SHRINE

Shared Health Research Information Network

A Federated Query Tool for i2b2 Databases

Use Cases

- Identifying cohorts for clinical trials
- Access to human specimens
- Population health surveillance
- Observational studies of genetic variants

SHRINE <u>Prototype</u>

- Goals
 - Query three i2b2 databases (4 hospitals)
 - Get approval from IRBs and hospital SVPs
 - Six month deadline
- Challenges
 - Protect the Developers
 - Protect the Patients
 - Protect the Hospitals

Protect the Developers

Limit the Scope

- Start with BIDMC, CHB, and PHS
- Simplify IRB process by limiting to aggregate queries and only seven users
- Limit ontology to demographics and diagnoses (ICD-9)
- Quick and dirty technical architecture

Protect the Patients

Obtain IRB Approval

- No central database
- Only data from 2006
- Destroy prototype after limited time
- Patients signed HIPAA notice allowing personal health information to be used for research
- Aggregate counts only; obfuscate by adding small random number; display "<10" for small counts
- Log all queries
- Local PI responsible for data

Protect the Hospitals

Get Approval from Senior Leadership

- Hospitals can back out at any time
- Hospitals not identified by name (e.g., Hospital #1, #2, #3)
- List counts in random order
- Scale counts based on size of hospital
- Reveal all counts simultaneously so the speed doesn't reveal hospital

Prototype Architecture



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



Demo

i2b2 Query & Analysis Tool

🗄 🔂 Albanian@02:31:25

🧑 📪 🕵 🧭 📪 🟞 **Navigate Terms Find Terms Query Tool** Query Name: 🖻 🚑 Demographics 🗄 🧰 Age Group 1 Group 2 Group 3 🗄 🔄 Gender Occurs > 0x Exclude Dates Occurs > 0x Exclude Dates Occurs > 0x Exclude Dates 🔊 Female 🚞 Regional enteritis 🔊 Male Neoplasms 🔊 Male Ulcerative colitis 🔊 Unknown 🗄 🧰 Language 🗄 🧰 Marital-Status one or none one or AND AND 🗄 🧰 Race more of of more of these these these 🗄 🧰 Vital-Status drag an 🗄 🚑 Diagnoses item from here New Query 3 Groups New Group Run Query 4 ळे 🖙 🟞 **Previous Queries** Query Status Executing query... 🗄 🔂 Noninfe-Female@16:39:03 Elapsed time (seconds): 14.0 🗄 🔂 Nonin-Femal-Neopl@16:39:11 Query Finished... 🗄 🔒 Circulatory sys@16:39:18 Matching patients (hospital 1): 332 (+/-3) E 🕀 Circulatory sys@17:01:03 Matching patients (hospital 2): 16 (+/-3) 🗄 📳 Circula-Events @17:04:11 Matching patients (hospital 3): 151 (+/-3) 🗄 🖓 Demographics@17:04:21 🗄 🔂 10-19 years old@17:04:39

Logout

Peer-to-Peer Architecture



Broadcast-Aggregation based on SPIN We need <u>your</u> help creating the ontology translator

Timeline

Year 1 (Regulatory 12/1/2008, Go-Live 6/30/2009)

- 1. Harvard-wide query capability for aggregate data
- 2. Limited data sets view one patient at a time

Year 2 (Regulatory 12/1/2009, Go-Live 6/30/2010)

1. Limited data sets - full download capability

If capacity is available and institutions agree

- 1. Limited data sets with NLP processed text notes
- 2. Limited data sets with tissue sharing