Inter-institutional data sharing: the CICTR project

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Nick Anderson, Ph.D.
Assistant Professor, Biomedical Health Informatics
University of Washington
Institute of Translational Health Sciences

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Information Exchange Pilot Project

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Overview

- Scope of project and current status
- Technical environments
- Challenges and next steps

Scope of Project

- Two year demonstration project (11/08-11/10)
- Three CTSA partners with academic medical centers
  - University of Washington ITHS
  - UC San Francisco CTSI
  - UC Davis CTSC
  - Harvard Catalyst (collaborator)
- Private data warehousing company Recombinant Data Systems
- www.i2b2.org

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Project Goals

- Foster data driven research collaborations
- Develop and test generalizability of using anonymized data to support federated querying across geographically distributed academic institutional medical systems
- Evaluate impact of systems and processes on different classes of end-users and institutions
- Pilot governance approaches to support/protect patients, researchers and institutions

Use case: Cohort discovery

- Q: How many patients in the UWMC system might be at risk for diabetes?
- Inclusion criteria
  - Ages 18-40
  - Obesity (ICD-9 278.*)
  - Other abnormal glucose (ICD-9 790.29)
- Exclusion criteria
  - Diabetes Mellitus (ICD-9 250.*)

Use case writ larger…

- How can (or just can) this query be parsed against external clinical populations?
- How can sensitivity and specificity be increased?
- How can these results be effectively used?

Multi-Institutional Use-cases and Users

- Anonymized cohort discovery for clinical trial recruitment
  - Current: aggregate counts and institutional source
  - Future:
    - » Descriptive metadata
    - » Local HIPAA de-identified Limited Data Sets
- Intended users:
  - Clinical translational investigators/study teams
  - Informaticians
  - Terminologists
  - Public health researchers (pending)

Four parallel processes

- Technical - IT/development/implementation/testing
- Governance - Data Use Agreements/IRB institutional alignment
- Ontology - Terminologies/semantic alignment
- Evaluation - Process, outcomes and usability evaluation

Human resources needed

- Formal (e.g. – paid)
  - Informaticians
  - ETL analysts
  - Terminologists
  - Software architects/Developers
  - Usability/Evaluation researchers
  - Informatics/Information science students
  - IT staff
- Informal (e.g. – priceless)
  - Support of project at highest institutional and regulatory levels - CIO/CTO
  - (new!) clinicians/clinical researchers

Technical environments

- Compatible server architectures/different DB environments architecture environments
- “Identical” I2b2 environments
- Common ETL and anonymization processes
- Common development environment
- Common knowledge environment
- Broadly similar governance processes

I2b2

- Informatics for Integrating Biology and the Bedside (www.i2b2.org)
- NCBC funded center - grew out of RPDR (Harvard, Partners Health, Mass Gen)
- Multiple biological cores – 1 core is software
- Deployed 29+ institutions world wide
- Implemented as web services against Oracle/SQL server/Sybase IQ
- Java/LAMP v1.3 (1.4 this month)
- GPL license

I2b2 Hive Environment

I2b2 Workbench

Client side (desktop or web)

