Changing Currents:
Finding Opportunity in Turmoil

Betsy L. Humphreys
Deputy Director
National Library of Medicine
blh@nlm.nih.gov

Constants

- Change
- Human Nature
- Our missions (if defined properly)
- Importance of Community Engagement

Constantly changing

- Knowledge relevant to medicine and health
- Information volume, format, availability, cost
- Information technology & delivery channels
- Environments in which information is used
- User expectations & needs
- Government policy affecting all of the above

General Theme: Transparency*

- Public Access to Information & Data
- Meaningful Use of Electronic Health Records
- Funded & Regulated Research/Researchers
- Community Benefit

* More information and data available, but ALSO more required to be submitted and/or released
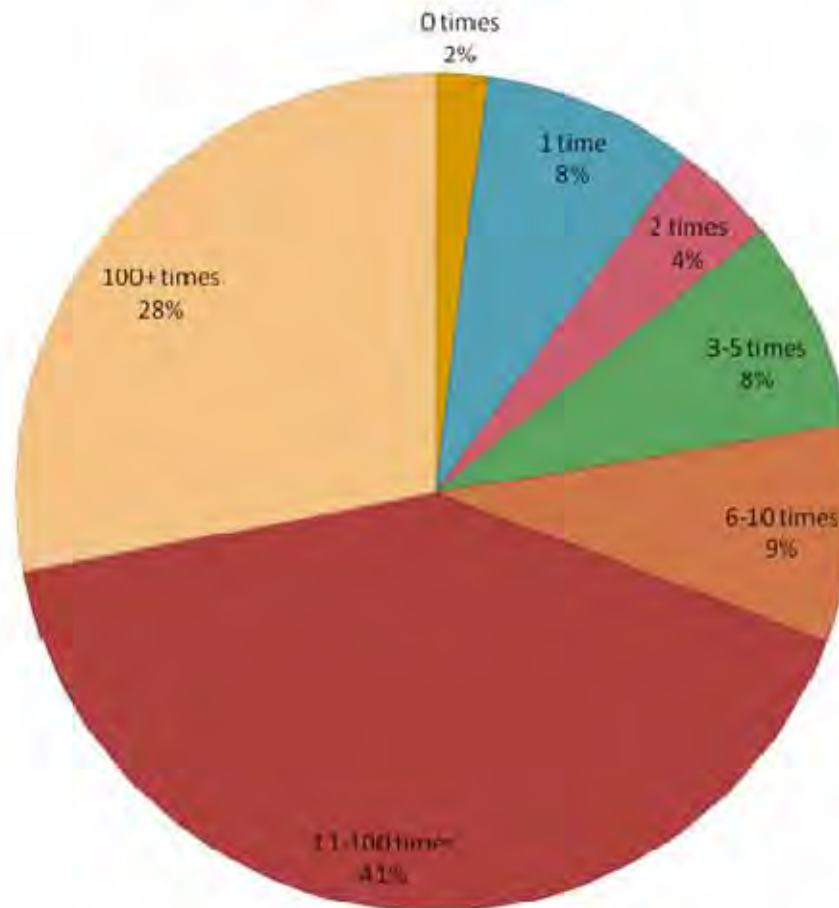
Electronic Full Text Articles

(as of Oct. 1, 2010; data from PubMed LinkOut)

	Total citations	% Linked to full text	% Linked to free text 2006
All PubMed	20,209,357	56.6%	15.1% 7.7%
1990 on	11,376,343	76.8%	18.9% 12.3%
2000 on	7,013,404	87.4%	21.9% 16.2%
2010 on	677,911	93.8%	11.6%

PubMed Central Article Request Frequency - calendar 2009
Available: 1.9 Million Articles
Used: 98%, Used > 10 times: 69%

0 times
2%

1 time
8%

2 times
4%

3-5 times
8%

6-10 times
9%

11-100 times
41%

100+ times
28%

<JATS-Con>

Journal Article Tag Suite Conference

November 1-2, 2010
Natcher Conference Center (Bldg 45) on
the NIH Campus in Bethesda, MD

JATS-Con is the first of what we hope will be an annual series of conferences for users of the Journal Article Tag Suite, that is, users of any of the NLM DTDs. JATS-Con is a peer-reviewed conference with a broad range of content on the Tag Suite from the technical to publishing theory — and the latest news on the Tag Suite.

Who should attend?

