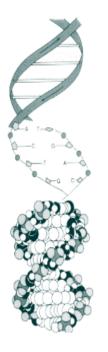


A National Center for Biomedical Computing



Enabling the Healthcare Enterprise for Discovery Research with i2b2

Shawn Murphy MD, Ph.D.

High Throughput Method for supporting Research

- Set of patients is selected from medical record data in a high throughput fashion
- Investigators work with the data of these patients using new i2b2 tools and a specialized team, both developed to work specifically with medical record data
- Using the Crimson system, tissues of these patients can be made available for genomic and biochemical analysis
- Automated discovery can be created from these projects to support further hypothesis-driven research

High Throughput Method for supporting Research

- Set of patients is selected from medical record data in a high throughput fashion
 - Eugene Braunwald
 - Henry Chueh
 - John Glaser
 - Diane Keogh

Research Patient Data Registry exists at Partners Healthcare

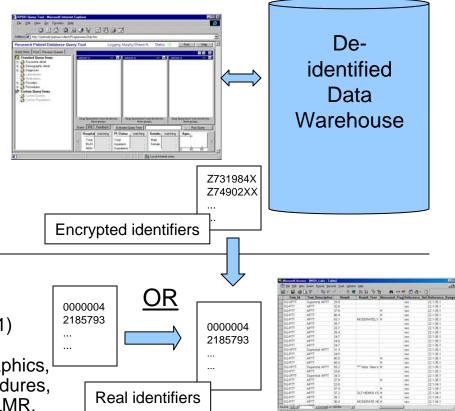
1) Queries for aggregate patient numbers

-Warehouse of in & outpatient clinical data

- 4.6 million Partners Healthcare patients

- 1.2 billion diagnoses, medications, procedures, genomics, laboratories, & physical findings coupled to demographic & visit data

- Authorized use by faculty status
- Clinicians can construct complex queries
- Queries cannot identify individuals, internally can produce identifiers for (2)



Query construction in web tool

2) Returns identified patient data

- Start with list of specific patients, usually from (1)
- Authorized use by IRB Protocol
- Returns contact and PCP information, demographics, providers, visits, diagnoses, medications, procedures, laboratories, microbiology, reports (discharge, LMR, operative, radiology, pathology, cardiology, pulmonary, endoscopy), and images into a Microsoft Access database and text files.

Security and Patient Confidentiality of Step 1

- All patients at Partners are added
 - HIPAA notification that their data may be used for research upon registration.
- RPDR data is anonymized at the Query Tool.
 - Aggregated numbers are obfuscated to prevent identification of individuals; automatic lock out occurs if pattern suggests identification of an individual is being attempted.

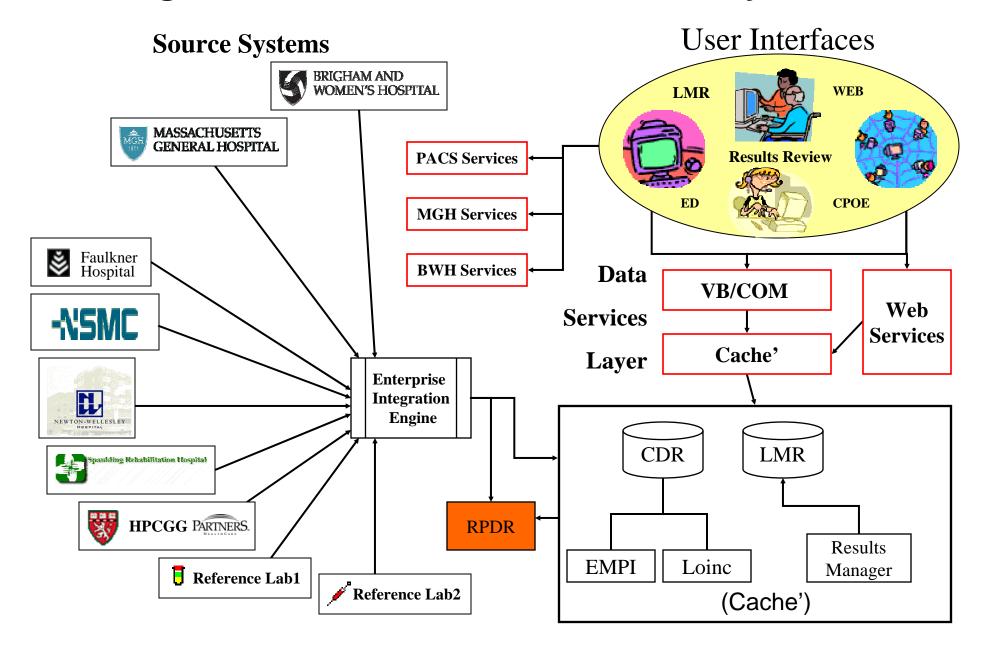
A Security Architecture for Query Tools used to Access Large Biomedical Databases Shawn N. Murphy, MD, Ph.D. and Henry C. Chueh, MD, M.S. Laboratory of Computer Science, Massachusetts General Hospital, Boston, MA.

- Queries done in Query Tool available for review by RPDR team, a user lock out will specifically direct a review.
- De-identified data warehouse is a "Limited Data Set" by HIPAA
 - Medical record numbers are encrypted and obvious identifiers are removed from data.
- Concept of "established medical investigator" is promoted by classification as a faculty sponsor.

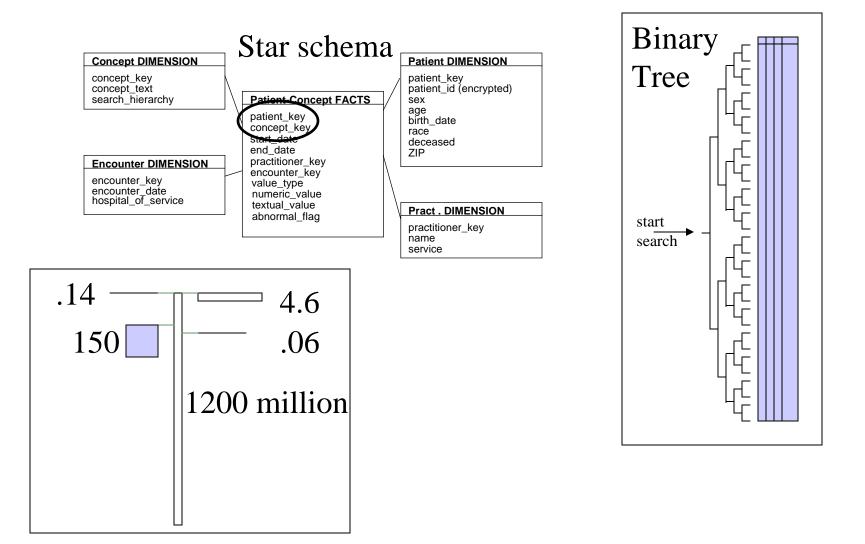
Security and Patient Confidentiality of Step 2

