

# Data Elements: Bridging Clinical & Research Data

HCS Research Collaboratory Grand Rounds  
December 6, 2013

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**Duke** Center for Health Informatics



**Duke** University  
School of Nursing

# Outline

- Definitions and sources for data elements
- Approaches to data standards for:
  - clinical data
  - research data
- Challenges
- Role of patient registries
- Role of The Collaboratory.... (?)

# Definitions

- **Data element** – a representation of a clinical concept that represents a patient state or attribute
  - e.g., diagnosis, diabetes, clinical visit, lab value, gender
  - encoded using standardized terminologies
- **Value set** – a list of numerical values and the individual descriptions from standard vocabularies used to define the clinical concepts
  - “Value sets define clinical concepts unambiguously.”

# Examples

Data element name	Value set
Diagnosis_a	ICD-9 CM
Diagnosis_b	SNOMED CT
Diagnosis of diabetes_a	249.xx, 250.xx, 357.2, 362.01-06, 366.41
Diagnosis of diabetes_b	Yes/no
Diagnosis of diabetes_c	New/old
.....	
Race	American Indian/Alaskan Native Asian Black or African American Native Hawaiian/Pacific Islander White
Route of substance administration	Chew; Diffusion, extracorporeal; Diffusion, hemodialysis; ..; Dissolve, oral; Dissolve, sublingual; ... Implantation; Infusion; Inhalation; Injection; .....
	<i>(&gt;100 codes in HL7 set!)</i>

Data element name	Value set
Diabetes Management Method	Diet/exercise only; pills; insulin
Laboratory test completed	LOINC
HbA1c value	--
<u>Most Recent HbA1c Value</u>	--
ABO GROUP TYPE	A, B, AB and O
Location of Pain	Face, Forearm, Hand, Leg, Arms, Trunk, ...
Assistive devices	Cane, walker, ....

# Sources of Data Elements

- NCI caDSR
- CDISC SHARE
- NINDS CDE Projects
- NIH Data Element Portal (NLM)
- PhenX
- PROMIS

*Research-oriented*

- PROMIS
- LOINC
- USHIK (AHRQ)
- NLM Value Set Authority Center

*Clinically-oriented*



# Approaches to Clinical Data Standards

- Informatics
  - Focus on models and semantics
  - Safety, scalability
- National plan
  - Incentives for EHR adoption
  - Incremental standards





# The Office of the National Coordinator for Health Information Technology

Health IT Home
HITECH & Funding Opportunities
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Certified Health IT Product List
Certification Requirements

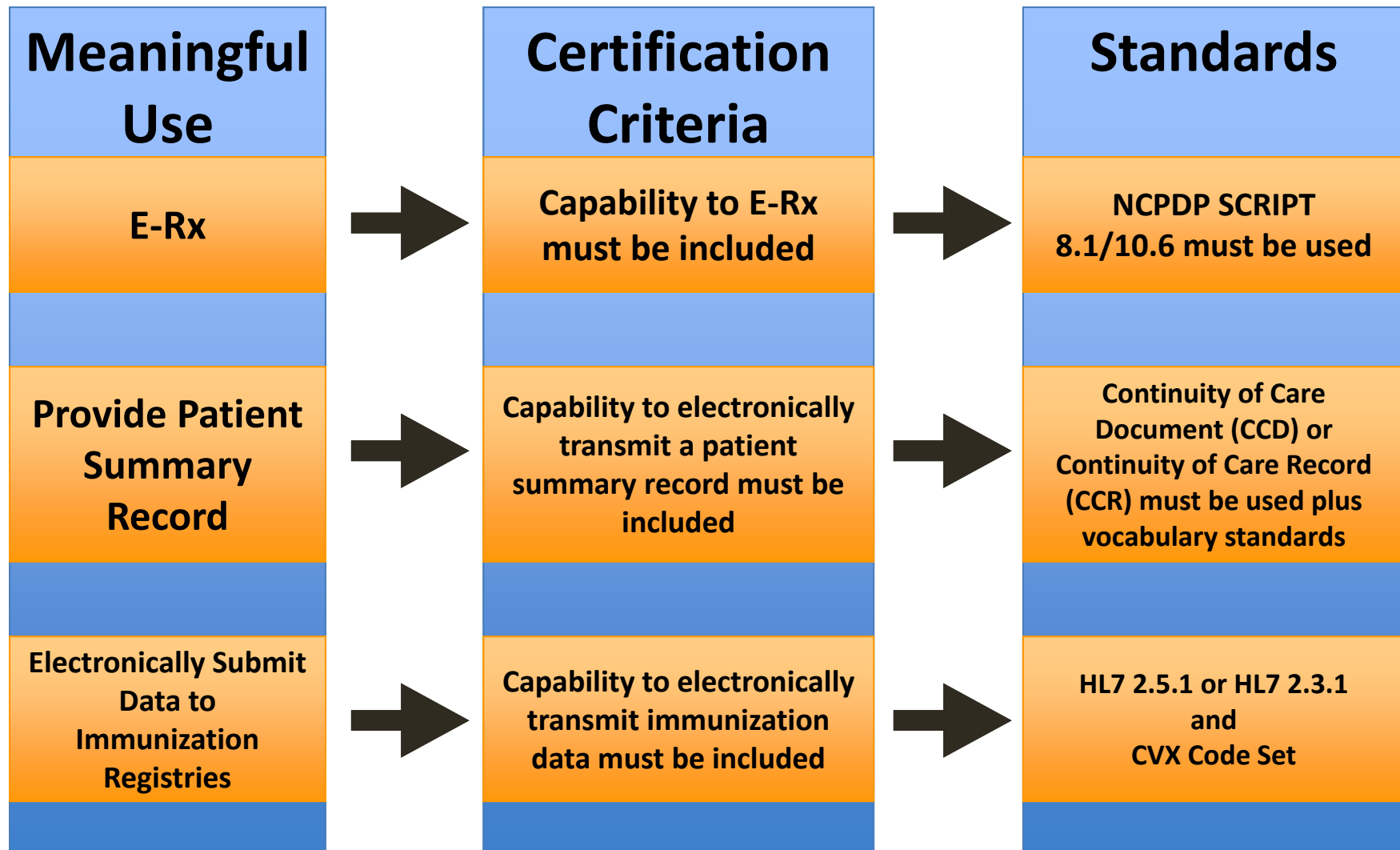
Home > Regulations & Guidance > Standards and Certification

## Standards & Certification

Providers and patients must be confident that the electronic health information technology (EHR) systems they use are secure, can maintain data confidentially, can work with other systems to share information, and can perform the functions they need. To this end, the following regulations and guidance have been issued:

- [Standards and Certification Criteria for Electronic Health Records](#) - Issued by the Office of the National Coordinator for Health Information Technology, this rule identifies the standards and certification criteria for eligible professionals and hospitals may be assured that the systems they adopt are secure and perform the functions they need.
- [Certification Programs](#) - A defined process to ensure that EHR technologies meet the technical and other requirements to achieve meaningful use of those records in systems.
  - [Temporary Certification Program](#)
  - [ONC-Authorized Testing and Certification Bodies](#)
  - [Certified Health IT Product List](#)
- [Metadata Standards \[PDF - 82 KB\]](#) - The Office of the National Coordinator for Health Information Technology announced advance notice of proposed rulemaking (ANPRM) on August 5, 2011, which solicits public comments on the proposed rule recommended by the HIT Standards Committee. ONC will accept public comments on the proposed rule.