(mostly) server side

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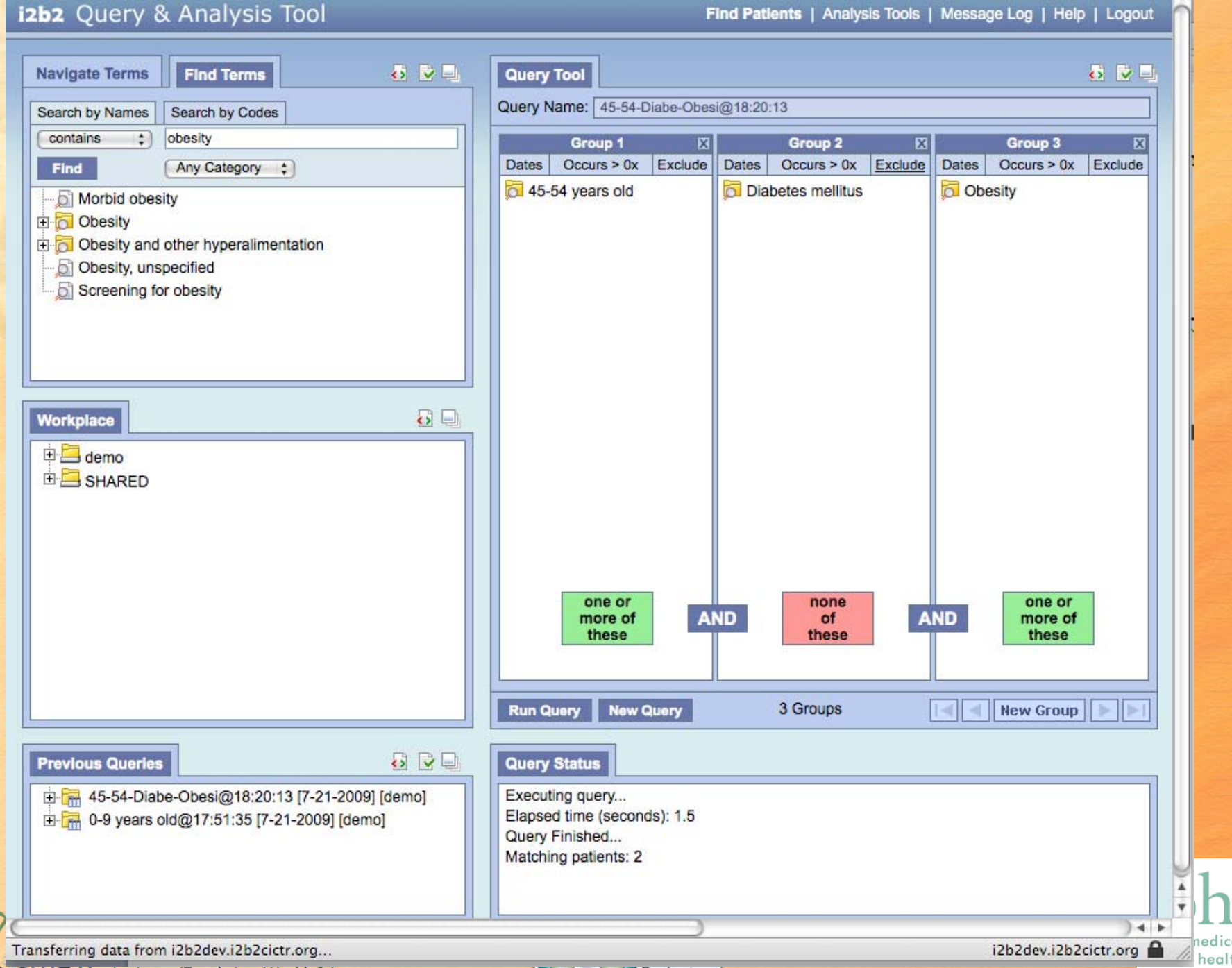