Anyone who is using or planning to use one of the "NLM DTDs" or a variation of the DTDs to publish, author, archive, or interchange journal articles or other documents. We are expecting a mix of publishers, XML developers, tool builders, and librarians for the first meeting.
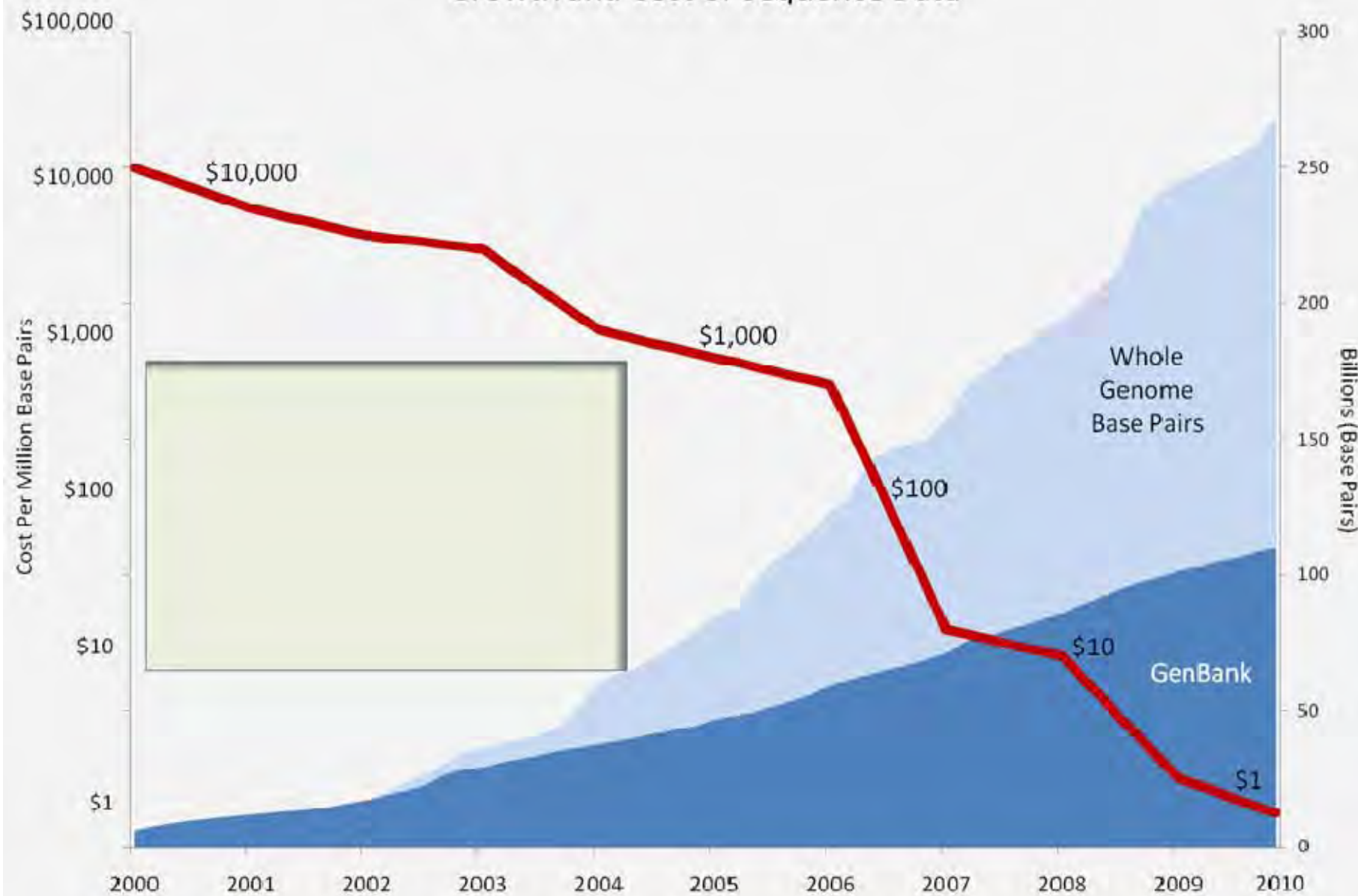
JATS-Con is hosted by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine on the National Institutes of Health Campus in Bethesda MD. See http://www.nih.gov/about/visitor/index.htm for information on visiting the NIH Campus. Please note that as of October 1, 2008, the use of all tobacco products is prohibited on the NIH Campus.
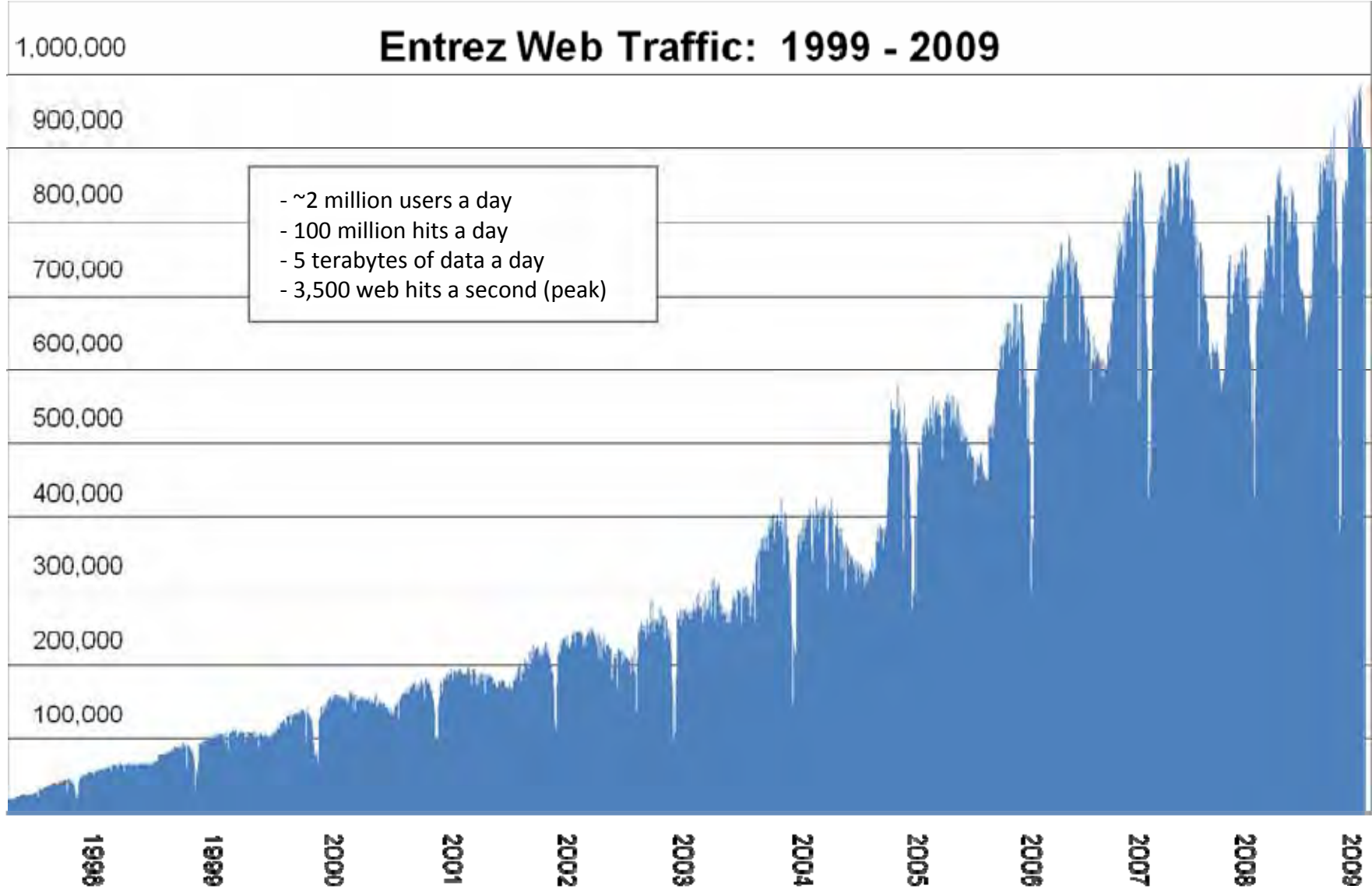
There is no cost for participation in the conference; however, pre-registration is required.

We are also trying to collect as much information on the use of the Tag Suite as we can to share at the meeting. Even if you cannot make the conference but would like to share how you are using the Journal Article Tag Suite with the community, please fill out our User Survey.

The Conference Committee

Growth and Cost of Sequence Data

Entrez Web Traffic: 1999 - 2009

- ~2 million users a day
- 100 million hits a day
- 5 terabytes of data a day
- 3,500 web hits a second (peak)

Many Non-NLM Apps (mobile & otherwise) Use NLM databases

such as PubMed, PubMed Central, ClinicalTrials.gov, Genetic databases, drug information (Pillbox, DailyMed,etc.) UMLS resources, etc.