# National Standards Strategy



# Codes and Meaning

“Numbness of left arm and right leg”

Numbness (44077006)

Left (7771000)

Arm (40983000)

Right (24028007)

Leg (30021000)

“Numbness of right arm and left leg”

Example from Stan Huff’s informative presentation of CEM, available at:  
<http://informatics.mayo.edu/recordings/CEM/ClinicalElementModel.swf>

# Application Context: Different Information Models

Date	Finding
28-Jul-2008	Hypertension

Date	Hypertension
28-Jul-2008	Observed

# Terminology – Information Model Interactions

Date	Finding
28-Jul-2008	Family History of Hypertension

Date	Finding	Subject
28-Jul-2008	38341003   hypertensive disorder	Father

Date	Finding	Subject
28-Jul-2008	160357008   FH: Hypertension   : 408732007   subject relationship context   = 66839005   father	Father

# Challenge

- Need standards for:
  - information model
  - controlled terminology

\* AND \*

- Interaction (specifications for use)

*See HL7's  
TermInfo  
group...*



# Solution:

## “Clinical Element Models”

- Standard models of clinically relevant and related concepts and relationships (from data & terminology)
  - Retain computable meaning for data exchange
  - Support use of data in decision support logic
- A global modeling effort as a whole
  - detailed clinical data models
  - instances of data
- **Reference standard**



# Main Page

Welcome to the **Clinical Information Modeling Initiative (CIMI)** wiki!

- [Introduction](#)
- [CIMI Glossary](#)
- [CIMI Models](#)
- [TF Meeting Minutes](#)
- [Help](#)
- [CIMI Style Guide](#)

Welcome to the CIMI Wiki. **The content of this site can be read by anyone - an account is not needed.** If you need to edit or add to the wiki content you may [request an authoring account](#).

To be added to the CIMI email list please contact Virginia Riehl at <mailto:virginia.riehl@verizon.net>

Quick Links	Taskforces	F2F Meetings & Summaries
<ul style="list-style-type: none"> <li>• <a href="#">CIMI Informatics-Modeling Terms, Tools ... (27-Oct-12)</a></li> <li>• <a href="#">CIMI Requirements: Summary; detailed spreadsheet</a></li> <li>• <a href="#">CIMI Modelling Taskforce - Call For Models DRAFT</a></li> <li>• <a href="#">Clinical Modeling Activity Discussion - CIMI Clinical test models page</a></li> <li>• <a href="#">Reference Model Patterns</a></li> <li>• <a href="#">Clinical Model Patterns</a></li> <li>• <a href="#">Clinical Models and SNOMED: comments from Kaiser</a></li> <li>• <a href="#">Governance proposals in development</a></li> <li>• <a href="#">Voting Rules</a></li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Archetype-Profile for UML (AML UML)</a></li> <li>• <a href="#">CIMI IEC</a></li> <li>• <a href="#">CIMI Modeling TF</a> <ul style="list-style-type: none"> <li>• <a href="#">Clinical Modeling Team</a></li> <li>• <a href="#">Technical Modeling Team</a></li> </ul> </li> <li>• <a href="#">CIM UML Taskforce (retired: now AML TF)</a></li> <li>• <a href="#">CIMI Reference Model TF (retired: now added to the Modeling TF)</a> <ul style="list-style-type: none"> <li>• <a href="#">CIMI Reference Model Taskforce - Mission and Approach</a></li> <li>• <a href="#">CIMI Reference Model Requirements</a></li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• <a href="#">Upcoming meetings:</a></li> <li>• <a href="#">Summaries</a> <ul style="list-style-type: none"> <li>• <a href="#">London Meeting resolutions</a></li> <li>• <a href="#">San Antonio Meeting Highlights</a></li> <li>• <a href="#">Pleasanton Meeting 2012 Materials</a></li> <li>• <a href="#">Pleasanton Meeting Highlights</a></li> <li>• <a href="#">Rockville, Maryland - Sept 2012</a></li> <li>• <a href="#">Modeling Task Force - UMC Groninger Netherlands December 2-4, 2012</a></li> <li>• <a href="#">Scottsdale, AZ January 18-20, 2013</a></li> <li>• <a href="#">Leeds/Rockville April 11-13, 2013</a></li> <li>• <a href="#">Leeds/Rockville 2013 Meeting Highligh</a></li> <li>• <a href="#">Arlington/Leeds June 26-28, 2013</a></li> </ul> </li> </ul>

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## Clinical Element Model for Systolic Blood Pressure

SystolicBPObs

stolicBP

data 138 mmHg

quals

BodyLocation BodyLocation

data Right Arm

PatientPosition PatientPosition

data Sitting



blood

Advanced

BloodGroupAntibodiesPresentPridPtSerPlasNomColdIncuba  
BloodGroupAntibodiesPresentPridPtSerPlasNomElutionLabt  
BloodGroupAntibodiesPresentPridPtSerPlasNomWarmAbso  
BloodGroupAntibodiesPresentPridPtSerPlasNomWarmIncut  
BloodGroupAntibodyInvestigationImpPtPlasRBCNomLabOb:  
BloodGroupAntibodyScreenACncPtSerPlasOrdLabObs (Inte  
BloodGroupAntibodyScreenACncPtSerPlasOrdPrewarmedL:  
BloodGroupAntigensPresentPridPtBldNomLabObs (Intermou  
BloodLossTotalIntraoperativeVolProcedureDurPatientQnCell  
BloodLossVolumeMeas (Intermountain)  
BloodLossVolumeRateMeas (Intermountain)  
**BloodPressurePanel (Intermountain)**  
BloodProductDispositionTypePtBPUNomLabObs (Intermoun  
BloodProductIdentifierPooledPridPtBPUNomLabObs (Interm  
BloodProductTypeTypePtBPUNomLabObs (Intermountain)  
BloodProductUnitIdentifierPridPtBPUNomLabObs (Intermou  
BloodProductUnitIDNumPtDoseQnLabObs (Intermountain)  
BloodSmearFindingPridPtBldNomMicroscopyLightLabObs (I  
BloodTypeAndRhEval (Intermountain)  
CarboxyhemoglobinHemoglobinTotalInArterialCordBloodQu:  
CarboxyhemoglobinHemoglobinTotalInVenousCordBloodQu  
CD14MO2PercentInBloodLabObs (Intermountain)

Compiled Tree

CDL Source

CDL Mind

BloodPressurePanel  
Information  
key = BloodPressurePanel\_KEY\_ECID  
SystolicBloodPressureMeas [0..1]  
DiastolicBloodPressureMeas [0..1]  
MeanArterialPressureMeas [0..1]  
MethodDevice [0..1]  
BodyLocationPrecoord [0..1]  
BodyPosition [0..1]  
RelativeTemporalContext [0..M]  
PatientPrecondition [0..M]  
Comment [0..M]  
Subject [0..1]  
Observed [0..1]  
ReportedReceived [0..1]  
Verified [0..1]  
Updated [0..1]

<http://www.clinicalelement.com>

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## Strategic Health IT Advanced Research Projects (SHARP) Research Focus Area 4 - Secondary Use of EHR Data *Increasing efficiency of patient care through electronic healthcare records*



Face to Face Group Photo June 11, 2012

Mayo Clinic, long a leader in the science of health care delivery, is proud to be a recipient of the Strategic Health IT Advanced Research Project award. The SHARP Program – part of the Office of the National Coordinator for Health care through Information Technology.