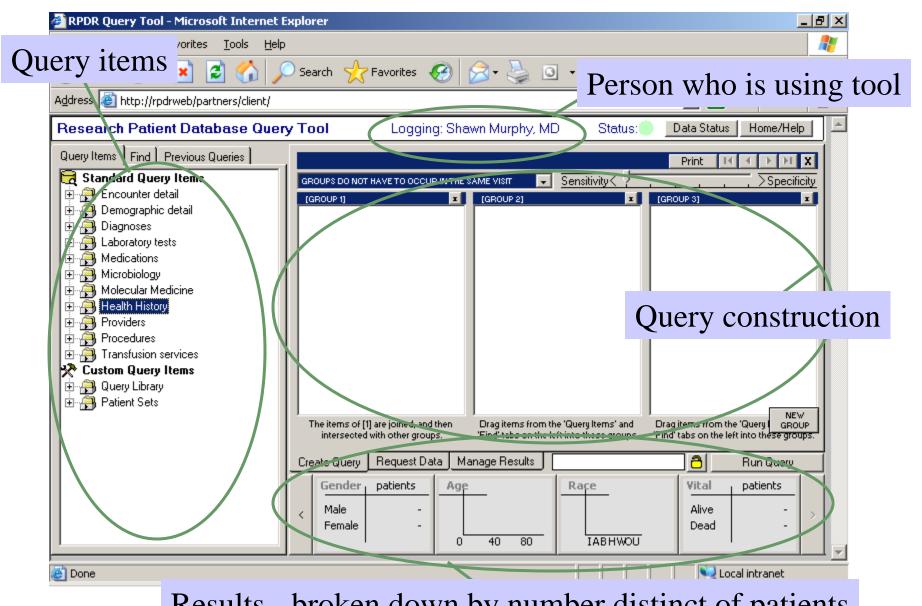
- Only studies approved by the Institutional Review Board (IRB) are allowed to receive identified data.
- Queries may be set up by workgroup member, but faculty sponsor on IRB protocol must directly approve all queries that return identified data.
- Special controls exist when distributing data regarding HIV antibody and antigen test results, substance abuse rehab programs, and genetic data, due to specific state and federal laws.
- Queries that return identified data are reviewed (retrospectively) by the IRB.

Getting data into the RPDR from clinical systems



Organizing data in the Clinical Data Warehouse



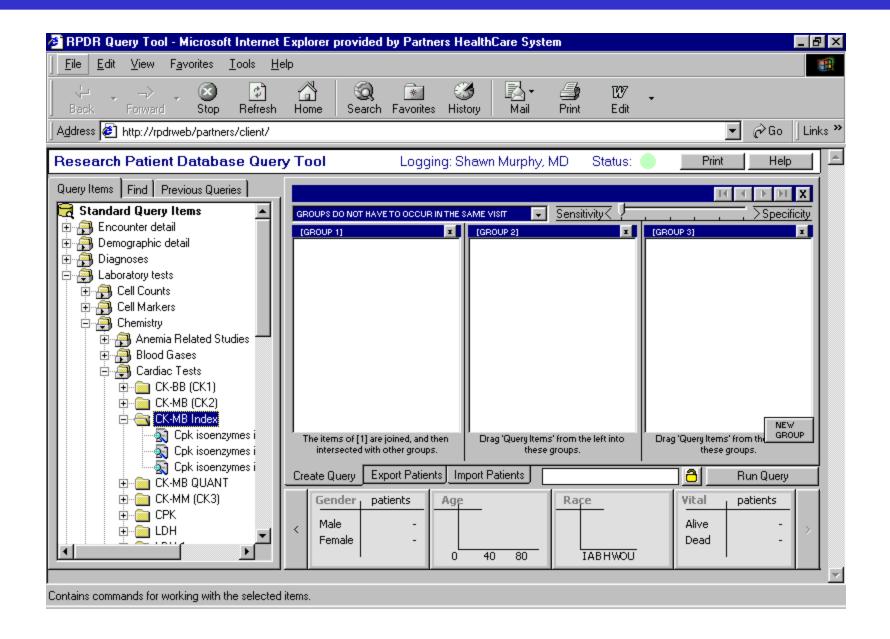


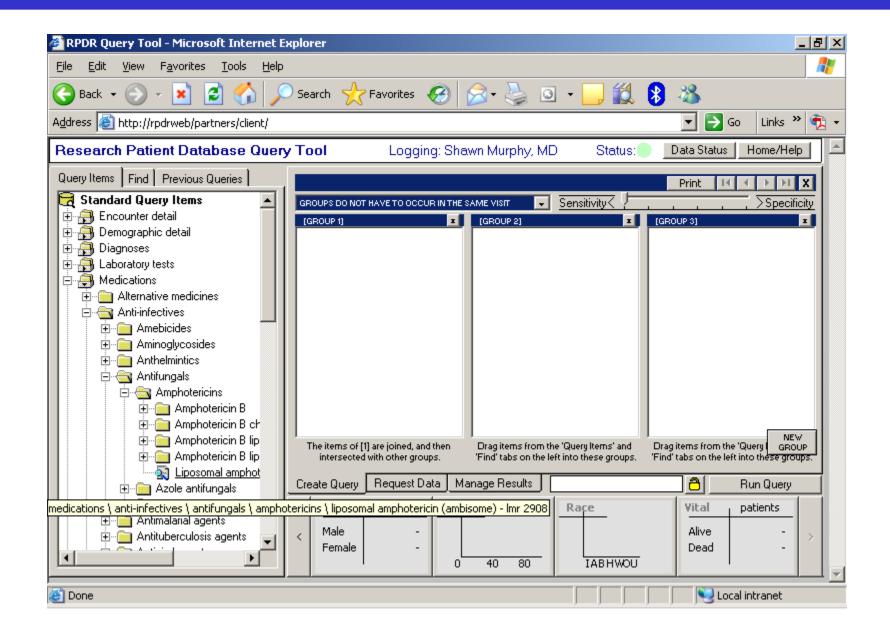
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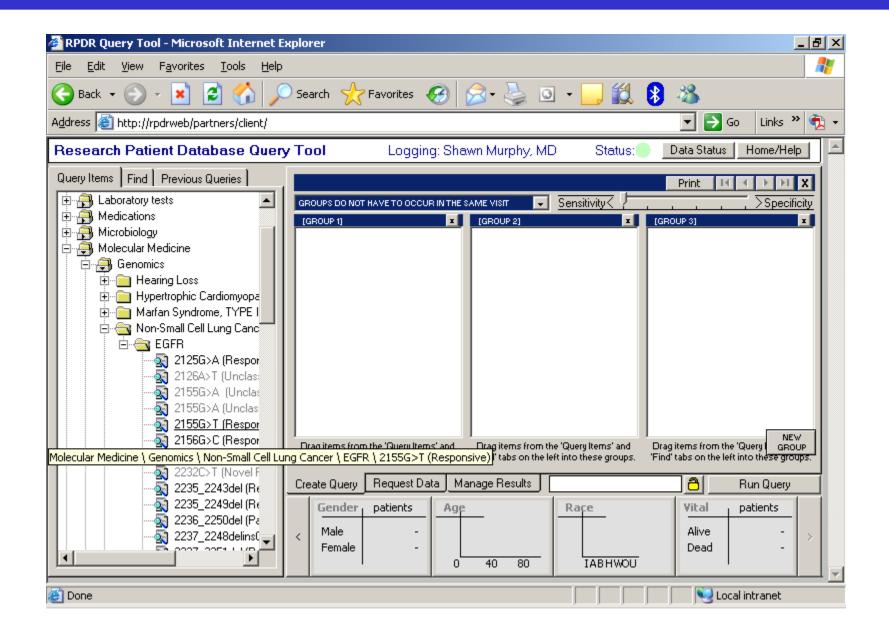
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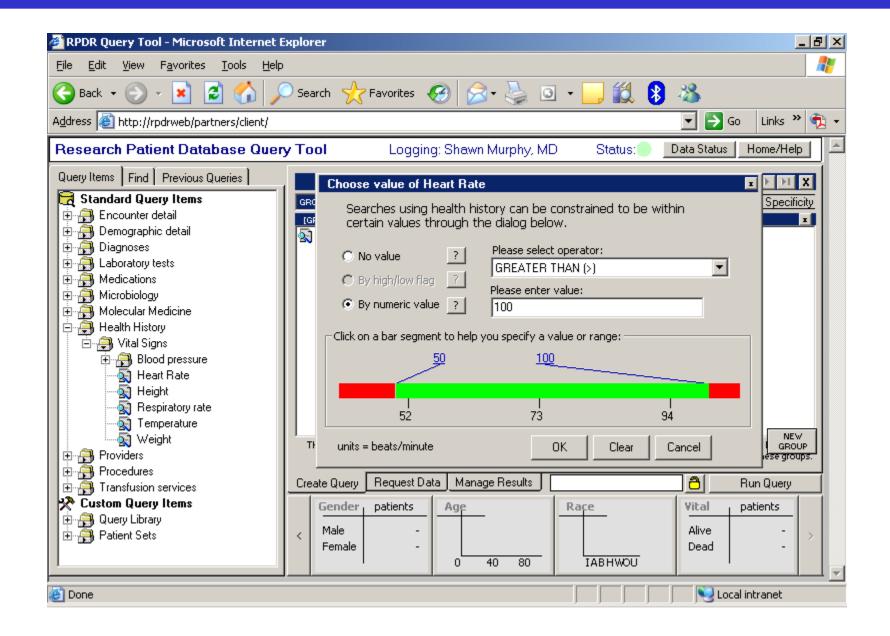
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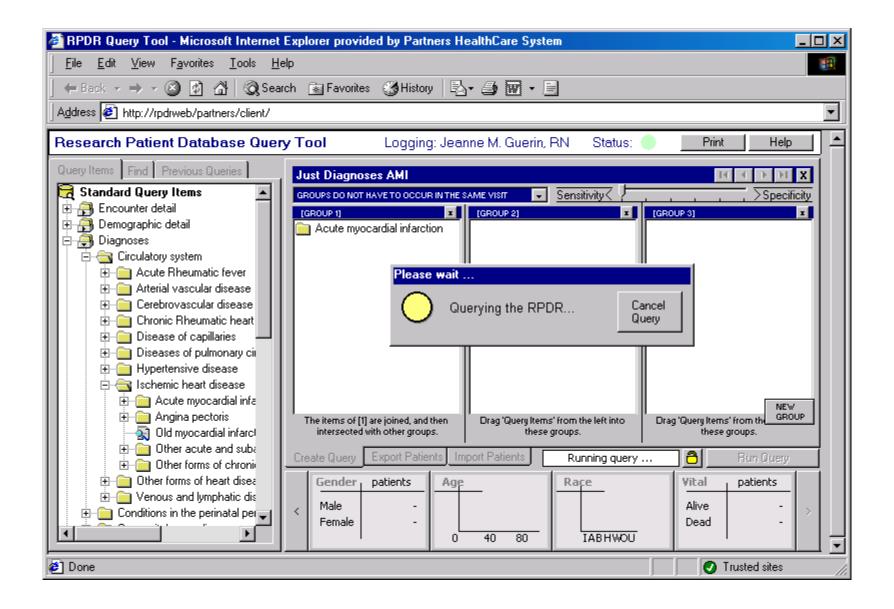