NLM has long history of promoting use of its data in outside apps, products, and systems (e.g., in commercial CD-ROM products in 1980s)

API Access now = 40% of Entrez Use

Total E-utility Requests (30-day average)
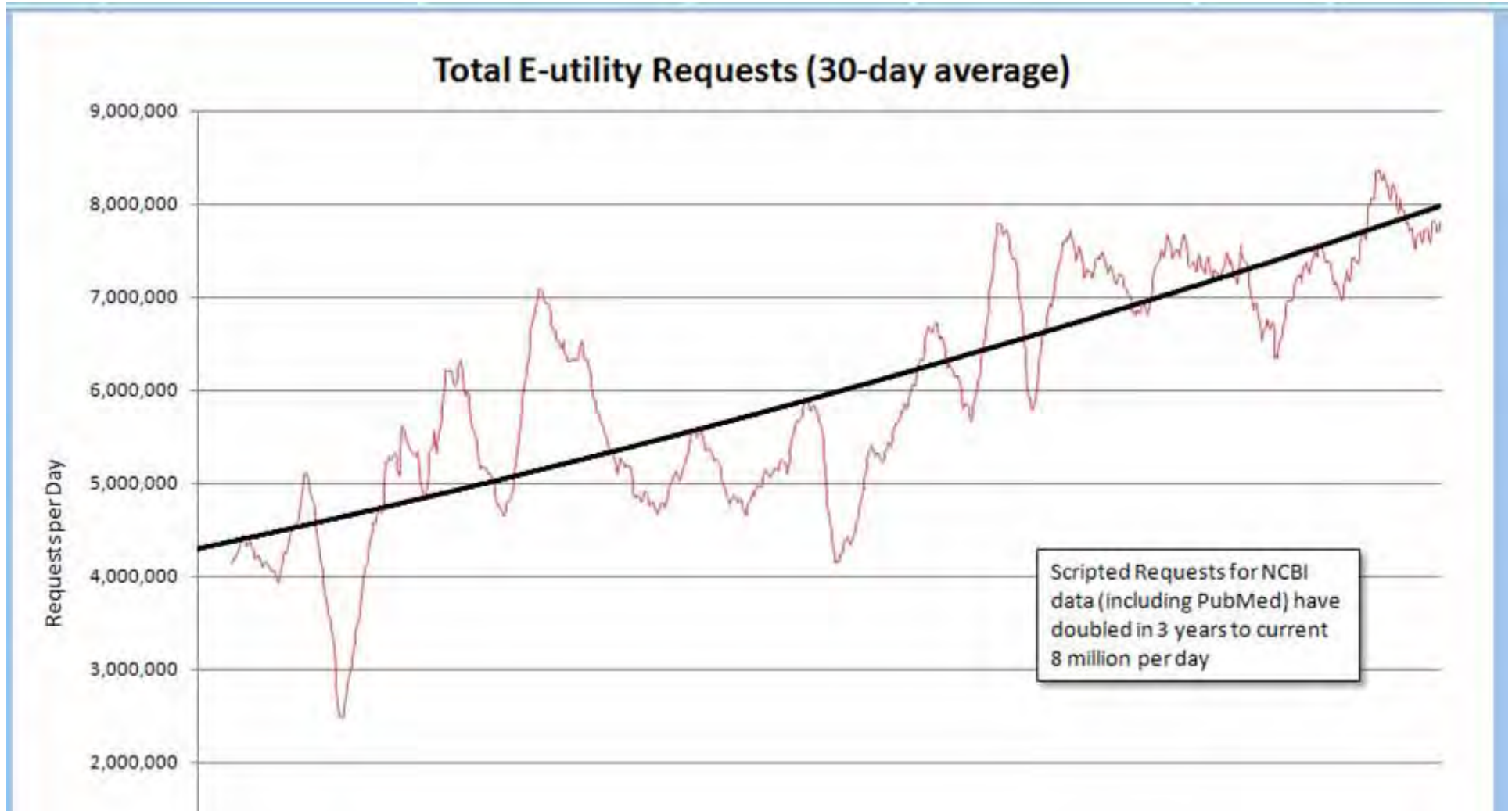
Recently added NLM portal page
Responds to White House Initiatives – Useful in reaching new audiences

NLM APIs

An Application Programming Interface (API) is a set of routines that an application uses to request and carry out lower-level services performed by a computer's operating system. For computers running a graphical user interface, an API manages an application's windows, icons, menus, and dialog boxes.

We invite you to develop computer and mobile applications for National Library of Medicine (NLM) resources. We encourage comments and recommendations for further API development to NLM customer service. Supported NLM APIs are listed below.

NLM Resources with Application Programming Interfaces (APIs)

API Documentation	Web Interface	API Description
Basic Local Alignment Search Tool (BLAST)	↗	API for Basic Local Alignment Search Tool (BLAST) services which find regions of local similarity between sequences. The program compares nucleotide or protein sequences to sequence databases and calculates the statistical significance of matches.
ClinicalTrials.gov	↗	Method for creating links to ClinicalTrials.gov or downloading ClinicalTrials.gov data in XML format. Obtain information including a trial's purpose, who may participate, locations, and phone numbers for more details about clinical trials being conducted throughout the United States and in many countries throughout the world.

NLM Mobile Websites – to accommodate device diversity, e.g.,
http://m.medlineplus.gov   http://m.medlineplus.gov/spanish
Launched in January 2010
3rd Qtr 2010: 270K page views; 110K unique visitors
[Regular sites:182M page views; 41.9M unique visitors]

Page ▾   Tools ▾

HHS.gov/Open

Search

+ − Font Size 🖨 ✉ **OPEN GOV**

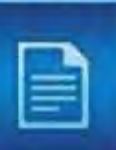**EXPLORE. ENGAGE. ENLIGHTEN.**

Data Sets   Tools   Our Plan   Discuss

Spotlight on

MedlinePlus

An extensive guide to health information resources, MedlinePlus includes common diseases and conditions, dictionaries, organizations, clearinghouses, publications, directories, consumer health libraries, MEDLINE and other medical databases. More details...

MedlinePlus®
Trusted Health Information for You

1 2 3 4 5

> Home   Data Sets   Tools   Our Plan   FOIA   Records Management   Get Involved   Innovate   Discuss   Leadership

The National Library of Medicine's New API Portal

Posted September 21, 2010 | Todd Park

"As we work to make data available through Open Government and data.gov, HHS is also enabling new applications of data to be put to use for many purposes to affect many aspects of health. The NLM API portal is an important step in that direction."

🖋 **Share Your Ideas**

Our Open Government Plan

NLM's Social Media Policy will be on the Web soon

United States
National Library of Medicine
National Institutes of Health

Search NLM Web Site
[ ] Go

NLM Home | Contact NLM | Site Map | FAQs

Follow, Fan and Connect with NLM

There are many ways to connect with NLM. Choose the one for you.

Follow us on Twitter

- **@AIDSinfo**: Updates on HIV/AIDS treatment, prevention, and research from AIDSinfo.
- **@medlineplus4you**: Stay up to date with the latest news and information on health, medicine, and wellness from MedlinePlus.
- **@ncbi**: News, updates and announcements about NCBI resources.
- **@ncbi_pubmed**: The latest about PubMed, LinkOut and more.
- **@NLMGlobalHealth**: Stay informed about activities related to NLM's current exhibit, *Against the Odds: Making a Difference in Global Health*.
- **@nlm_harrypotter**: Follow NLM's Harry Potter exhibit as it travels the USA. The exhibition explores the magical world of Harry Potter and its roots in Renaissance Science.
- **@NLM_LHC**: Find out about new content in Profiles in Science and Genetics Home Reference brought to you by the Lister Hill National Center for Biomedical Communication.
- **@nlm_newsroom**: Daily tweets for the media.
- **@NLM_SIS**: Toxicology, environmental health and disaster information updates.
- **@WomensHealthNIH**: Updates on women's health research being done and funded by NIH.

