



U.S. Department of
Health and Human
Services



National Institutes
of Health



National Heart, Lung,
and Blood Institute

Michael Twery
National Heart, Lung, and Blood Institute

Polysomnographic Data Sharing: An NIH Perspective

January, 2006

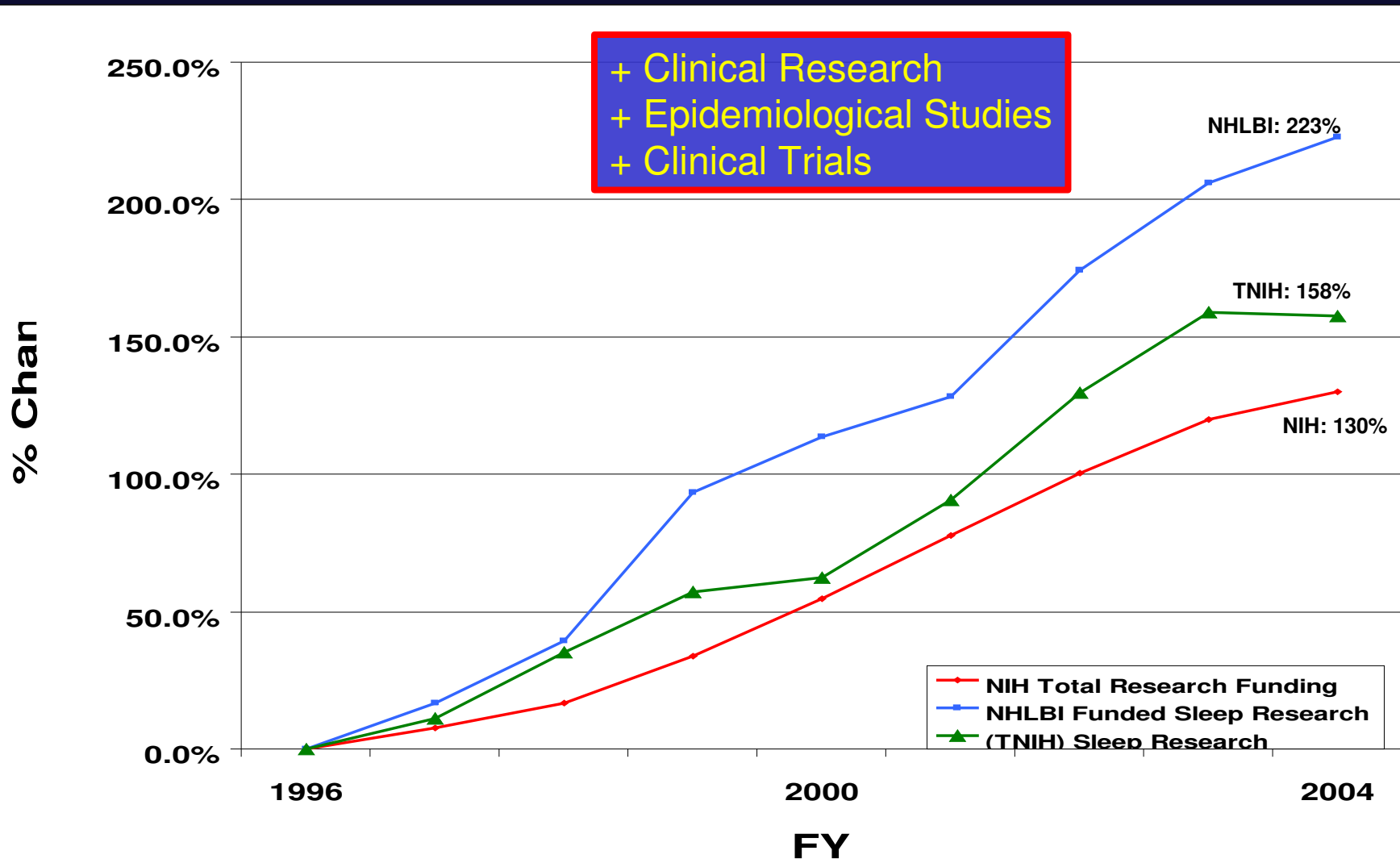


Trans-NIH Sleep Research Coordination

NHLBI	Michael Twery, PhD
NIA	Andrew Monjan, PhD
NIAAA	Ellen Witt, PhD
NIAMS	Deborah Ader, PhD
NCI	Ann O'Mara, PhD, MPH, RN
NICHD	Marian Willinger, PhD
NCCAM	Nancy Pearson, PhD
NIDA	Harold Gordon, PhD
NIDDK	to be determined
NIMH	William Riley, PhD
NINDS	Merrill M. Mitler, PhD
NINR	Kathy Mann Koepke, PhD
ORWH	Eleanor Z. Hanna, PhD

