High-Reliability Health Care Systems and the National Library of Medicine: Making it Happen

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Director
National Library of Medicine
We’re all on a journey together to improve health and health care!
Let me know what’s on your mind – let’s make this an engagement, not entertainment!

Can you name one high-reliability health care system?

Besides cataloging great studies, what does NLM do?

How does a library help a hospital thrive?
High Reliability Health Care Systems

- Condition of persistent mindfulness within an organization
- Cultivate resilience by relentlessly prioritizing safety over other performance pressures
# Idealized characteristics of High Reliability Health Care Systems

| Preoccupation with Failure                  | • Heightened vigilance  
|                                            | • Awareness of plausible threats |
| Reluctance to Simplify                     | • Appreciates complexity  
|                                            | • Recognizes variability & standardized |
| Sensitivity to operations                  | • Benefits from situational awareness  
|                                            | • Current state -> future consequences |
| Deference to expertise                     | • People closest to the work are most knowledgeable  
|                                            | • Org climate encourages exchange |
| Commitment to resilience                   | • Unpredictability is a norm  
|                                            | • Multiple points of monitoring |

Why do most health care systems miss the mark for HIGH RELIABILITY?

• Fuzzy organizational boundaries
  – Not just across health care providing services (e.g. handoffs) but also interdependencies across industrials with widely different incentives

• Culture
  – “low expectations”
  – dismissive hierarchies
  – intimidation
How does a health care system achieve HIGH RELIABILITY?
BEYOND STANDARDIZATION

• Nimbleness
• Rapid Response
• Robust process improvement (RPI)—a combination of lean, six sigma, and change management
The National Library of Medicine role in advancing high reliability health care
Translating Knowledge into Health
How the NLM helps
The partnership between NLM, Administrators, Clinicians & PATIENTS

- Design and deliver care processes uncovered through inquiry and supported by research
- Use data effectively in the research process
- Transform practice by research
- Shape public dialogue and policies
  - patient privacy
  - social good
What does the NLM do to enhance High Reliability Health Systems?

- Enhance Information Delivery
- Streamline Identity and Access Management
- Foster Common Data Elements
- Curate Value Sets
Enhance information delivery
Literature is the primary repository of knowledge
PubMed Daily Usage

- 27+ million articles
- 2.5 million users daily
- ~3 million searches
- 9 million page views

- North America: 40%
- South America: 4%
- Europe: 23%
- Asia: 25%
- Africa: 4%
- Oceania: 4%
Why IMPROVE search?

- 27M articles
- 1M each year
- 2 per minute

Image: goo.gl/FLCjZP
Today’s user search behavior

- “The best place to hide a dead body is page 2 of search results”

Most (>80%) clicks happened in top 20 positions.
Over half of PubMed queries return more than 20 results.
Motivation

• To improve **search quality**: help users to find the most relevant & high-quality information efficiently

• To improve **usability**: help users to have better experience with their literature needs
What is PubMed Labs?

PubMed Labs is a test site where we are experimenting with new features and tools that eventually may be incorporated in PubMed, in their current or a revised form based on the input we receive. Please try the site and let us know what you think.
Search Results Page

Influenza vaccine effectiveness in the 2011-2012 season: protection against each circulating virus and the effect of prior vaccination on estimates.
BACKGROUND: Each year, the US Influenza Vaccine Effectiveness Network examines the effectiveness of influenza vaccines in... Overall adjusted vaccine effectiveness was 47% (95% confidence interval [C...

Effectiveness of seasonal influenza vaccine in community-dwelling elderly people: a meta-analysis of test-negative design case-control studies.
BACKGROUND: The application of test-negative design case-control studies to assess the effectiveness of influenza vaccine... confounding bias by risk factors is limited by design. We aimed to assess the...

Efficacy and effectiveness of live attenuated influenza vaccine in school-age children.
Evidence of high efficacy of live attenuated influenza vaccine (LAIV) from randomized controlled trials is strong for... that included 'FluMist', 'LAIV', 'CAIV', 'cold adapted influenza vaccine', 'live attenuated...
Relevance based retrieval
(2017)

Best matches for otitis media treatment:
- Otitis media: diagnosis and treatment
- Effectiveness of conservative treatment in the management of secretory otitis media
- Complementary and alternative medicine for pediatric otitis media

Anonymous PubMed search logs
Training data
Learning-to-rank algorithm
150+ features

Offline
Online

Pubmed
Best Match ranking model
Top 500 returned articles by relative term frequency
Snippets (w/ highlighted keywords)

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**Efficacy** and **effectiveness** of live attenuated influenza vaccine in school-age children.
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Efficacy and Effectiveness of Live Attenuated Influenza Vaccine in School-Age Children

Kathleen Coelingh, Ifedapo Rosemary Olajide ... Ram Yogev

Abstract

Evidence of high efficacy of live attenuated influenza vaccine (LAIV) in randomized controlled trials is strong for children 2-6 years of age and young children < 2 years of age. We reviewed the published data on efficacy of LAIV in school-age children ≥5 years. QUOSA (Elsevier database) was searched for randomized controlled trials that included 'FluMist', 'LAIV', 'CAIV', 'cold adapted influenza vaccine', 'live attenuated cold adapted' or 'live attenuated influenza vaccine' and compared randomized controlled trials, effectiveness and indirect protection against influenza A and B strains. Our systematic review demonstrates that LAIV has considerable efficacy and effectiveness in school-age children.