Area four's SHARP project will enhance patient safety and improve patient medical outcomes through the use of an electronic health record. Traditionally, a patient's medical information, such as medical history, exam data, hospital electronically and non-electronically. We propose research that will generate a framework of open-source services that can be dynamically configured to transform EHR data into standards-conforming, comparable information suitat

Area four's mission is to enable the use of EHR data for secondary purposes, such as clinical research and public health. By creating tangible, scalable, and open-source tools, services and software for large-scale health record dat through the use of an electronic health care record.

SHARPN for Clinical Data Users	SHARPN for Researchers
<a href="#">About SHARP</a> <a href="#">Program Areas</a> <a href="#">Working with Structured EHR data</a> <a href="#">Working with Unstructured EHR text</a> <a href="#">Electronic Algorithms for Clinical Trials, Data Quality Measures, etc</a>	<a href="#">Data Normalization</a> <a href="#">Clinical Element Models</a> <a href="#">Terminologies and CTS2</a> <a href="#">Natural Language Processing</a> <a href="#">High-throughput Phenotyping</a>

# More Models

- Models of Use - Supports *Data Capture*
  - Application
  - System Level
  
- Models of Meaning – Support *Decision Support*
  - Truth
  - Semantics

Extensive work here by Alan Rector, MD, Prof. of Medical Informatics, Univ. of Manchester.



*"I'm afraid you've had a paradigm shift."*



# NINDS Common Data Elements

Harmonizing Information. Streamlining Research.

- ▼ CDEs
- ▼ Tools
- ▼ Learn



### Important notice!

Improvements are in process. We encourage you to contact us so we can provide any incremental updates. Changes will be ongoing until at least November 2013. Please contact us directly at: [nindscode@emmes.com](mailto:nindscode@emmes.com) for the most recent updates.

## Streamline Your Neuroscience Clinical Research

using content standards that enable clinical investigators to systematically collect, analyze, and share data across the research community.

The NINDS strongly encourages researchers who receive funding from the Institute to ensure their data collection is compatible with these common data elements (CDEs). [Learn more about the CDE Project.](#)



### Launch Your Own Studies Faster

- ▶ Case report form modules
- ▶ Standardized data element definitions
- ▶ Instrument recommendations



### Incorporate CDEs Into Systems

- ▶ Search for current CDEs
- ▶ Download CDE metadata
- ▶ Download Case Report Forms



### Learn About the CDE Project

- ▶ Project overview and background
- ▶ Meetings and Presentations
- ▶ Collaboration with developers around the world

CDEs Now Available	CDEs Under Review	CDEs in Development
General (CDEs that cross diseases)		
Amyotrophic Lateral Sclerosis		
Epilepsy		
Friedreich's Ataxia		
Headache		
Huntington's Disease		
Multiple Sclerosis		
Neuromuscular Diseases		
Congenital Muscular Dystrophy		
Duchenne Muscular Dystrophy		

[Project Overview](#) | [Contact](#) | [Privacy Statement](#) | [NINDS](#) | [NIH](#) | [HHS](#) | [USA.gov](#) | [NLM CDEs](#)



## The CDISC Mission

The CDISC mission is to develop and support global, platform-independent data standards that enable information system interoperability to improve medical research and related areas of healthcare.



## What's New

[ASTHMA Therapeutic Area Data Standard User Guide v 1.0 \(TAUG-Asthma\) is Now Available!](#)

[CDASH Serious Adverse Event Supplement v 1.0 is Now Available](#)

[CDISC StudyDataSet-XML Draft Standard Now Available for Public Review - Comments Due 3 January 2014](#)

[Call for Abstracts for the CDISC European Interchange is Open until 16 December 2013](#)

[CDISC New Jersey User Network Meeting on 14 January 2014 - Registration Open](#)

[Announcing the October Newsletter with our New eReader Format! Click here.](#)

[CDISC Press Release - CFAST Sparks Pathways for Developing New Therapeutics For Unmet Patient Needs.](#)

[CDISC Japan Interchange in Tokyo, Japan on 3-6 December 2013](#)

[Registration is Available.](#)

[Call for abstracts is extended until Friday, 18 October 2013.](#)

[Sponsorship opportunity available.](#)

[Exhibitor opportunity available.](#)

[\\*\\*FDA Announces Intent to Require CDISC Standards\\*\\*](#)

[What is CDISC SHARE? Watch this Video!](#)

[Sponsorship Opportunities for Upcoming CDISC Interchanges](#)

[Click the image below to view the 2012 CDISC Annual Report](#)



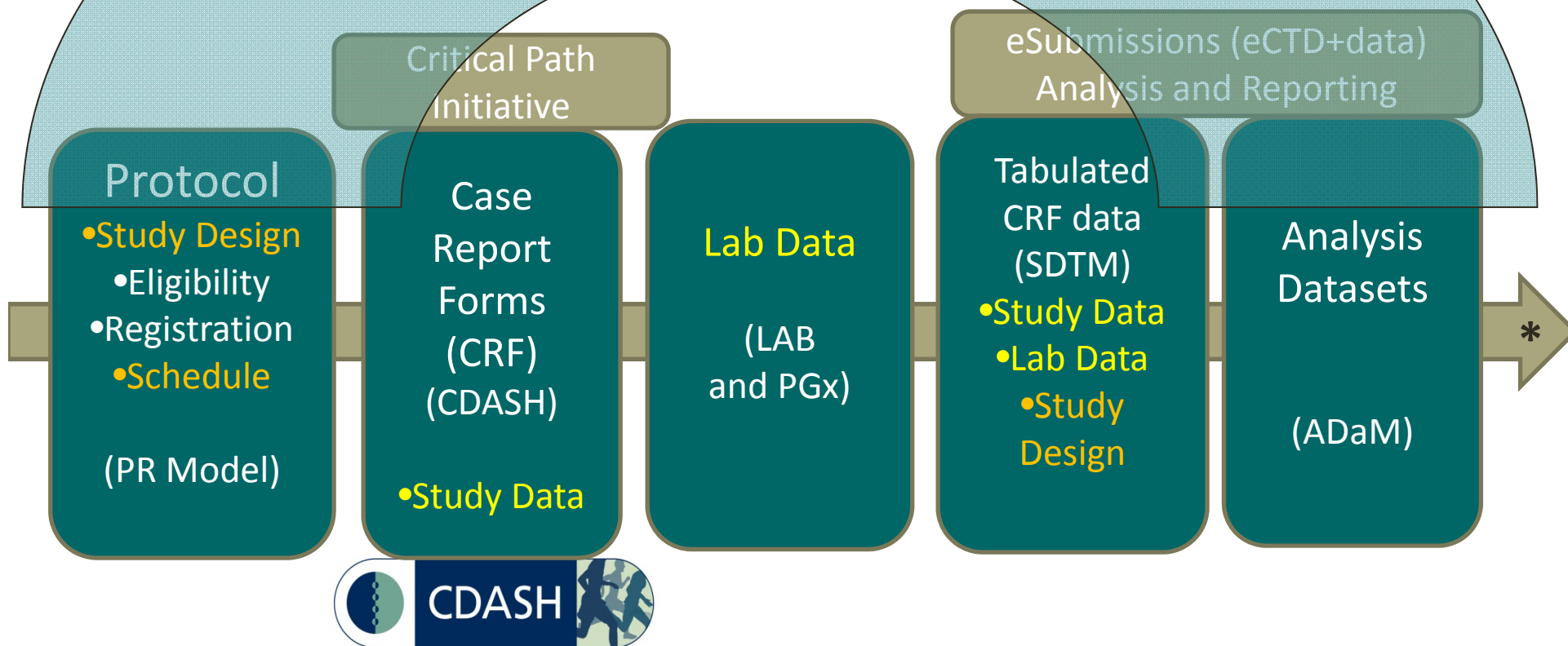
[Become a CDISC Member](#)