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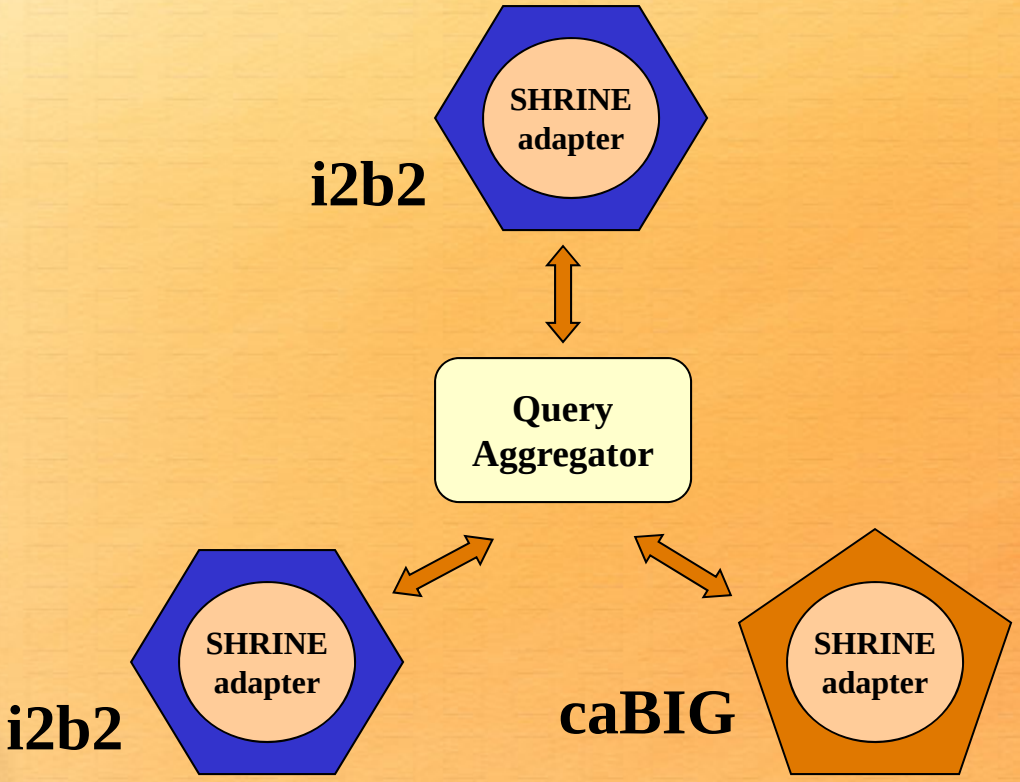
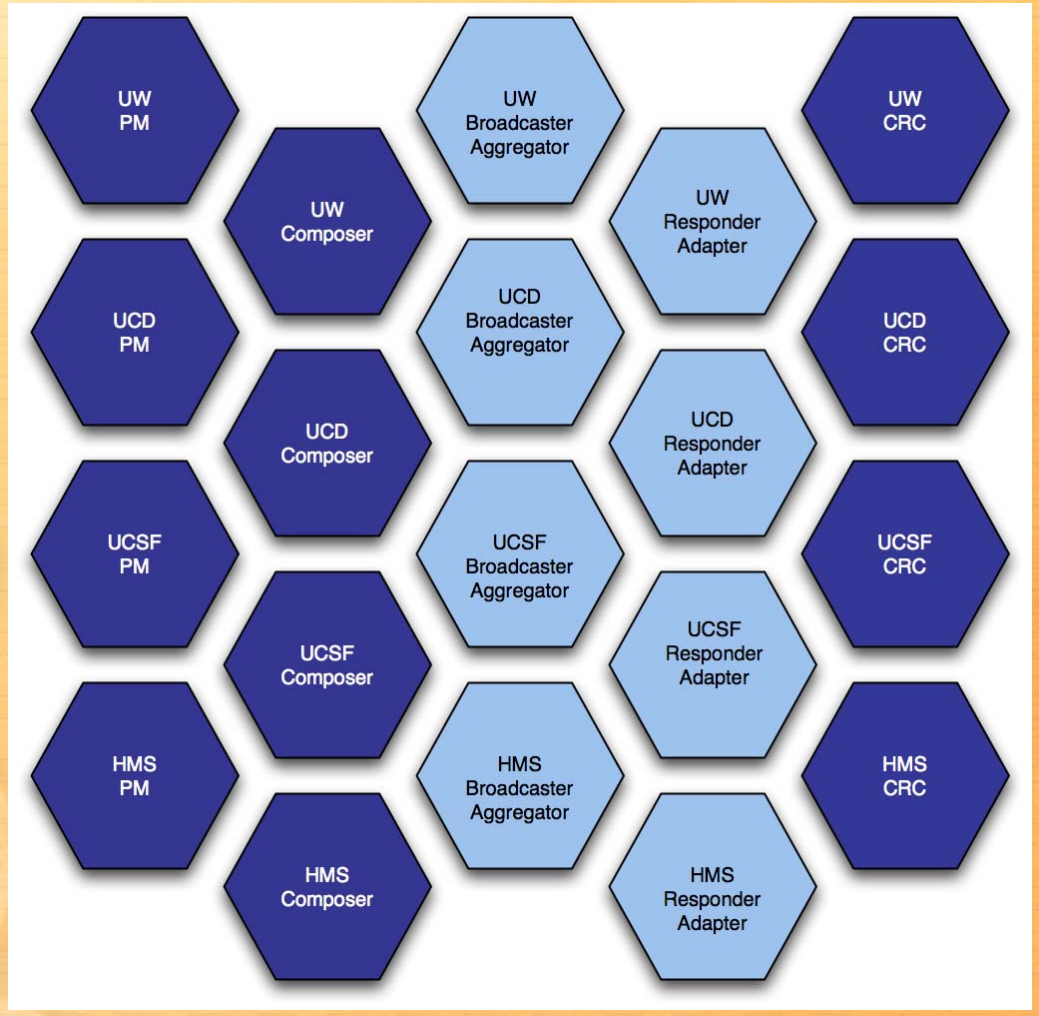
Shared Research Informatics Network (SHRINE) Distributed Queries



