

# Knowledge Services and the Role of Medical Libraries in Health Care Information Technology

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# Our policy goals from ARRA

1. Technologies that protect the privacy of health information and promote security in a qualified electronic health record, including for the segmentation and protection from disclosure of specific and sensitive individually identifiable health information
2. A nationwide health information technology infrastructure that allows for the electronic use and accurate exchange of health information
3. The utilization of a certified electronic health record for each person in the United States by 2014
4. Technologies that as a part of a qualified electronic health record allow for an accounting of disclosures made by a covered entity
5. The use of certified electronic health records to improve the quality of health care
6. Technologies that allow individually identifiable health information to be rendered unusable, unreadable, or indecipherable to unauthorized individuals
7. The use of electronic systems to ensure the comprehensive collection of patient demographic data, including at a minimum, race, ethnicity, primary language, and gender information
8. Technologies that address the needs of children and other vulnerable populations

# Grand Challenge #1

## Consent to Share Data

- No consent = share as needed for treatment, payment, and operations
- Opt-Out = data is exchanged by default unless restricted by the patient
- Opt-In = data is not exchanged by default until the patient consents
- Opt-Out or Opt-In with restrictions = a subset of data is exchanged with patient consent based on institution, use of data, type of data, and situation

# Institutional example

- Opt Out = I do not wish the information at this institution to be shared
- Opt In = I agree to share all information from this institution
- Restricted = I agree to share my medications and labs but not my problem list and notes from this institution

# Use of Data example

- Opt Out = I do not want to participate in this research study
- Opt In = I want my data used by all stakeholders with audit protections, to optimize my health
- Restricted = I want all my data shared with emergency providers, primary care physicians, payers and public health agencies, but not with pharmaceutical firms

# Type of Data example

- Opt Out = I do not want my laboratory records shared
- Opt In = I want my data from labs, pharmacies and payers shared with providers
- Restricted = I want my pharmacy records shared except medications used for mental health, HIV, and substance abuse treatment

# Situation Example

- Opt Out = I do not want my data shared for simple office visits with one-time providers i.e. out of town visit to an urgent care for a small laceration repair
- Opt In = I want my data shared for all care situations
- Restricted = I want my data shared for all emergency visits but not for routine care

# Examples

```
<consent>
<scope="Institution">
  <code code="311570" displayName="Beth Israel Deaconess Medical
Center" />
  <statusCode code="opt-in" />
  <time value='20041001132534-0500' />
</scope>
<scope="UseofData">
  <code code = "12345678" displayName="Harvard Clinical Research Institute" />
  <statusCode code="opt-out" />
  <time value='20060923153527-0500' />
</scope>
</consent>
```

# Examples

```
<consent>
  <scope="TypeofData">
    <code code="987654321" displayName="Walgreens Pharmacy"/>
    <statusCode code="restricted"/>
    <time value='20051103161524-0500'/>
  <exclusion code="34343434" displayName="Mental Health"/>
</scope>
  <scope="Situation">
    <code code="IIIIII" displayName="Emergency Department Care" />
    <statusCode code="opt-in"/>
  <time value='20060201113715-0500'/>
</scope>
</consent>
```

# What this means

- I opt-in to share all my data from Beth Israel Deaconess Medical Center
- I opt-out of participating in a clinical trial at Harvard Clinical Research Institute
- I opt-in to sharing my Walgreens prescription data except mental health medications
- I opt-in to sharing all data (including mental health medications) for emergency care

# Implementation details

- Medical Library Role - We need medical record metadata and a consent vocabulary to maintain confidentiality per patient preferences
- A Consent Wizard would need to enforce integrity of consent options to avoid conflicting preferences i.e. patients cannot both opt-out and opt-in for data sharing with the same use and situation
- A hierarchy must be created to ensure consistent interpretation of complex consent such as situation > institution > use of data > type of data i.e. an opt-in for emergency care data sharing overrides type of data opt-outs

