuring cognitive, emotional, motor and sensory function. Subject Areas | More...	4 batteries of tests, each with 5-24 tests	Publications	NIH
NINDS Common Data Elements	NINDS CDEs	A core set of data elements for use in NINDS-funded studies, including core and supplementary sets of data elements for use in disease-specific studies. Subject Areas | More...	10,000 unique variables, 550+	Studies	NINDS

Subject Areas of NIH CDE Initiatives

This table lists the Subject Areas covered by NIH CDE Initiatives. More information on NIH CDE Initiatives: Summary Table, Detailed Summaries

XX indicates that the subject area is a major focus, while X indicates that the subject area is a minor focus. Subject areas listed here may change as additional Resources are added to the CDE Resource Portal or as existing Resources are expanded into new subject areas (subject areas assessed in January 2013).

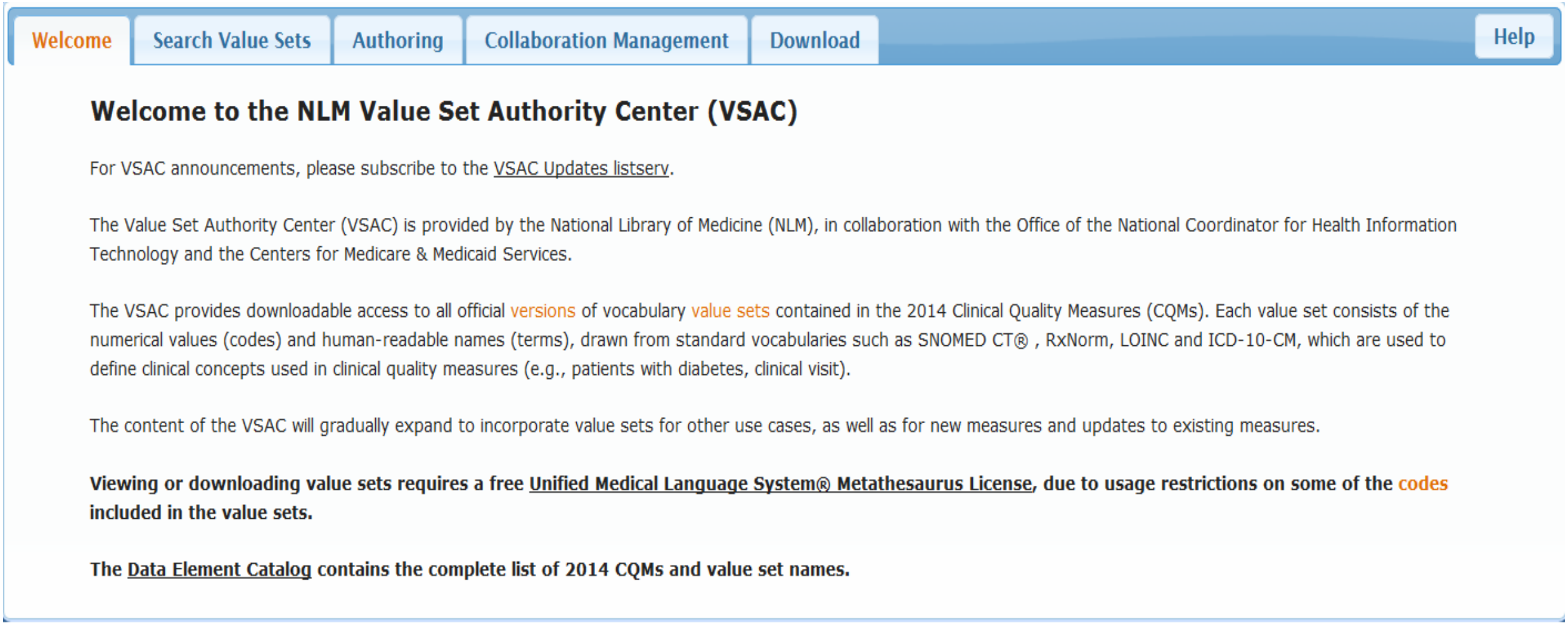
Show 50 entries Search:

Subject Area	Asthma CDEs	cLBP	EDRN	eyeGENE	GRDR	Neuro-QOL	NIDA EHR	NIH Toolbox	NINDS CDEs	PhenX	PROMIS
Respiratory	XX		X						X	XX	X
Alcohol, Tobacco, and Other Substances			X				XX		X	XX	
Cancer			X							XX	
Cardiovascular and Circulatory									XX	XX	
Demographics and Patient Contact Info.			X	X	XX				XX	XX	
Diabetes and Other Endocrine									X	XX	
Environmental Exposures			X						X	XX	
Excretory			X						X		
Gastrointestinal			X						X	XX	
Infectious Diseases and Immunity									X	XX	
Laboratory Tests			X	XX					X	X	
Medical History			X		XX				XX	X	
Medications, Devices, and Treatments		XX	X		XX				XX	X	
Neurology		X				XX		XX	XX	XX	

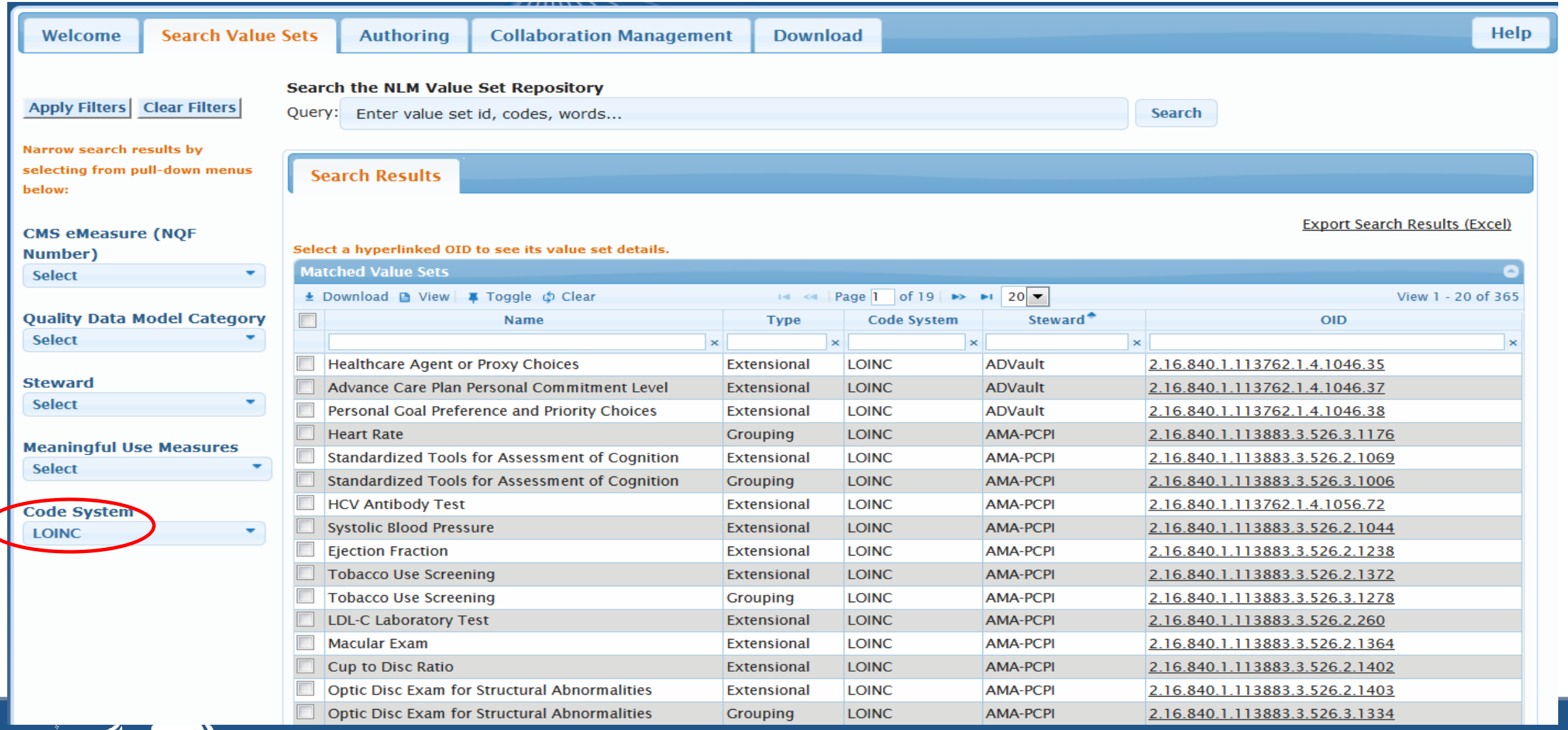
Value Sets

A ***list of codes*** and their terms, derived from standard vocabularies, that ***define clinical concepts for a particular purpose*** (like diabetes, blood glucose tests, antibiotic prescriptions) to support effective and interoperable health information exchange.

Value Set Authority Center



VSAC – Search Value Sets



Name	Type	Code System	Steward	OID
Healthcare Agent or Proxy Choices	Extensional	LOINC	ADVault	2.16.840.1.113762.1.4.1046.35
Advance Care Plan Personal Commitment Level	Extensional	LOINC	ADVault	2.16.840.1.113762.1.4.1046.37
Personal Goal Preference and Priority Choices	Extensional	LOINC	ADVault	2.16.840.1.113762.1.4.1046.38
Heart Rate	Grouping	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.3.1176
Standardized Tools for Assessment of Cognition	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1069
Standardized Tools for Assessment of Cognition	Grouping	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.3.1006
HCV Antibody Test	Extensional	LOINC	AMA-PCPI	2.16.840.1.113762.1.4.1056.72
Systolic Blood Pressure	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1044
Ejection Fraction	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1238
Tobacco Use Screening	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1372
Tobacco Use Screening	Grouping	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.3.1278
LDL-C Laboratory Test	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.260
