

Opportunities and Limitations of Big Data to Address Diversity

Shawn Murphy MD, Ph.D.

The Research Data Warehouse at Partners Healthcare

Partners Enterprise

Research Patient Data Registry

Multiple Systems at Partners:

Billing Data

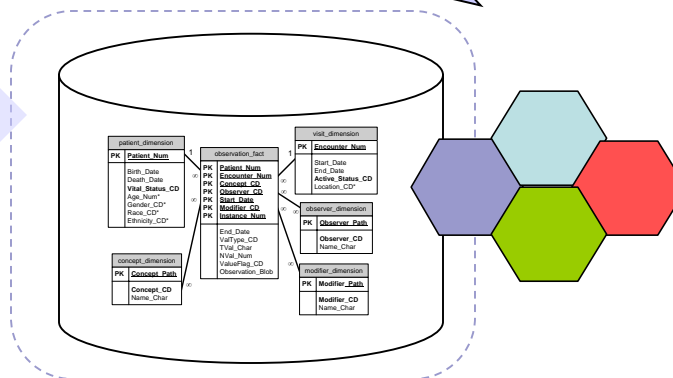
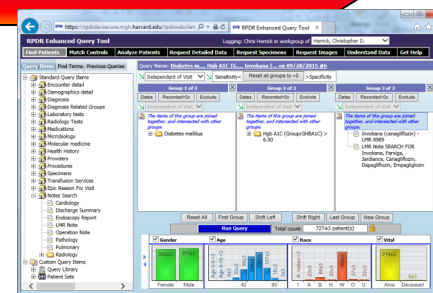
Epic Data

Research Data (consent to contact)

Specimen Data

Laboratory Data

...

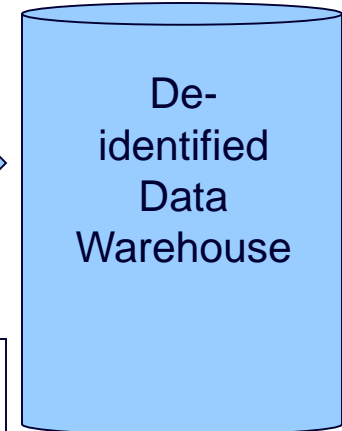
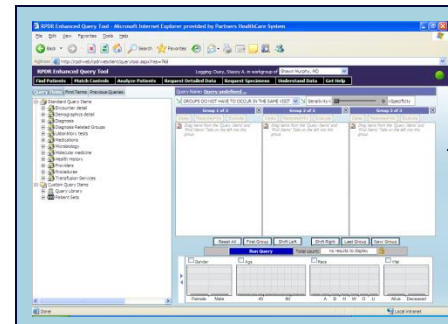


Research Patient Data Registry (RPDR) at Partners Healthcare to find patient cohorts for clinical research

1) Queries for aggregate patient numbers

- Warehouse of in & outpatient clinical data
- 6.5 million Partners Healthcare patients
- 2.2 billion diagnoses, medications, procedures, 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

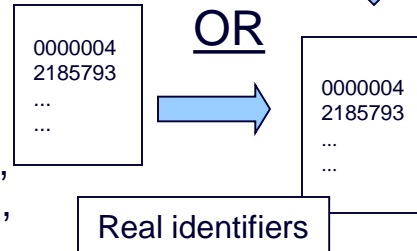


Encrypted identifiers

Z731984X
Z74902XX
...

2) Returns detailed 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.



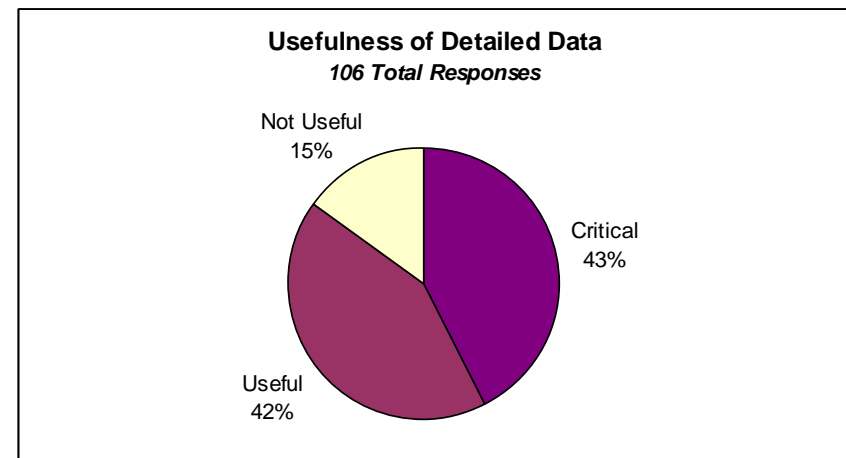
Real identifiers

The screenshot shows a Microsoft Access database with a table of patient data. The table has columns for Test ID, Test Description, Result, Result Text, Abnormal Flag, Reference, Unit Reference, and Range.

Test ID	Test Description	Result	Result Text	Abnormal Flag	Reference	Unit Reference	Range
SO-PTT	Superior APPT	29.8				sec	22.1-35.1
SO-PTT	APTT	29.8				sec	22.1-35.1
SO-PTT	APTT	27.8				sec	22.1-35.1
SO-PTT	APTT	40.4				sec	22.1-35.1
SO-PTT	APTT	43.1				sec	22.1-35.1
SO-PTT	APTT	26.7				sec	22.1-35.1
SO-PTT	APTT	27.7				sec	22.1-35.1
SO-PTT	APTT	26.4				sec	22.1-35.1
SO-PTT	APTT	24.7				sec	22.1-35.1
SO-PTT	APTT	24.0				sec	22.1-35.1
SO-PTT	Superior APPT	31.3				sec	22.1-35.1
SO-PTT	APTT	34.5				sec	22.1-35.1
SO-PTT	APTT	40.0				sec	22.1-35.1
SO-PTT	APTT	48.0				sec	22.1-35.1
SO-PTT	Superior APPT	50.2				sec	22.1-35.1
SO-PTT	APTT	38.6				sec	22.1-35.1
SO-PTT	Superior APPT	34.3				sec	22.1-35.1
SO-PTT	APTT	37.9				sec	22.1-35.1
SO-PTT	APTT	22.6				sec	22.1-35.1
SO-PTT	APTT	37.4				sec	22.1-35.1
SO-PTT	APTT	37.2				sec	22.1-35.1
SO-PTT	APTT	36.1				sec	22.1-35.1
SO-PTT	APTT	38.4				sec	22.1-35.1

2014's usage of RPDR

- > 5100 registered users over 12 years, 655 new in 2014
- 583 teams/year gathering data for research studies
- 2634 detailed patient data sets returned to these teams in 2014, containing data of 24.7 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.
 - \$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



Security and Patient Confidentiality of Step 1

- All patients at Partners are added when seen in “Affiliated Covered Entity”
 - HIPAA notification that their data may be used for research and operations 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.
- Concept of “established medical investigator” is promoted by classification as a faculty member or designated list from IRB.

Security and Patient Confidentiality of Step 2

- Only studies approved by designated Directors of Operation at Hospitals or the Institutional Review Board (IRB) are allowed to receive detailed data.
- Queries may be set up by a workgroup member, but faculty sponsor on Approval / 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.

FINDING PATIENTS

Query items

Person who is using tool

RPDR Enhanced Query Tool - Microsoft Internet Explorer provided by Partners HealthCare System

Tools Help

Address <http://rpdweb/rpdwebclient/querytool.aspx?res=768>

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patients Match Controls Analyze Patients Request Detailed Data Request Specimens Understand Data Get Help

Query Items Find Terms Previous Queries

Standard Query Items

- Encounter detail
- Demographics detail
- Diagnosis
- Diagnosis Related Groups
- Laboratory tests
- Medications
- Microbiology
- Molecular medicine
- Health History
- Providers
- Procedures
- Transfusion Services

Custom Query Items

- Query Library
- Patient Sets

Query Name: Query undefined ...

☒ GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT ☐ Sensitivity: 0 > Specificity

Group 1 of 3 Group 2 of 3 Group 3 of 3

Dates Recorded > 0x Exclude

Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.

Reset All Run Query Total count: no results to display

Gender Age Race Vital

Female Male 40 80 A B H W O U Alive Deceased

Done Local intranet

Query construction

Results - broken down by number distinct of patients

RPDR Enhanced Query Tool

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Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items Find Terms Previous Queries

Standard Query Items

- Encounter detail
- Demographics detail
- Diagnosis
 - Circulatory system
 - Acute Rheumatic fever
 - Arterial vascular disease
 - Cardiac problem-Oncall
 - Cardiac risk factors-Oncall
 - Cardiac risk stratification-Oncall
 - Cerebrovascular disease
 - Chronic Rheumatic heart disease
 - Disease of capillaries
 - Diseases of pulmonary circulation
 - Hypertensive disease
 - Ischemia-Oncall
 - Ischemic heart disease
 - Acute myocardial infarction
 - Angina pectoris
 - Ischemic heart disease-Oncall
 - Old myocardial infarction
 - Other acute and subacute forms of ischemic
 - Other forms of chronic ischemic heart disease
 - Other forms of heart disease
 - Vascular problem-Oncall
 - Venous and lymphatic disease
- Conditions in the perinatal period
- Congenital anomalies
- Digestive system
- Endocrine disorders
- Events of pregnancy

Query Name: Query undefined ...

GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT Sensitivity < 0 >Specificity

Group 1 of 3	Group 2 of 3	Group 3 of 3
<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <p>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</p> </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <p>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</p> </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <p>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</p> </div>

Reset All First Group Shift Left Shift Right Last Group New Group

Run Query Total count: no results to display

Gender	Age	Race	Vital
<input type="checkbox"/> Female <input type="checkbox"/> Male	<input type="checkbox"/> 40 <input type="checkbox"/> 80	<input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> H <input type="checkbox"/> W <input type="checkbox"/> O <input type="checkbox"/> U	<input type="checkbox"/> Alive <input type="checkbox"/> Deceased



Address http://rpdrweb/rpdrwebclient/querytool.aspx?res=768

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Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items Find Terms Previous Queries

Standard Query Items

- ☒ Encounter detail
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 - ☒ Ischemia-Oncall
 - ☒ Ischemic heart disease
 - ☒ Acute myocardial infarction
 - ☒ Angina pectoris
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 - ☒ Old myocardial infarction
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 - ☒ Congenital anomalies
 - ☒ Digestive system
 - ☒ Endocrine disorders
 - ☒ Events of pregnancy

Query Name: Query undefined ...

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Group 1 of 3	Group 2 of 3	Group 3 of 3
<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> One or more items recorded <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Acute myocardial infarction </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group. <ul style="list-style-type: none"> </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group. <ul style="list-style-type: none"> </div>

Total count: no results to display

Gender	Age	Race	Vital
<input type="checkbox"/> Female <input type="checkbox"/> Male	<input type="checkbox"/> 40 <input type="checkbox"/> 80	<input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> H <input type="checkbox"/> W <input type="checkbox"/> O <input type="checkbox"/> U	<input type="checkbox"/> Alive <input type="checkbox"/> Deceased

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of

Find Patients Match Controls Analyze Patients Request Detailed Data Request Specimens Understand Data Get Help

Query Items Find Terms Previous Queries

Query Name: **Acute myocardial infarction on 01/24/2011**

Standard Query Items

- Encounter detail
- Demographics detail
- Diagnosis
 - Circulatory system
 - Acute Rheumatic fever
 - Arterial vascular disease
 - Cardiac problem-Oncall
 - Cardiac risk factors-Oncall
 - Cardiac risk stratification-Oncall
 - Cerebrovascular disease
 - Chronic Rheumatic heart disease
 - Disease of capillaries
 - Diseases of pulmonary circulation
 - Hypertensive disease
 - Ischemia-Oncall
 - Ischemic heart disease
 - Acute myocardial infarction
 - Angina pectoris
 - Ischemic heart disease-Oncall
 - Old myocardial infarction
 - Other acute and subacute forms of ischemic heart disease
 - Other forms of chronic ischemic heart disease
 - Other forms of heart disease
 - Vascular problem-Oncall
 - Venous and lymphatic disease
 - Conditions in the perinatal period
 - Congenital anomalies
 - Digestive system
 - Endocrine disorders
 - Events of pregnancy

Please complete...

Please supply a name for this query:

Jsut Diagnos AMI

☐ Create a patient set from this query [What's this?](#)

Please choose one of these two timing models ...

Either (1) Some item from each group must have occurred in the same visit; or
(2) Some item from each group may have occurred at any visit. For example, if one wanted to find patients whose diabetes was treated at the MGH while an inpatient, choose the timing model where items occurred at the same visit.

☐ Same Visit

		Groups		
Patient	Date	1	2	3
0000004	12/15/1999	MGH	Inpatient	Diabetes

☒ Any Visit

		Groups		
Patient	Date	1	2	3
0000004	2/28/1999	B'wH	Inpatient	Seizure
0000004	10/05/1999	MGH	Outpatient	Afib
0000004	12/15/1999	B'wH	Outpatient	Diabetes

☐ Run the query as background job

☒ Switch to Previous Queries

Run

Cancel



RPDR Enhanced Query Tool

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Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items Find Terms Previous Queries

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 - ☐ Other forms of heart disease
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 - ☐ Venous and lymphatic disease
- ☐ Conditions in the perinatal period
- ☐ Congenital anomalies
- ☐ Digestive system
- ☐ Endocrine disorders
- ☐ Events of pregnancy

Query Name: **Acute myocardial infarction on 01/24/2011**

Sensitivity < 0 > Specificity

Group 1 of 3	Group 2 of 3	Group 3 of 3
<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> One or more items recorded <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Acute myocardial infarction </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group. </div>	<div> <input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/> </div> <div> <input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group. </div>

Running query, please wait...

Time elapsed: 1 seconds.

Total count: Running query...

Gender	Age	Race	Vital
<input type="checkbox"/> Female <input type="checkbox"/> Male	<input type="checkbox"/> 40 <input type="checkbox"/> 80	<input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> H <input type="checkbox"/> W <input type="checkbox"/> O <input type="checkbox"/> U	<input type="checkbox"/> Alive <input type="checkbox"/> Deceased



Address http://rpdweb/rpdwebclient/querytool.aspx?res=768

RPDR Enhanced Query Tool

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Query Items Find Terms Previous Queries

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 - ☒ Venous and lymphatic disease
 - ☒ Conditions in the perinatal period
 - ☒ Congenital anomalies
 - ☒ Digestive system
 - ☒ Endocrine disorders
 - ☒ Events of pregnancy

Query Name: Isut Diagnos AMI

☒ GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT

Group 1 of 3	Group 2 of 3	Group 3 of 3
Dates	Recorded>0x	Exclude
<input checked="" type="checkbox"/> One or more items recorded <input checked="" type="checkbox"/> Acute myocardial infarction	<input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.	<input checked="" type="checkbox"/> Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.