# How should we store and communicate consent?

- Persistently, with each disclosure of data
- In the PHR
- In the EHR
- In the HIE - local, regional or national
- At the payer

# Grand Challenge #2

## Engaging the Patient

- We have a foundation of early work with tethered and non-tethered PHRs
- ARRA requires
  - patient online access to records including educational materials
  - electronic lifetime health record, inpatient and outpatient summaries on request
  - reminders
- There is no national identifier and no easy way for multiple providers to bidirectionally exchange data with patients using different PHRs

Welcome to

# PatientSite™

Healthcare you can connect with

**Sign In**




*First Time Here?*  
**Take a Tour**

*Want to Join?*  
**Register Now!**


[Minimum Browser Requirements](#)

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Home 

## Services

Mail  
Prescriptions  
Appointments  
Referrals

**Google Health** 

Links  
Account Statement

## About Me

Records  
Personal Profile

## Support

Tech Support  
FAQ/Tutorial

Privacy Policy

## Google Health

 Help

### PatientSite and Google Health Connection

You can upload your personal health information from PatientSite to your Google Health profile. Currently, you can upload medications, allergies and diagnoses. We will make options for uploading other health information available in the future. You always have complete control over whether and when information is uploaded to your Google Health profile. You can deactivate your PatientSite and Google Health Connection at any time.

To upload your health information, please select one or more options and then click the **Upload** button below.

Diagnoses  Medications  Allergies

**Upload**

To view your health information in Google Health, please click the **Google Health** link below.

[Google Health](#)

To deactivate your PatientSite and Google Health Connection, please click the **Deactivate** button below.

**Deactivate**

Google Health BETA Search the web Read about health topics »

- jdhalamka
- Notices
- Drug interactions
- Profile details
- Age, sex, height...
- Conditions
- Medications
- Allergies
- Procedures
- Test results
- Immunizations
- Add to this profile
- Import medical records
- Explore health services
- Medical contacts
- Find a doctor
- Create a new profile

- Add to this Google Health profile**  
Learn about your health issues and find helpful resources
- Import medical records**  
Copy and get automatic updates of your records
- Explore online health services**  
Find online tools for managing your health
- Find a doctor**  
Search by name, location, and specialty

**Beth Israel Deaconess Medical Center**  
[Make an Appointment](#)  
[Email Your Doctor](#)  
[Request a Refill](#)

**Profile summary**

Age, sex, height...  
 170 pounds  
 6 feet 2 inches  
 21.82 body mass index (BMI)

Conditions  
 Arrhythmia [Reference](#)  
 Vegan

Medications  
 Centrum Silver Tablet  
 Vitamin D 1,000 unit Capsule

Allergies  
 Penicillins - Unknown

Procedures  
 RFID Implant

Test results  
 25-Hydroxy Vitamin D - 16 ng/ml

Immunizations  
 Hepatitis A Vaccine, Adult  
 Tetanus/Diphtheria (Td) Toxoids, Older Children and Adults



# The HealthURL

An industry standard virtual front door to every PHR, so that EHR vendors could easily route patient records to the PHR of a patient's preference. Every patient can get a standard URL i.e.

- <http://www.google.com/health/jhalamatka>
- <http://www.healthvault.com/jhalamatka>
- <http://www.patientsite.org/jhalamatka>

With this URL, the EHR or Hospital Information System could use send a summary of care to the patient's desired repository.