[Read about the benefits of membership and how to join here more...](#)

[Volunteer for CDISC!](#)

[Follow the link.](#)

Harmonized through BRIDG Model\*\*  
Controlled Terminology (NCI-EVS)  
Glossary



\*Transport: CDISC ODM, SASXPT and/or HL7

\*\* CDISC, ISO/CEN, HL7 Standard (JIC)



# FDA Goal (CDER)

Standardize **efficacy** data elements in 57 therapeutic areas

- FDA will likely require submission using these standards

## Priority Disease/Domain Areas for Data Standardization

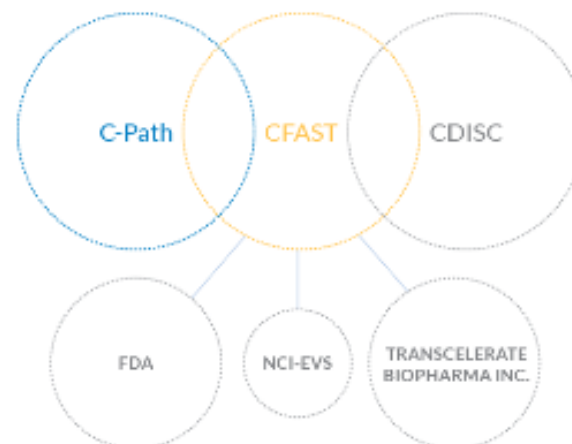
Tier 1		
Acne	Pain*	Schizophrenia
Alzheimer's Disease*	Parkinson's Disease*	Solid organ transplantation
Anti-diabetic agents*	Prevention of pregnancy	Treatment of Hepatitis C*
Crohn's Disease	Psoriasis	Treatment of postmenopausal osteoporosis
Infections of skin and/or subcutaneous tissue	QT Studies	Tuberculosis*
Oncology: time to efficacy event other than overall survival*	Rheumatoid arthritis	Urinary tract infections
Tier 2		
Addiction	Gastroesophageal reflux disease	Pneumonia
Anticonvulsants	Influenza	Prevention of HIV
Asthma	Irritable bowel syndrome	Treatment of HIV
Bipolar Disorder	Lipid-altering drug groups	Treatment of overactive bladder
Clostridium difficile colitis	Major depressive disorder	Treatment of vasomotor symptoms due to menopause
Diabetic nephropathy	Objective tumor response*	Ulcerative colitis
Tier 3		
Actinic keratoses	Decompensated CHF	Tinea pedis
Aerosolized antimicrobials for cystic fibrosis	Diagnostic radiopharmaceuticals	Tramatic brain injury
Atrial fibrillation	General Anxiety Disorder	Treatment of cough
Attention Deficit Hyperactivity Disorder	Helicobacter pylori ulcer disease	Treatment of erectile dysfunction
Bacterial vaginosis	Infectious diseases of the abdomen	Treatment of hepatitis B
Chemotherapy-induced	MRI contrast agents	

# Coalition For Accelerating Standards and Therapies

Accelerating clinical research and medical product development  
by creating and maintaining data standards, tools, and methods.

[Overview](#)[Tools](#)[Collaborators](#)

CFAST, a joint initiative of C-Path and the Clinical Data Interchange Standards Consortium (CDISC), was established in June 2012 to accelerate clinical research and medical product development by facilitating the establishment and maintenance of data standards, tools and methods for conducting research in therapeutic areas important to public health. CFAST collaborators include the U.S. Food and Drug Administration (FDA), TransCelerate BioPharma and the National Cancer Institute Enterprise Vocabulary Services (NCI-EVS), with participation and input from many C-Path and CDISC members as well as other organizations.



The CFAST Therapeutic Area Program Steering Committee (TAPSC) prioritizes, reviews status and approves CDISC TA standards development projects. The CFAST Scientific Advisory Council (SAC) provides scientific guidance and advice to the CFAST TAPSC and other CFAST project-related teams as needed.

## CFAST

[Introduction](#)[Recent Highlights](#)[CFAST Team](#)



# Program Overview – November 2013

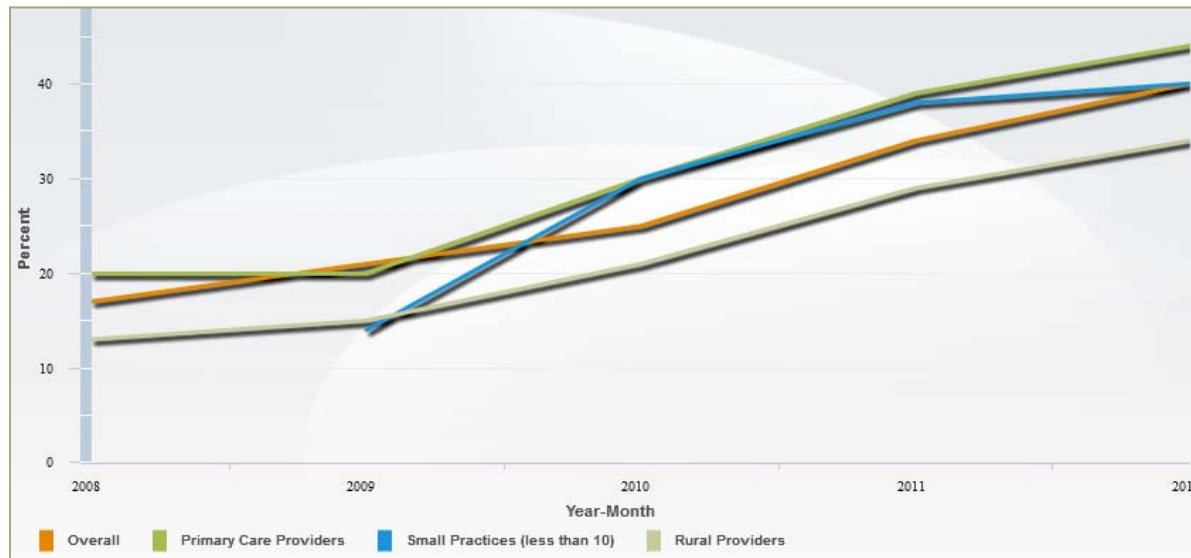
## Approved Therapeutic Area Standards Projects