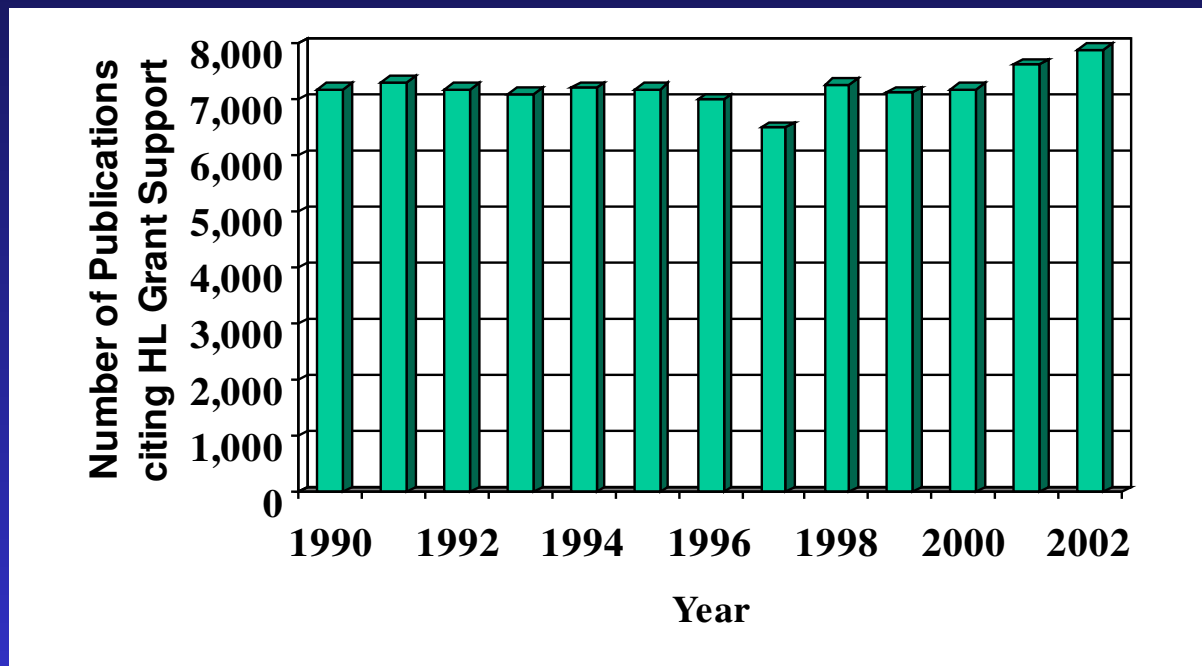


Percent Change 1996–2004 Total NIH Research Grant Funding



Citation of NHLBI Grant Support Medline 1990-2002

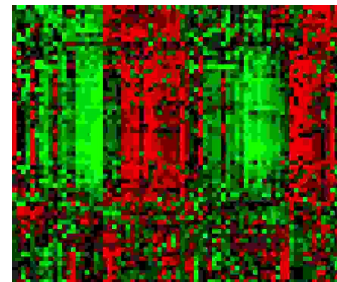
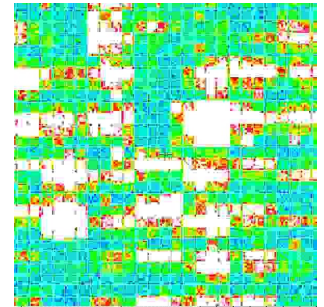
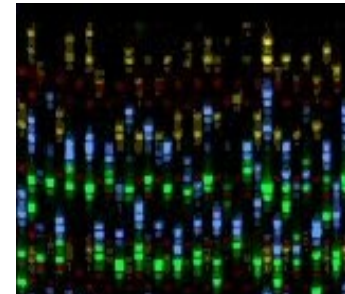
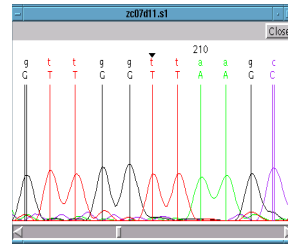
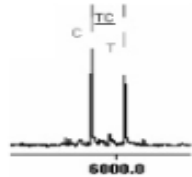
- Citing HL grant support, average 7100/year
- “Chokepoints” in the Research Enterprise?
 - Number of publication pages?
 - Accessibility to data?





Center
for
Bioinformatics

incredible developments in biomedical information generation

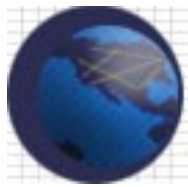




Informatics tower of Babel

- Each research community speaks its own scientific “dialect”
 - Publishes in specialty journals
 - Creates its own databases
- Each analytic tool requires custom inputs and outputs
- Integration critical to achieve promise of molecular medicine