Fan us on Facebook

- National Library of Medicine (NLM): Covers all of the Library's program areas. Learn what's going on at the largest medical library in the world.
- National Library of Medicine Exhibition Program: Includes information about public exhibitions and
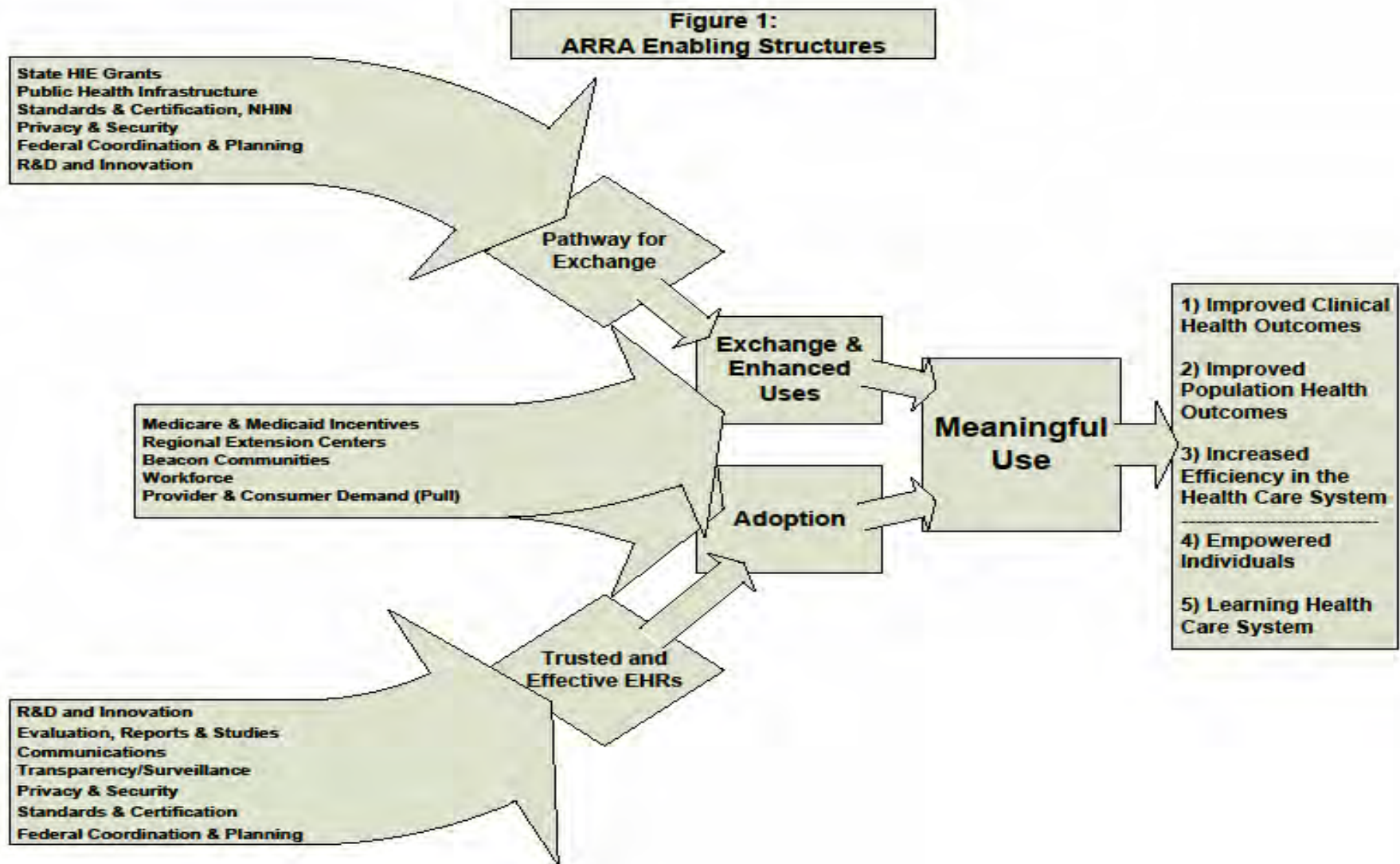
Constantly changing

- Knowledge relevant to medicine and health
- Information content, volume, formats, availability, cost
- Information technology & delivery channels
- Environments in which information is used
- User expectations & needs
- Government policy affecting all of the above

General Theme: Transparency*

- Public Access to Information & Data
- **Meaningful Use of Electronic Health Records**
- Funded & Regulated Research/Researchers
- Community benefit

* More information and data available, but ALSO more required to be submitted and/or released

ARRA HITECH Enabling Structures

Figure 1:
ARRA Enabling Structures

State HIE Grants
Public Health Infrastructure
Standards & Certification, NHIN
Privacy & Security
Federal Coordination & Planning
R&D and Innovation

Pathway for Exchange

Exchange & Enhanced Uses

Medicare & Medicaid Incentives
Regional Extension Centers
Beacon Communities
Workforce
Provider & Consumer Demand (Pull)

Adoption

Meaningful Use

Trusted and Effective EHRs

R&D and Innovation
Evaluation, Reports & Studies
Communications
Transparency/Surveillance
Privacy & Security
Standards & Certification
Federal Coordination & Planning

1) Improved Clinical Health Outcomes

2) Improved Population Health Outcomes

3) Increased Efficiency in the Health Care System
----
4) Empowered Individuals

5) Learning Health Care System

American Recovery & Revitalization Act (ARRA) (2/09)
Health IT for Economic & Clinical Health(HITECH*)*
establishes/funds *(among many other things)*

- Incentives for Medicare/Medicaid providers to implement and demonstrate "meaningful use" of "certified" electronic health records (EHRs)
  - Incentives begin - 2011
  - Non-use penalties begin – 2016

"Meaningful Use" Implementation
The Fine Print

- Centers for Medicare and Medicaid Services (CMS)
  - Eligibility, payment procedures, & phase 1 "meaningful use" criteria (*Final Rule* 7/10)
- Office of the National Coordinator for Health Information Technology (ONC)
  - Standards, implementation specifications & criteria for certification of EHRs, aligned with initial "meaningful use" criteria (*Final Rule* 7/10)
  - Interim certification program (*Final Rule* 6/10) & designation of interim certification bodies (8/10)
- National Institute of Standards and Technology (NIST)
  - Test procedures to be used in interim certification of EHRs (8/10)

"Meaningful Use" Basics

- Slightly different criteria for Eligible Professionals/Hospitals, Medicare/Medicaid
- Requirements planned to escalate: 2011, 2013, 2015
- 2011 Criteria: Core (Mandatory) & *Menu (Up to 5 may be deferred)*
- Requirements in multiple areas:
  - Patient data capture & Orders for drugs, procedures, etc.
  - Exchange of patient data between providers
  - Provision of data & *educational information* to patients
  - Reporting quality measures
  - Privacy/security protections
- *Must* use health data standards to meet some criteria

change between draft and final CMS rules

Example 1

2011 Meaningful Use *Menu* Criterion (CMS Rule)

Objective: Use certified EHR technology to identify patient-specific education resources and provide these resources to the patient if appropriate.