Total count: 120144±3 patient(s)

<input type="checkbox"/> Gender	<input type="checkbox"/> Age	<input type="checkbox"/> Race	<input type="checkbox"/> Vital
<div> <div>click the image or check box to request an aggregated count by patient gender for this query.</div> <div> <input type="checkbox"/> Female <input type="checkbox"/> Male </div> </div>	<div> <div>40</div> <div>80</div> </div>	<div> <div>A</div> <div>B</div> <div>H</div> <div>W</div> <div>O</div> <div>U</div> </div>	<div> <div>Alive</div> <div>Deceased</div> </div>



Address <http://rpdweb/rpdwebclient/querytool.aspx?res=768>

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items **Find Terms** Previous Queries

Search For:

Containing

All Categories

- Search Items
 - CK-MB Index (Group:CKMBRI)
 - CK-MB INDEX (Test:sc400.4452)
 - Cpk isoenzymes index (Test:mckmbri)
 - Cpk isoenzymes index (Test:mcsq-ckmbri)
 - Cpk isoenzymes index/dr.kbl (Test:mckblidx)
 - CPK-MB INDEX (Test:lc1522)
 - CK-MB INDEX (Test:sc400.4452)

Query Name: Jsut Diagnos AMI

☒ GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT

Group 1 of 3	Group 2 of 3	Group 3 of 3
<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>	<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>	<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>
<p><i>One or more items recorded</i></p> <p><input type="checkbox"/> Acute myocardial infarction</p>	<p><i>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</i></p>	<p><i>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</i></p>

Run Query

Total count: 120144±3 patient(s)

Gender	Age	Race	Vital
<input type="checkbox"/> Female <input type="checkbox"/> Male	<input type="checkbox"/> 40 <input type="checkbox"/> 80	<input type="checkbox"/> A <input type="checkbox"/> B <input type="checkbox"/> H <input type="checkbox"/> W <input type="checkbox"/> O <input type="checkbox"/> U	<input type="checkbox"/> Alive <input type="checkbox"/> Deceased

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Query Name: **Jsut Diagnos AMI**

GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT Sensitivity < > Specificity

Reset all groups to >0

>Specificity

Group 3 of 3

☐ es ☒ Recorded>0x ☐ Exclude

Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.

Choose value for CK-MB Index (Group:CKMBRI)

Searches by Lab values can be constrained by the high/low flag set by the performing laboratory, or by the values themselves.

☐ No value

?

Please select operators:

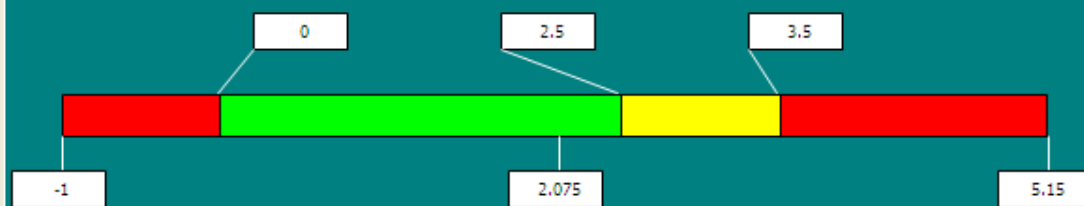
GREATER THAN ($>$)

Please enter numeric value:

☒ By numeric value

3.5

Click on a bar segment to help you specify a value or range:



Units: %

OK

Clear

Cancel

☐ Gender☐ Age☐ Race

[illegible]

Female Male

A B H W O U

Alive	Deceased
-------	----------

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patients Match Controls Analyze Patients Request Detailed Data Request Specimens Understand Data Get Help

Query Items Find Terms Previous Queries

Search For:

Containing ck-mb index

All Categories Find

- Search Items
 - CK-MB Index (Group:CKMBRI)
 - CK-MB INDEX (Test:sc400.4452)

Query Name: Query Undefined

GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT Sensitivity< Reset all groups to >0 >Specificity

Group 1 of 3	Group 2 of 3	Group 3 of 3
<div> <div>Dates</div> <div>Recorded>0x</div> <div>Exclude</div> </div> <div>One or more items recorded</div> <div>Acute myocardial infarction</div>	<div> <div>Dates</div> <div>Recorded>0x</div> <div>Exclude</div> </div> <div>One or more items recorded</div> <div>CK-MB Index (Group:CKMBRI) > 3.5</div>	<div> <div>Dates</div> <div>Recorded>0x</div> <div>Exclude</div> </div> <div>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</div>

Reset All First Group Shift Left Shift Right Last Group New Group

Run Query Total count: 0

<input type="checkbox"/> Gender <div>Female Male</div>	<input type="checkbox"/> Age <div>40 80</div>	<input type="checkbox"/> Race <div>A B H W O U</div>	<input type="checkbox"/> Vital <div>Alive Deceased</div>
---	--	---	---



Address <http://rpdrweb/rpdrwebclient/querytool.aspx?res=768>

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of

Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items **Find Terms** Previous Queries

Query Name: **Acute myocardia..., CK-MB Index (Gr... on 01/24/2011**

Search For:

ck-mb index

Find

Search Items

- CK-MB Index (Group:CKMBRI)
- CK-MB INDEX (Test:sc400.4452)

Please complete...

Please supply a name for this query:

AMI and CK-MB .3.5

☐ Create a patient set from this query [What's this?](#)

Please choose one of these two timing models ...

Either (1) Some item from each group must have occurred in the same visit; or
(2) Some item from each group may have occurred at any visit. For example, if
one wanted to find patients whose diabetes was treated at the MGH while an
inpatient, choose the timing model where items occurred at the same visit.

☐ Same Visit

		----- Groups -----		
Patient	Date	1	2	3
0000004	12/15/1999	MGH	Inpatient	Diabetes

☒ Any Visit

		----- Groups -----		
Patient	Date	1	2	3
0000004	2/28/1999	B'WH	Inpatient	Seizure
0000004	10/05/1999	MGH	Outpatient	Afib
0000004	12/15/1999	B'WH	Outpatient	Diabetes

☐ Run the query as background job

☒ Switch to Previous Queries

Run

Cancel



Address <http://rpdrweb/rpdrwebclient/querytool.aspx?res=768>

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items **Find Terms** Previous Queries

Search For:

Containing

All Categories

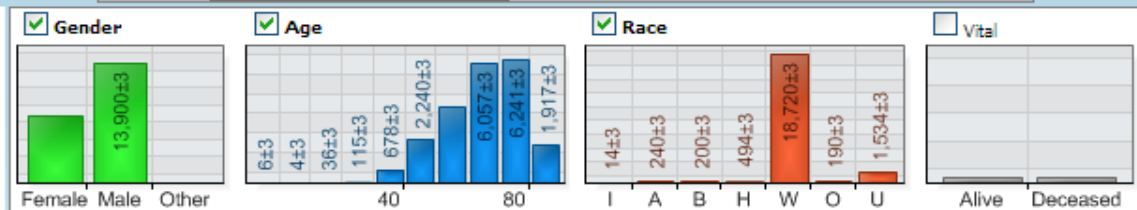
- Search Items
 - CK-MB Index (Group:CKMBRI)
 - CK-MB INDEX (Test:sc400.4452)

Query Name: **Acute myocardia..., CK-MB Index (Gr... on 01/24/2011 #2**

☒ GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT

Group 1 of 3	Group 2 of 3	Group 3 of 3
<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>	<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>	<input type="button" value="Dates"/> <input type="button" value="Recorded>0x"/> <input type="button" value="Exclude"/>
<p><i>One or more items recorded</i></p> <ul style="list-style-type: none"> Acute myocardial infarction 	<p><i>One or more items recorded</i></p> <ul style="list-style-type: none"> CK-MB Index (Group:CKMBRI) > 3.5 	<p><i>Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.</i></p>

Total count: 21647±3 patient(s)





Address <http://rpdrweb/rpdrwebclient/querytool.aspx?res=768>

RPDR Enhanced Query Tool

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patients **Match Controls** **Analyze Patients** **Request Detailed Data** **Request Specimens** **Understand Data** **Get Help**

Query Items **Find Terms** Previous Queries

Search For:

Containing

All Categories

Search Items

- EGFR
 - eGFR (Test:bc1-1384)
 - eGFR (Test:fc500.1750)
 - eGFR (Test:fc500.1800)
 - eGFR (Test:fc500.1850)
 - eGFR (Test:mcsq-egfr)
 - eGFR (Test:mcsq-egfr1)
 - eGFR (Test:mcsq-pegfr)
 - eGFR (Test:ncgfrnaa)
- EGFR Gene Mutations (Group:EGFR)
- EGFR Sequencing (Test:mcsq-egfrs)

Query Name: **EGFR, Respiratory and... on 01/24/2011 #3**

☒ GROUPS DO NOT HAVE TO OCCUR IN THE SAME VISIT

Group 1 of 3

One or more items recorded

- EGFR
 - [2236_2252del; 2258del (Responsive)]
 - 2235_2249del (Responsive)
 - 2236_2252del 2257delC (Responsive)
 - 2261A>G (Presumed Res)
 - 2264C>A (Presumed Res)
 - 2314_2319dup (Unknown Significance)
 - 2317_2319dupCAC (Unknown Significance)
 - c.2065G>C (Unknown Sig)
 - c.2093C>T (Unknown Sig)
 - c.2117T>C (Unknown Sig)
 - c.2125G>A (Responsive)
 - c.2126A>T (Unknown Sig)

Group 2 of 3

One or more items recorded

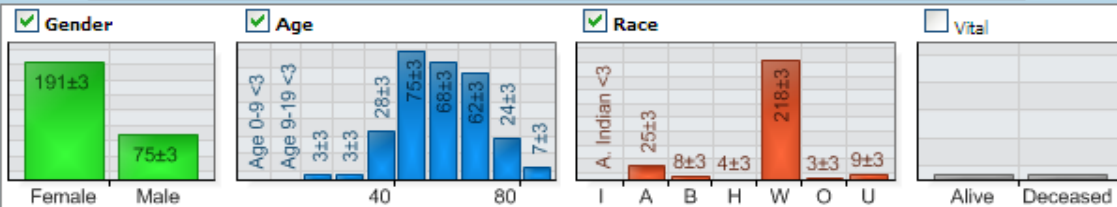
- Respiratory and intrathoracic organs
 - Malignant neoplasm of larynx
 - Malignant neoplasm of nasal cavities, middle ear and accessory sinuses
 - Malignant neoplasm of other and ill-defined sites within the respiratory system and intrathoracic organs
 - Malignant neoplasm of pleura
 - Malignant neoplasm of thymus, heart, and mediastinum
 - Malignant neoplasm of

Group 3 of 3

Drag items from the 'Query Items' and 'Find Items' Tabs on the left into this group.

Run Query

Total count: 269±3 patient(s)



MATCHING PATIENTS

Previous query items

Case set construction

Control set construction

Estimate set size and run program

RPDR Enhanced Query Tool - Microsoft Internet Explorer provided by Partners HealthCare System

Address: http://rpdrweb/rpdrwebclient/querytool.aspx?res=768

Logging: Duey, Stacey A. in workgroup of Shawn Murphy, MD

Find Patient | Match Controls | Analyze Patients | Request Detailed Data | Request Specimens | Understand Data

Query Items | Find Terms | Previous Queries

☐ Show Data Requests [Refresh List](#)

Query Name	By	Status	Date
Group comparison for Acute Rheum...	as084	Queued	01/24/11 15:23:01
Acute myocardia..., CK-MB Index ...	as084	Ready	01/24/11 15:21:01
Patient breakdowns for Acute myo...	as084	Queued	01/24/11 15:19:34
Matched set for Acute myocardia...	as084	Queued	01/24/11 15:14:17
EGFR, Respiratory and... on 01/2...	as084	Ready	01/24/11 15:14:14
EGFR, Respiratory and... on 01/2...	as084	Ready	01/24/11 15:03:00
Acute myocardia..., CK-MB Index ...	as084	Ready	01/24/11 14:59:11
AMI and CK-MB >3.5	as084	Ready	01/24/11 14:59:12
Just Diagnos AMI	as084	Ready	01/24/11 14:55:34
EGFR, Respiratory and... on 01/2...	as084	Ready	01/24/11 13:14:11
Acute myocardia..., CK-MB Index ...	as084	Ready	01/24/11 13:05:33
Acute myocardia..., CK-MB Index ...	as084	Ready	01/24/11 13:04:35
AMI and CK-MB >3.5	as084	Ready	01/24/11 13:03:36
Just diagnose AMI	as084	Ready	01/24/11 12:58:17
Resection or debr..., Iletin II po...	snm0	Ready	01/24/11 09:00:30
Resection or debr..., Insulin glar...	snm0	Ready	01/24/11 07:48:22
Resection or debridement of pa...	snm0	Ready	01/24/11 07:45:52

Page 1 of 269 (4570 queries)

Create a matched set of control patients from a previous RPDR query

Query Name: Matched set for Acute myocardia..., CK-MB Index Explain

IDENTIFY CASES

Query for which you want a matched set of patients: [] ±3

IDENTIFY CONTROLS

I want [3] control patient(s) for each patient found by the above query.

Match by: ☒ Age (10 year intervals) ☒ Gender
☒ Race/Ethnicity ☐ Comparative Health
☐ Use exact matches only

Matched patients will be sampled from all RPDR patients or can only be sampled from patients in the query below:

drag and drop a query here... [] ±3

Patients should be included from:
☐ MGH ☒ BWH/FH

Patients can be specified is specified below (cases are always excluded):

drag and drop a query here... [] ±3

for specific purposes, you may wish to exclude these patients:
☒ Patients that are no longer living
☒ Patients that have had bone marrow transplants

Total to be found: [] ±3

Submit request to find set of Control patients Reset All

Welcome to the RPDR Data Request Wizards

The RPDR is a HIPAA compliant system, which returns aggregate patient information via a Query Tool, based on user-defined criteria. With proper IRB approval, RPDR users can:

- use their previously queried patient set
- or import their own approved set of Medical Record Numbers

to request detailed or identified patient clinical data. These wizards are included in the RPDR for human research investigators to request identified patient data from their respective Partners sites.