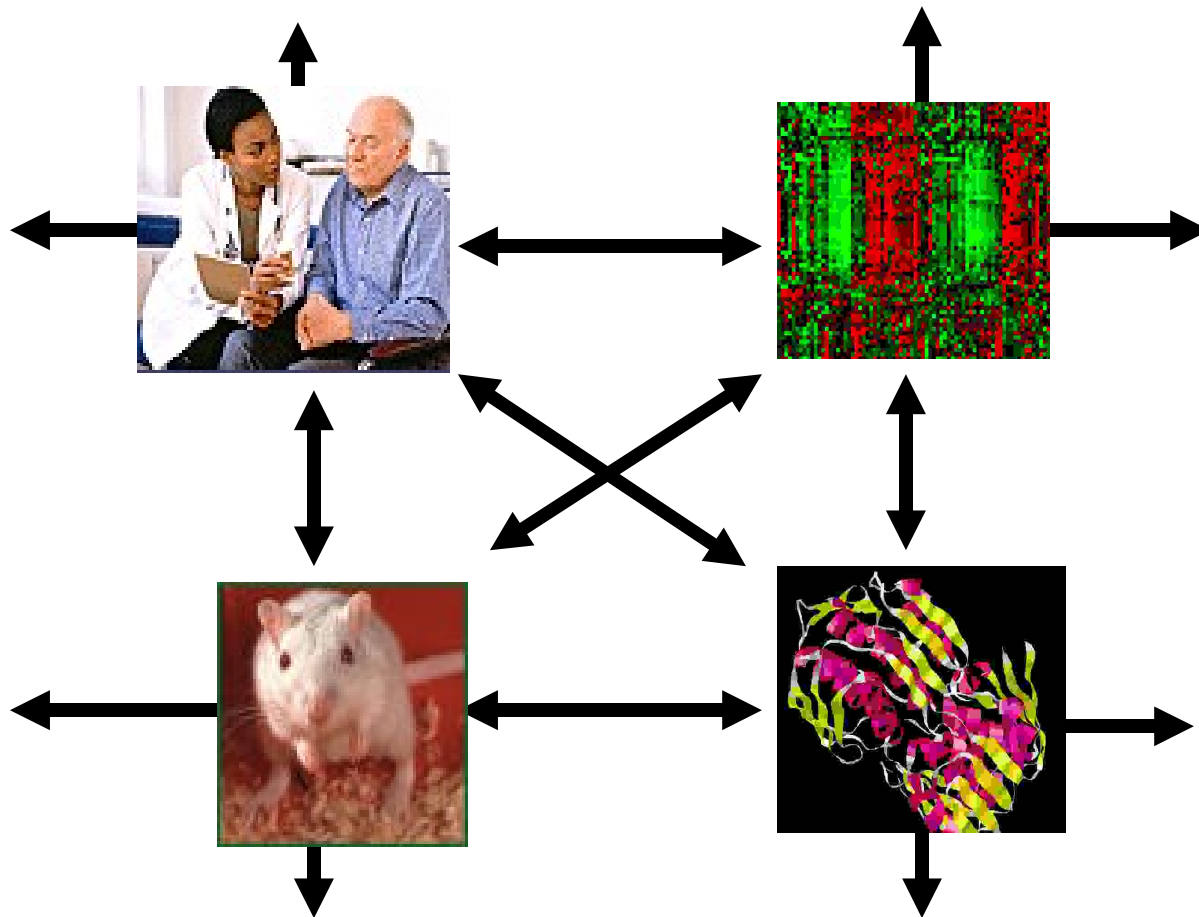


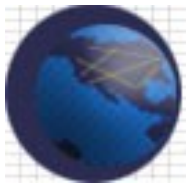


caBIG

cancer Biomedical
Informatics Grid

caBIG infrastructure joins diverse data within an institution



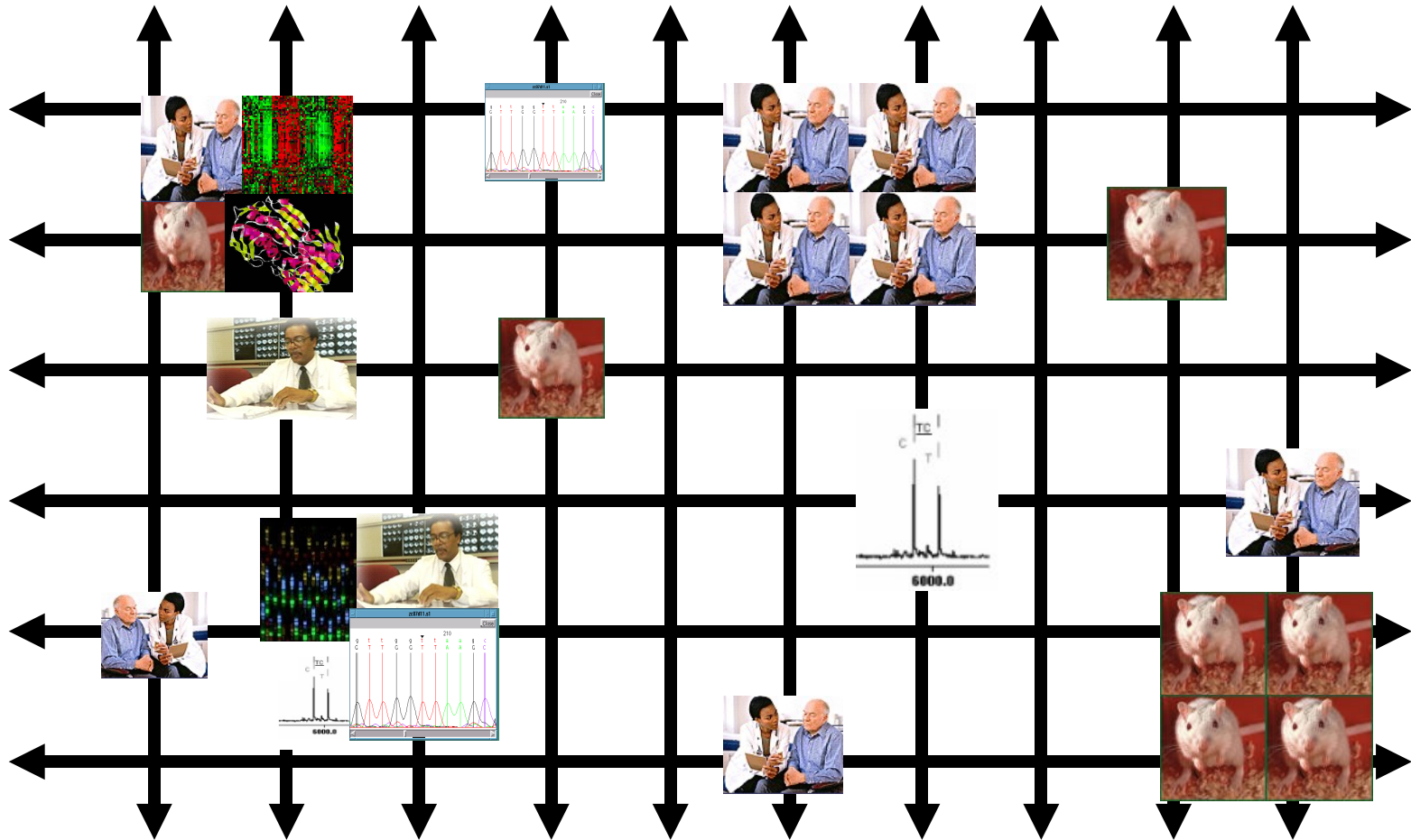


caBIG

cancer Biomedical
Informatics Grid



caBIG will join together cancer research communities



Electronic Research

- Sleep Research capabilities must keep pace with the expansion of modern research capabilities
- Accessibility
 - *Information that is not electronically accessible is quickly lost*
- New Approaches
 - *Systematic collection of electronically interpretable information is needed to foster integrative approaches, e.g. pathway and network models*
- Use the Information collected more efficiently

NIH

- **Data Sharing Policy**
- **Current capabilities**
- **Future Directions**

FINAL NIH STATEMENT ON SHARING RESEARCH DATA 2006

- All investigator-initiated applications with direct costs greater than \$500,000 in any single year will be expected to address data sharing in their application.
- Data should be made as widely and freely available as possible while safeguarding the privacy of participants, and protecting confidential and proprietary data.
- http://grants2.nih.gov/grants/policy/data_sharing/

FINAL NIH STATEMENT ON SHARING RESEARCH DATA 2006

- **Final Research Data**

“The recorded factual material commonly accepted in the scientific community as necessary to document, support, and validate research findings. This does not mean summary statistics or tables; rather, it means the data on which summary statistics and tables are based.”