Therapeutic Area	Coordinating Organization(s)	Start Date	Stage 0	Stage 1	Stage 2	Stage 3a	Stage 3b	Stage 3c	Notes
	Project Manager		Scoping & Input	Concept Modeling	Standards Development	Internal Review	Public Review	Publication	
Alzheimer's Disease v2	CPATH/CDISC Jon Neville	Jan 13	Jan	Mar	Jun	Sep	Oct	Q413	
Asthma v1	CDISC Rhonda Facile	Nov 12	Jan	Mar	Jun	Jul	Oct	Q413	
Cardiovascular Endpoints v1	CDISC/DCRI Amy Palmer	Jun 13	Jul	Sep	Nov	Dec		Q214	Dependent on new Clinical Decisions (CD) domains
Multiple Sclerosis v1	CPATH/CDISC Bess Leroy	Mar 13	May	Oct	Nov	Dec		Q114	Parallel development of Stage 1 & 2.
Diabetes v1	TCB/CDISC Rachael Zirkle	Apr 13	May	Aug	Nov	Dec		Q114	
QT Studies v1	TCB/CDISC John Owen	Aug 13	Oct	Nov	Jan			Q214	
Traumatic Brain Injury v1	CDISC Rhonda Facile	Oct 13	Nov	Dec				2014	
Hepatitis C v1	TCB/CDISC John Owen	Nov 13	Jan					2014	
Schizophrenia v1	CDISC/DCRI Amy Palmer	Oct 13	Nov	Dec				2014	
Breast Cancer v1	TCB/CDISC/UCSF Sarah Davis	Q1 14						2014	
Influenza	TBD	Jan 14						2015	
COPD v1	TBD								

Key: ■ Stage completed | ■ Stage ongoing | *Italics*=Projected | Months reflect when stage completed

# National Electronic Data Stores Growing.....

## Office-Based Adoption of Basic EHRs (Percent)



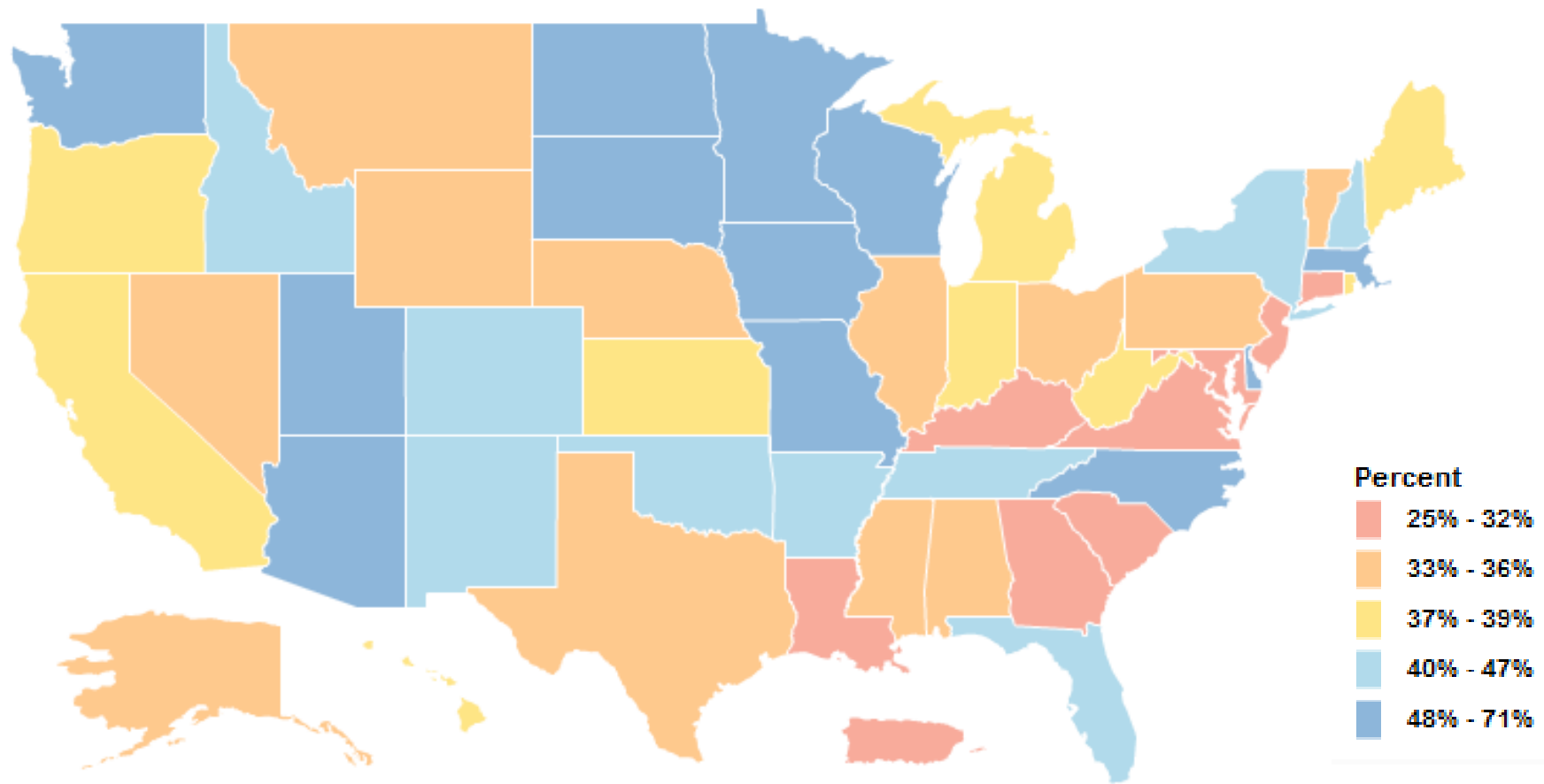
*44% of office-based providers implemented a "basic" EHR by 2012.*

## Hospital Adoption of Basic EHRs (Percent)



*40% of non-federal acute care hospitals implemented "basic" EHR by 2012.*

## Electronic Health Record Adoption EHR Adoption by Office-Based Providers (2012) National



44% percent of office-based providers implemented at least a "basic" EHR system by 2012.

# Growing National Resources from HITECH...

## “Basic EHR Functions”

- patient demographics
- patient problem lists
- electronic lists of patient medications taken
- clinical notes
- orders for prescriptions
- laboratory results viewing
- imaging results viewing

## Type of Data

- patient demographics\*
- patient problems\*
- medications\*
  
- clinical data (narrative)
- medications\*
- lab results\*
  
- images

*\*uses controlled vocabulary/coding system*

ONC  
Advertisement

# The Path to Critical Mass

- Today, distributed queries are generally limited to
  - Organizations with large IT & research budgets
  - Some exceptions (e.g., NYC PCIP, MDPHNet)
- Missing: Primary Care, FQHCs, CAHs, HIEs, etc... In other words, most places where clinical care is delivered and recorded
- **Path to critical mass depends on**
  - **Query Health Standards**
  - **Health IT vendor participation**