You are now launching a wizard in order to request identified patient data.

Your request must conform and comply with the allowances of your Partners sponsored IRB human studies protocol. This responsibility rests entirely on the faculty sponsor who is requesting the identified data or who is approving the request of identified data from a workgroup member. It is very important that the correct IRB protocol number be chosen for each request of protected health information.

This information is protected under the Partners Privacy and Confidentiality Policy and provided with approval by the Human Research Committee only for the use specified in your protocol number. It may not be used for any other purpose without specific approval by the Human Research Committee. It may not be distributed to any individual not specifically authorized under that approval. The data must be managed in a manner that complies with HIPAA Security Regulations.

I accept responsibility for the data returned by this query.

[Accept](#) [Cancel](#)

Partners Healthcare System HIPAA Compliance

Additional HIPAA information for the research community is available from these links, sponsored by Partners and the Human Research Council (PHRC).

[HIPAA and the Privacy Rule](#)

[HIPAA Central](#)

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 [here](#))

- ☒ 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)

Help

< Back

STEP 2

Next >

Cancel

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 protocol number(s)

Partners IRB (required):

Title: RPDR protocol - Demonstration IRB number for Dr. Murphy
Status: Active

Newton Wellesley Hospital IRB:

Title: test
Status: Active

Spaulding Rehabilitation Hospital IRB:

Options for returned set of patients:

- ☐ Create a static set of patients from this query that can be used in other RPDR queries
☒ Rerun the base query shown above to obtain a fresh set of patients

Help

< Back

STEP 3

Next >

Cancel

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

Selected faculty sponsor(s):
 Shawn Murphy, MD

Available

Peng, Zhaoping Z.
 Nalichowski, Ruth

Add ->

Add All ->>

<- Remove

<<- Remove All

Chosen

Gainer, Vivian S

Help

< Back

STEP 5

Next >

Cancel

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

**Please select if you would like a HIPAA-defined (deidentified)
limited data set or an identified data set**

What's a limited data set?

☐ **Limited Data Set**

- The files that result from this request will be available in a protected file share with no special encryption.

☒ **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.

Help

< Back

STEP 8

Next >

Cancel

RPDR Detailed Data Request Wizard -- Web Page Dialog

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 types of data that should be returned from the RPDR

Only data allowed by your protocol should be chosen

(Identified data sets will always return a set of identified patient medical numbers)



Detail Data Items

- ☐ Demographic Data
- ☐ Identifying Patient Information - not available for Limited Data Sets
- ☐ LMR (Longitudinal Medical Record)
- ☐ Medications, Diagnoses and Procedures
- ☐ Medications, Diagnoses and Procedures from Billing Data - only visits where query criteria occur all in the same visit
- ☐ Patient Clinical Reports- not available for Limited Data Sets
 - ☐ Cardiology Reports
 - ☐ Discharge Summaries
 - ☐ Endoscopy Reports
 - ☒ Microbiology Data
 - ☒ Operative Notes
 - ☐ Pathology Reports
 - ☐ Pulmonary Reports
 - ☐ Radiology Reports
 - ☐ Transfusion Data, Blood Bank Data

Help

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STEP 9

Next >

Cancel

RPDR DETAILED DATA REQUEST WIZARD -- Web Page Dialog

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

Search for

Back to top view

Find

Laboratory Data Items

Laboratory tests

Cell Counts

Cell Markers

Chemistry

Anemia Related Studies

Blood Gases

Blood Gases/Oximetry

Cardiac Tests

BNP (Group:BNP)

CK Isos (Group:CK-MMT)

CK-BB (CK1) (Group:CK1/BB)

CK-BB% (Group:%CK1BB)

CK-MB (CK2) (Group:CK2/ME

CK-MB Index (Group:CKMBR

CK-MB QUANT (Group:CPK-M

CK-MB% (Group:%CKMB)

Selected Data Items

CK-MB Index (Group:CKMBRI) (Loinc:2158-4)

Please select the laboratory tests that should be returned

(Drag the lab items from the left panel and drop into the panel below)

Help

< Back

STEP 8

Next >

Cancel

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](#)

Enter IRB Password:

Help

< Back

STEP 11

Next >

Cancel

Identified data is gathered

Output files placed
in special directory

Process IRB files ...

Environment Record Options Help

File: SNM0_022502164303648842.XML

File Type: Control File Current Production Database: RPDR_12 RPDR_12_5241

Update Status ☒ Start Process After 9:00:00 PM

IRB Information

IRB Number: 2000P000000 Ends:

Date from: 01/01/1900 Date to: 01/01/1900

Primary User: snm0

Files to MGH Users: Partners\snm0.Partners\zsp.Partners\kcs3

B/W Users: Partners\kcs1.Partners\snm0.Partners\kcs3

Data Requested

Demographics ☐ Medical Record Numbers ☒ Chemistry ☒

Encounters ☐ Contact Information ☐ Radiology ☐

Hematology ☐ PCP ☐ Pathology ☐

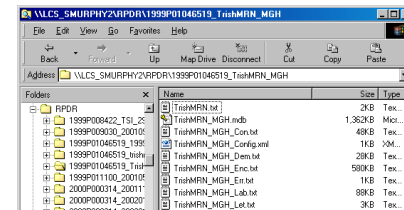
Discharge Summaries ☒ Immunology ☐ LMR Notes ☐

Medications ☒ Operative Notes ☐ LMR Problems ☐

LMR Allergies ☐ LMR Medications ☐ Build Access Database ☒

Groups: BUN

Run Close Clear

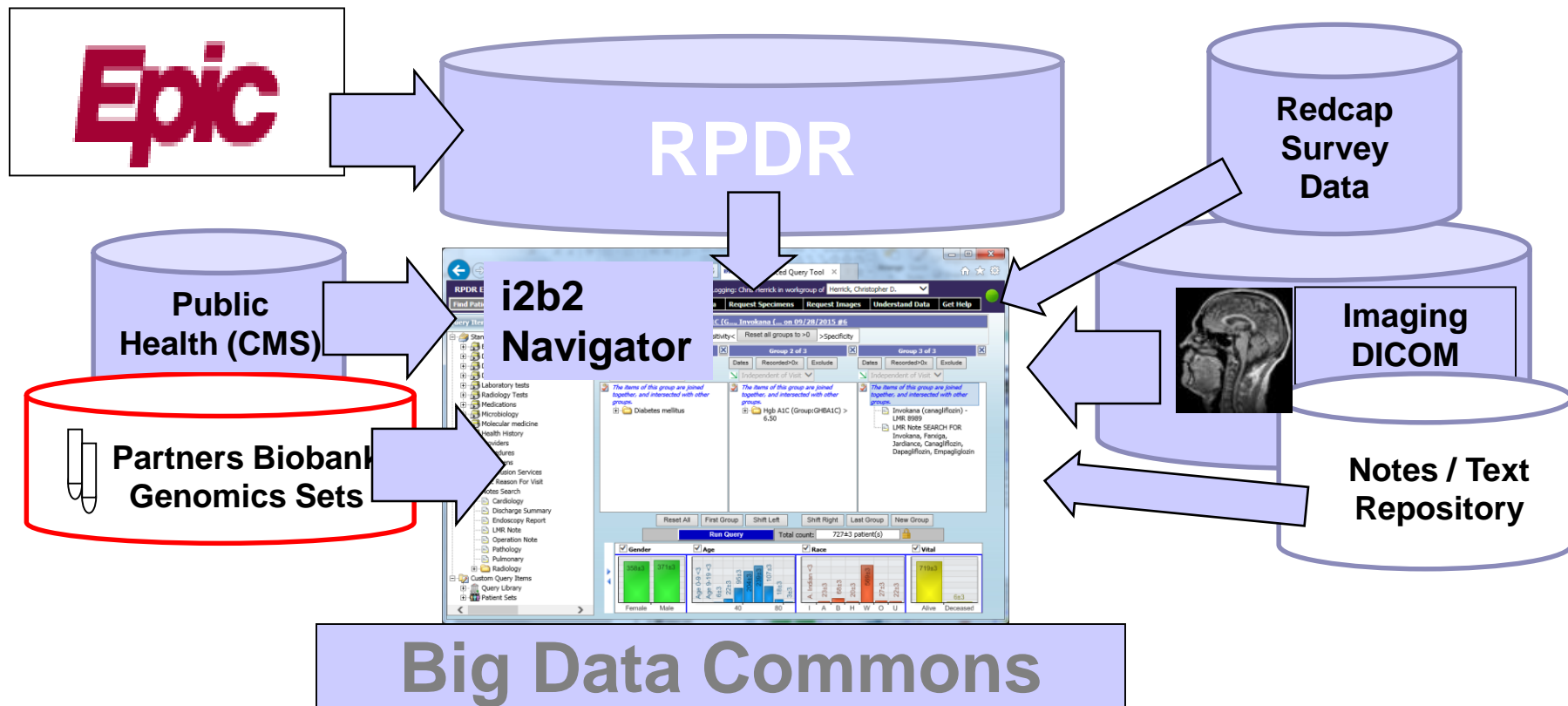


Test Id	Test Description	Result	Result Text	Abnormal Flag	Reference Unit	Reference Range
SQ-XPTT	Superstat APTT	29.8			sec	22.1-35.1
SQ-PTT	APTT	32.8			sec	22.1-35.1
SQ-PTT	APTT	37.8		H	sec	22.1-35.1
SQ-PTT	APTT	46.4		H	sec	22.1-35.1
SQ-PTT	APTT	43.1	MODERATELY	H	sec	22.1-35.1
SQ-PTT	APTT	25.7			sec	22.1-35.1
SQ-PTT	APTT	23.7			sec	22.1-35.1
SQ-PTT	APTT	25.4			sec	22.1-35.1
SQ-PTT	APTT	24.7			sec	22.1-35.1
SQ-PTT	APTT	24.0			sec	22.1-35.1
SQ-PTT	APTT	24.7			sec	22.1-35.1
SQ-XPTT	Superstat APTT	31.3			sec	22.1-35.1
SQ-PTT	APTT	34.5			sec	22.1-35.1
SQ-PTT	APTT	40.0		H	sec	22.1-35.1
SQ-PTT	APTT	45.0		H	sec	22.1-35.1
SQ-XPTT	Superstat APTT	55.2	*** Note: New n	H	sec	22.1-35.1
SQ-PTT	APTT	33.6			sec	22.1-35.1
SQ-XPTT	Superstat APTT	34.3			sec	22.1-35.1
SQ-PTT	APTT	37.9		H	sec	22.1-35.1
SQ-PTT	APTT	22.6			sec	22.1-34.1
SQ-PTT	APTT	37.4		H	sec	22.1-34.1
SQ-PTT	APTT	37.2	SLT HEMOLYS	H	sec	22.1-34.1
SQ-PTT	APTT	35.1		H	sec	22.1-34.1
SQ-PTT	APTT	36.4	MODERATE HE	H	sec	22.1-34.1

Data is gathered from RPDR
and other Partners sources

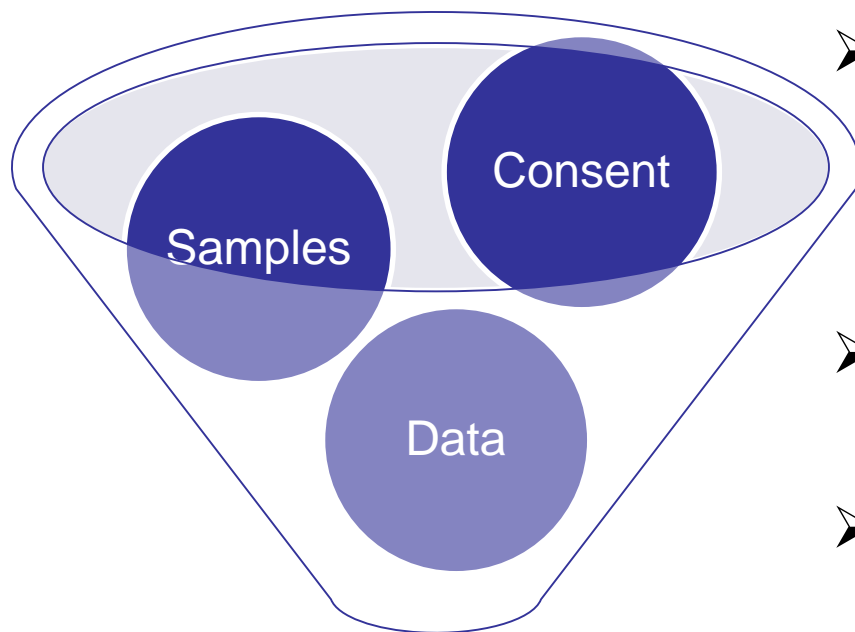
Files include a Microsoft Access Database

Creating Enterprise Wide Query and Analysis System for Big Data



Integrates disparate islands of patient data (clinical and research data) onto a Common Big Data Platform