- The guideline does not stipulate the precise content for documentation, formatting, presentation, or transport of data.
- http://grants2.nih.gov/grants/policy/data_sharing/

FINAL NIH STATEMENT ON SHARING RESEARCH DATA 2006

- **Unique Data**
Data that cannot be readily replicated
- **Documentation**
Documentation is needed to ensure that others can use the dataset and to prevent misuse, mis-interpretation, and confusion. Documentation provides information about the methodology and procedures used to collect the data, details about codes, definitions of variables, variable field locations, frequencies
- **Attribution**
scientific authors to acknowledge the source of data upon which their manuscript is based

Federal Health Initiative

NHII HOME COORDINATING ACTIVITIES PUBLIC HEALTH RELATED ACTIVITIES STANDARDS ORGANIZATIONS HEALTH CARE ORGANIZATIONS STATE & LOCAL ACTIVITIES MEETINGS DOCUMENTS BENEFIT OF HEALTH CARE IT SITE INDEX




Standards

Summary: Technology and Standards for Health Care

Messaging Standards	
HL7	Clinical data
X12N	Financial data, HIPAA mandated transactions
DICOM	Images
NCPDP	Standards for pharmacy business functions, HIPAA mandated transactions
IEEE	Bedside instruments, medical information bus

Terminology Standards	
LOINC	
Drugs	NLM/FDA/VA collaboration on RxNorm, NDF-RT
Billing	CPT, ICD-9CM
Clinical	UMLS, SNOMED and others

 [Printer-Friendly Version](#)
[HTML](#) [PDF](#)

American Society for Testing and Materials (ASTM)