Measure: More than 10% of all unique patients seen/admitted are provided patient-specific education resources.

2011 EHR certification criterion (ONC Rule)

Enable a user to electronically identify and provide patient-specific education resources to, at a minimum, the data elements included in the patient's *problem list*, *medication list*, and *laboratory test results*; as well as provide such resources to the patient.

Chart Health

Welcome to...
MyChart MyHealth

- Communicate with your doctor
- Access your test results
- Request prescription renewals
- View your recent clinic visits

Thanks for using MyChart.
You have been logged out.

MyChartMyHealth ID

Forgot MyChartMyHealth ID?

Password

Forgot Password?

Sign In

MyChart @ Epic Systems Corporation

New User?

Sign Up Now

Learn About Swineflu

Your secure, online health connection

Your health is important to you around the clock—not just during office hours. That's why The Institute for Family Health offers MyChart, MyHealth. With this Internet connection to your doctor's office, you can schedule appointments, request prescription refills, review your health history and more—online, any time!

Learn More...

- FAQs
- Privacy Policy
- Terms and Conditions

Urgent Medical Matters

Please do not use MyChart, MyHealth to send any messages requiring urgent attention. For urgent medical matters, contact your doctor's office.

My Chart My Health

THE INSTITUTE FOR FAMILY HEALTH

Home | Log Out

Welcome, Michelle ...

▼My Medical Record
- Health Summary
- Test Results
- Medications
- Allergies
- Immunizations
- Medical History
- Current Health Issues

►Message Center

►Appointments

►Billing & Insurance

►Administrative

►Preferences

MedLine Plus
Find information on:

[Search]

Health Summary

Use the links to jump directly to a section of your Health Summary.

Current Health Issues | Medications | Allergies | Immunizations

Current Health Issues

Back to Top

Health Issue	Date Noted
DEPRESSION	03/31/2008
DIABETES	10/14/2008
TOBACCO USE	10/14/2008
ELEVATED BLOOD PRESSURE	10/14/2008
ABNORMAL PAP SMEAR (LGSIL)	10/14/2005
POSITIVE PPD	10/14/2008
ROUTINE PHYSICAL EXAM	10/14/2008
SEASONAL ALLERGIES	01/07/2009
HIGH CHOLESTEROL	06/08/2009
SCHIZOPHRENIA	10/26/2009
IMPAIRED RENAL FUNCT DISORDERS NEC	10/26/2009
NERVE DAMAGE FROM DIABETES	10/26/2009
ASTHMA	10/26/2009

MedlinePlus Connect - public release this month

Example 2

2011 Meaningful Use *Core* Criterion (CMS Rule)

Objective: Maintain active medication list

Measure: More than 80% of all unique patients seen/admitted have at least 1 entry (or indication that patient has no currently prescribed medication) recorded *as structured data*

2011 Vocabulary Standard (ONC Rule)

Medications. Standard. Any source vocabulary that is included in *RxNorm*, a standardized nomenclature for clinical drugs produced by the United States National Library of Medicine

"Meaningful Use" *promotes* interest in/use of:

- NLM-supported vocabulary standards:
  - LOINC – Lab test results
  - RxNorm – Medications
  - SNOMED CT – Problem list (1 of 2 options)
- Related resources/tools – UMLS, subsets, mappings to statistical/billing codes, user support services
- Direct connections between EHRs and NLM information services

Due to 2011 requirements AND *signals about future, more stringent requirements*

NO SURPRISE...
Increased Interest/Use = More Demand
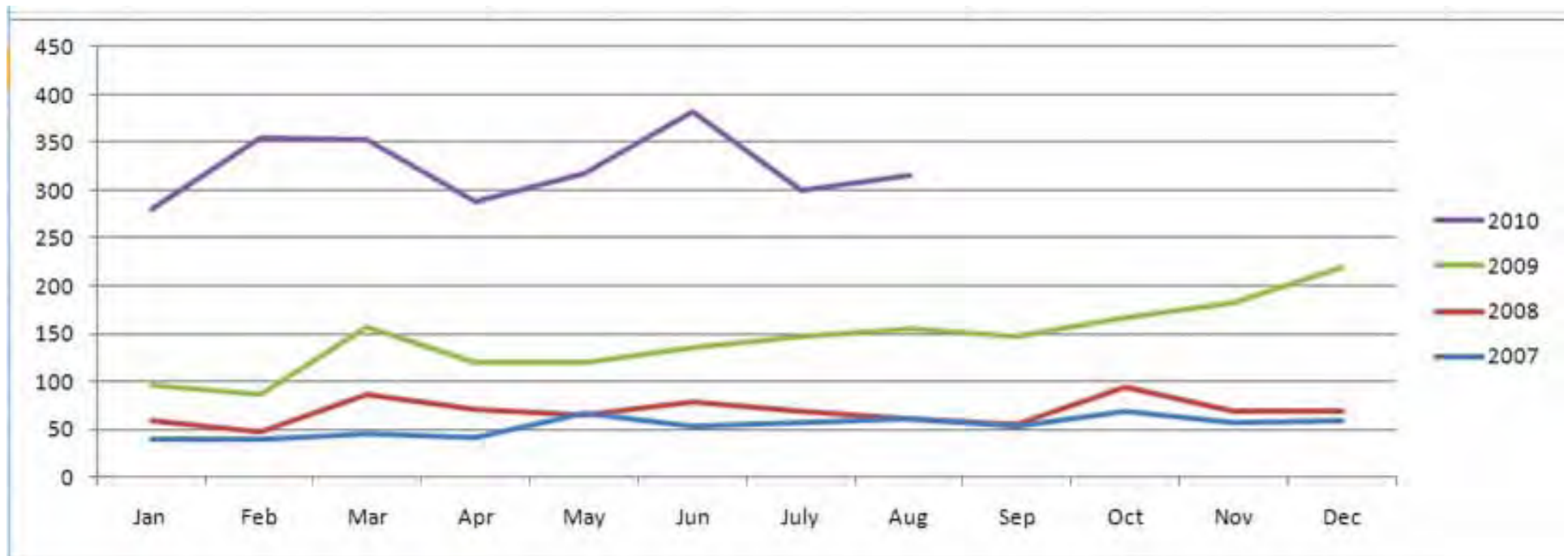
UMLS Licenses Issued Per Month*

2007-August 2010

required for use of SNOMED CT, parts of RxNorm, etc.