Macular Exam	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1364
Cup to Disc Ratio	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1402
Optic Disc Exam for Structural Abnormalities	Extensional	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.2.1403
Optic Disc Exam for Structural Abnormalities	Grouping	LOINC	AMA-PCPI	2.16.840.1.113883.3.526.3.1334

Value Set Details

Apply Filters | Clear Filters

Narrow search results by selecting from pull-down menus below:

CMS eMeasure (NQF Number)
Select

Quality Data Model Category
Select

Steward
Select

Meaningful Use Measures
FY 2014 EH, CY 2014 EP

Code System
LOINC

Search the NLM Value Set Repository

Query: Enter value set id, codes, words... Search

Search Results | Value Set Details

Value Set Information Available Updates: Approved By Steward Expansion Versions: MU2 Update 2017-01-06 Export Value Set Results (Excel)

Metadata | Description | Measure

Name: Neutrophil count
Type: Extensional
Steward: Lantana
OID: 2.16.840.1.113883.3.666.5.1035
Definition Version: 20160331
Program: CMS, MU2 Update 2017-01-06 using this value set

Value Set Members

Expanded Code List

View | Toggle | Clear Page 1 of 1 20 View 1 - 14 of 14

Code	Descriptor	Code System	Version	Code System OID
23761-0	Neutrophils/100 leukocytes in Blood by Manual count	LOINC	2.54	2.16.840.1.113883.6.1
30229-9	Band form neutrophils [#/volume] in Blood by Automated count	LOINC	2.54	2.16.840.1.113883.6.1
32200-8	Segmented neutrophils/100 leukocytes in Blood by Automated count	LOINC	2.54	2.16.840.1.113883.6.1
35332-6	Band form neutrophils/100 leukocytes in Blood by Automated count	LOINC	2.54	2.16.840.1.113883.6.1
751-8	Neutrophils [#/volume] in Blood by Automated count	LOINC	2.54	2.16.840.1.113883.6.1
753-4	Neutrophils [#/volume] in Blood by Manual count	LOINC	2.54	2.16.840.1.113883.6.1
761-7	Neutrophils [#/volume] in Urine by Automated count	LOINC	2.54	2.16.840.1.113883.6.1
763-3	Band form neutrophils [#/volume] in Blood by Manual count	LOINC	2.54	2.16.840.1.113883.6.1
764-1	Band form neutrophils/100 leukocytes in Blood by Manual count	LOINC	2.54	2.16.840.1.113883.6.1