Keywords: effectiveness; efficacy; influenza vaccine; live attenuated influenza vaccine; school-age children.

DOI: 10.1586/14760584.2015.1078732
Manage Access and Identity Management at Scale

Who Are YOU?

What data are in here?

Do YOU have rights to this data?

Data Commons

Remote Host Service

Authentication Service

Registry Service

Access Control Service

Research Repository

(to be published in future)
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.

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, including the value sets in the Value Set Authority Center (VSAC).

Search
Search for individual data elements, by definition, users or sources. Search for sets of data elements ("boards") identified by a particular group for a particular use (e.g. particular research solicitation).

Compare / Harmonize
Analyze and resolve differences between data elements. Assure that your forms are using variables that will be usable by certified EHRs.

Create
Draw upon the experience of colleagues and others to design unique data elements and measures.
Common Data Elements
Make data findable, interoperable

- Structured human & machine readable definitions of NIH CDEs allowing
  - Search for individual CDE or sets per programs
  - Compare & harmonize similar but distinct CDEs
  - Select or create CDEs with minimal duplication
Value Set Authority
What is a Value Set?

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.
VSAC – Search Value Sets

Search the NLM Value Set Repository

Search Results

Matched Value Sets

<table>
<thead>
<tr>
<th>Name</th>
<th>Type</th>
<th>Code System</th>
<th>OID</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare Agent or Proxy Choices</td>
<td>Extension</td>
<td>LOINC</td>
<td>2.16.840.1.113762.1.4.1046.35</td>
</tr>
<tr>
<td>Advance Care Plan Personal Commitment Level</td>
<td>Extension</td>
<td>LOINC</td>
<td>2.16.840.1.113762.1.4.1046.37</td>
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<td>Personal Coal Preference and Priority Choices</td>
<td>Extension</td>
<td>LOINC</td>
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<tr>
<td>Heart Rate</td>
<td>Grouping</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Standardized Tools for Assessment of Cognition</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
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<td>AMA-PCCI</td>
</tr>
<tr>
<td>HCV Antibody Test</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Systolic Blood Pressure</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Ejection Fraction</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Tobacco Use Screening</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
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<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>LDL-C Laboratory Test</td>
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<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Macular Exam</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Cup to Disc Ratio</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
<tr>
<td>Optic Disc Exam for Structural Abnormalities</td>
<td>Extension</td>
<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
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<td>LOINC</td>
<td>AMA-PCCI</td>
</tr>
</tbody>
</table>

Code System

Select

- CMS eMeasure (NQF Number)
- Quality Data Model Category
- Steward
- Meaningful Use Measures
- Code System

 NIH
 U.S. National Library of Medicine
### Value Set Details

**Search the NLM Value Set Repository**

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

**Value Set Information**
- Available Updates: Approved By Steward
- Expansion Versions: MU2 Update 2017-01-06

**Metadata**
- **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**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>23761-0</td>
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<td>LOINC</td>
<td>2.54</td>
<td>2.16.840.1.113883.6.1</td>
</tr>
</tbody>
</table>
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


Resulting XML

```xml
<ns0:RetrieveMultipleValueSetsResponse>
  <ns0:DescribedValueSet ID="2.16.840.1.113762.1.4.1095.51" display="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:ConceptList>
      <ns0:Type>Grouping</ns0:Type>
      <ns0:Binding>Dynamic</ns0:Binding>
      <ns0:Status>Active</ns0:Status>
    </ns0:ConceptList>
  </ns0:DescribedValueSet>
</ns0:RetrieveMultipleValueSetsResponse>
```
...truncated
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**

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

**Denominator:**  
# diabetic patients [age 5-17]

- Type 1 or Type 2 diabetes  
  [Excludes gestational diabetes]
- Requires date of birth

List of SNOMED CT or ICD-10-CM codes

List of LOINC codes

Tests for HbA1c

Data Element

Slide adapted from O. Bodenreider
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
Transforming Information into Discovery

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

NLMTownHall@mail.nih.gov
Accelerate discovery and advance health through data-driven research

Goal 1

1.1 Connect the resources of a digital research enterprise
1.2 Advance research and development in biomedical informatics and data science
1.3 Foster open science policies and practices
1.4 Create a sustainable institutional, physical, and computational infrastructure
Fostering a ecosphere of discovery
digital research objects
Goal 2

2.1 Know NLM users and engage with persistence
2.2 Foster distinctiveness of NLM as a reliable, trustable source of health information and biomedical data
2.3 Support research in biomedical and health information access methods and information dissemination strategies
2.4 Enhance information delivery

Reach more people in more ways through enhanced dissemination and engagement
The 21st Century Collection

COLLECT | CONNECT | KNOW

- Innovative attribution
- Automated curation
- Personalized presentation & delivery
Goal 3

3.1 Expand and enhance research training for biomedical informatics and data science
3.2 Assure data science and open science proficiency
3.3 Increase workforce diversity
3.4 Engage the next generation and promote data literacy

Build a workforce for data-driven research and health

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