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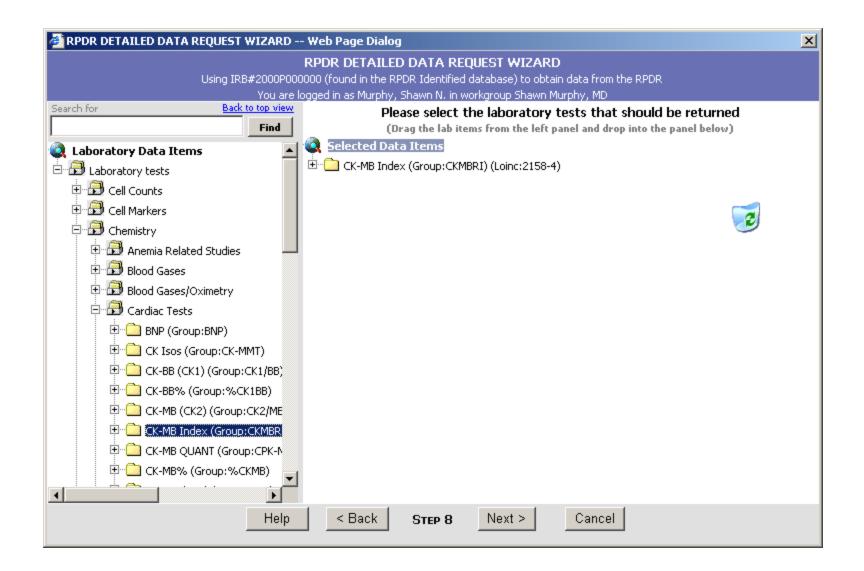
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RPDR DETAILED DATA REQUEST WIZARD Using IRB#mgh-demo-1 (found in the RPDR Identified database) to obtain data from the RPDR You are logged in as Murphy, Shawn N. in workgroup Shawn Murphy, MD	
Select the sites from which you would like to receive data (Please note that different sites and Institutional Review Boards (IRBs) may have different policies regarding obtaining patient data. Detail of the policies can be read <u>here</u>)	
Massachusetts General Hospital (MGH)	
Brigham and Women's Hospital (BWH)	
Newton Wellesley Hospital (NWH)	
Spaulding Rehabilitation Hospital (SRH)	
Faulkner Hospital (FH)	
North Shore Medical Center (NSMC)	
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🚰 RPDR Detailed Data Request Wizard Web Page I	Dialog
	DETAILED DATA REQUEST WIZARD
	d in the RPDR Identified database) to obtain data from the RPDR
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	Select protocol number(s)
Partners IRB (required):	mgh-demo-1
	Title: RPDR protocol - Demonstration IRB number for Dr. Murphy
	Status: Active
Newton Wellesley Hospital IRB:	NWH Demo 1
	Title: test
	Status: Active
Spaulding Rehabilitation Hospital IRB:	
Options for returned set of patien	ts:
Create a static set of patie	nts from this query that can be used in other RPDR queries
Rerun the base query sho	wn above to obtain a fresh set of patients
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RPDR DETAILED DATA REQUEST WIZARD Using IRB#mgh-demo-1 (found in the RPDR Identified database) to obtain data from the RPDR You are logged in as Murphy, Shawn N. in workgroup Shawn Murphy, MD	
Select others who require access to this data	
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 C Limited Data Set The files that result from this request will be available in a protected file share with no special encryption. C Identified Data Set The text files that result from this request will be encrypted and the Microsoft Access file will be password protected. In order to access the data, a password will be provided. 	
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RPDR DETAILED DATA REQUEST WIZARD Using IRB#2000P000000 (found in the RPDR Identified database) to obtain data from the RPDR You are logged in as Murphy, Shawn N. in workgroup Shawn Murphy, MD	
RPDR DISCLAIMER: All requests, such as this one, are reviewed by the IRB to assure compliance with the written protocol. If the data requested is not authorized by the protocol, those involved with its retrieval face disciplinary action including loss of federal funding, loss of employment, and/or criminal prosecution.	
Read Full IRB Policy	
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Identified data is gathered

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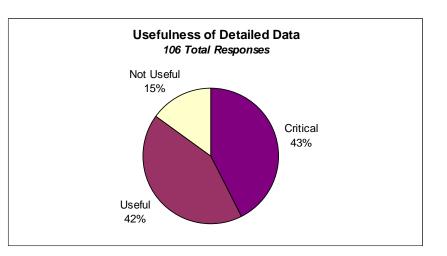
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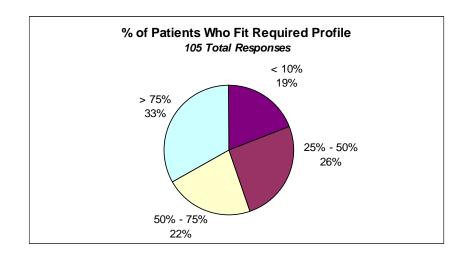
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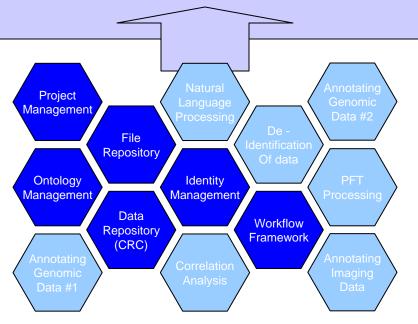
2007's usage of RPDR