# The HealthURL

- Medical Library Role - Enables the delivery of patient specific educational materials driven by vocabularies
- Solves the national identifier problem
- Identity proofing can be done by demonstrating you have access to a HealthURL
- Does not require complex consent options
- No regulatory restrictions
- Does not require any new infrastructure or technology

# Grand Challenge #3

## Standards enablers

- Content
- Vocabulary
- Transmission with appropriate security

# Standards Enablers

- Most content standards are good enough - HL7 2.5 I, CCD using HITSP C32, CCR, NCPDP Script 10.6, X12 5010
- Implementation details must be part of the regulations or issued as guidance
- Political and technical barriers can be overcome i.e. CCR is expanded to include more metadata and unstructured text or CCD is implemented using Green CDA

# Example

```
<?xml version="1.0" encoding="UTF-8" standalone="no"?>
<ClinicalDocument>
  <PatientInformation>
    <Patient birthDate="19410506" gender="M">
      <id authority="12345678" idValue="110094"/>
      <name>
        <given given="Elmer"/>
        <family family="Fudd"/>
        <suffix suffix="Jr"/>
      </name>
    </Patient>
  </PatientInformation>
  <ProblemSet>
    <Problem status="55561003">
      <TimeRange end="" start="20100515"/>
      <Topic code="233604007" codeSystem="2.16.840.1.115885.7.97">
      </Topic>
    </Problem>
  </ProblemSet>
</ClinicalDocument>
```