The Partners Biobank



Research Discoveries

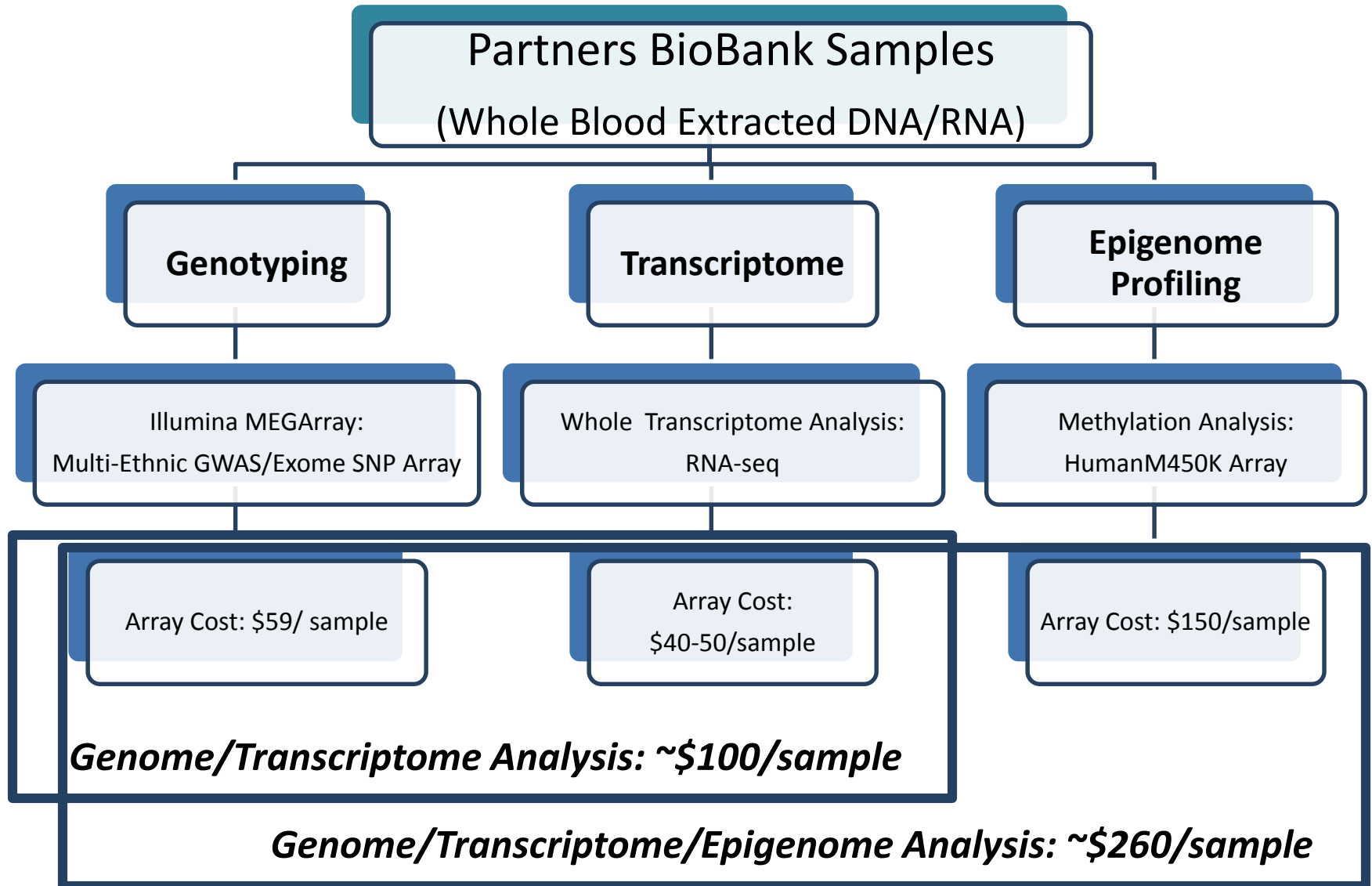


Improved Clinical Care for All Patients

- The Partners Biobank provides samples (plasma, serum, and DNA) collected from consented patients.
- 31,000 patients have consented to date!
- Samples are available for distribution to Partners investigators* to help identify novel Personalized Medicine opportunities that reduce cost and provide better care

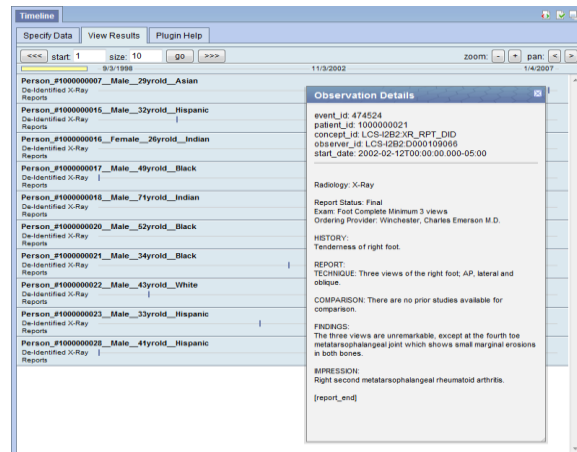
**with required approval from the Partners Institutional Review Board (IRB).*

Biobank Integrative Genomics Strategy

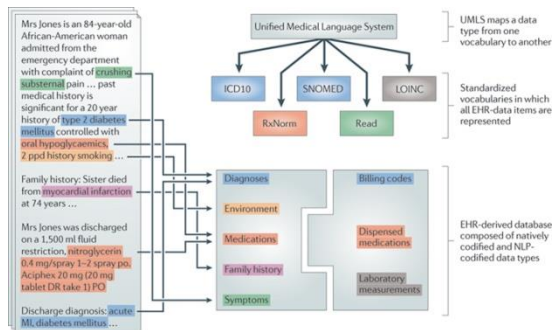


Curating a Disease Algorithm

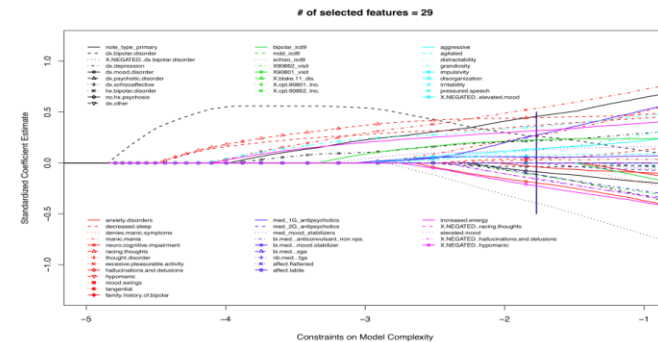
1. Create a gold standard training set.



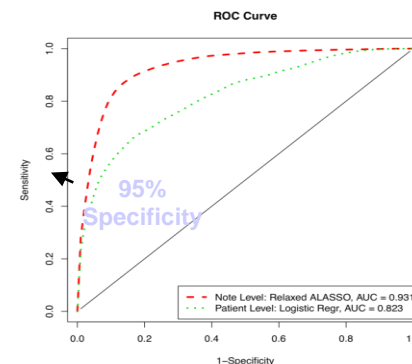
2. Create a comprehensive list of features (concepts/variables) that describe the phenotype of interest



3. Develop the classification algorithm. Using the data analysis file and the training set from step 1, assess the frequency of each variable. Remove variables with low prevalence. Apply adaptive LASSO penalized logistic regression to identify highly predictive variables for the algorithm



4. Apply the algorithm to all subjects in the superset and assign each subject a probability of having the phenotype



Biobank Portal | Curated Diseases

Validated Phenotype	Count*	Predictive Positive Value
Bipolar Disease	71	89%
Congestive Heart Failure	387	90%
Coronary Artery Disease	2,420	97%
Crohn's Disease	453	90%
Multiple Sclerosis	94	90%
Rheumatoid Arthritis	550	90%
Type 2 Diabetes Mellitus	1,887	97%
Ulcerative Colitis	330	90%

Healthy Controls based on Charlson Index	Count**
0 – 10-year survival probability is >98.3%	2,206
1 – 10-year survival probability is >95.87%	4,343
2 – 10-year survival probability is >90.15%	6,545

* Based on 15,880 patients

** Based on 21,300 patients

Biobank Portal | Run a Query

Step 1: Run a query in the Biobank Portal

Two criteria: a. The patient is a smoker (from the Health Information Survey)
b. The patient agrees to be re-contacted

The screenshot displays the Partners Biobank Portal web application. The browser address bar shows the URL: `biobankportal.partners.org/webclient/?user=snm0#`. The page header includes the "PARTNERS BIOBANK PORTAL" logo, the text "Project: Biobank Portal Prod", and navigation links for "Find Patients", "Request Samples", "Help & Support", and a user profile for "Murphy, Shawn N.". On the left, a "Navigate Terms" sidebar lists various categories like "Biobank Consent Information", "Biobank Health Information Survey", and "Biobank Sample Types". The main area features a "Query Tool" with a "Query Name" field containing "Patient- 1. Yes@21:18:45". Below this, a "Temporal Constraint" dropdown is set to "Treat all groups independently". The query is structured into three groups, each with a table of criteria:

Group 1			Group 2			Group 3		
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude
Treat Independently			Treat Independently			Treat Independently		
Patient agrees to be recontacted			1. Yes, currently smoke					

Below the groups, logical connectors are shown: "one or more of these" (green box) followed by "AND" (blue box), then another "one or more of these" (green box) followed by "AND" (blue box), and finally a "drop a term on here" (yellow box). At the bottom of the query tool, buttons for "Run Query", "Clear", and "Print Query" are visible, along with a "2 Groups" indicator and a "New Group" button. A "Query Status" section at the bottom right shows the results for the query:

Query Status

Vietnamese: 0
White: 451

Specimen type breakdown for "Patient- 1. Yes@21:18:45"

is DNA: 524
is Plasma: 517
is Serum: 519

Partners Biobank Portal – Using Curated Phenotypes

Partners Biobank Portal

biobankportaldev.partners.org/devclient/

Partners Healthcare

BIOBANK PORTAL

Find Patients

Make Request

Help & Support

Watta

Navigate Terms

Find

Biobank Consent Information

Biobank Demographics

Biobank Genomics

- People with genomic data - 4930
 - Illumina Multi-Ethnic GWAS/Exome SNP Array - 4930

Biobank Health Information Survey

Biobank Sample Types

Curated Disease Populations

- Bipolar Disorder (BD)
- Congestive Heart Failure (CHF)
- Coronary Artery Disease (CAD)
- Crohn's Disease (CD)
- Multiple Sclerosis (MS)
- Rheumatoid Arthritis (RA)
 - RA - current or past history (PPV 0.90) - 717
 - RA - no history (NPV 0.99) - 24086
- Type 2 Diabetes Mellitus (T2DM)
- Ulcerative Colitis (UC)

Healthcare Data

Healthy Populations (Controls)

Query Tool

Query Name: RA - -Adali-Illum@15:46:12

Temporal Constraint: Treat all groups independently

Group 1			Group 2			Group 3		
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude
Treat Independently			Treat Independently			Treat Independently		
RA - current or past history (PPV 0.90) - 717			Adalimumab - 689			Illumina Multi-Ethnic GWAS/Exome SNP Array - 4930		

Run Query

Clear

3 Groups

New Group

Show Query Status

Graph Results

Query Report

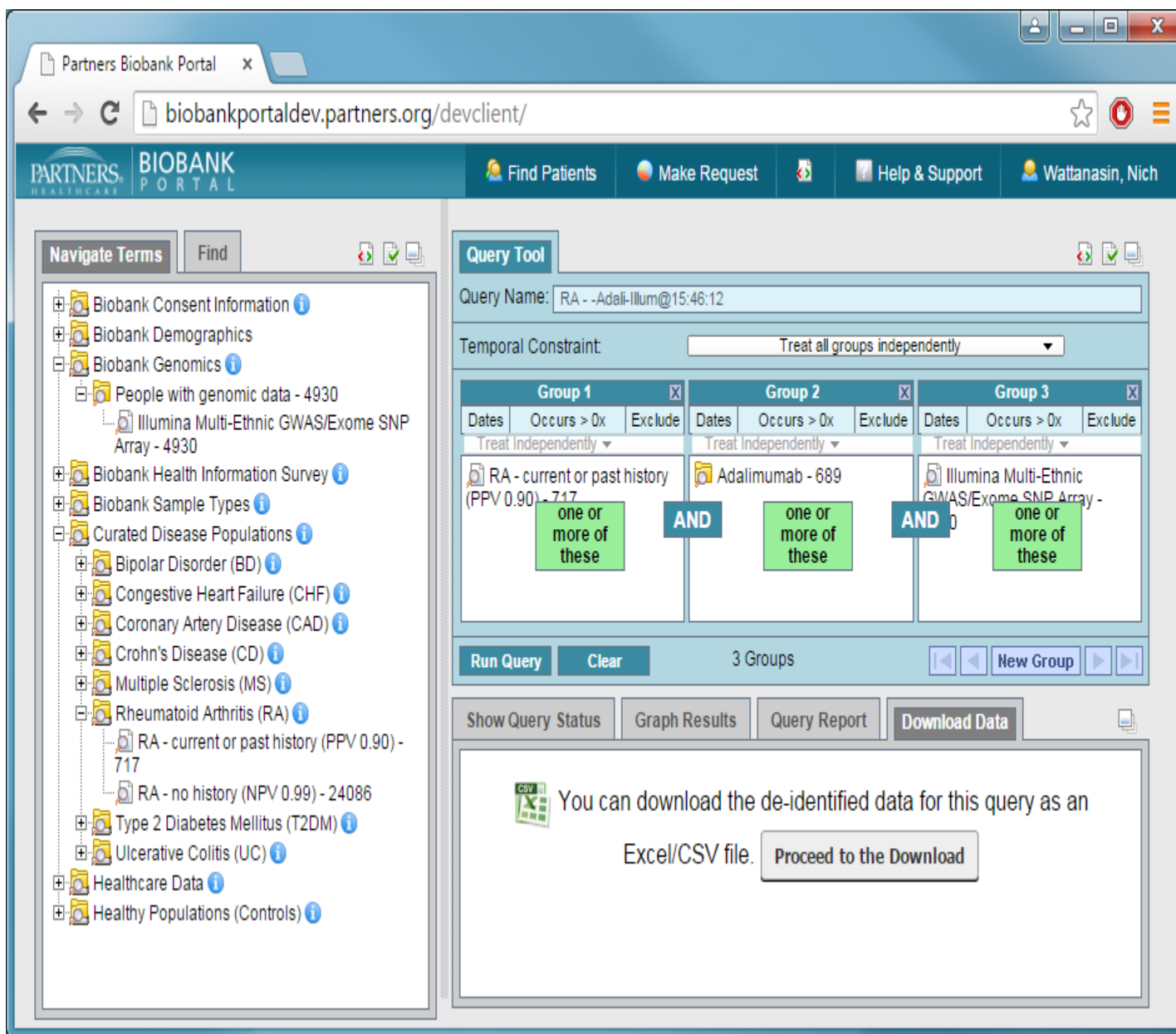
Download Data

Number of patients

70

For Query "RA - -Adali-Illum@15:46:12"

Partners Biobank Portal – Download De-Identified Data



Patient Set Viewer

Setting up Parameters > View Result Table

1. Drop a Patient Set or a Previous Query into the Patient Set box. The ontology terms (Concepts) used in the Previous Query will automatically populate the Concepts box.

2. Additional Concepts can be dropped into the same Concepts box by dragging them from the Navigate Terms panel or the Workplace panel to the left.