- 1,580 registered users, 332 new in 2007
- 294 teams gathering data for research studies
- 815 identified patient data sets returned to these teams, containing data for of 8.8 million patient records.
- From a survey of 153 teams
 - Importance of the data received from the RPDR was evaluated in relation to the study it was supporting.
 - The adequacy of the match of a patient profile that could be obtained through the RPDR query tool was estimated.
- \$94-136 million total research support critically dependent on RPDR from patient data received throughout life of funding.
- ~300 data marts were created to support hospital operations, representing about 80 million patient records



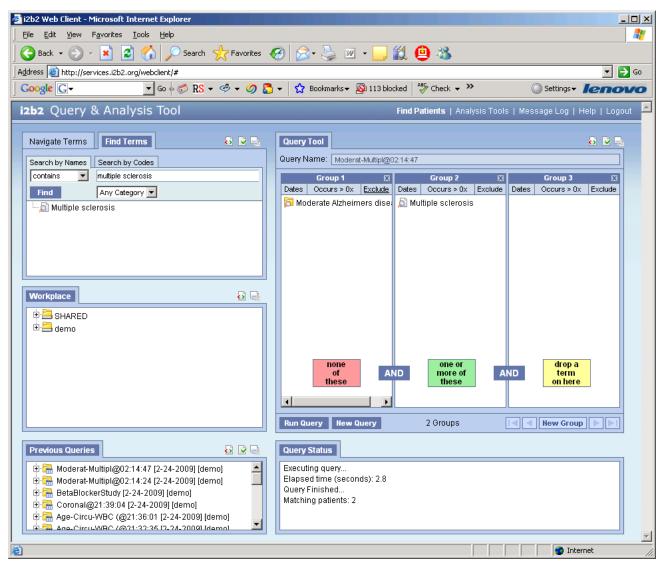


Enterprise-wide repurposing and distribution of medical record data for research



- Enable high performance collection of medical record data for querying and distribution
 - Enterprise web client
 - Create patient cohorts for further investigation
- Enable discovery within data on enterprise wide scale
 - Relevance networks
 - Health Surveillance

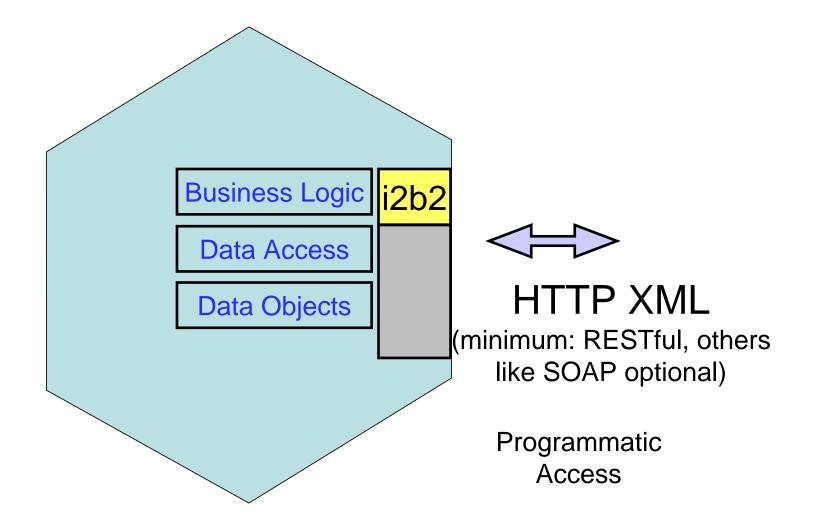
Enterprise web client http://services.i2b2.org/webclient/



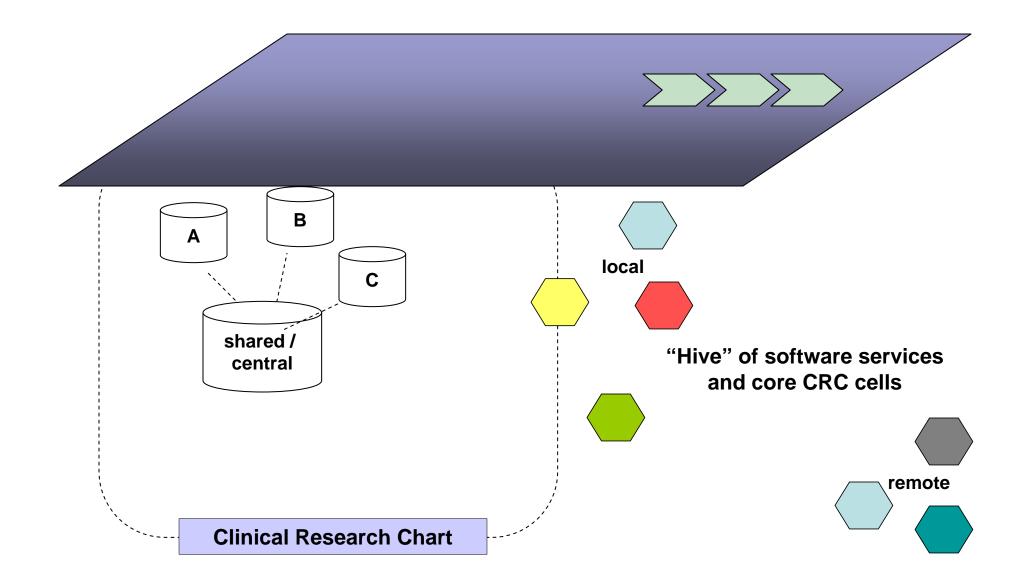
Technical Overview

- Formed as a collection of interoperable services provided by i2b2 Cells
- Loosely coupled
- Makes no assumptions about proximity
- Connected by Web services
- Activity can be directed manually or automatically

i2b2 Cell: Canonical Hive Unit



i2b2 Environment



i2b2

A National Center for Biomedical Computing



Informatics for Integrating Biology & the Bedside



CTSAs* Adopting i2b2 CTSAs* Evaluating i2b2 platform Academic Medical Centers Adopting i2b2 Platform Foreign Medical Centers Adopting i2b2 Platform

Community

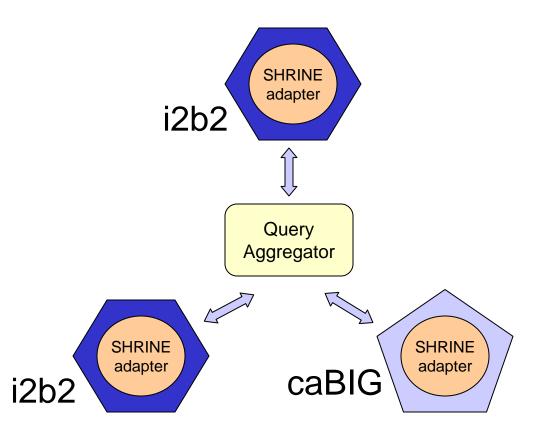
United States

- Beth Israel Deaconness Hospital, Boston, MA
- Boston University School of Medicine, Boston, MA
- Brigham and Women's Hospital, Boston, MA
- Children's Hospital, Boston, MA
- Denver Children's Hospital, Denver, CO
- Cincinnati Children's Hospital, Cincinnati, OH
- Cleveland Clinic, Cleveland, OH
- Weil Medical College of Cornell, NYC, NY
- Group Health Cooperative
- Harvard Medical School, Boston, MA
- Massachusetts General Hospital, Boston, MA
- Maine Medical Center, Portland, ME
- Marshfield Clinic, Wisconsin
- Morehouse School of Medicine, Atlanta, GA
- Oregon Health & Science University, Portland, OR
- Ohio State University Medical Center, Columbus, OH
- Philadelphia Children's Hospital, Philadelphia, PA
- Renaissance Computing Institute, Chapel Hill, NC
- Tufts New England Medical Center, Boston, MA
- University of California Davis, Davis, CA
- University of California San Francisco, SF, CA
- University of Massachusetts Medical School, Worcester, MA
- University of Michigan Medical Center, Ann Arbor, MI
- University of Pennsylvania School of Medicine, Philadelphia, PA
- University of Rochester Medical Center, Rochester, NY
- University of Texas Health Sciences Center Houston, Houston, TX
- University of Texas Health Sciences Center San Antonio, SA, TX
- University of Texas Health Sciences Center Southwestern,
- Utah Health Science Center, Salt Lake City, UT
- University of Washington, Seattle, WA