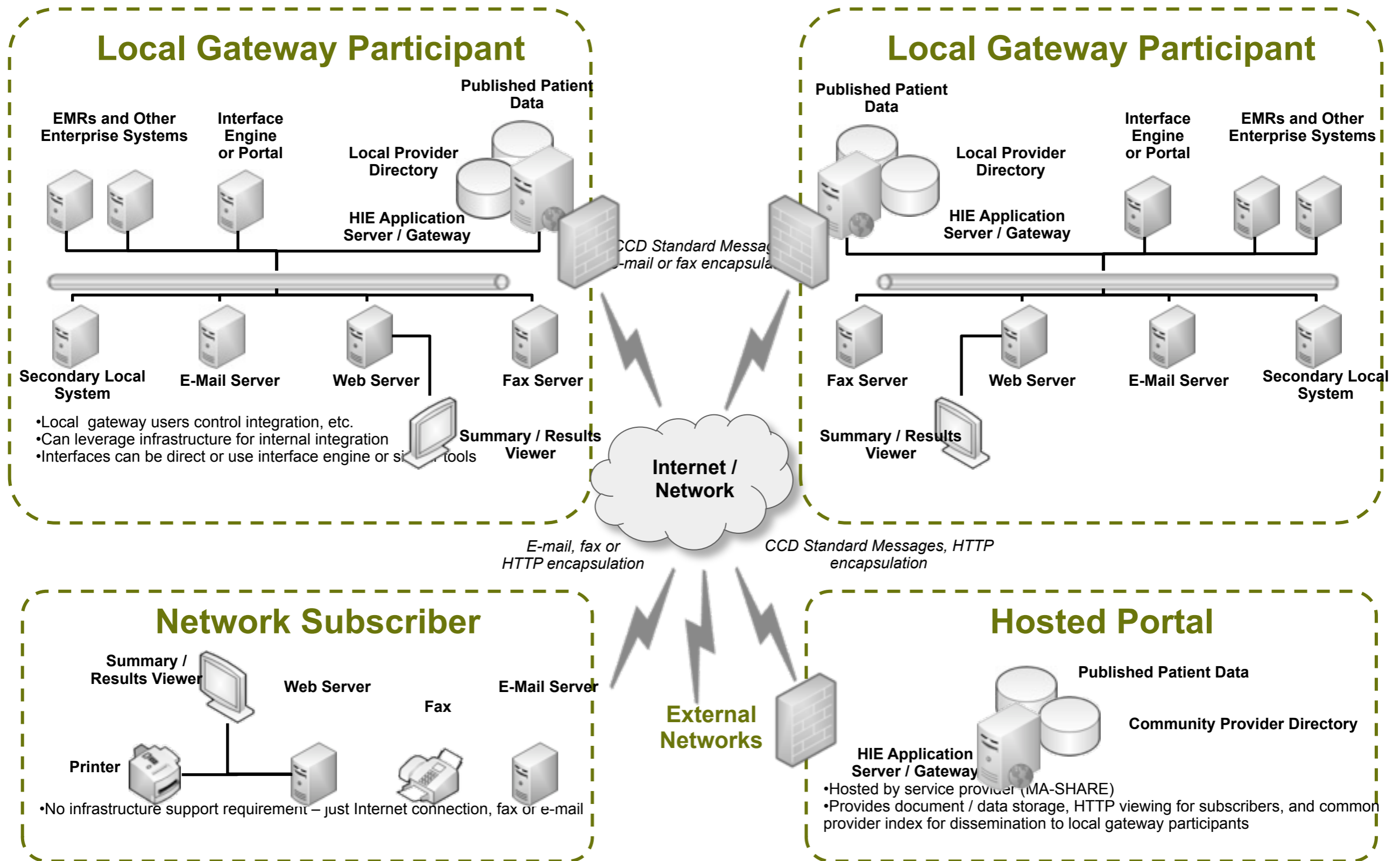
# Standards Enablers

- Medical Library Role - National Vocabulary and Codeset repository
  - SNOMED-CT and SNOMED-CT Core subset
  - LOINC and LOINC orderable subset
  - RxNorm
  - Mappings - SNOMED-CT to ICD9 and SNOMED-CT to ICD10
- Making structured data easy for clinicians to enter

# Standards Enablers

- Need simple implementation guides for Transmission methods
  - SMTP/TLS
  - REST
  - SOAP
- Political and technical barriers can be overcome - Surescripts has already done it. Pick REST with certificates at the endpoints and declare victory
- Gateways and Direct Connections

# Architecture Overview



# Grand Challenge #4

## Aggregating Data

- Who do you trust?
- Central, local, or federated?
- Encounter-based or “data atomic”?
- Documents or messages?
- Structured or unstructured?
- Where do you put the complexity?
- Identified or de-identified?