3. Change the default options by clicking on the Options box to suit your display needs.

4. Click on Create Table to start getting the Patients and the Concepts you entered.

Patient Set:

Diabetes mellit@12:09:29 [10-5-2015] [demo]

Size = 22093

Concept(s):

Diabetes mellitus

Count

Family history [Contains: diabetes]

Count

HGB A1C (LOINC:4548-4)

Count

HGB A1C (LOINC:4548-4)

Min

HGB A1C (LOINC:4548-4)

Max

HGB A1C (LOINC:4548-4)

Average

Options:

Starting with the 1st Patient, retrieve 100 Patients

Table Size:

100

Max = 200, Min = 1

Starting with the

1

st Patient

Create Table ▶

Download table and select patients

Patient Set Viewer										
Setting up Parameters > View Result Table										
0 / 100 Selected										
<input type="checkbox"/>	ID	Gender	Age	Race	Diabetes mellitus	Family history [Contains: Diabetes]	HGB A1C (LOINC:4548-4)	HGB A1C (LOINC:4548-4)	HGB A1C (LOINC:4548-4)	
					count	count	count	min	max	
<input type="checkbox"/>	1000000003	Male	41	asian	12	54	43	4.1	6.9	
<input type="checkbox"/>	1000000008	Male	23	hispanic	3	12	54	4.2	6.7	
<input type="checkbox"/>	1000000011	Female	60	white	21	21	43	4.6	7.1	
<input type="checkbox"/>	1000000013	Female	83	black	34	9	65	4.7	5.9	
<input type="checkbox"/>	1000000015	Male	32	hispanic	1	10	34	4.4	6.3	
<input type="checkbox"/>	1000000029	Male	25	hispanic	3	25	25	5.1	6.8	
<input type="checkbox"/>	1000000043	Male	61	hispanic	23	14	21	4.9	6.5	
<input type="checkbox"/>	1000000045	Female	89	asian	37	15	54	4.9	6.6	
<input type="checkbox"/>	1000000054	Female	66	asian	43	6	45	4.8	6.6	
<input type="checkbox"/>	1000000066	Female	22	black	32	4	33	5.2	7.0	
<input type="checkbox"/>	1000000070	Male	38	black	43	11	38	5.5	6.5	
<input type="checkbox"/>	1000000077	Male	13	black	12	8	42	4.4	6.7	
<input type="checkbox"/>	1000000080	Male	33	indian	32	13	48	4.2	6.5	
<input type="checkbox"/>	1000000083	Female	65	black	33	4	39	4.7	6.6	
<input type="checkbox"/>	1000000087	Male	55	asian	36	6	42	4.8	6.9	
<input type="checkbox"/>	1000000096	Female	76	black	54	17	43	4.9	6.5	
<input type="checkbox"/>	1000000099	Male	36	black	32	0	39	5.2	6.6	
<input type="checkbox"/>	1000000108	Male	66	asian	43	1	25	5.3	6.7	
<input type="checkbox"/>	1000000109	Male	63	hispanic	31	4	29	4.9	5.9	
<input type="checkbox"/>	1000000112	Male	17	black	17	0	14	4.7	6.8	
<input type="checkbox"/>	1000000119	Female	72	white	43	32	45	4.4	5.9	
<input type="checkbox"/>	1000000133	Female	16	asian	20	2	25	4.9	6.6	
Showing Patients 1 to 100 of total 22093										
Previous 0									Next 100	

Partners Biobank Portal – Request Genetic Data

The screenshot shows a web browser window with the URL `biobankportaldev.partners.org/devclient/`. The page title is "Partners Biobank Portal". The navigation bar includes links for "Find Patients", "Make Request", "Help & Support", and a user profile for "Wattanasin, Nich". The main content area is titled "Request Genomics" and "Biobank Portal Genomics Request". It includes a login status "Logged-in: Wattanasin, Nich (nw096)" and a user role "Admin". The page contains instructions on how to request genomic data, a "Step 1. Patient Selection:" section with options to "Enter a list of Biobank Subject IDs" or "Select a Previous Query", and a "Your Patient List:" section with a text area containing a list of subject IDs. Below this is a "Step 2. Details of Request:" section with radio buttons for "Request Type*" (De-Identified or Identified) and input fields for "Contact Name*" and "Contact E-mail*".

Partners Biobank Portal

biobankportaldev.partners.org/devclient/

Find Patients Make Request Help & Support Wattanasin, Nich

Request Genomics

Biobank Portal Genomics Request

Logged-in: Wattanasin, Nich (nw096)
nwattanasin@partners.org Admin

The Biobank contains subjects who have consented to make their genomic data available for research. To request genomic data, please fill out the form below.

Once you have submitted this form, you will be contacted by the Biobank team to complete your request. Please note that no genomic data will be sent out without a discussion with the Biobank team.

For more assistance on making a genomic data request, please refer to the Biobank Wiki section [How to Make Genomic Requests Using the Biobank Portal](#) or [contact us](#).

Step 1. Patient Selection:

Choose Your Patients: [Enter a list of Biobank Subject IDs](#) OR [Select a Previous Query](#)

Your Patient List*: Type or paste a list of Biobank Subject IDs, one per line. You can find Subject IDs by [downloading the de-identified data set](#). Do not enter MRNs.

10021040
10022384
10018624
10018243
10019029
10020963

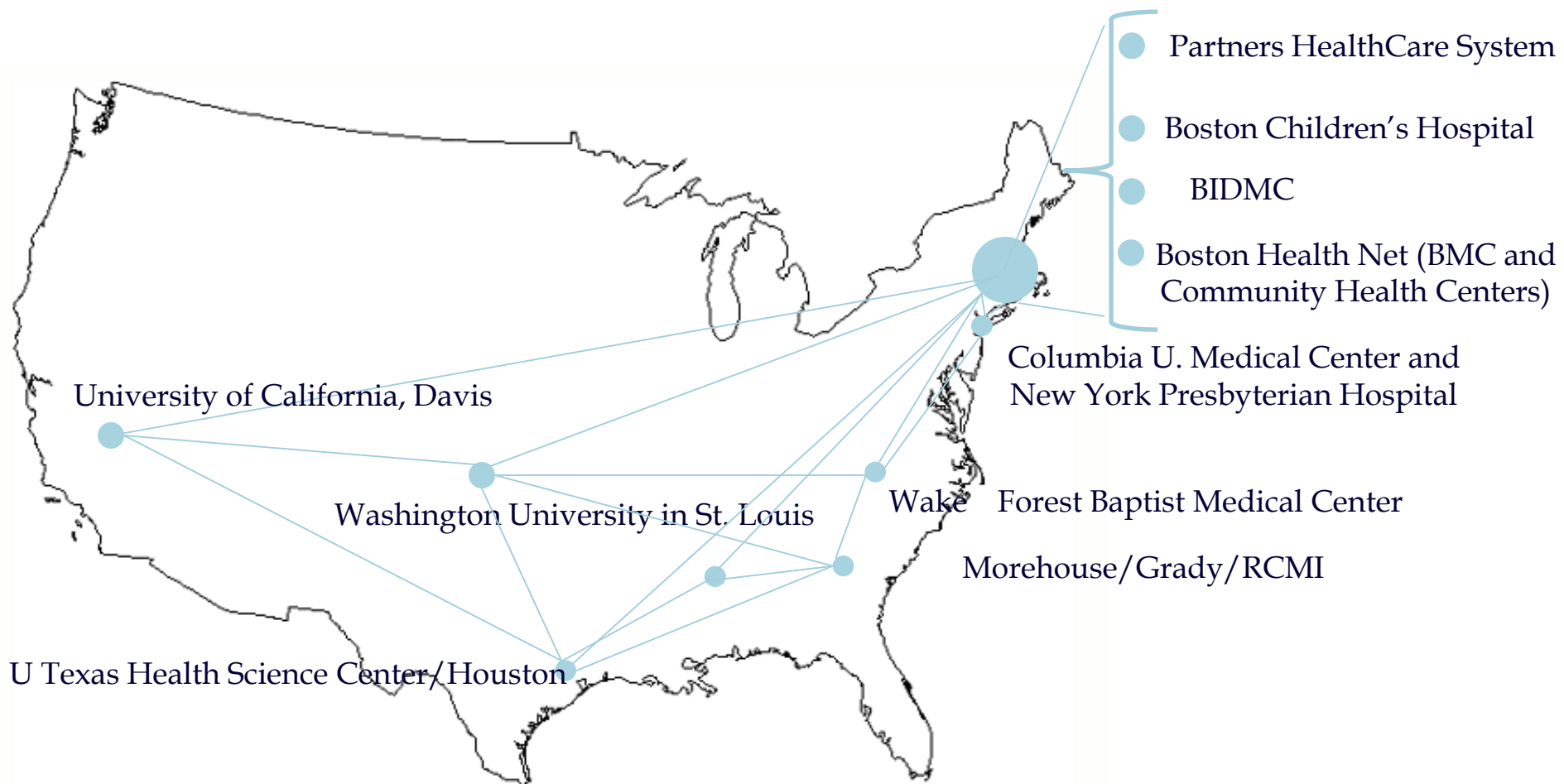
Step 2. Details of Request:

Request Type*: ☒ De-Identified OR ☐ Identified

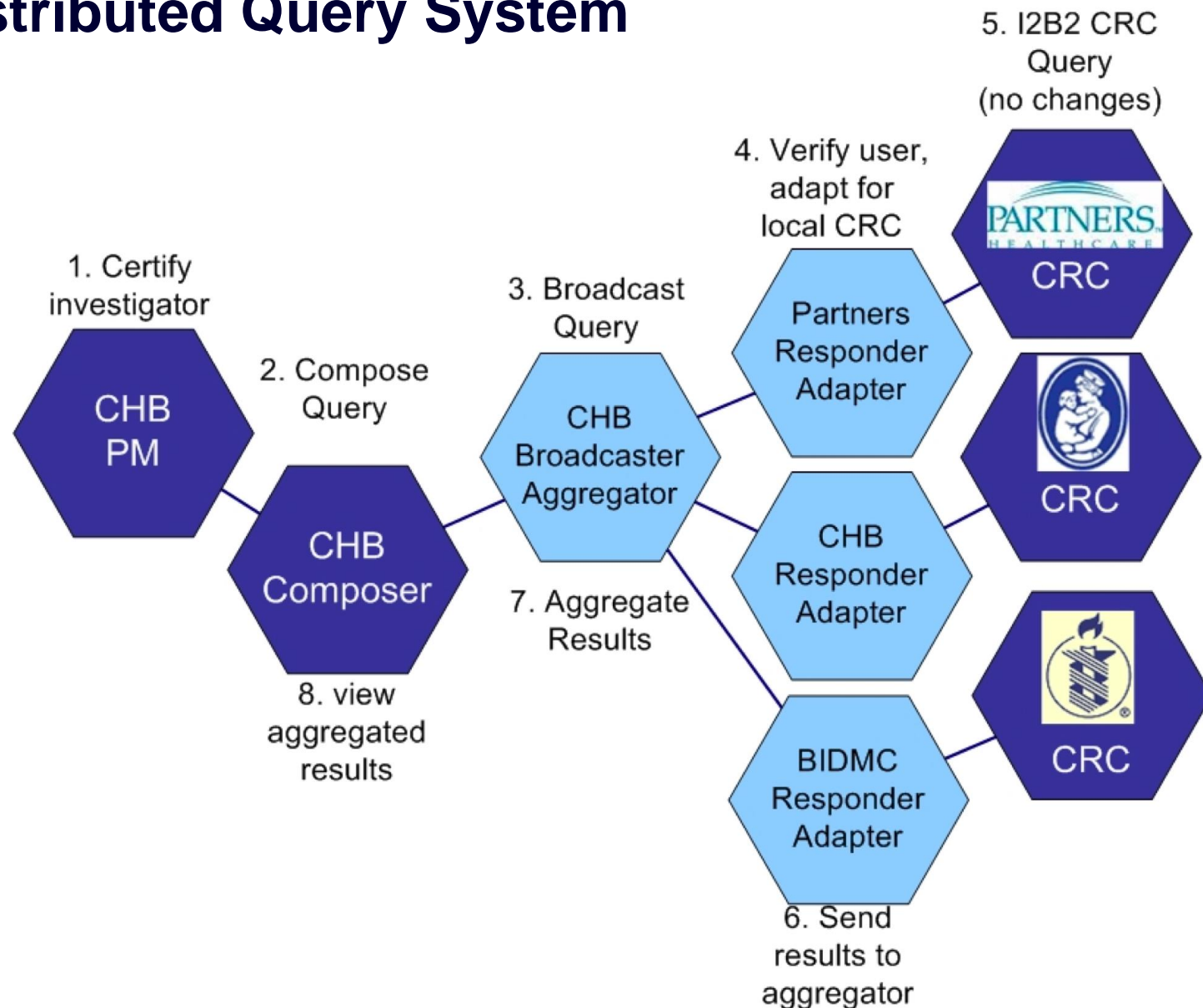
Contact Name*: Wattanasin, Nich

Contact E-mail*: nwattanasin@partners.org

SCILHS Clinical Data Research Network



Distributed Query System



Workflow at the sites to find patients for a clinical trial:

- After a query is run across the “SHRINE” network, the query is automatically saved at every site
- The query saved at each site is transformed into a patient set
- The patient set is studied and sorted for the specific patients eligible for the Clinical Trial

Run Query Using SHRINE

SHRINE Project: SHRINE User: Shawn Murphy Find Patients | Message Log | Help | Logout

Navigate Terms **Find Terms**

Search by Names Search by Codes

Containing hepatitis c

Find Any Category

- Hepatitis b core antibody measurement
- Hepatitis b core igm antibody test
- Hepatitis b surface antigen [hbsag] carrier
- Hepatitis b vaccine injection administered or previous
- Hepatitis b virus (hbv) status assessed and results i
- Hepatitis c antibody**
- Hepatitis c antibody
- Hepatitis c antibody
- Hepatitis c antibody confirmatory test
- Hepatitis c antibody; confirmatory test (eg, immunobl
- Hepatitis c antibody measurement
- Hepatitis c antibody test

Query Tool

Query Name: Acute hepatitis@12:45:50

Group 1			Group 2			Group 3		
Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude	Dates	Occurs > 0x	Exclude
Treat Independently			Treat Independently			Treat Independently		
Acute hepatitis c with hepatic co								
Acute hepatitis c without mentio								
Unspecified viral hepatitis c								
Unspecified viral hepatitis								
Unspecified viral hepatitis								
Unspec one or more of these			AND			drop a term on here		
			AND					

Run Query Clear Print Query 1 Group New Group

Previous Queries

- Arthropathies a@17:23:51 [2-11-2015] [smurphy]
- Nephritis, neph@15:56:29 [2-11-2015] [smurphy]
- Major-Femal-18-34@17:36:09 [2-4-2015] [smurphy]
- Major d-Female@17:34:30 [2-4-2015] [smurphy]
- Major depressiv@17:32:43 [2-4-2015] [smurphy]
- Appendi-Black o@15:57:24 [1-28-2015] [smurphy]
- Appendicitis@15:55:07 [1-28-2015] [smurphy]

Query Status

Finished Query: "Acute hepatitis@12:45:50" [63.5 secs]

- Temple - 10 patients or fewer FINISHED [2.0 secs]
- Wake - 4274 ±3 patients FINISHED [3.0 secs]
- BCH - 501 ±3 patients FINISHED [4.1 secs]
- BMC - 8922 ±3 patients FINISHED [4.6 secs]
- CCHMC - 212 ±3 patients FINISHED [8.0 secs]
- Partners HealthCare - 18750 ±3 patients FINISHED [6.1 secs]
- UT - 3516 ±3 patients FINISHED [26.8 secs]

I2b2 Workbench works directly on new database created from patient set LOCALLY.