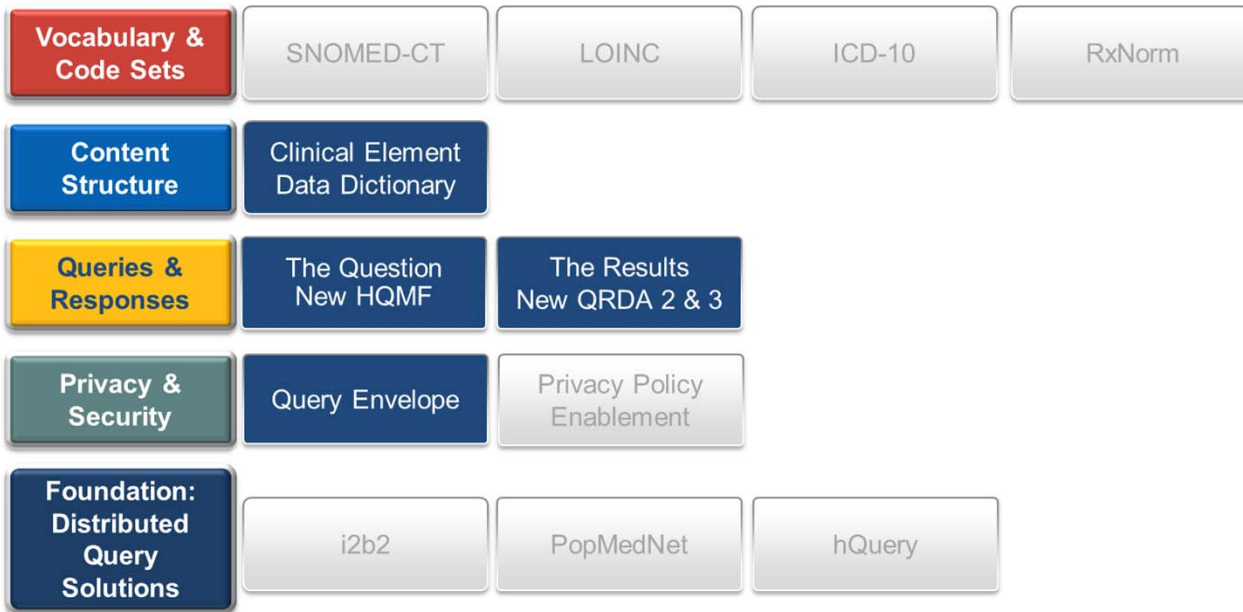
## Health IT vendors

Allscripts	Amazing Charts
AZZLY	Cerner
dbMotion	ClinicalWorks
Epic	eRECORDS
IBEZA	InterSystems
Medicity	Microsoft
National Health Data Systems	
NextGen	RelayHealth
Siemens	

Check back - more to come at  
**QueryHealth.org**



# ONC Query Health Initiative





Welcome

Search Value Sets

Download

Help

Authoring Guidance

## Welcome to the NLM Value Set Authority Center (VSAC)

For VSAC announcements, please subscribe to the [VSAC Updates listserv](#).

The Value Set Authority Center (VSAC) is provided by the National Library of Medicine (NLM), in collaboration with the Office of the National Coordinator for Health Information Technology and the Centers for Medicare & Medicaid Services.

The VSAC has published the annual update for the 2014 Eligible Hospital Clinical Quality Measure (CQM) Value Sets. The update includes revised value sets to address deleted and remapped codes in the latest terminology versions, as well as new codes for addressing CQM logic corrections and clarifications.

The VSAC provides downloadable access to all official **versions** of vocabulary **value sets** contained in the 2014 Clinical Quality Measures (CQMs). The value sets in the VSAC describe the specific populations included and excluded in order to properly calculate each 2014 CQM.

Each value set consists of the numerical values and human-readable names, drawn from standard vocabularies such as SNOMED CT® and ICD-10-CM, which are used to define clinical concepts used in clinical quality measures (e.g., patients with diabetes, clinical visit).

The content of the VSAC will gradually expand to incorporate value sets for other use cases, as well as for new measures and updates to existing measures. **Viewing and/or downloading value sets requires a free [Unified Medical Language System® Metathesaurus License](#), due to usage restrictions on some of the **codes** included in the value sets.**


The [Data Element Catalog](#) contains the complete list of 2014 CQMs and value set names.

The NLM maintains the data element catalog value sets with the [Value Set Authority Center](https://vsac.nlm.nih.gov/) (VSAC): <https://vsac.nlm.nih.gov/>

# Data Elements Catalog

	A	B	C	D	E	F	G	H	I	J	K
1	Measure Title	Data Element	CMS eMeasure	NQ	eMeasure Type	eMeasure Value	eMeasure Value	Short Description	Case Set	Category	Element Vocabulary
1908	Child and Adolescent Major Depressive Disorder	Face-to-Face Interaction	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		SNOMEDCT
1909	Child and Adolescent Major Depressive Disorder	Group Psychotherapy	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1910	Child and Adolescent Major Depressive Disorder	Office Visit	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1911	Child and Adolescent Major Depressive Disorder	Outpatient Consultation	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1912	Child and Adolescent Major Depressive Disorder	Patient Provider Interaction	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		SNOMEDCT
1913	Child and Adolescent Major Depressive Disorder	Psychoanalysis	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1914	Child and Adolescent Major Depressive Disorder	Psych Visit - Diagnostic Evaluation	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1915	Child and Adolescent Major Depressive Disorder	Psych Visit - Family Psychotherapy	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1916	Child and Adolescent Major Depressive Disorder	Psych Visit - Psychotherapy	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Encounter		CPT
1917	Child and Adolescent Major Depressive Disorder	birth date	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Individual Characteristic		LOINC
1918	Child and Adolescent Major Depressive Disorder	Ethnicity	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Individual Characteristic		CDCREC
1919	Child and Adolescent Major Depressive Disorder	ONC Administrative Sex	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Individual Characteristic		AdministrativeSex
1920	Child and Adolescent Major Depressive Disorder	Pager	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Individual Characteristic		SOP
1921	Child and Adolescent Major Depressive Disorder	Race	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Individual Characteristic		CDCREC
1922	Child and Adolescent Major Depressive Disorder	Suicide Risk Assessment	CMS177v2	1365	EP	177	2	CAMDD_SuicideRisk	Ambulatory Intervention		SNOMEDCT
1923	ADE Prevention and Monitoring: Warfarin	Atrial Fibrillation/Flutter	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Condition/Diagnosis/Problem		ICD10CM, ICD9CM, SNOMEDCT
1924	ADE Prevention and Monitoring: Warfarin	Valvular Heart Disease	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Condition/Diagnosis/Problem		ICD10CM, ICD9CM, SNOMEDCT
1925	ADE Prevention and Monitoring: Warfarin	Face-to-Face Interaction	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Encounter		SNOMEDCT
1926	ADE Prevention and Monitoring: Warfarin	Office Visit	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Encounter		CPT
1927	ADE Prevention and Monitoring: Warfarin	birth date	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Individual Characteristic		LOINC
1928	ADE Prevention and Monitoring: Warfarin	Ethnicity	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Individual Characteristic		CDCREC
1929	ADE Prevention and Monitoring: Warfarin	ONC Administrative Sex	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Individual Characteristic		AdministrativeSex
1930	ADE Prevention and Monitoring: Warfarin	Pager	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Individual Characteristic		SOP
1931	ADE Prevention and Monitoring: Warfarin	Race	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Individual Characteristic		CDCREC
1932	ADE Prevention and Monitoring: Warfarin	Computed Value INR percent TTR	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Laboratory Test		LOINC
1933	ADE Prevention and Monitoring: Warfarin	INR	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Laboratory Test		LOINC
1934	ADE Prevention and Monitoring: Warfarin	Warfarin	CMS179v2	XXXX	EP	179	2	ADE_TTR	Ambulatory Medication		RXNORM
1935	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Acute Myocardial Infarction	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Condition/Diagnosis/Problem		ICD10CM, ICD9CM, SNOMEDCT
1936	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Ischemic Vascular Disease	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Condition/Diagnosis/Problem		ICD10CM, ICD9CM, SNOMEDCT
1937	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Annual Wellness Visit	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		HCPSCS
1938	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Face-to-Face Interaction	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		SNOMEDCT
1939	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Home Healthcare Services	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		CPT
1940	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Office Visit	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		CPT
1941	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Preventive Care Services - Established Office Visit, 18 and Up	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		CPT
1942	Ischemic Vascular Disease (IVD): Coronary Artery Disease	Preventive Care Services-Initial Office Visit, 18 and Up	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Encounter		CPT
1943	Ischemic Vascular Disease (IVD): Coronary Artery Disease	birth date	CMS182v2	0075	EP	182	2	IVD_Lipid_LDL	Ambulatory Individual Characteristic		LOINC