VSAC Authoring Tool – Query for Codes

Code Systems | UMLS Concepts | My Value Sets

Search Code System

Query: neutrophils Search

Filter By

Code System: LOINC

- All
- CDCREC
- CDT
- CPT
- CVX
- HCPCS
- HSLOC
- ICD10CM
- ICD10PCS
- ICD9CM
- LOINC
- NCI
- NUCCPT
- RXNORM
- SNOMEDCT
- SOP
- UMLS
- ***HL7V2.5***
  - AdministrativeSex
  - DischargeDisposition

LOINC

Include inactive codes

Criteria: neutrophils

Code

← Add to Value Set | Page 1 of 29 | 20

Code	Descriptor	Code Systen	TT			
11115-3	Neutrophils/100 cells in Bone marrow by Manual count	LOINC	LC			
14277-8	Neutrophil cytoplasmic Ab.classic [Titer] in Serum by Immunofluorescence	LOINC	LC			
14278-6	Neutrophil cytoplasmic Ab.perinuclear [Titer] in Serum by Immunofluorescence	LOINC	LC			
16290-9	Neutrophils [Presence] in Stool	LOINC	LC			
17346-8	Neutrophil Ab [Presence] in Serum by Immunofluorescence	LOINC	LC	Laboratory	Yes	2.56
17347-6	Neutrophil Ab [Units/volume] in Serum by Immunofluorescence	LOINC	LC	Laboratory	Yes	2.56

What are Value Sets Used For?

- Clinical Quality Measurement (67%)
- Clinical Data Registries
- Computable Clinical Phenotyping from EHRs
- Public Health Reporting
- Electronic Lab Reporting
- EHR Structured Documents (C-CDA)
- Reportable Conditions Alerts (RCKMS)
- National and International EHR Patient Summary Exchange

Clinical Quality Measure
(implementation)

Hemoglobin A1c Test for Pediatric Patients

List of LOINC codes

Tests for HbA1c

Numerator: # diabetic patients [age 5-17] *tested for HbA1c*

Denominator: # diabetic patients [age 5-17]

Type 1 or Type 2 diabetes
[Excludes gestational diabetes]

List of SNOMED CT or
ICD-10-CM codes

Data Element

Requires date of birth

Current Value Set Contributors in VSAC

American Academy of Neurology
American Nurses Association
American Society of Clinical Oncology
Austin Regional Clinic
Centers for Medicare and Medicaid Services
Children's Hospital of Philadelphia
Emergency Care Research Institute
Federal Health Interoperability Modeling and Standards
Minnesota Community Measurement
National Minority Quality Forum
Pharmacy e-Health Information Technology Collaborative
Council of State and Territorial Epidemiologists
Vanderbilt University Electronic Medical Record and Genomics Network

Example API Call and Resulting XML

Use Case

Retrieve all value sets and metadata for value set OID **2.16.840.1.113762.1.4.1095.51**

API Code

GET https://vsac.nlm.nih.gov/vsac/svs/**RetrieveMultipleValueSets?id=2.16.840.1.113762.1.4.1095.51**&ticket=ST-1309720-6jasRzoISNuFUtKyN9fK-cas