- At the Local site, one will:
 - View a patient list summary with matched criteria
 - Review a patient's health data one at a time
 - Designate suitable patients
 - Export to Excel / CSV format

Review de-identified Patients

i2b2 Workbench

File Window Help

i2b2 Workbench for i2b2 Demo (Oracle)

i2b2 User Status: ● i2b2

Navigate Term Find Terms Timeline View Analysis View Patient Mapping View CT Viewer

Select Patients Select Concepts Render Tables

Search by Names Search by Codes

Containing reductase inhibitors

Find Any Category

HMG-CoA reductase inhibitors

- Atorvastatin
- Cerivastatin
- Fluvastatin
- Lovastatin
- Lovastatin-niacin
- Pravastatin
- Rosuvastatin
- Simvastatin

Previous Query Patient Sets

Search By Name

Containing

Find Any Category

Patient Set for "Asthma-Albuter@01:06:16"

- 1000000001 [24 y/o F black]
- 1000000002 [44 y/o F white]
- 1000000003 [41 y/o M asian]
- 1000000004 [34 y/o M black]
- 1000000005 [37 y/o F hispanic]
- 1000000010 [33 y/o F hispanic]

Be... 02-14-2014 0:45:29

Set #	Patient Set Name
1	Patient Set for "Asthma-Albuter@01:06:16"

SMART	Patient ID	PSet #	Patient Name	Gender	Race	Date of Birth	Age	Obesity	Acute Myocardial..	HMG-CoA reduc
✖	1000000001	1+1	xxxxx, xxxxx	F	black	1985-11-17T...	21	✓	✓	✓
✖	1000000002	1+1	xxxxx, xxxxx	F	white	1966-08-29T...	40	✗	✓	✗
✖	1000000003	1	xxxxx, xxxxx	M	asian	1969-03-07T...	38	✓	✗	✗
✖	1000000004	1	xxxxx, xxxxx	M	black	1976-08-13T...	30	✓	✓	✓
✖	1000000005	1	xxxxx, xxxxx	F	hispanic	1973-06-25T...	33	✓	✓	✓
✖	1000000006	1	xxxxx, xxxxx	F	black	1981-08-05T...	25	✓	✗	✓
✖	1000000007	1	xxxxx, xxxxx	M	asian	1981-07-10T...	25	✓	✓	✗
✖	1000000008	1	xxxxx, xxxxx	M	hispanic	1986-12-16T...	20	✓	✓	✓
✖	1000000009	1	xxxxx, xxxxx	F	hispanic	1989-01-11T...	18	✗	✓	✓
✖	1000000010	1	xxxxx, xxxxx	F	hispanic	1976-11-23T...	30	✗	✓	✗
✖	1000000011	1	xxxxx, xxxxx	F	white	2049-10-19T...	57	✓	✗	✓
✖	1000000012	1	xxxxx, xxxxx	F	black	1991-03-29T...	16	✓	✗	✓
✖	1000000013	1	xxxxx, xxxxx	F	black	2027-02-27T...	80	✗	✗	✓
✖	1000000014	1	xxxxx, xxxxx	M	white	1956-05-22T...	50	✗	✗	✓
✖	1000000015	1	xxxxx, xxxxx	M	hispanic	1978-09-11T...	28	✓	✗	✓
✖	1000000016	1	xxxxx, xxxxx	F	indian	1983-11-19T...	23	✓	✓	✓

Workplace

SHARED

- Clinical Trial 'Asthma'
- Maybe
- NO
- YES
- demo

Review identified Patients

i2b2 Workbench

File Window Help

i2b2 Workbench

Navigate Term

Search by Names

Containing

Find

Any

Previous Query

Search By Name

Containing

Find

Any

Patient Set for "Asthma"

1000000001 [24]

1000000002 [44]

1000000003 [41]

1000000004 [34]

1000000005 [37]

1000000010 [33]

Be... 02-14-2014 0:45:29

SMART EMR View

Patient Number: 1000000001

Num: 1000000001 Sex: Male

Birth Date: 1986-12-16 Race: Hispanic

Age: 26 years (current)

Select View

Medications

Problems

Lab Results

Vital Signs

Medications

Meds List

DRUG NAME	START DATE	END DATE
Qvar 80 mcg/inh aerosol with adapter 3 M Pharmaceuticals	2002-04-04	2002-04-04
▼ Atrovent 18 mcg/inh aerosol Boehringer-Ingelheim	2002-04-04	2002-07-17
▶ Atrovent 18 mcg/inh aerosol Boehringer-Ingelheim	2002-04-04	2002-04-04
▶ Atrovent 18 mcg/inh aerosol Boehringer-Ingelheim	2002-07-17	2002-07-17
▶ Cutivate 0.005% ointment Glaxo Wellcome	2008-06-25	2008-06-25
▶ Ibuprofen 200mg tablet Zenith Goldline Pharmaceuticals	2009-01-02	2009-01-02

BP Centiles

Short Term View Long Term View Table View Calculator References

mmHg

100 110 120 130 140 150

70 80 90 100 110 120 130 140 150

OK OK

Cardiac Risk

LDL "bad" cholesterol

Optimal <100 mg/dL

Near Optimal 100-129 mg/dL

Border High 130-159 mg/dL

Very High ≥160 mg/dL

HDL "good" cholesterol

Low <40 mg/dL

Normal 40-119 mg/dL

High ≥120 mg/dL

Your Risk

You show an elevated risk of cardiovascular disease. If you're a smoker with normal blood pressure, (130 mm/Hg) but family history of heart attack before the age of 60 (one or both parents) your risk over 10 years is: **1%**

Problems List

NAME	FIRST SEEN	LAST SEEN
▶ Abdominal pain, other specified site; multiple sites	2002-04-22	2002-08-07
▶ Abscess of lung with pneumonia (disorder)	1999-07-20	2004-01-14
▶ Abscess of orbit	2003-05-19	2003-05-19
▶ Acquired pes planus	2001-03-20	2002-03-15
▼ Acute pharyngitis (disorder)	2001-11-09	2003-02-10
Acute pharyngitis (disorder)	2001-11-09	2001-11-09
Acute pharyngitis (disorder)	2001-11-20	2001-11-20

Workplace

2b2 User Status: i2b2

SHARED

- Clinical Trial 'Asthma'
- Maybe
- NO
- YES
- demo

A “Criteria Matcher” App can help assess candidate patients using the clinical trial metadata

View Patient with SMART Apps

Patient Centric View Patient Number: 1000000001

Patient 1000000001
Num: 1000000001
Birth Date: 1985-11-17
Age: 26 years (current)
Sex: Female
Race: Black

Click an icon to add a new SMART app

Meds List CT Selector Problems List Cardiac Risk Labs List

Select View

- Medications
- Problems
- Lab Results
- Vital Signs
- Notes
- Clinical Trials

Clinical Trials

Save Layout Rename Delete View

CT Selector

Your active clinical trial is currently set to:

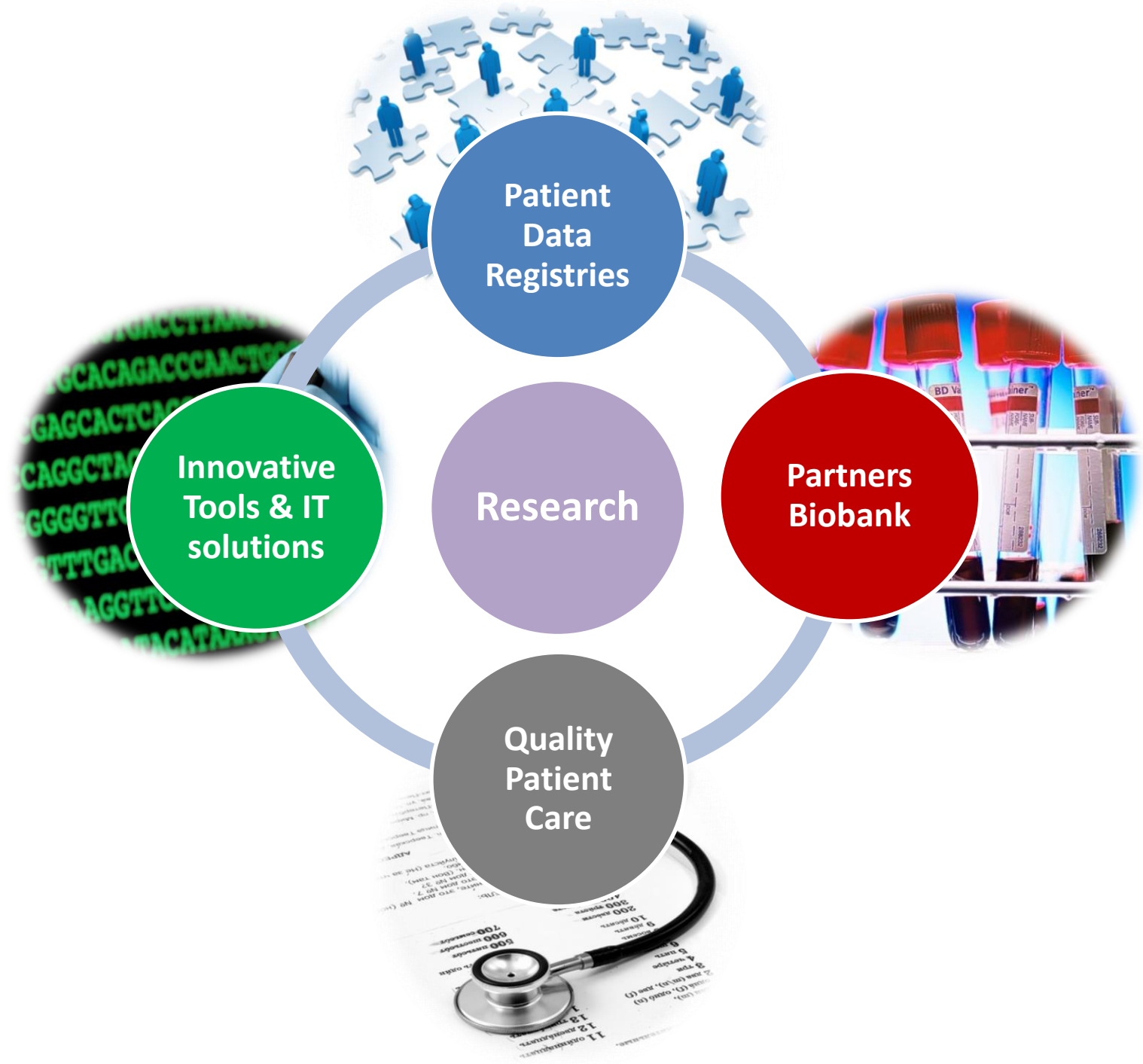
Pilot Study of Pioglitazone for the Treatment of Moderate to Severe Asthma in Obese Asthmatics (v2)

History Load Previous Clinical Trial Specify A New Clinical Trial

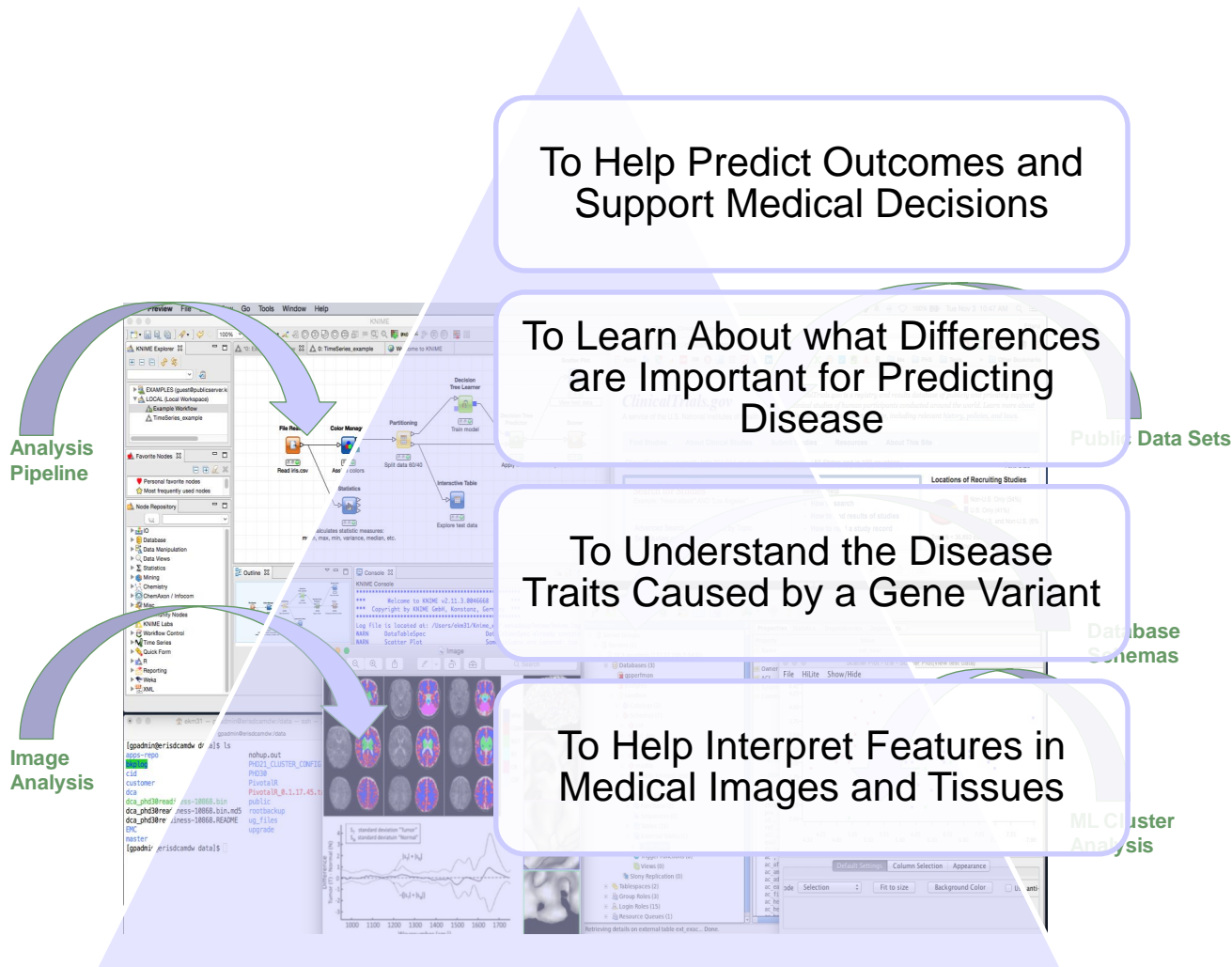
CT Matcher

	100%	Searched	Matched
Demographics	✓	Age between 18 and 60 Both	Age 26; Both
Medications	✗	actos; pioglitazone	
Notes	✗	asthma; wheezing asthmatics	wheezing [1],
Problems	✗	asthma; wheezing; obesity	Asthma, unspecified without mention of status asthmaticus; Asthma, unspecified type, with acute exacerbation; Extrinsic asthma without status asthmaticus; Cough

Drop a new patient record here to load it.