Standards and Standards Organizations

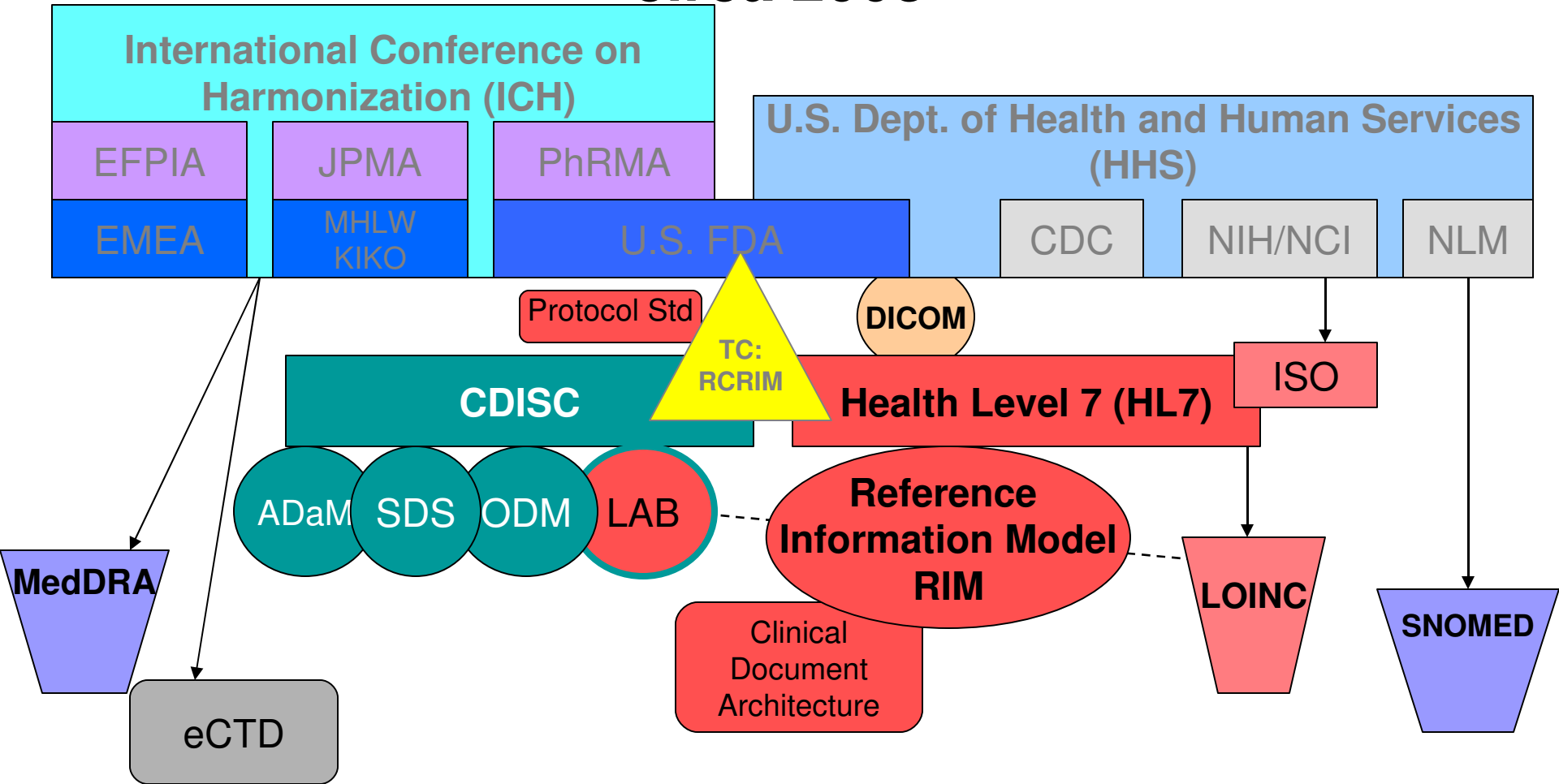
- ASTM
- CPT
- DICOM
- Health Level 7
- HISB
- IEEE
- IOM Patient Safety Data Standards
- ICD-9CM
- LOINC
- MedBiquitous
- NCPDP
- NDF-RT and RxNorm
- SNOMED
- UMLS
- X12