Resulting XML

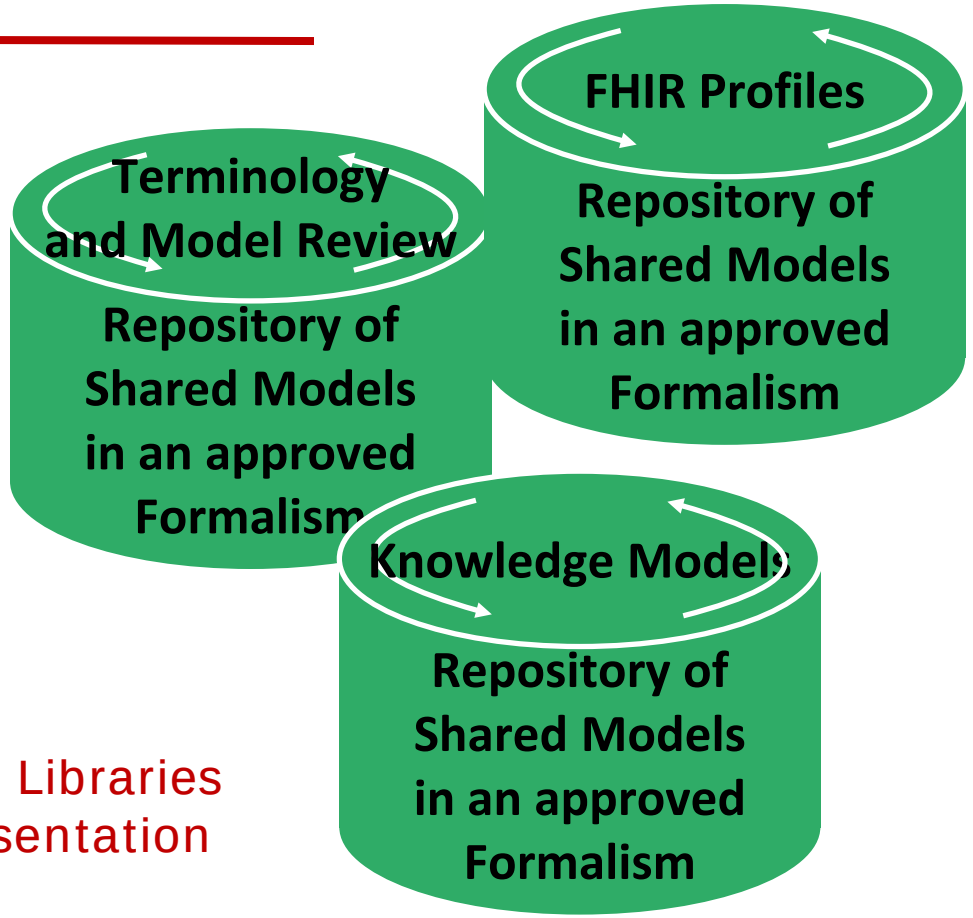

```
– <ns0:RetrieveMultipleValueSetsResponse>
 -<ns0:DescribedValueSet ID="2.16.840.1.113762.1.4.1095.51" displayName="Enteral Nutrition Composition" version="20160929">
  +<ns0:ConceptList></ns0:ConceptList>
    <ns0:Source>Academy of Nutrition and Dietetics</ns0:Source>
   – <ns0:Purpose>
      (Clinical Focus: Enteral formulas and modular components intended for infants, children and adults),(Data Element Scope: These terms are part of an
      intervention/recommendation for nutrition care via enteral delivery.),(Inclusion Criteria: Any formula or modular component that alone or together with
      another substance constitute an enteral formula for an individuals.),(Exclusion Criteria: Nutrition components administered via IV or per oral consumption.)
    </ns0:Purpose>
   – <ns0:Definition>
      (2.16.840.1.113762.1.4.1095.50:Enteral Nutrition Composition)
    </ns0:Definition>
    <ns0:Type>Grouping</ns0:Type>
    <ns0:Binding>Dynamic</ns0:Binding>
    <ns0:Status>Active</ns0:Status>
...truncated
```

VSAC Summary

- Agnostic tools
- Standard terminologies enable semantic interoperability
- Computational data comparison: requires semantic interoperability

WHAT IS THE ROLE OF THE LIBRARY IN FOSTERING…

- Consistent definitions of data elements
- Standard data exchange
- Standardized knowledge representation and content exchange



Terminology and Model Libraries
Clinical Content Representation

Reaching NLM

https://vsac.nlm.nih.gov

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