International

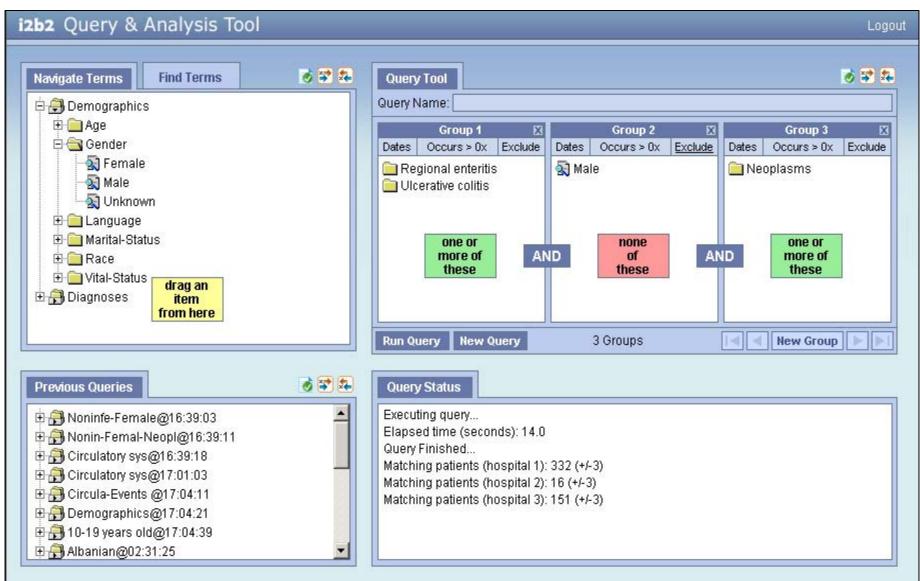
- Georges Pompidous Hospital, Paris, France
- University of Goettingen, Goettingen, Germany
- University of Pavia, Pavia, Italy
- University of Seoul, Seoul, Korea

SHRINE (Shared Research Informatics Network) = Distributed Queries



Central "aggregator" broadcasts query to local hospital "adaptors", which return aggregate counts only

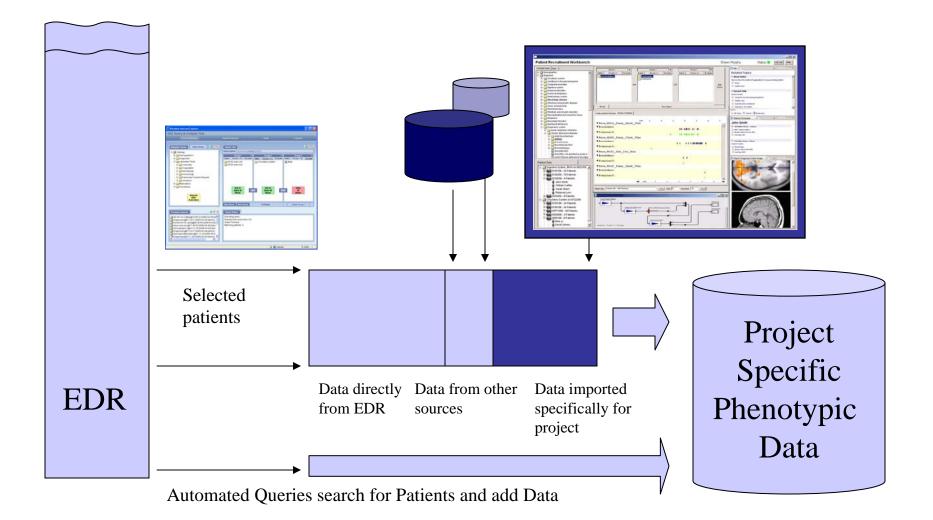
SHRINE



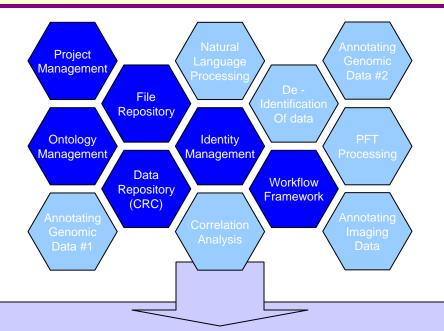
High Throughput Method for supporting Research

- Set of patients is selected from medical record data in a high throughput fashion
- Investigators work with the data of these patients using new i2b2 tools and a specialized team, both developed to work specifically with medical record data
 - Isaac Kohane
 - John Glaser
 - Susanne Churchill
 - □ Henry Chueh
 - Griffin Weber
 - Michael Mendis
 - □ Andrew McMurry
 - Vivian Gainer
 - Lori Phillips
 - Rajesh Kuttan
 - Wensong Pan

Set of patients is selected through Enterprise Repository and data is gathered into a data mart

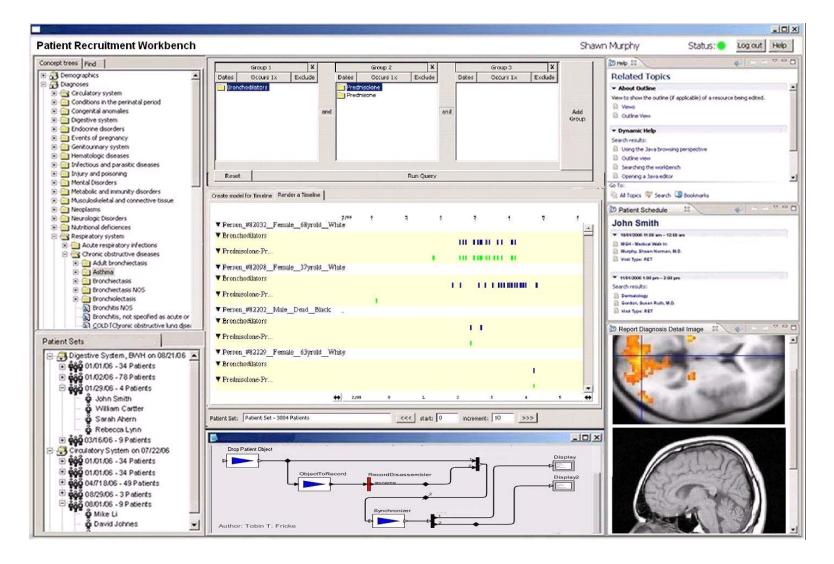


- Repurpose medical record information for research studies
 - I2b2 Workbench
 - Natural language processing
- Enable Genomic Studies and Public Heath
 - Tissue/blood selection
 - Health Reporting