Central “aggregator” broadcasts query to local hospital “adaptors”, which return aggregate, “blurred” counts only

(Murphy 2009)

I2b2 CICTR SHRINE Network View



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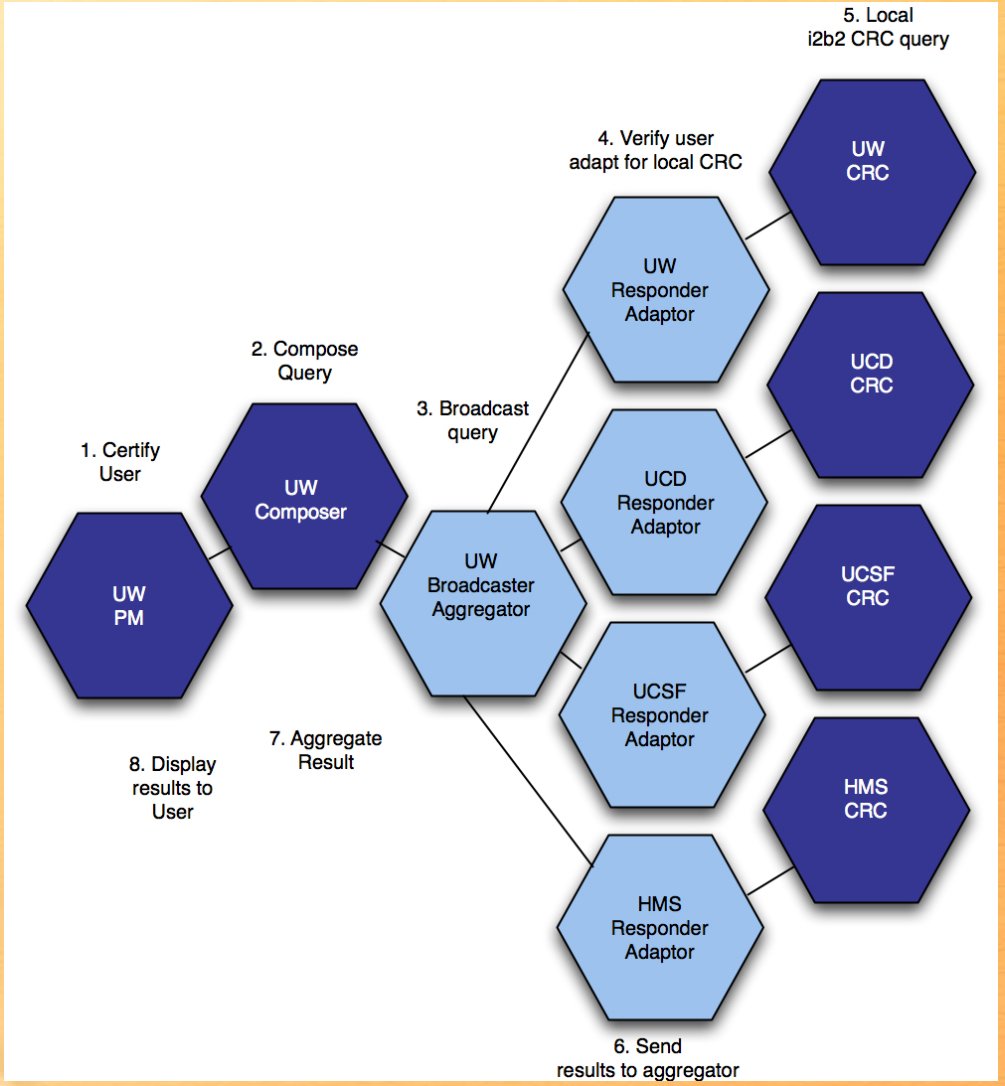
SHRINE marshalling a federated query