LOINC: new subset, search tool (6/10)

RxNorm: Expanded content (6/10)

NLM Adds Veterans Health Administration Drug Terminology, NDF-RT, to RxNorm

New Resource Will Enhance Exchange of Drug Information among Computerized Systems

Effective with the RxNorm release on Monday, June 7th, the National Library of Medicine (NLM), the world's largest medical library and an arm of the National Institutes of Health (NIH), will add the US Department of Veterans Affairs, Veterans Health Administration (VHA) National Drug File-Reference Terminology (NDF-RT) as a source vocabulary in its RxNorm database (http://www.nlm.nih.gov/research/umls/rxnorm/). RxNorm is a standardized nomenclature for clinical drugs, produced by NLM, which includes and links many source vocabularies that are commonly used in pharmacy management and electronic medical record systems.

The June release of RxNorm, including NDFRT, is available at http://download.nlm.nih.gov/umls/kss/rxnorm/RxNorm_full_06072010.zip. A UMLS Metathesaurus license is required and can be obtained free of charge from the same site.

NDF-RT is a terminology used to classify drugs according to their clinical properties, including mechanism of action, physiologic effect, therapeutic category, structural class and the established pharmacologic class used by the FDA. It is an extension of the VHA National Drug File (VANDF), another RxNorm source vocabulary. The addition of NDF-RT to RxNorm is a major step towards achieving interoperability of computerized drug information systems.

RxNorm Access

Year	Number of queries	
2007	8,216	
2008	62,659	
2009	2,298,213	
2010	5,107,774	(Jan-Jun)

RxNav

A Semantic Navigation Tool for Clinical Drugs

Lister Hill National Center for
Biomedical Communications

Launch the RxNorm Navigator

Introduction

RxNav is a browser for RxNorm, the NLM repository of standard names for clinical drugs. RxNav displays links from clinical drugs, both branded and generic, to their active ingredients, drug components and related brand names. RxNorm is one of a suite of designated standards for use in U.S. Federal Government systems for the electronic exchange of clinical health information.
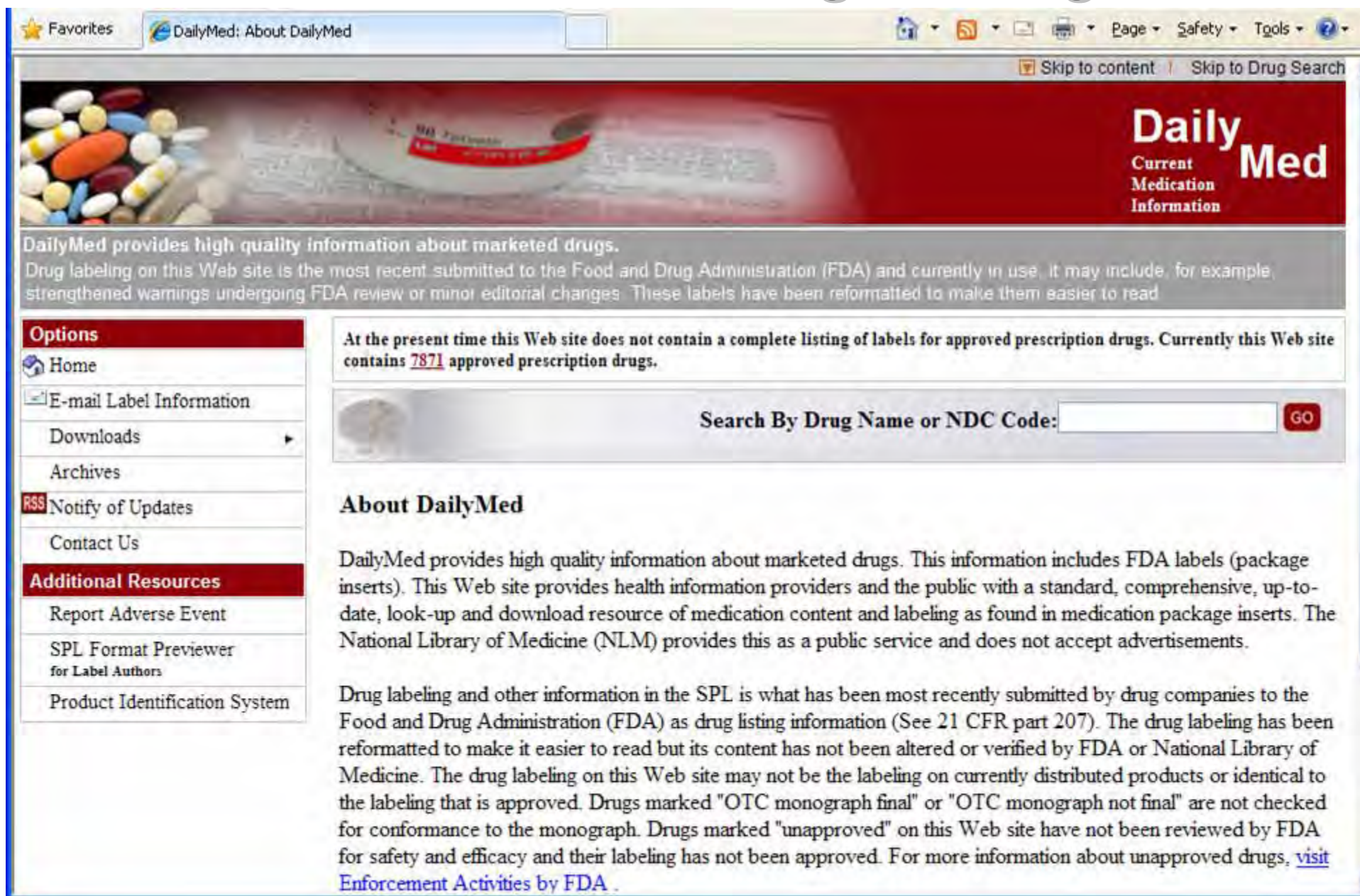
API Users: A RESTful Web API is now available for RxNorm data. See the User's Guide for more details.

▶ RxNorm API (updated 9/07/2010)
▶ RxNav new features (updated 9/07/2010)
▶ Publications
▶ More information on RxNorm

Starting RxNav

To start RxNav, click on "Launch the RxNorm Navigator" if the link is present; Otherwise, click on "Download and install the lastest JRE and the RxNorm Navigator". You will arrive at the Sun download homepage, browse to find the JRE download link, and install it. Then return to this RxNav home page, where the link now should read "Launch the RxNorm Navigator" and RxNav installation will be automatically launched. During installation, you can elect to have the shortcut on your desktop.