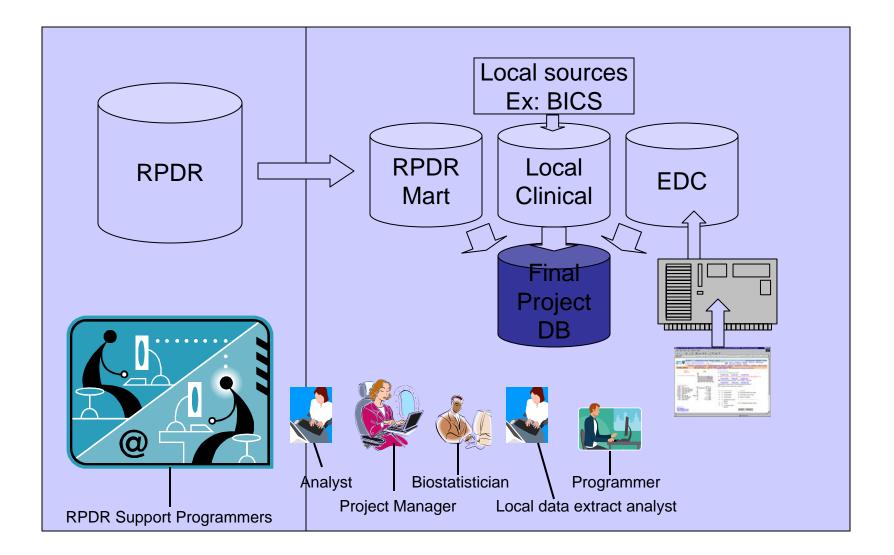


Use of medical record data in clinical studies focused upon teamwork and workflow

Data is available through the i2b2 Workbench



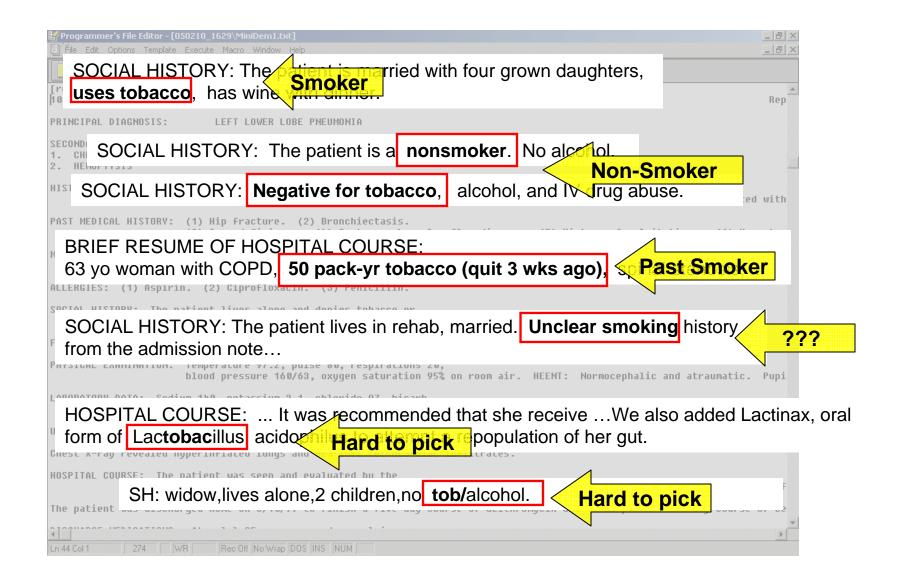
Team support for Projects



NLP Workflow



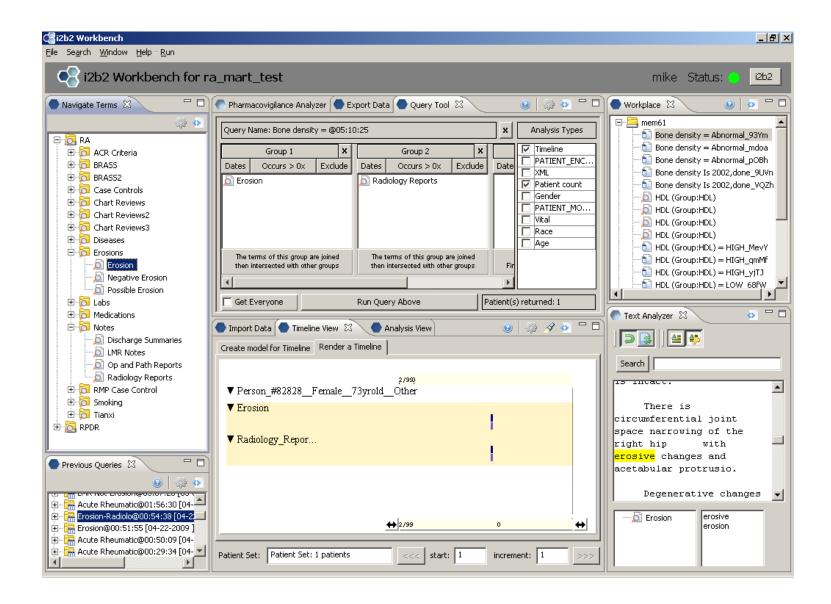
NLP (and comedy) is not pretty



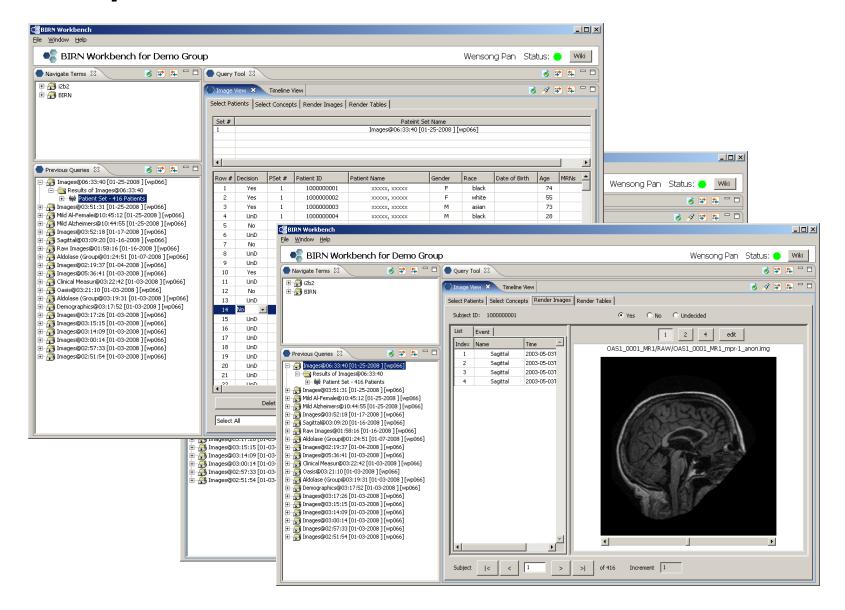
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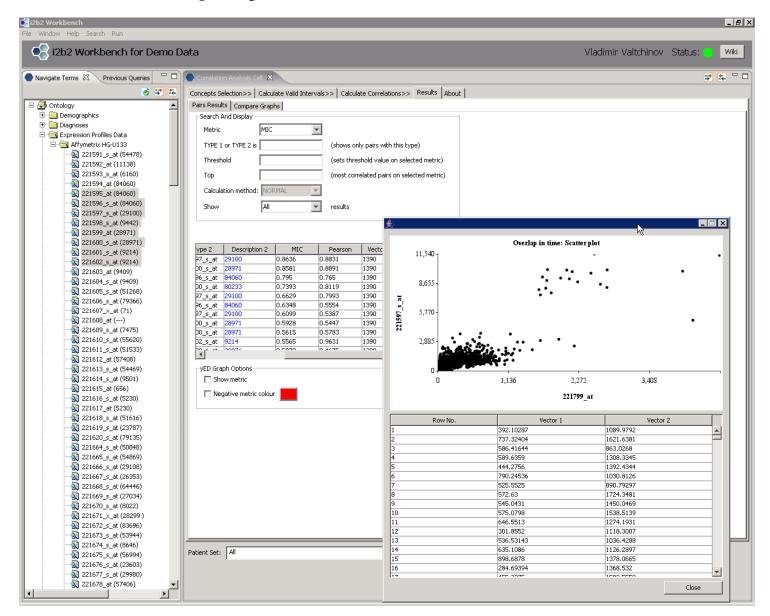
Investigator Review