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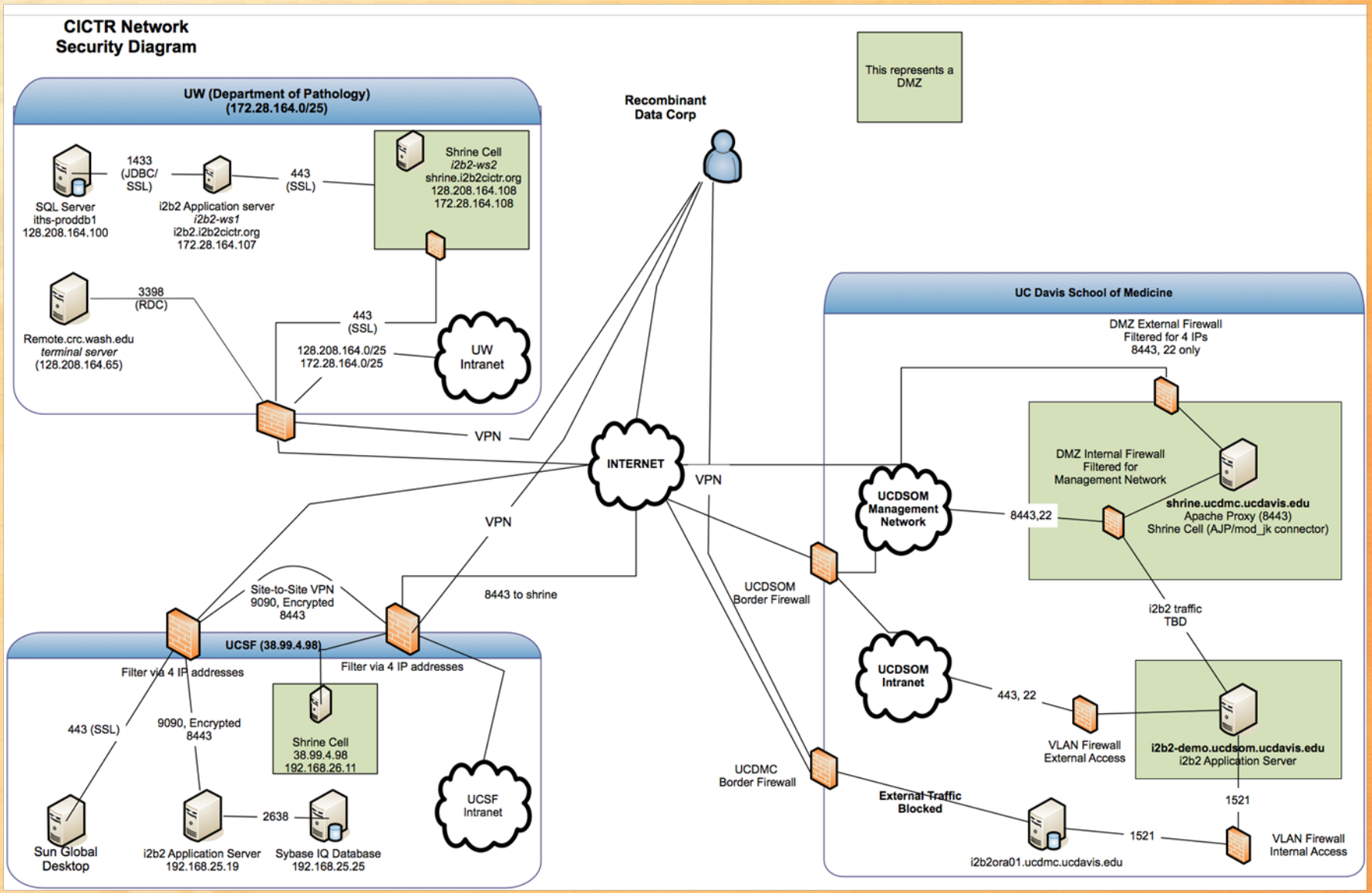