Over the counter drugs coming…

United States
National Library of Medicine
National Institutes of Health

Search NLM Web Site

[Go]

NLM Home | Contact NLM | Site Map | FAQs

Unified Medical Language System® (UMLS®)

About the UMLS | FAQs | Customer Support | UMLS Site Map

Home > Biomedical Research & Informatics > UMLS

The CORE Problem List Subset of SNOMED CT®

Data Files
(expect a new version of the subset for each new release of SNOMED CT and the UMLS Metathesaurus)

CORE Problem List Subset Version	Derived from SNOMED CT version	Derived from UMLS Metathesaurus version
SNOMEDCT_CORE_SUBSET_201008	July 2010 International Release	2010AA
SNOMEDCT_CORE_SUBSET_201005	January 2010 International	2010AA

Surge in use; demand for mappings to ICD-9-CM, ICD-10-CM

U.S. National Library of Medicine

Newborn Screening Coding and Terminology Guide

Data Standards for Electronic Reporting

Home | Views | Downloads | HL7 | Resources | Code Standards | About | Contact Us

The goal of the Newborn Screening Coding and Terminology Guide is to promote and facilitate the use of electronic health data standards in recording and transmitting newborn screening test results. The Web site includes standard codes and terminology for newborn tests and the conditions for which they screen, and links to other related sites. The codes and vocabulary standards are provided in a series of tables that you can view on the Web and/or download for your own use. These tables cover conditions recommended for screening by the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) or by a state within the U.S.

Use of these standards can speed the delivery of newborn screening reports, facilitate the care and follow-up of infants with positive test results, enable the use (and comparison) of data from different laboratories, and support the development of strategies for improving the newborn screening process.

This website also includes draft guidance for creating an HL7 version 2.x message using these codes with examples. If you would like us to notify you about updates to this guidance and other new content, please subscribe to the NBS-Announcements e-mail list from the U.S. National Library of Medicine.

You can reach these various resources by picking a choice below.

Views: Generate customized Web views from the tables of conditions and analytes/measurements maintained by the U.S. National Library of Medicine (NLM®).

- Conditions — Conditions that are targeted by newborn screening
- Analytes/Measurements — Tests that are used as markers for newborn screening conditions
- Tailored Views — Specify subsets, or see relationships between conditions and analytes/measurements

Downloads: Download the tables of newborn screening conditions, of markers for these conditions and/or of mappings between conditions and their markers.

Regional Extension Centers

- New Jersey Institute of Technology
  Sebastian@njit.edu

  http://www.njit.edu

- New York eHealth Collaborative (NYeC)
  pwilder@nyehealth.org

  http://www.nyehealth.org

- NYC REACH

  aparsons@health.nyc.gov
  http://www.nycreach.org

State Health Information Exchange
Cooperative Agreement Program

- New Jersey Health Care Facilities Financing Authority
- New York eHealth Collaborative Inc.

Health Information Technology

Get email updates   Follow us on   Contact us

Health IT Home

HITECH & Funding Opportunities

HITECH Programs

Beacon Community Program

State Health Information Exchange Program

HIT Extension Program

Strategic Health IT Advanced Research Projects Program

Community College Consortia to Educate Health IT Professionals

» **Curriculum Development Centers Program**

Program of Assistance for University-Based Training

Competency Examination Program

Federal Advisory Committees

Curriculum Development Centers Program

The purpose of the Curriculum Development Centers Program, one component of the Workforce Program, is to provide funding to institutions of higher education (or consortia thereof) to support health information technology curriculum development. The materials developed under this program will be used by the member colleges of the regional Community College Consortia as well as be available to institutions of higher education across the country.

In April 2010, ONC awarded $10 million in grants to five domestic institutions of higher education to develop curriculum and instructional materials to enhance workforce training programs primarily at the community college level.   One of the awardees under this program, Oregon Health & Science University, will receive additional funding to serve as the National Training and Dissemination Center (NTDC) that will host an in-person training event for community college faculty, establish a secure electronic site from which all materials may be downloaded, collect feedback from instructors and students, and coordinate subsequent revisions of the curriculum materials.

Curriculum Development Centers Program Awardees:

- Oregon Health & Science University $2,720,000 (includes $900,000 for NTDC)

- University of Alabama at Birmingham $1,820,000

- Johns Hopkins University $1,820,000

- Columbia University $1,820,000

- Duke University $1,820,000

Feature

New Regional Extension Centers

The selection of two new Regional Extension Centers (RECs) and expanded coverage for two more RECs completes coverage for all areas of the country.

Quick Links

- ATCBs
- HITECH Programs
- Certification Programs
- Privacy & Security
- Meaningful Use
- HIT Policy

Internet   100%

Community College Consortia to Educate Health Information Technology Professionals in Health Care

NY-NJ Participants

- Bronx Community College – NY
- Brookdale Community College – NJ
- Burlington County College – NJ
- Camden County College – NJ
- Essex County College – NJ
- Gloucester County College – NJ
- Ocean County College – NJ
- Passaic County Community College – NJ
- Raritan Valley Community College – NJ
- Suffolk County Community College – NY
- Westchester Community College - NY

Meaningful Use of Electronic Health Records
Opportunities

- You could help your institution:
  - Keep track of all the announcements, follow what is happening in advisory committees
  - Analyze 2011 requirements & availability of data and EHR capabilities to meet them
  - Refocus quality improvement efforts; find best practice evidence
  - Connect knowledge resources to EHRs
  - Implement standard vocabularies in EHRs –focus on frequently occurring items
  - Think about what broader availability of EHRs can lead to – *for research, education, health care, public health, information delivery*

- You could help Regional Extension Centers (RECs)
  - Increase awareness of relevant resources/tools
  - Educate/train clinician practices/clinics
  - Network with colleagues who are working with RECs

- You could help teach/take advantage of HITECH offerings in local colleges

United States
National Library of Medicine
NLM National Institutes of Health

Home > **Health Information Technology**

Related Sites

Health Information Technology and Health Data Standards at NLM

🖨 **Printer-friendly Version**

> **NLM is the central coordinating body for clinical terminology standards within the Department of Health and Human Services (HHS). NLM works closely with the Office of the National Coordinator for Health Information Technology (ONC) to ensure NLM's efforts are aligned with the goal of the President and HHS Secretary for the nationwide implementation of an interoperable health information technology infrastructure to improve the quality and efficiency of health care.**

▶ **Health Data Standards**

NLM supports the development, enhancement, and distribution of clinically specific vocabularies to facilitate the exchange of clinical data and improve retrieval of health information.

- Clinical Vocabularies supported, licensed, or developed by NLM:
  SNOMED CT | LOINC | RxNorm
- Uniform distribution mechanism for HIPAA and clinical vocabulary standards through the UMLS Metathesaurus
- SNOMED CT Subsets:
  - CORE Problem List Subset of SNOMED CT
  - UMLS Enhanced VA/KP Problem List Subset of SNOMED CT

NLM distributes FDA approved Structured Product Labels linked to RxNorm and related medication information:

- DailyMed

NLM coordinates efforts to develop mappings between HIPAA code sets and standard clinical vocabularies.