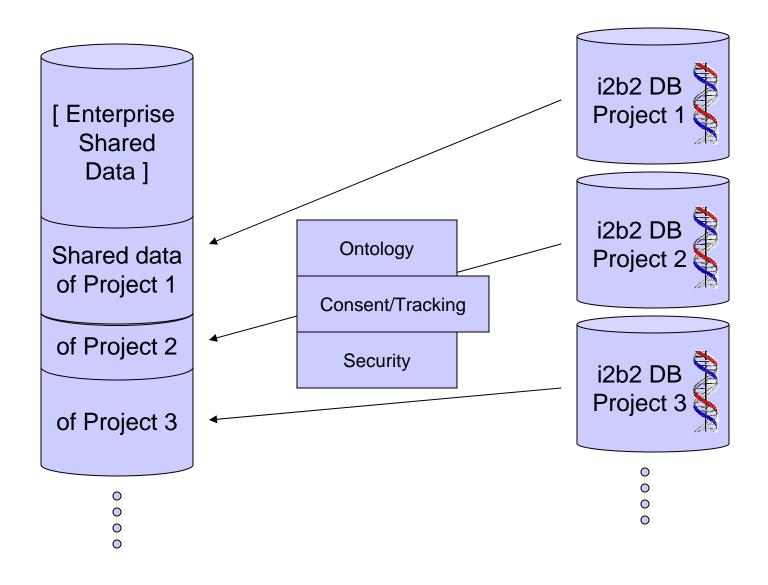
Select patients for clinical trials



Workbench display of Mutual Inform. Correlations



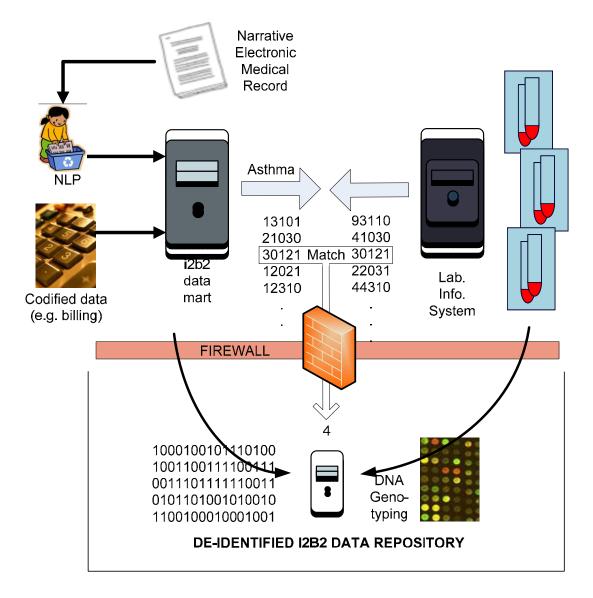
Project data can be added back to Enterprise Repository



High Throughput Method for supporting Research

- Set of patients is selected from medical record data in a high throughput fashion
- Investigators work with the data of these patients using new i2b2 tools and a specialized team, both developed to work specifically with medical record data
- Using the BETR/Crimson system, tissues of these patients can be made available for genomic and biochemical analysis
 - Lynn Bry
 - Natalie Boutin

Genotype samples and compare to controls

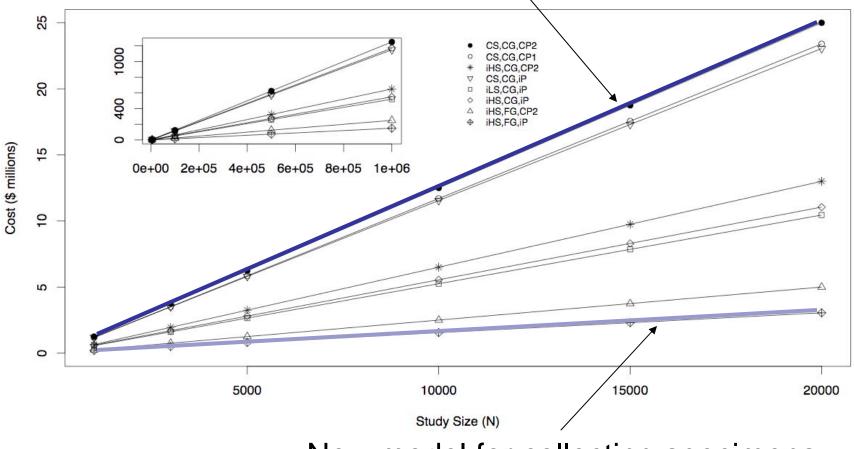


Cost and time benefit of Instrumenting with Sample Collection for Modest-size Study with 10,000 subjects (cases + controls)

Old vs. New	Cost (\$)	Time
1 chart review per patient (CP1)	\$20	15 minutes/subject
High-throughput phenotyping (iP) through RPDR and i2b2	\$50K Total	1 month total (conservative high estimate)
Sample acquisition through primary care provider (CP)	\$650	3-5 subjects/week ¹
High-throughput sample acquisition through RPDR and BETR/Crimson.	\$20	50-200 subjects /week ²

= \$6.7 million/study vs. \$250 thousand/study

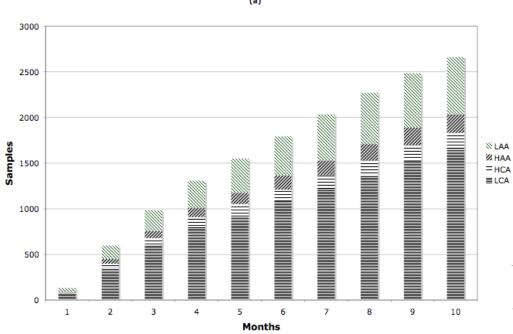
Escalating cost and time benefit of Instrumenting with Sample Collection