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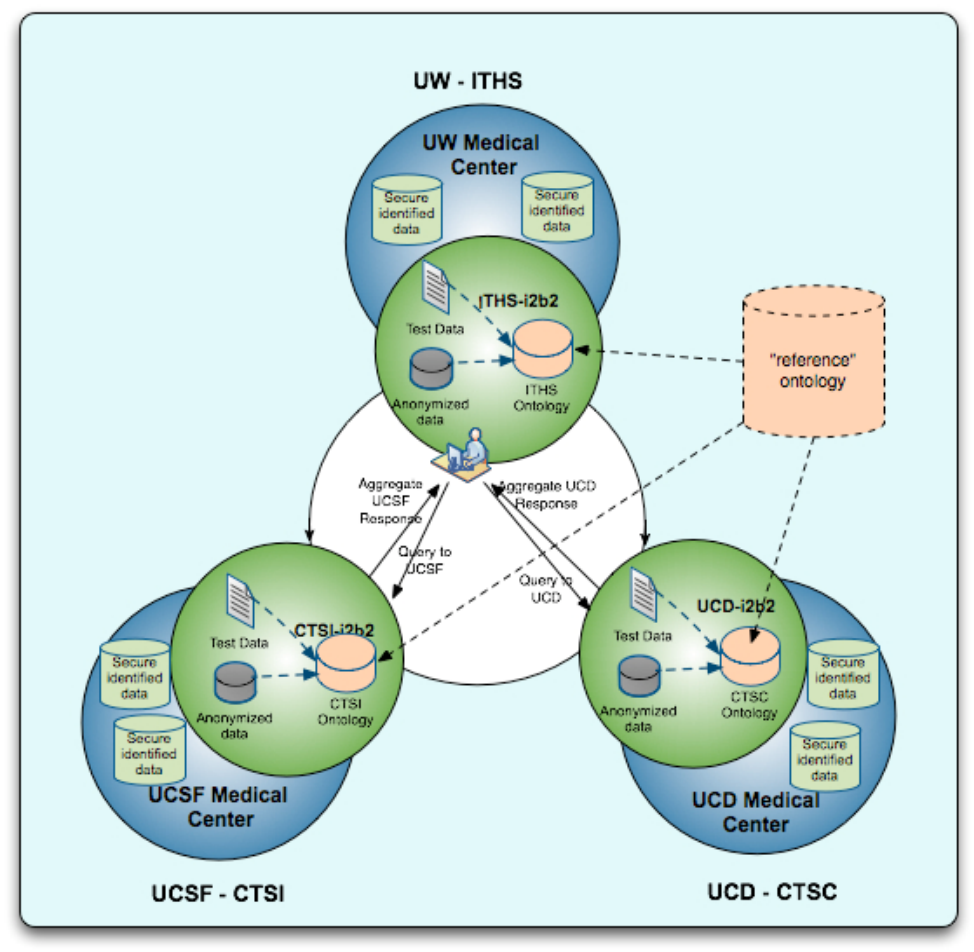
Accomplishments

- Deployed secure environments with real data at 4 sites (three real partners and Harvard)
- Approaching 2.5 million de-identified patient records in three site secure network
- Ability to simultaneously query on demographics and disease diagnoses (ICD-9)
- Secondary research into:
  - usability of federated query systems,
  - anonymization approaches
  - Standards development

Phase 3: Moving to support anonymized semantically rich data discovery



- Disease/domain focus
  - Diabetes
  - Cardiovascular disease
- Pilot ability to search for "poorly characterized" disease criteria across geographically and culturally unique medical centers
- Support rare disease hypothesis generation/pruning

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Current I2b2 CICTR Data Elements

Available and anticipated data elements			
Demographics	**Diagnoses**	***Medications***	***Laboratory***
Age	Date of diagnoses	*Date of encounter*	*Date of lab*
Gender	ICD-9 numeric codes	*Medication name (generic/brand)*	*Lab values*
Race/Ethnicity	iCD-9 supplemental classifications influencing health status	*Dose form*	
Geocode (3 digit zip prefix)	ICD-9 supplemental classification of external causes of injury and poisoning		
Vital status			
Marital status			
Language *(tbd)*			
Religion *(tbd)*			