Using Big Data to Find Similar People



Deciding to Perform a Genetic Test

Inherited Heart Disease - Cardiomyopathy

Population Background Driven Analysis

MRN-00000 Mother Goose 1/1/1850

Test To Evaluate

Hypertrophic Cardiomyopathy (HCM) Panel

Export Matching Cases

Filter

☐ all

☒ clinic

☐ family

min relatedness 2

☐ Proband Ethnicity Only

Add Gene

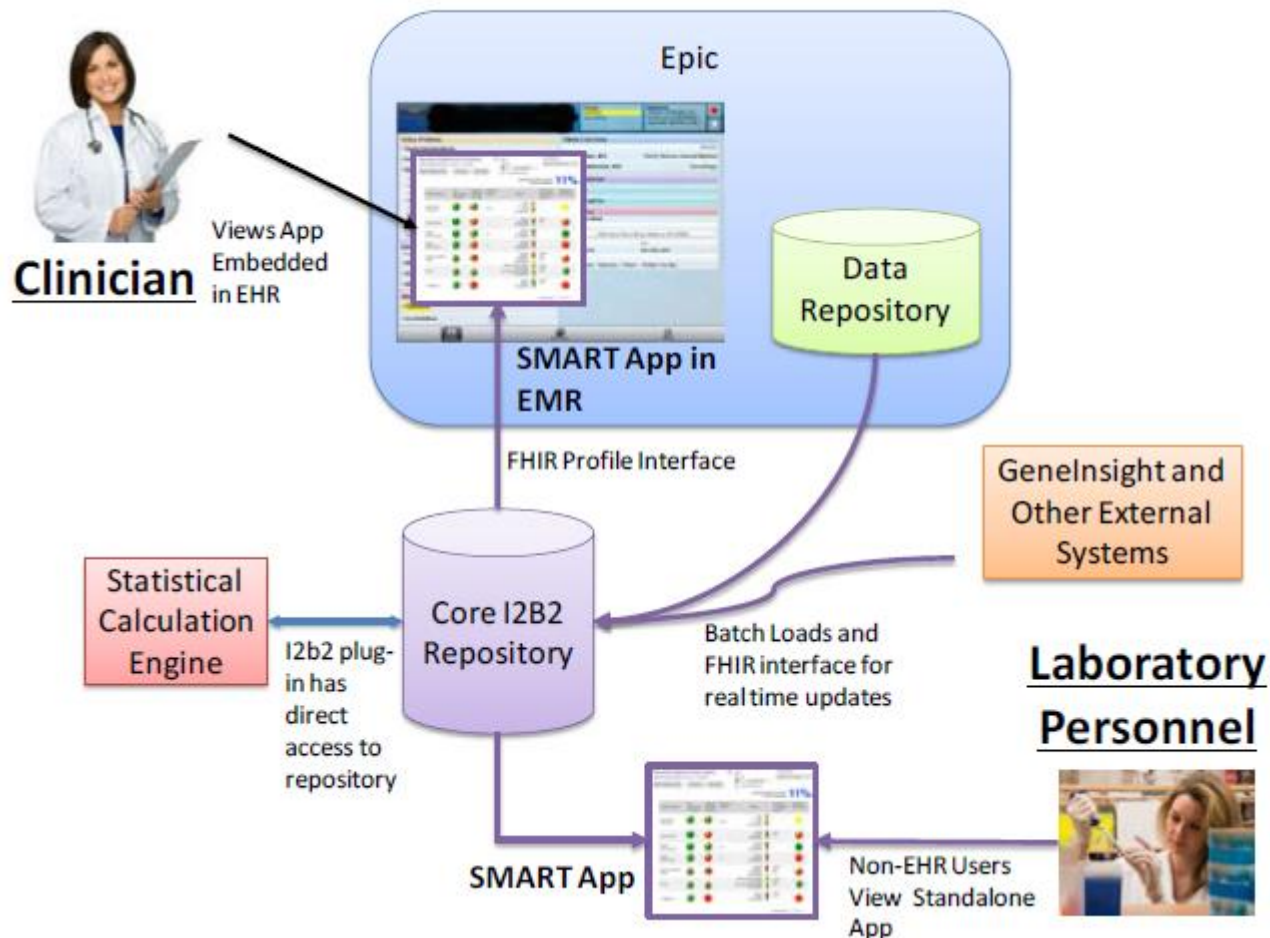
Add Variant

Hypertrophic Cardiomyopathy (HCM) Panel
Calculated Positive
Pretest Probability

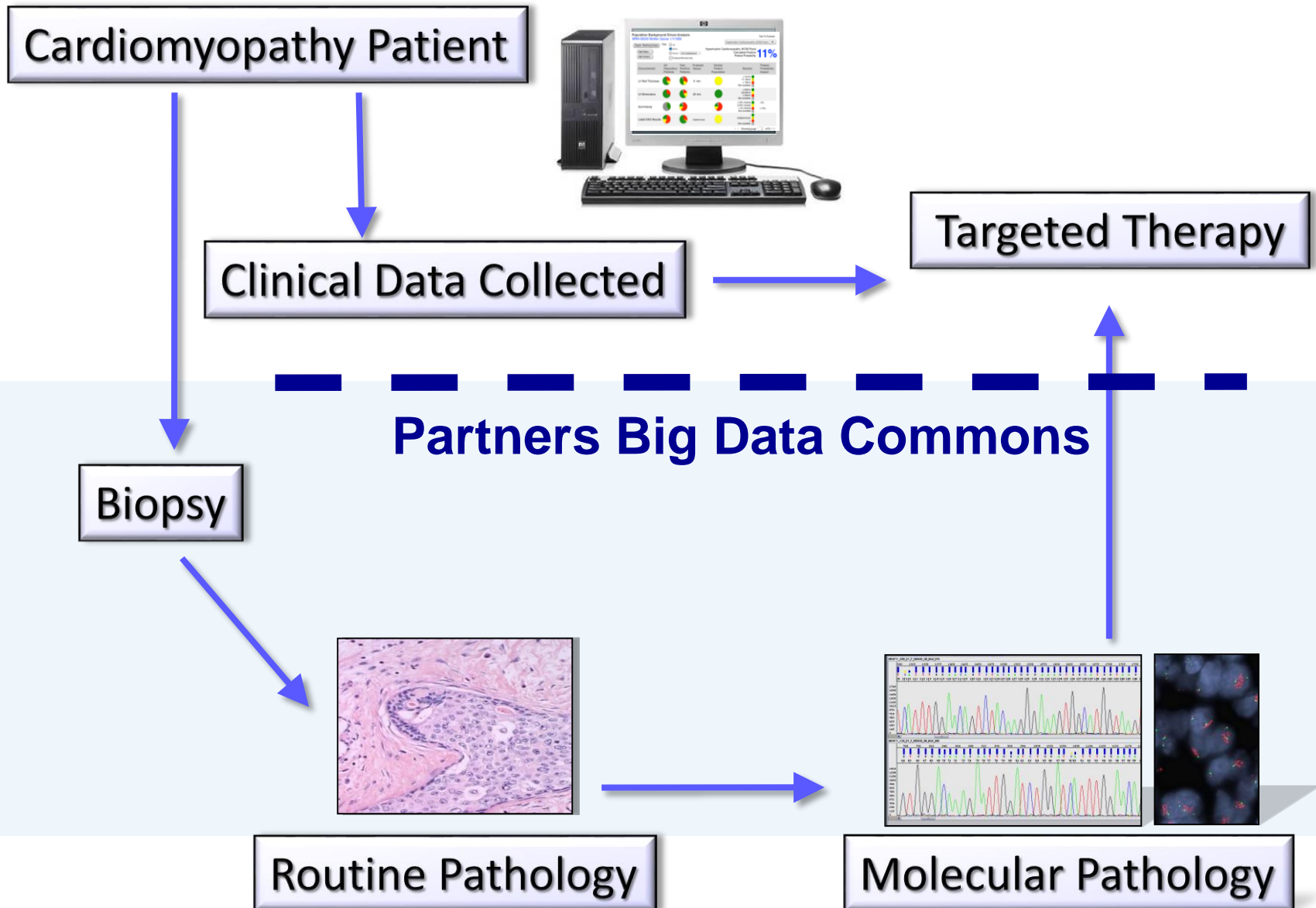
11%

Characteristic	All Repository Patients	Test Positive Patients	Proband Values	Similar Patient Population	Results	Pretest Probability Impact
LV Wall Thickness			11 mm		<div>< 11mm</div> <div>11-15mm x</div> <div>> 15mm</div> <div>Not available</div>	
LV Dimensions			42 mm		<div>< 52mm x</div> <div>52-54mm</div> <div>> 54mm</div> <div>Not available</div>	
GLA Activity					<div>> 20% Activity</div> <div>5-20% Activity</div> <div>< 5% Activity</div> <div>Not available</div>	- 6% + 70%
Latest EKG Results			Indeterminant		<div>-</div> <div>Indeterminant x</div> <div>+</div> <div>Not available</div>	