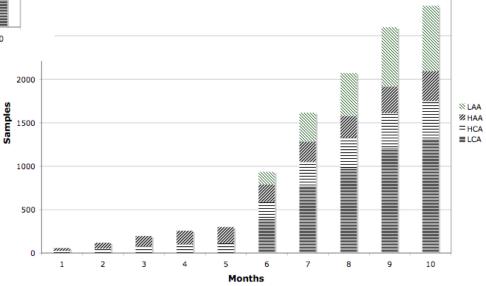


Previous model for collecting specimens

New model for collecting specimens

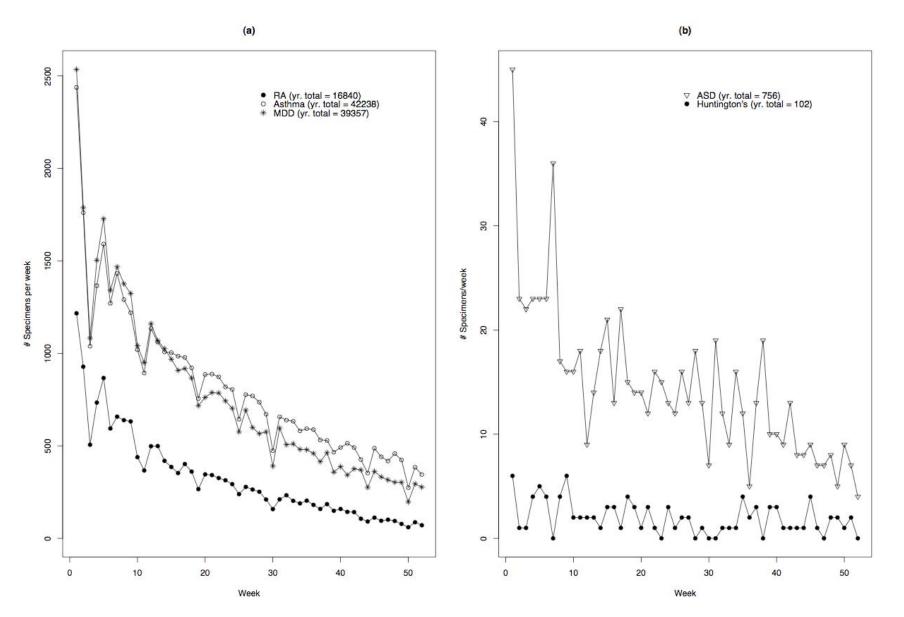
Meeting Expectations





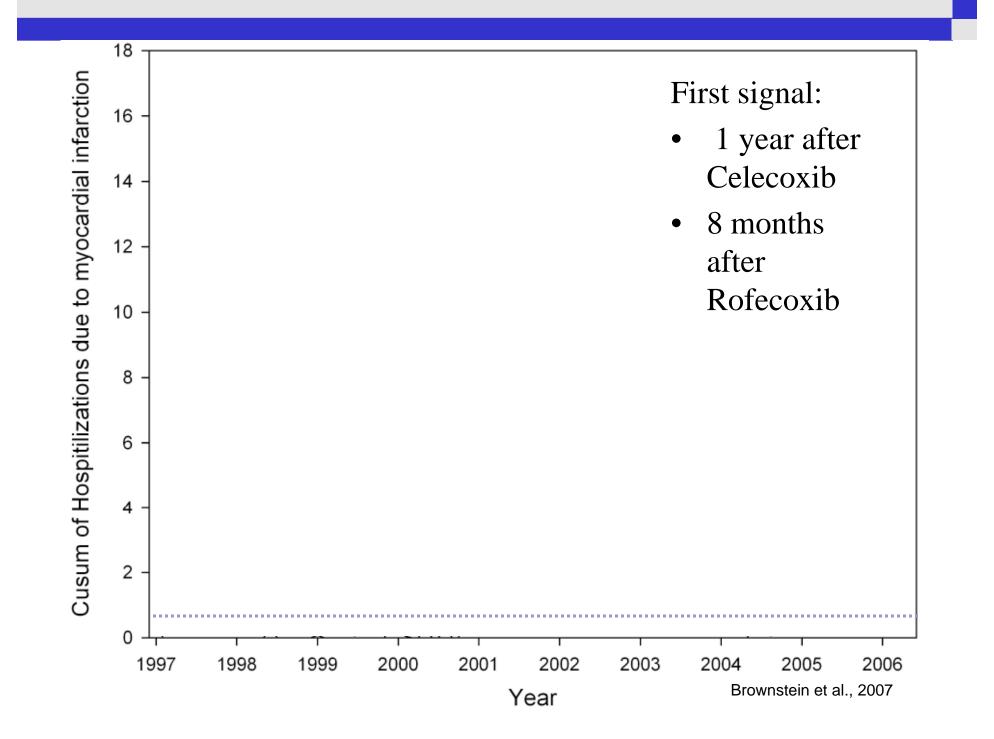
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Accrual Rates

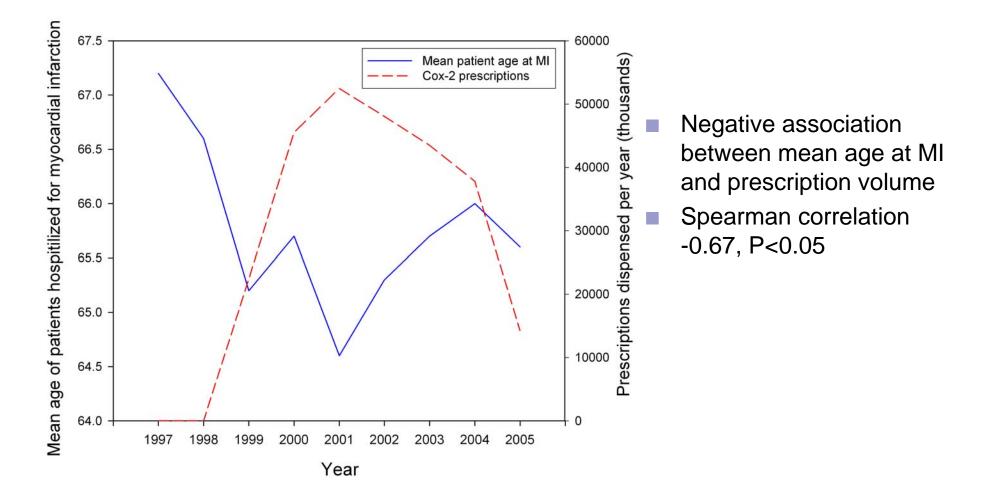


High Throughput Method for supporting Research

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- Using the Crimson system, tissues of these patients can be made available for genomic and biochemical analysis
- Automated discovery can be created from these projects to support further hypothesis-driven research
 - John Brownstein
 - Judy Colecchi



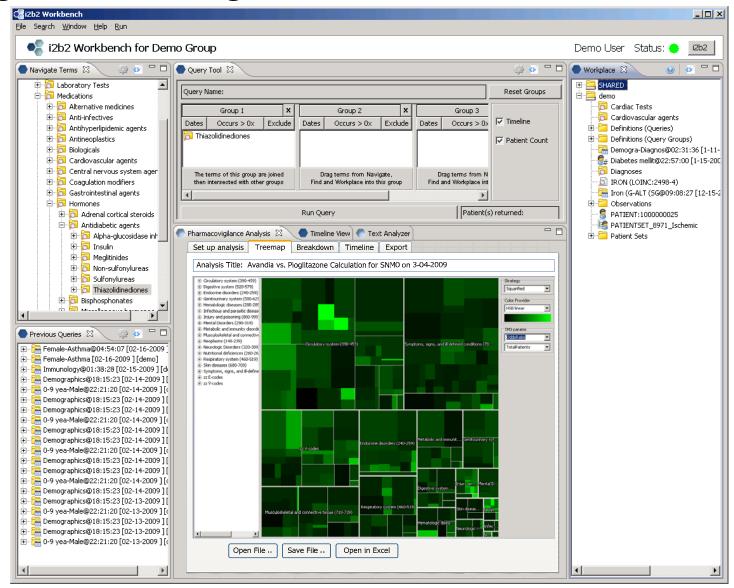
Effect on patient age



Centrally supported Automated Discovery Projects Clinical trials performed in-silico

- Performing an observational, phase IV study is an expensive and complex process that can be potentially modeled in a retrospective database using groups of patients available in the large amounts of highly organized medical data.
- Fundamental problems complicate this approach:
 - Patients drift in and out of the system. Sophisticated statistical models using adequate control populations are necessary to compensate.
 - Confounding variables are not found in the database. Sophisticated natural language processing is needed to extract the confounders from textual reports to allow these confounders to be controlled.
 - Missing data disrupts typical statistical approaches

Odds Ratios for Diseases expressed in comparing Rosiglitazone vs. Pioglitazone



Take-away points from i2b2

- 1) Enable Enterprise use of Patients for Research
- 2) Power comes from Numbers of Patients Recruited
- 3) Extensible Architecture for Developers
- 4) Enable Scientist Workflow
- 5) Enable Teamwork between Informaticians and Researchers
- 6) Communicate through Visualizations
- 7) Enable Natural Language Processing
- 8) High throughput Tissue acquisition for Genomic Research
- 9) Enable Health Surveillance
- 10) Enable Data Sharing

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