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Challenges and Next Steps

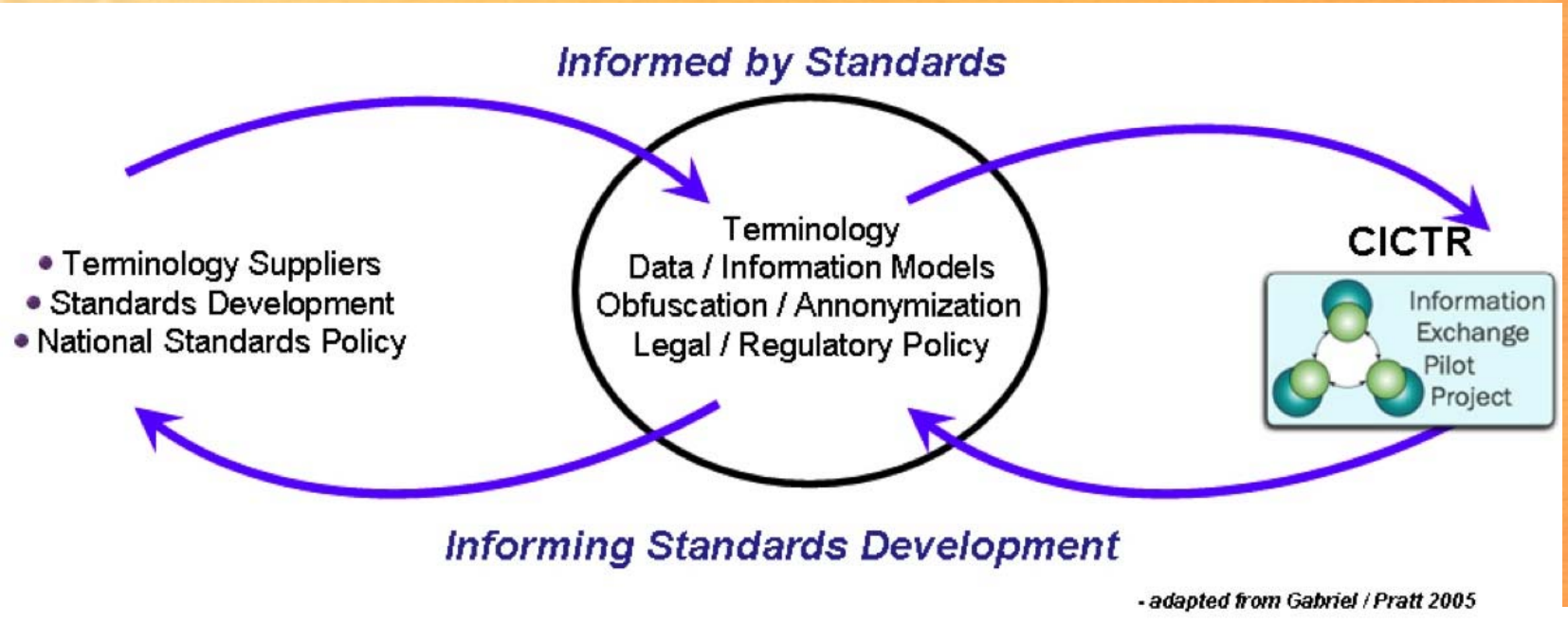
- Define/evaluate complex mapping methodologies (medications and laboratory values)
- Evaluating quality of knowledge mappings locally and network-wide, both qualitatively and quantitatively
- Develop/refine well-governed access to systems

Complex mapping challenges

- Defining common standard-based data exchange formats by LCD method
- Building or adapting tools that support federated querying/SHRINE/i2b2 environment
- Automating/enhancing labor intensive processes (ETL/Anonymization->i2b2 schemas)

Evolving Best Practices

- Developing two-way dialog with National Standards projects, organizations, development
- Increasing ability to vet evolving standards in practical research environment



Use of Standards to date

- Factors considered in the selection
  - HITSP recommended
  - SHRIMP / Harvard Ontology selections
  - Common data availability (Diagnoses) across sites
  - Widespread use: HL7 demographic value sets

Use of Standards

- Selected Standards
  - Gender: HL7 001
  - Race / Ethnicity: OMB5
  - Language: ISO 693.2
  - Marital Status: HL7 002
  - Vital Status: HL7 Entity.LivingSubject.deceasedInd
  - Religion: HL7 Religious Affiliation value set
  - Diagnoses: ICD-9 numeric, V and E codes
  - Medications: RxNorm (Ingredient table)
  - Laboratory: LOINC