<http://aspe.hhs.gov/sp/nhii/standards.html>

Many Stakeholders and Their Representatives in Developing Standards

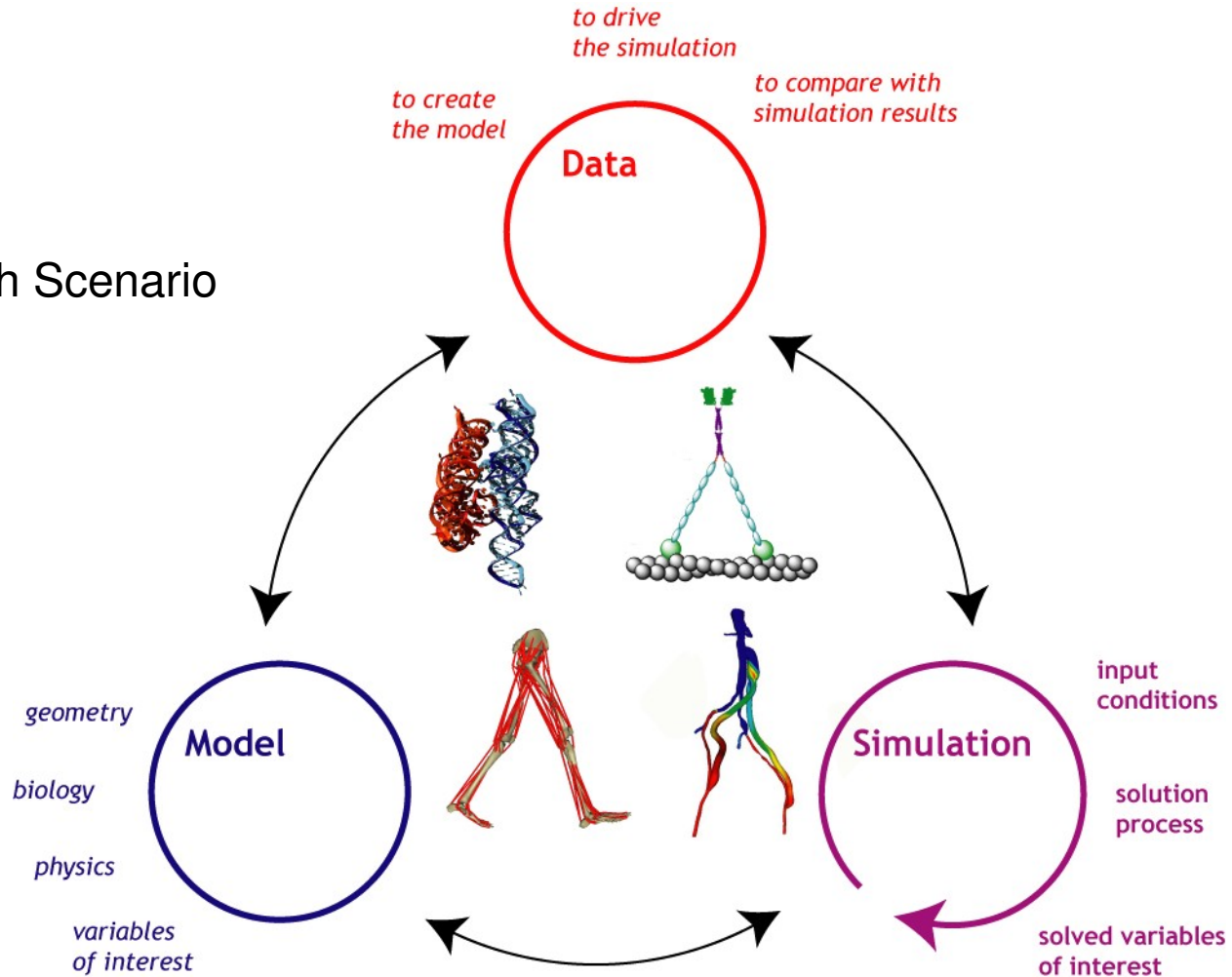
- **National and International Coordinating Organizations**
 - International Organization for Standardization (ISO)
 - American National Standards Institute (ANSI)
 - European Committee for Standardization (CEN)
- **Standards Development Organizations**
 - Health Level Seven (HL7)
 - International Conference on Harmonization (ICH)
 - Clinical Data Interchange Standard Consortium (CDISC)
- **Government Organizations**
 - FDA Data Council
 - Consolidated Health Informatics (Federal Interagency)

“Electronic Health Record” circa 2003



Circle of Life

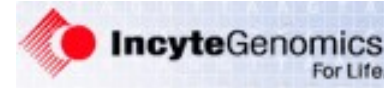
A Research Scenario



WormBase

Ontologies are essential to make sense of biomedical data

FlyBase



QuickTime™ and a TIFF (Uncompressed) decompressor are needed to see this picture.



UniProt
the universal protein resource



Musen, 2005

2. Integration Versus Interoperability

See for example "Australia releases e-health framework," FCW.Com, August 22, 2005 (4th paragraph).

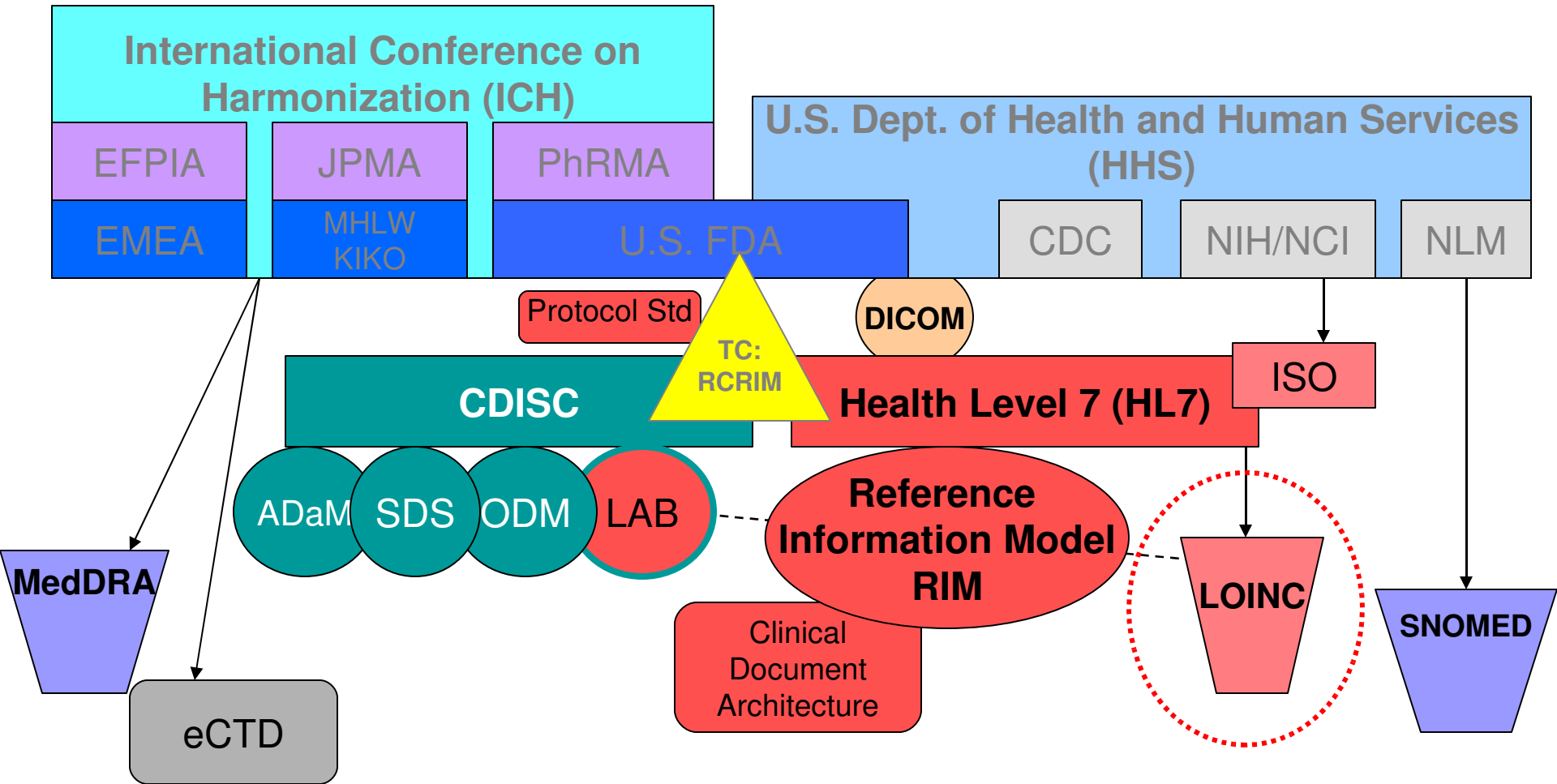
- Integration:
 - Participant systems are assimilated into a larger whole
 - Systems must conform to a specific way of doing things
 - Connections (physical and logical) are brittle
 - Rules are programmed in custom code, functions, or scripts
 - Standard data vocabularies are encouraged
- Interoperability:
 - Participant systems remain autonomous and independent
 - Systems may share information without strict standards conformance
 - Connections (physical and logical) are loosely coupled
 - Rules are modeled in schemas, domain models, and mappings
 - Local data vocabularies are encouraged