N=1953



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Data Element Catalog

Data Elem	Count
Ethnicity	93
ONC Administrative Sex	93
Payer	93
Race	93
birth date	82
Office Visit	47
Face-to-Face Interaction	44
Home Healthcare Services	25
Medical Reason	25
Preventive Care Services - Established Office Visit, 18 +	22
Preventive Care Services-Initial Office Visit, 18 +	22
Emergency Department Visit	20
Palliative Care	17
Annual Wellness Visit	16
Outpatient Consultation	14
Patient Refusal	13
Principal Diagnosis	13
Patient Reason	12
Inpatient Encounter	11

# Value Sets – Future Directions

- **Quality assurance** of value sets:

Are they valid? Complete? Consistent? Metrics?

- NLM: Bodenreider, Winnenberg (papers 2012 – 13)

- Can they support decision support?
- Can they support research? PCOR?
- How can we manage growth?

**Table 1. Use of QDM Value Sets within eMERGE Case/Control algorithms.**

Algorithm	Clinical Information	Terminology	No. of Value Sets Used			
Diabetic retinopathy	Cases	Diagnosis	ICD-9	5		
			ICD-10	1		
			SNOMED-CT	1		
			Grouped	1		
			Keywords	2		
	Controls	Diagnosis	ICD-9	5		
			ICD-10	1		
			SNOMED-CT	1		
			Grouped	1		
		Keywords	1			
Procedure	CPT	3				
	Grouped	1				
Peripheral arterial disease	Diagnosis	ICD-9	4			
		Laboratory	LOINC	1		
		Medication	RXNORM	1		
		Procedure	CPT	4		
			ICD-9	4		
	Physical Exam	Grouped	4			
		Grouped	1			
		Keywords	2			
		Resistant hypertension	Cases	Diagnosis	ICD-9	1
				Diagnostic Study	UMLS CUI	1
Laboratory	LOINC			1		
Medication	RXNORM			10		
Physical Exam	LOINC			2		
Controls	Diagnosis		ICD-9	2		
			ICD-10	1		
			SNOMED-CT	1		
			Grouped	1		
	Medication		RXNORM	10		
Physical Exam	Grouped	1				
	LOINC	2				
	Grouped	2				
Type 2 diabetes	Diagnosis	ICD-9	3			
	Laboratory	LOINC	3			
	Medication	RXNORM	1			
	Encounter	CPT	7			
		Grouped	1			
	Patient Char.	HL7	1			

An evaluation of the NQF Quality Data Model for representing Electronic Health Record driven phenotyping algorithms. [Thompson WK](#), [Rasmussen LV](#), [Pacheco JA](#), [Peissig PL](#), [Denny JC](#), [Kho AN](#), [Miller A](#), [Pathak J](#).

[AMIA Annu Symp Proc.](#) 2012;2012:911-20. Epub 2012 Nov 3.

Table 2. Use of QDM Value Sets within eMERGE continuous measure algorithms.

Algorithm	Clinical Information	Terminology	No. of Value Sets Used
Height	Diagnosis	ICD-9	12
		Grouped	2
	Laboratory	LOINC	1
		Medication	RXNORM
	Patient Char. Physical Exam	Grouped	1
		SNOMED-CT	1
		LOINC	1
Serum lipid level	Diagnosis	SNOMED-CT	1
		Grouped	1
		ICD-9	4
		ICD-10	2
	Laboratory	SNOMED-CT	2
		Grouped	3
	Medication	LOINC	4
Grouped		1	
RXNORM		8	
Low HDL cholesterol level	Diagnosis	Grouped	2
		ICD-9	4
		ICD-10	2
		SNOMED-CT	2
		Grouped	3
	Laboratory	Keywords	1
		LOINC	1
Medication	Grouped	1	
	RXNORM	7	
	Grouped	1	
QRS duration	Diagnosis	ICD-9	2
	Diagnostic Study	UMLS CUI	1
	Laboratory	LOINC	3
	Medication	RXNORM	2
	Physical Exam	SNOMED-CT	1

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[AMIA Annu Symp Proc.](#) 2012;2012:911-20. Epub 2012 Nov 3.