Multi-site issues Informing Standards

- RxNorm feedback
- HITSP EHR-to-CTMS Value Case
  - Deals with only point to point intra-institutional data sharing
  - Participated in public comment with many to many points in mind
- IHE Redaction Services Functional Profile
- HL7 CIC Diabetes Domain Analysis Model
- End-user roles (PI's, study coordinators)

Federated mapping approaches

- Option 1: “Everybody” agree on the same target reference terminologies, and conforms
  - Seems to works for simple cases (eg. ICD-9)
  - I2b2 has tool that begins to do this (SHRIMP)

  ..but
  - Potential loss of information for complex mappings (e.g. “rich” local to LCD network to target – everybody loses)
  - What if local needs require common targets to change- who mediates?

Federated mapping approaches

- Option 2: Use a public terminology repository (e.g. OpenMDR), build local maps against public maps that are then checked-in/out/updated by services that require them (such as SHRINE)
  - caGRID world likes this (and potentially provides a bridge to caGRID environments)
  - Current tool at UCSF (Ontomapper) is doing this
  - Not much on the “agnostic” repositories yet (needs content)
  - Incompatible with SHRINE at present..

Federated mapping approaches

- Option 3: Blend/test/deploy/test these
- Leverage SHRINE/SHRIMP/I2b2 terminology philosophy
  - Extend SHRIMP to use OntoMapper capabilities
  - Let the site decide
  - Will require additional SHRINE/i2b2 configuration/development
- … Will report results soon…

Evaluating end-user needs

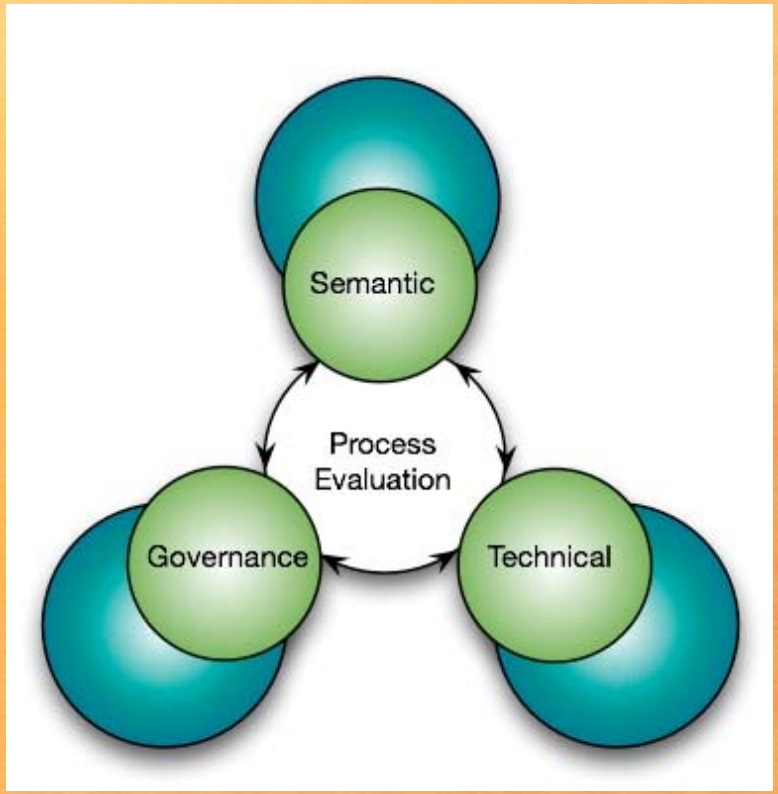
- Resulting data organization may not intuitively support how researchers create structured queries
  - Testing use of system expectations locally and nationally via Davis evaluation group
  - Planning near-term focused diabetes group

Providing access for researchers

- Significant institutional sensitivity to the use of such systems
- Hypothesis: best researcher use is a governed approach that puts them in the query-seat
  - How to facilitate this? Currently data is technically “not human subjects”, yet sensitivity and emphasis on secure control remains

Pandora's box issues

- There is a risk of being successful…
  - Business intelligence
  - Setting wrong expectations/freaking people out
  - Create unnecessary new branches of code/process
- Best practices/technologies are evolving..
- Maintaining scope and control
  - Protecting the patients
  - Protecting the partners
  - Protecting the developer



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