Source: Semantic Information Interoperability in Adaptive Information, by Jeffrey Pollack and Ralph Hodgson, Wiley Inter-Science, 2004, page 38.


Levels of Inter-operability


- **Basic**
 - Message Exchange
- **Functional**
 - Formats, message syntax
- **Semantic**
 - Controlled vocabularies, ontology


“World of Standards” 2003



 = Organization

 = Dictionary, Codelist

 = Standard

 = Model

 = Document Standard, or Architecture



LOINC

home

Logical Observation Identifiers Names and Codes (LOINC®)

The purpose of the LOINC database is to facilitate the exchange and pooling of results, such as blood hemoglobin, serum potassium, or vital signs, for clinical care, outcomes management, and research. Currently, most laboratories and other diagnostic services use HL7 to send their results electronically from their reporting systems to their care systems. However, most laboratories and other diagnostic care services identify tests in these messages by means of their internal and idiosyncratic code values. Thus, the care system cannot fully "understand" and properly file the results they receive unless they either adopt the producer's laboratory codes (which is impossible if they receive results from multiple sources), or invest in the work to map each result producer's code system to their internal code system. LOINC codes are universal identifiers for laboratory and other clinical observations that solve this problem.

The laboratory portion of the LOINC database contains the usual categories of chemistry, hematology, serology, microbiology (including parasitology and virology), and toxicology;

Current Version

LOINC 2.16

(released: December 5, 2005)

RELMA 3.16

(released: December 5, 2005)

[Click to Download](#)

HHS Announcement 3

HHS Proposes Standards for Electronic Health Care Attachments

NCQA/HEDIS

HEDIS supports the use of LOINC codes.

- [HOME](#)
- [BACKGROUND](#)
- [RELMA](#)
- [DOWNLOADS](#)
- [SUBMISSIONS](#)
- [NEWS](#)
- [INTERNATIONAL](#)
- [MEETINGS](#)
- [SLIDESHOWS](#)
- [ARTICLES](#)
- [DISCUSSION](#)
- DOCUMENTS
- [FUNDING SUPPORT](#)
- [TERMS OF USE](#)
- [LOINC E-MAIL LIST](#)
- [CONTACT LOINC](#)

<http://www.regenstrief.org/loinc/>

NIH Research: A Multi-Level Approach

04

05

06

07

“Centrally-Driven” Model (e.g. NCI caCORE)

- rapid implementation → NIH platform available today
- data harmonization → maximizes data integration and “sharing”
- ideal to leverage large-scale resources and clinical research

“Community-Driven” Model (e.g. NCRR BIRN)