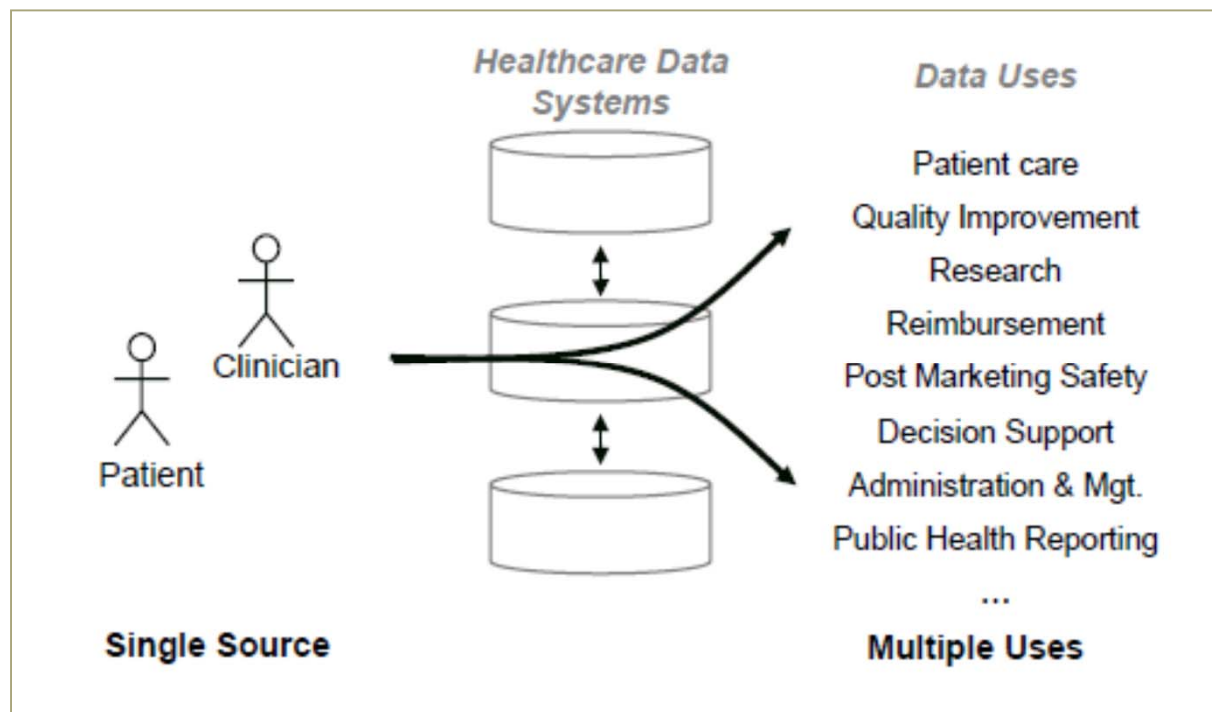
# BRIDGING Clinical vs. Research Worlds

- Computable Phenotypes
  - ICD and other coding systems
  - Limited set of data elements
  - Appropriateness for various research questions
- More (and “better”) data elements (& Value Sets)
  - Good design and QA practices
  - Multi-stakeholder engagement
  - Uniform adoption in EHRs?
  - Standardize or harmonize?
- Who is in charge?



# What could drive this?

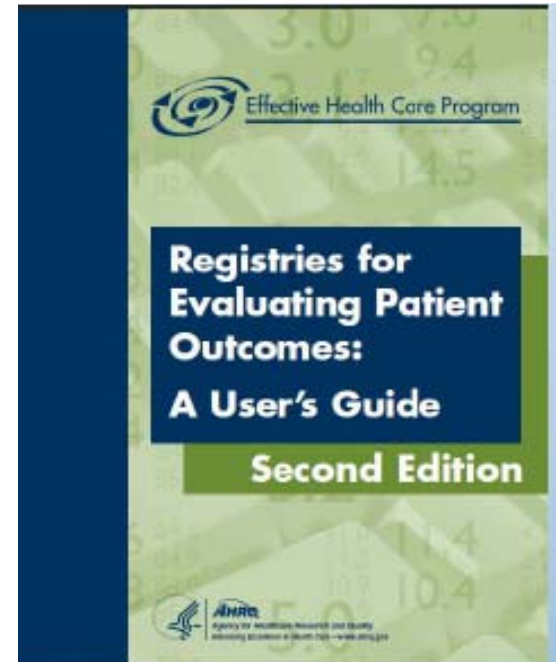
- Business cases for EHR-derived data to support research uses
- Routine



# Patient Registries

- Natural history of disease
- Effectiveness
- Safety
- Quality

AHRQ: “Registries for Evaluating Patient Outcomes”

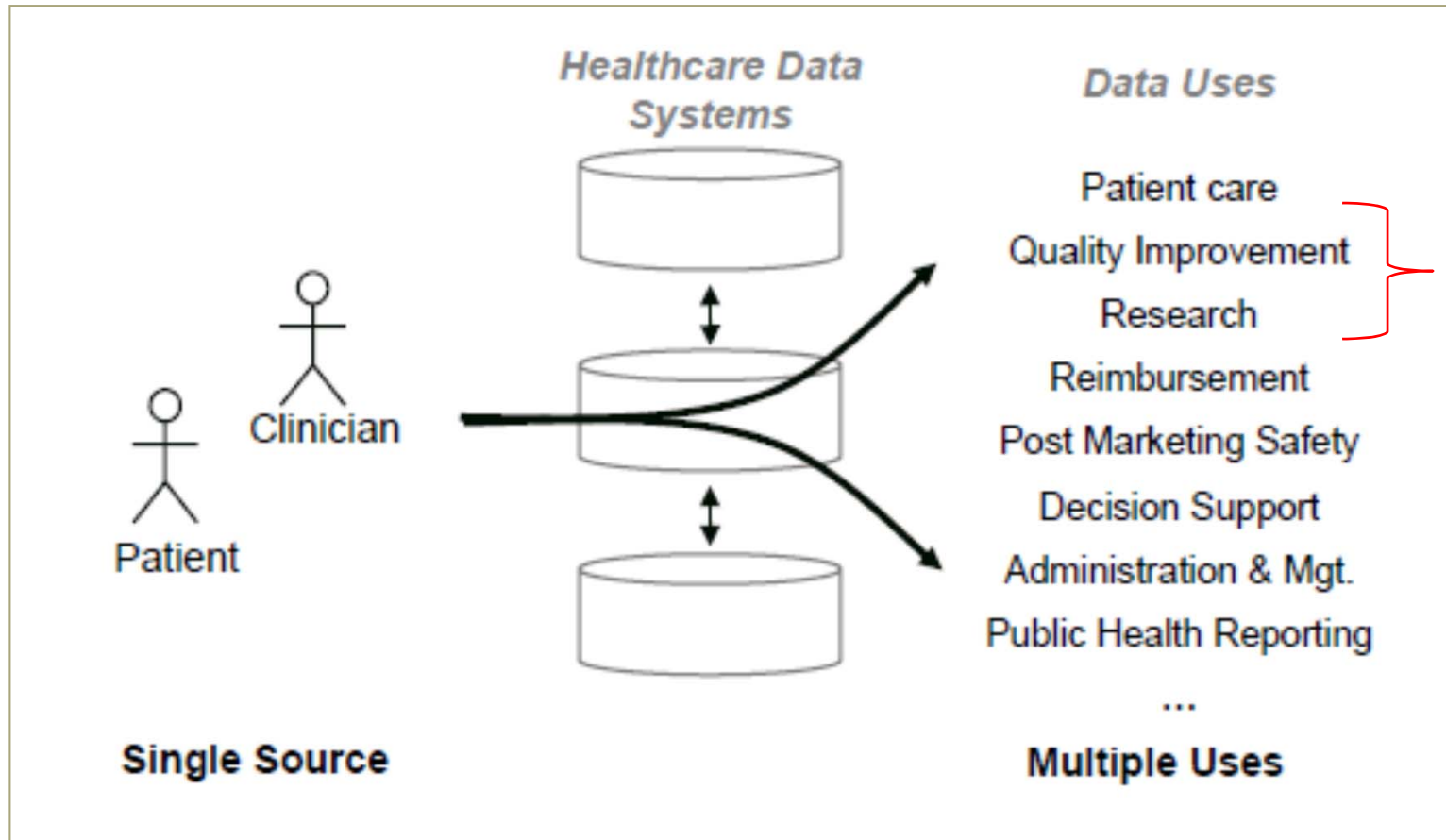


- Chronic Disease Management

CHF Report on Registries in Chronic Disease Management:

<http://www.chcf.org/publications/2004/02/using-computerized-registries-in-chronic-disease-care>

# Future....



# HCS Research Collaboratory

Clinics  
throughout the  
United States



PATIENT  
CARE



Registries



RESEARCH



Leverage and expand  
capabilities to enable:

- Research
- Quality Improvement

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# Future....

The Collaboratory

(?)

EHR Vendors

Public, Providers,  
Patients, and  
Advocacy  
Organizations

*Standard data elements*