Health Innovation Platform Architecture

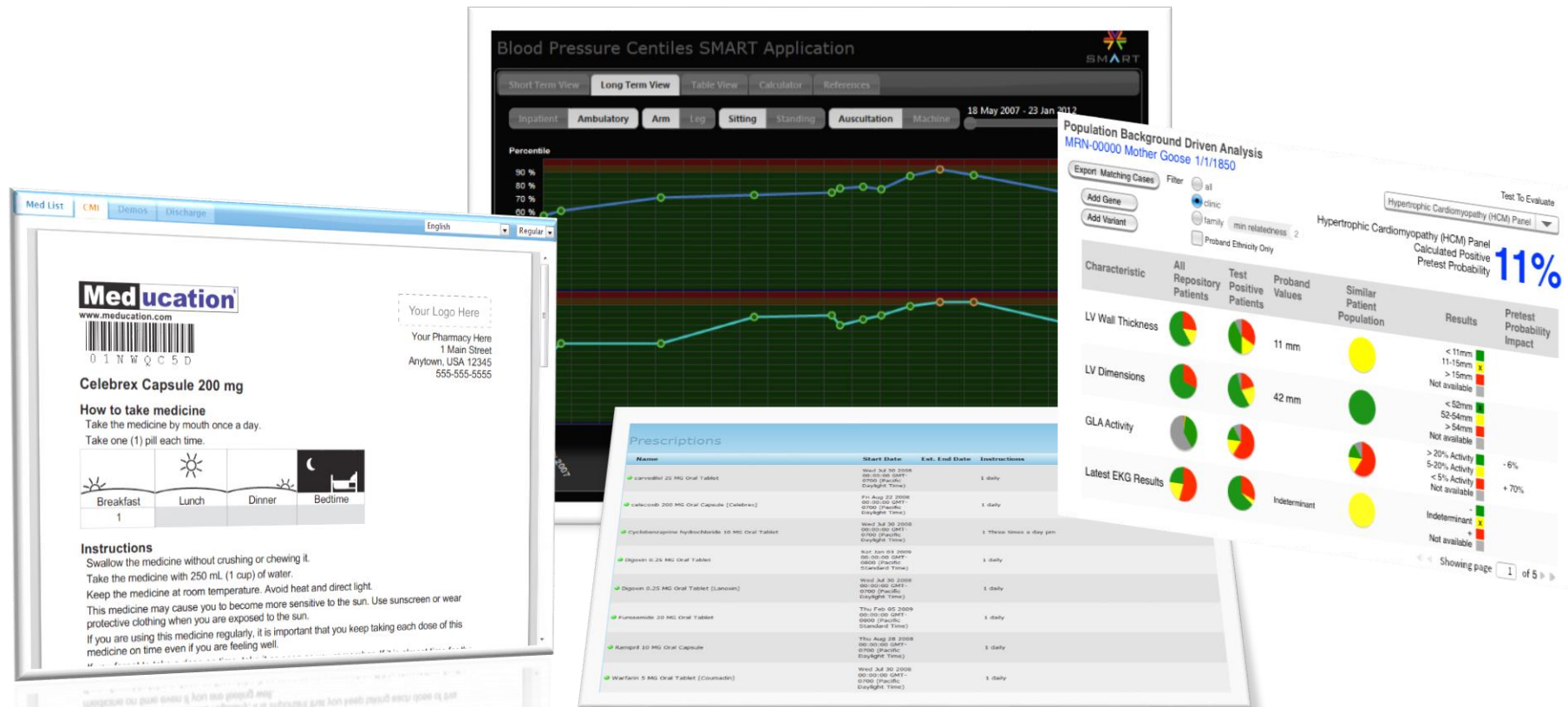


Treating IHD Patient with Precision Medicine

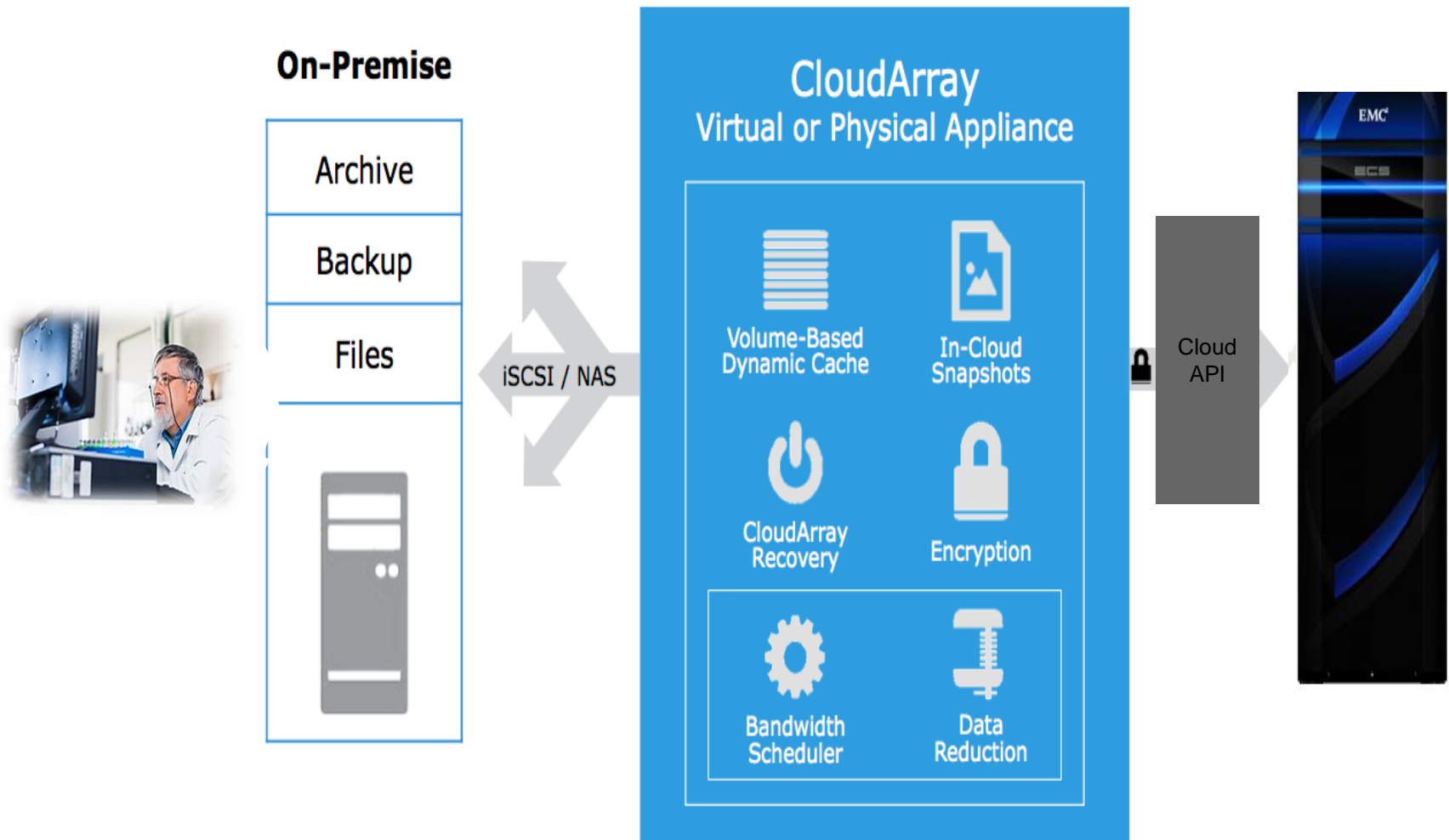


SMART Apps link i2b2 to the EMR

- Substitutable Medical Application and Reusable Technology – Commissioned from the Office of the National Coordinator
- Allows Big Data from i2b2 to integrate Clinical “Apps” into the Epic EMR.
- Paradigm is similar to Mobile Apps with a proposed standard interface using FHIR sponsored by the National Argonaut EMR Project.

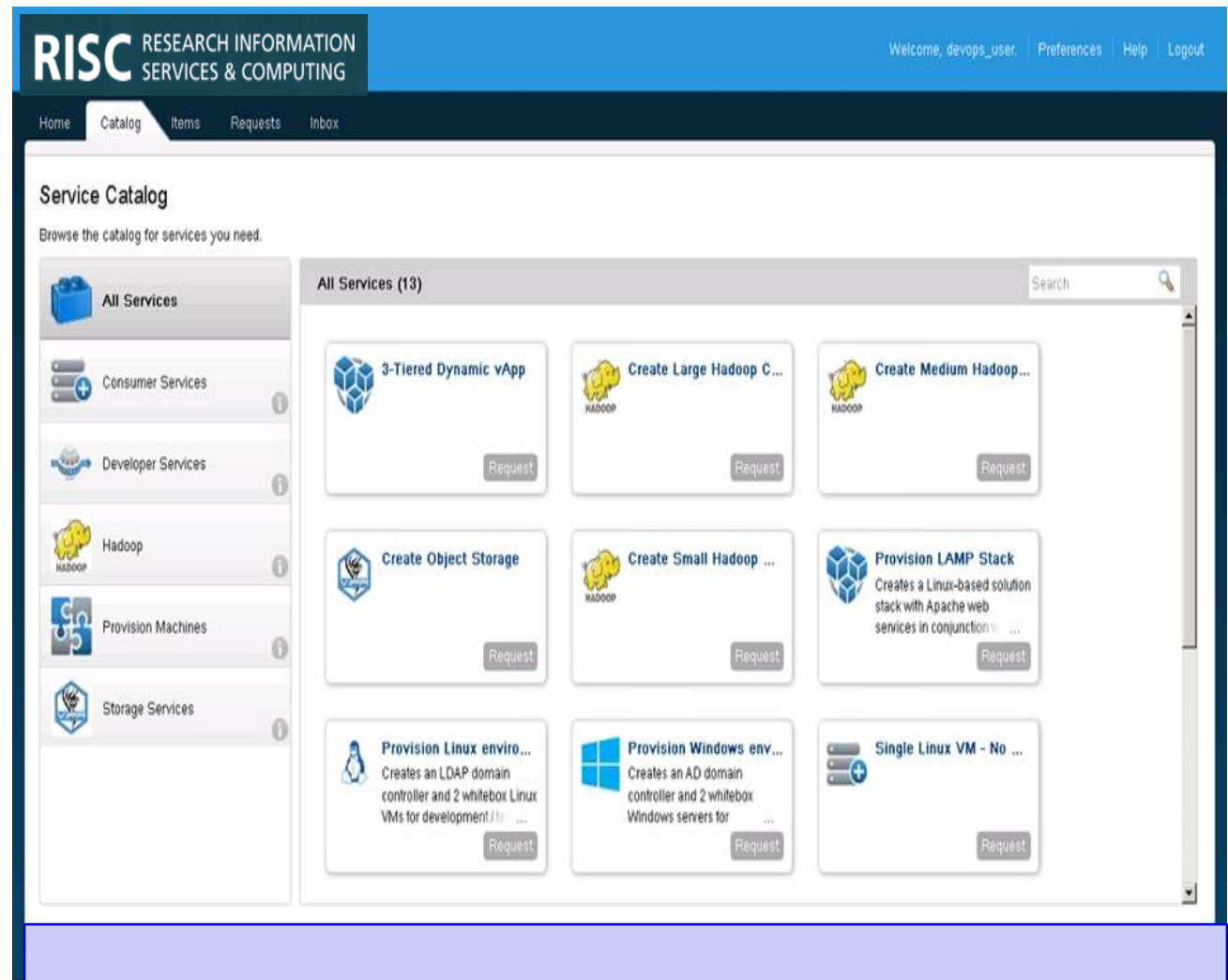


New network storage in the cloud



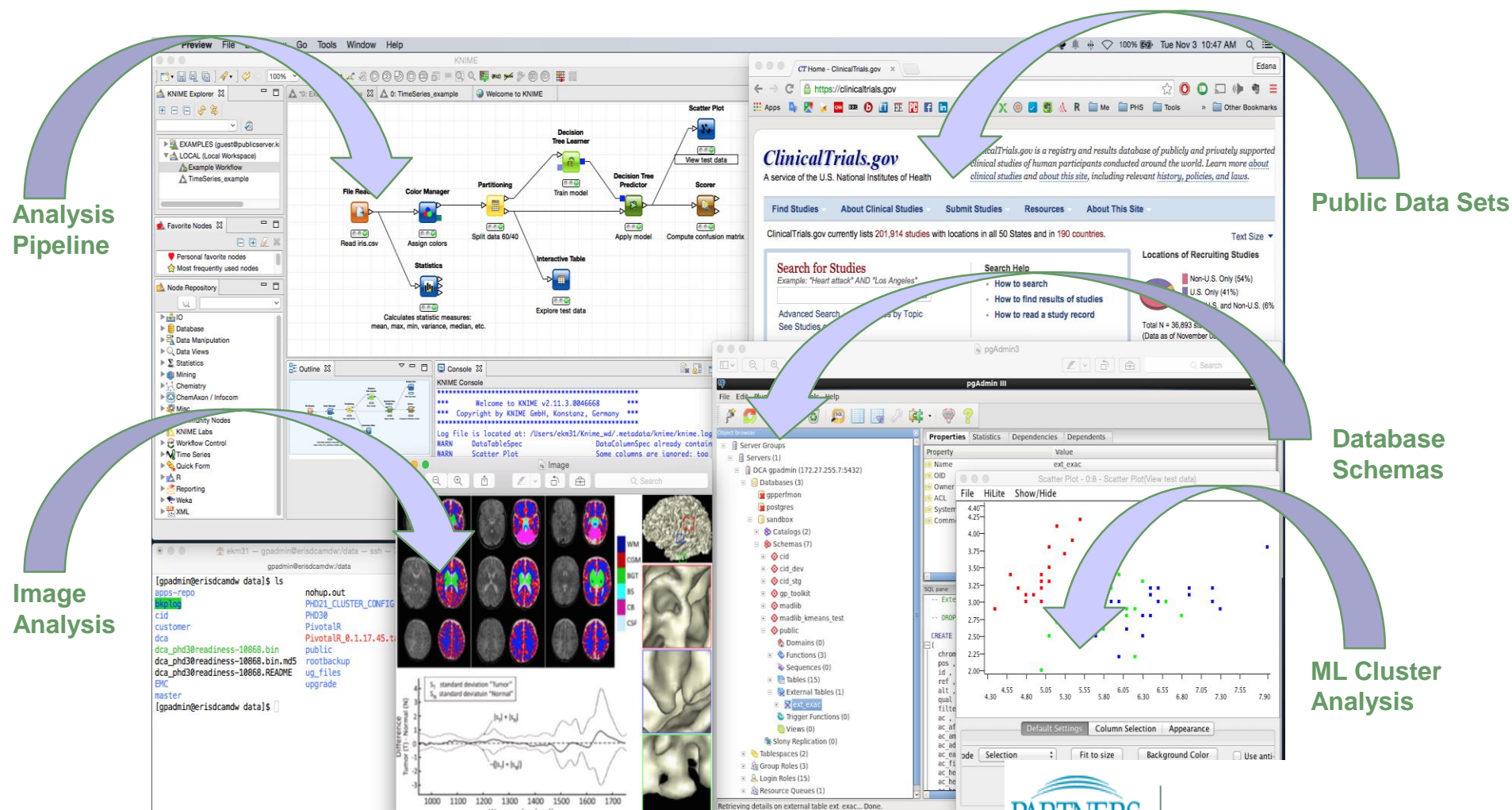
delivered as a Service

Self-Service in 2016



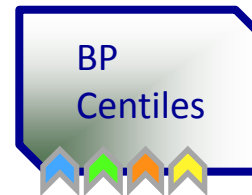
Presenting the researcher desktop

Robust desktop capabilities for the Partners researcher

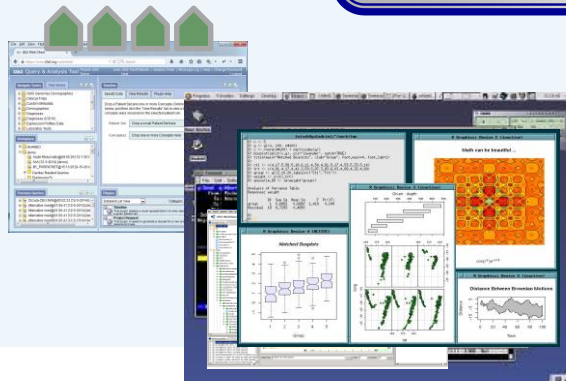
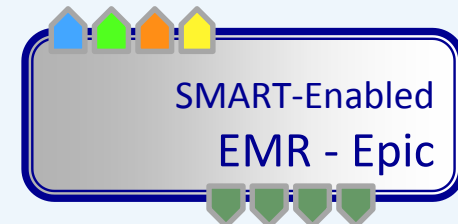
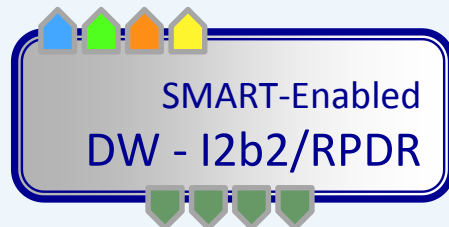


Enabling Innovation to reach into EMR

SMART
Apps run
in EMR



Partners Big Data Commons



Big Data Analytics
performed with High
Performance Computing

Tribute to...

■ RPDR/I2b2 Core Team

- Shawn Murphy
- Christopher Herrick
- Mariah Mitchell
- Vivian Gainer
- Alyssa Goodson
- Martin Rees
- Charles Wang
- Laurie Bogosian
- Stacey Duey
- Andrew Cagan
- Michael Mendis
- Lori Phillips
- Janice Donahoe
- Nich Wattanasin
- David Wang

■ Biobank Team

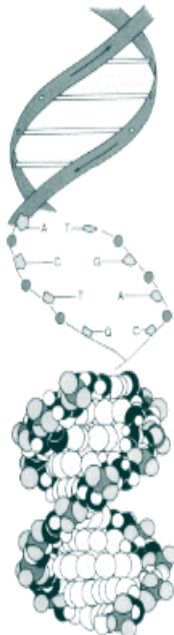
- Natalie Boutin
- Scott Weiss
- Vivian Gainer

■ HPC and Cloud Team

- Brent Richter
- Jon Jackson
- Alan Harris

■ Genomics Innovation Team

- Sandy Aronson
- Heidi Rehm
- Calum MacRea



I2b2 and SMART Information and Software on the Web

i2b2 Homepage (<https://www.i2b2.org>)

i2b2 Software (<https://www.i2b2.org/software>)

i2b2 Community Site (<https://community.i2b2.org>)

SMART Platforms Homepage (<http://smarthealthit.org>)