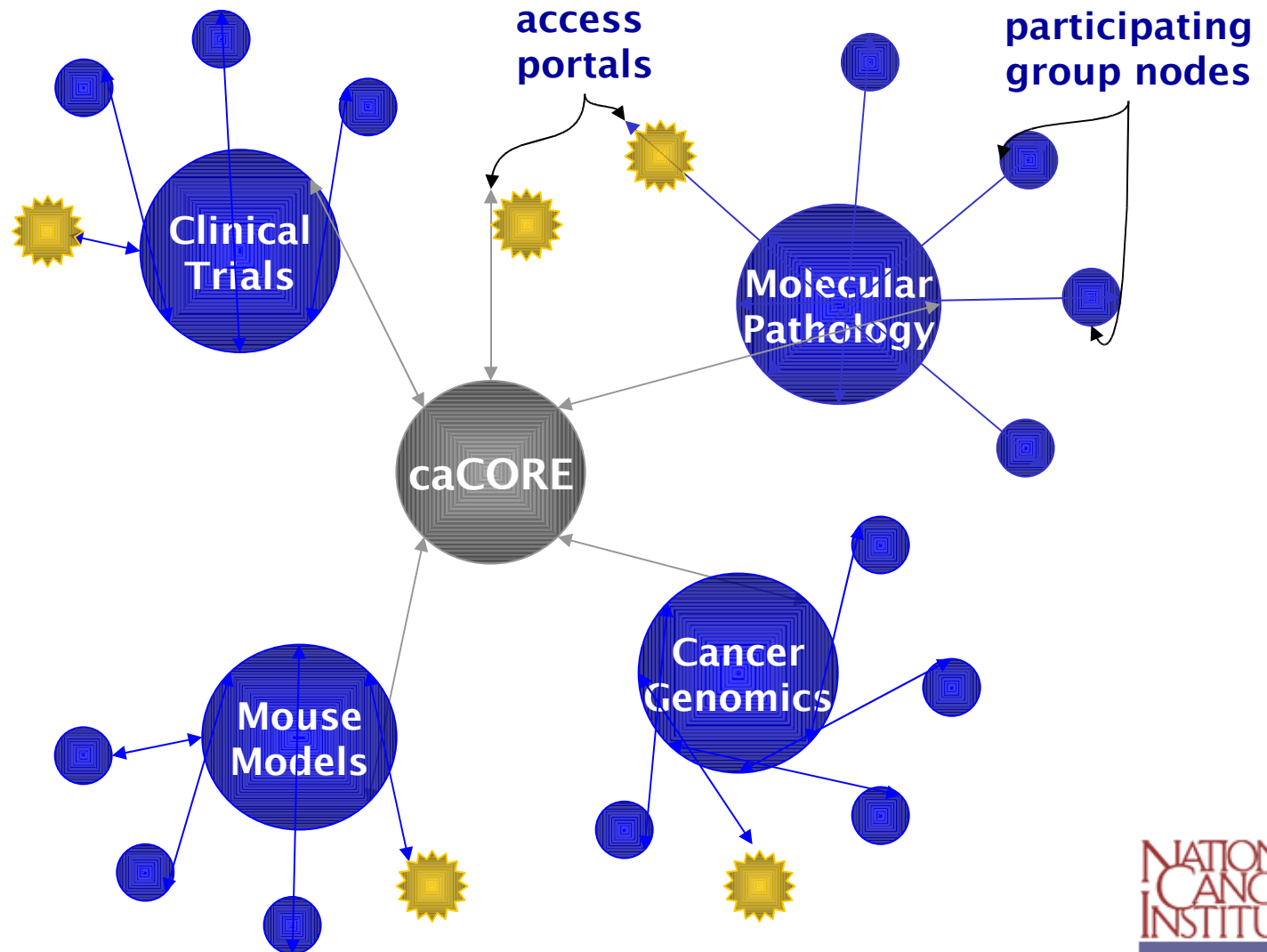
- operating principle: members “Must Give to Receive”
- ideal for focused electronic interdisciplinary collaboration
- NIH platform under development (FY05-FY06)

Other models for specialized electronic collaboration

- Alliance for Cell Signaling (NIGMS)
- BioSPICE (DARPA)



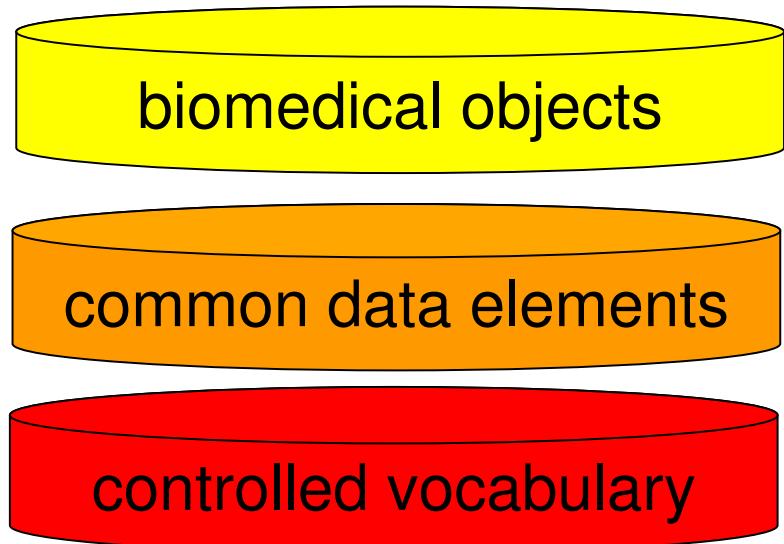
building common architecture, common tools, and common standards





caCORE – common ontologic representation environment

- Information integration
- Cross–discipline reasoning



Summary

- **Knowledge Integration and Application**

using computational and analytical tools
to find, select, distil and present information

- **Data Acquisition and Management**

defining data and the processes used for data collection

- **Research Teams**

enhancing collaboration between biomedical
and computational investigators