- SNOMED CT to ICD-9-CM | SNOMED CT to CPT | LOINC to CPT

Related Sites

HealthIT (U.S. Government Health Information Technology Web Site)

Office of the National Coordinator for Health Information Technology (ONC)

AHRQ National Resource Center for Health IT

USHIK (United States Health Information Knowledgebase)

NIH Initiatives

Clinical and Translational Science Awards

CaBIG (Cancer Biomedical

The Office of the National Coordinator for
Health Information Technology

Search [____] GO

Get email updates ✉   Follow us on ⓔ   Contact us ⬛

» **Health IT Home**

HITECH & Funding Opportunities

HITECH Programs

Federal Advisory Committees

Regulations & Guidance

ONC Initiatives

Outreach, Events, & Resources

About ONC

Health IT Buzz Blog

Federal Advisory Committee Blog

Health IT Journey
Stories from the road

Home

Secretary Sebelius announces final rules to support meaningful use of electronic health records.

PAUSE II

Meaningful Use

Certification Program

Privacy and Security

HITECH Programs

On the Frontlines of Health Information Technology

Federal Advisory Committees

Feature

New Regional Extension Centers

The selection of two new Regional Extension Centers (RECs) and expanded coverage for two more RECs completes coverage for all areas of the country.

Why Health IT?

Health information technology (health IT) makes it possible for health care providers to better manage

What's New

› **Certified Health IT Product List (CHPL)**

General Theme: Transparency*

- Public Access to Information & Data

- Meaningful Use of Electronic Health Records

- Funded & Regulated Research/Researchers

- Community Benefit

* More information and data available, but ALSO more required to be submitted and/or released

NPRM in Development: FDAAA clinical trials reporting

FDAAA Clinical Trials Reporting NPRM

- Scope
  - Clarify statutory requirements for registration and basic results reporting
  - Address possible expansion of results reporting requirements, e.g.,
    - Unapproved products
    - Narrative technical and/or lay summaries
    - Submission of protocol documents

An increasingly important source of results data for IRBs & systematic reviews

ClinicalTrials.gov
A service of the U.S. National Institutes of Health

Search

List Results   Refine Search   Results by Topic   Results on Map   Search Details

Found 2367 studies with search of: Studies With Results

Hide studies that are not seeking new volunteers.

Display Options

Rank	Status	Study
1	Completed Has Results	**BAY43-9006 - Phase II in Advance Breast Cancer** Conditions: Cancer; Breast Cancer Intervention: Drug: Nexavar (Sorafenib, BAY43-9006)
2	Completed Has Results	**Comparative Study of Gemcitabine,Cisplatin and Radiation Versus Cisplatin and Radiation in Cancer of the Cervix** Condition: Cancer of Cervix Interventions: Drug: Gemcitabine; Drug: Cisplatin; Radiation: Brachytherapy; Radiation: Pelvic radiation
3	Completed Has Results	**Follow-up Study 16-20 Years After Primary Vaccination Against Hepatitis B of Newborns From HBeAg+ & HBsAg+ Mothers** Condition: Hepatitis B Intervention: Biological: Engerix™-B
4	Completed Has Results	**A Placebo-Controlled Study of Safety and Effectiveness of Myozyme (Alglucosidase Alfa) in Patients With Late-Onset Pompe Disease** Conditions: Pompe Disease (Late-onset); Glycogen Storage Disease Type II (GSD-II); Acid Maltase Deficiency Disease; Glycogenosis 2 Interventions: Biological: alglucosidase alfa; Drug: Placebo
5	Completed Has Results	**Study Evaluating the Efficacy and Safety of Pantoprazole in Infants With Symptomatic Gastroesophageal Reflux Disease (GERD)** Condition: Gastroesophageal Reflux Interventions: Drug: pantoprazole; Drug: Placebo
6	Completed Has Results	**A Clinical Trial To Assess Fesoterodine On Treatment Satisfaction And Symptom Improvement In Overactive Bladder Patients** Condition: Overactive Bladder Intervention: Drug: fesoterodine fumarate
7	Active, not	**RCT of ChondroCelect® (in an ACI Procedure) vs Microfracture in the Repair of Cartilage Defects of the Knee**

http://report.nih.gov/

Page ▾ Tools ▾

VIVO
enabling national
networking of scientists

Search

Home   About   Download   Support   Contact

An interdisciplinary national network

Find out how your institution can participate

Enabling collaboration and discovery between scientists across all disciplines.

The national network of scientists will facilitate the discovery of researchers and collaborators across the country. Institutions will participate in the network by installing VIVO, or by providing semantic web-compliant data to the network.

VIVO Conference 2011
August 24-26, 2011
Gaylord Hotel & Conference Center, Washington DC

VIVO Conference 2010

In the Press

August 1, 2010
VIVO: A Digital Matchmaker for Scientists
Source: NSF Current

Events

Mid Atlantic Chapter of the Medical Libraries Association
Oct 15 - Oct 19, 2010
Chapel Hill, NC

Blog

SEP 25 VIVO and the Linking Open Data Cloud

CKAN, the open registry of data and content

General Theme: Transparency*

- Public Access to Information & Data

- Meaningful Use of Electronic Health Records

- Funded & Regulated Research/Researchers

- **Community Benefit**

* More information and data available, but ALSO more required to be submitted and/or released

Community Engagement

- An enduring opportunity to help yourself as a by-product of helping others
  - Health information outreach
  - Health Literacy – interaction with Health IT, Health insurance reform
  - Disaster preparedness (**DISASTR-OUTREACH-LIB Listserv**)
  - Research based on community priorities – assessment, interventions, "measuring the difference"

Please fill out the following form. You cannot save data typed into this form.
Please print your completed form if you would like a copy for your records.

Highlight Field

Form **13790** (May 2006)	**COMPLIANCE CHECK QUESTIONNAIRE** **TAX-EXEMPT HOSPITALS**	OMB No. 1545-2015

*This questionnaire asks for information about your hospital and how it operates. Answer the questions based on your hospital's **most recently completed tax period**. If additional space is needed, attach additional sheets. Please complete the questionnaire and follow the instructions in the letter for returning the information to us.*

PART I – ORGANIZATION

Name of Hospital:	EIN:	Most Recently Completed Tax Period:

PART II – OPERATIONS

1) Please indicate the category below that best described your hospital or the type of service it provided to the majority of admissions. **Check only one box.**

☐ General medical and surgical
☐ Hospital unit of an institution *(prison, college etc)*
☐ Hospital unit within an institution for the mentally retarded
☐ Surgical
☐ Psychiatric
☐ Tuberculosis and other respiratory diseases
☐ Cancer
☐ Heart
☐ Alcoholism and other chemical dependency
☐ Organization is not a §501(c)(3) hospital. If you checked

☐ Obstetrics and gynecology
☐ Eye, ear, nose and throat
☐ Rehabilitation
☐ Orthopedic
☐ Chronic disease
☐ Institution for the mentally retarded
☐ Acute long-term care
☐ Other — Specify:

The IRS – a new friend of librarians in non-profit hospitals…

NLM Associate Fellows
Help Recruit Great People for Great Opportunities

Stephen Kiyoi, Julie Adamo, Salima M'seffar, Caitlin Sticco, Kristen Greenland, Kristen Burgess.

Betsy L. Humphreys
Deputy Director
National Library of Medicine
blh@nlm.nih.gov