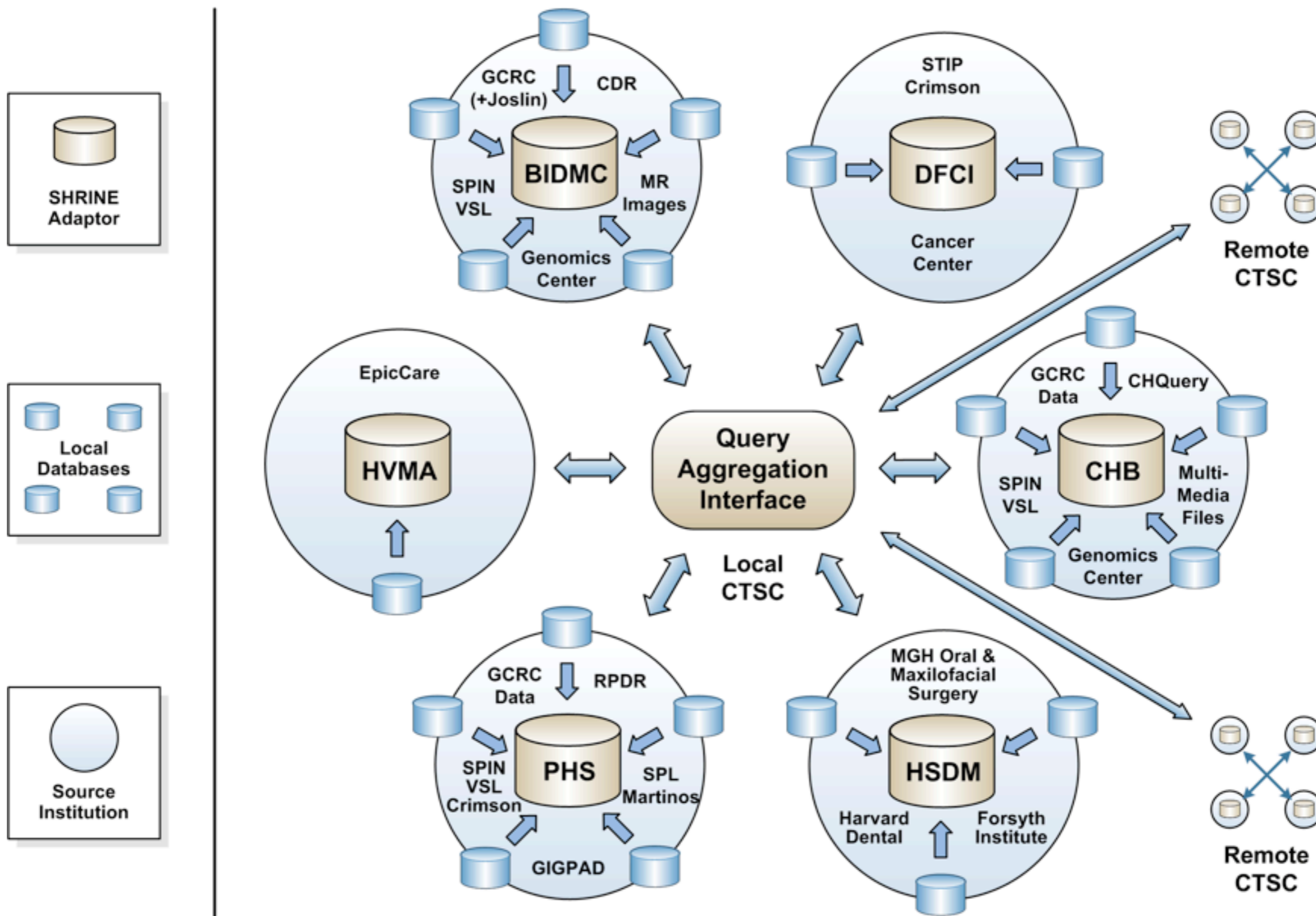
# Aggregating Data

- Medical Library Role - Structured problem lists, medication lists, allergy lists and labs plus unstructured inpatient, outpatient and ED documents that illustrate the thought process
- Keep it as close to the source as possible
- Use federated, network approaches
- Different forms for different purposes - documents for care coordination, data elements with metadata for population health
- Move complexity to the edges - EHRs that emit good metadata making aggregation and analysis easy
- As de-identified as possible

# Aggregating Data

- There are multiple identification and de-identification strategies
- Probabilistic matching
- Record locator service
- Hashing the identifiers
- Separating the identity indexes
- Sip and drink

# SHRINE – Shared Health Research Information Network



# SHRINE – Shared Health Research Information Network

i2b2 Query & Analysis Tool

Find Patients      Analysis Tools      Logout

Concepts

- Standard Query Items
  - Encounter detail
  - Demographic detail
    - Age
    - Country
    - Gender
    - Zip codes
  - Diagnosis
  - Laboratory tests
  - Microbiology
  - Medications
  - Procedures
  - Transfusion services

Databases

- Harvard Medical School
  - BIDMC
  - CHB
  - DFCI
  - HSDM
  - HVMA
  - PHS
- UCSF Medical Center
- Univ. of Massachusetts

Query: Untitled

Groups must all occur in the same visit      Sensitivity ——— Specificity

Group 1: 45-54 years old, 55-64 years old  
 Group 2: Morbid obesity  
 Group 3: Male

one or more of these      AND      one or more of these      AND      none of these

Databases:
 

- Local Database
- Selected Databases (selected)
  - BIDMC
  - CHB
  - DFCI
- Find All Databases

New Group      3 Groups      Run Query

Item Info      Runtime Options      Query Status      Request Details

BIDMC	CHB	DFCI	HSDM	HVMA	PHS
2619	OFFLINE	712	Running... Progress	2280	3025
					 BWH MGH

Done      Internet

Plugin Viewer

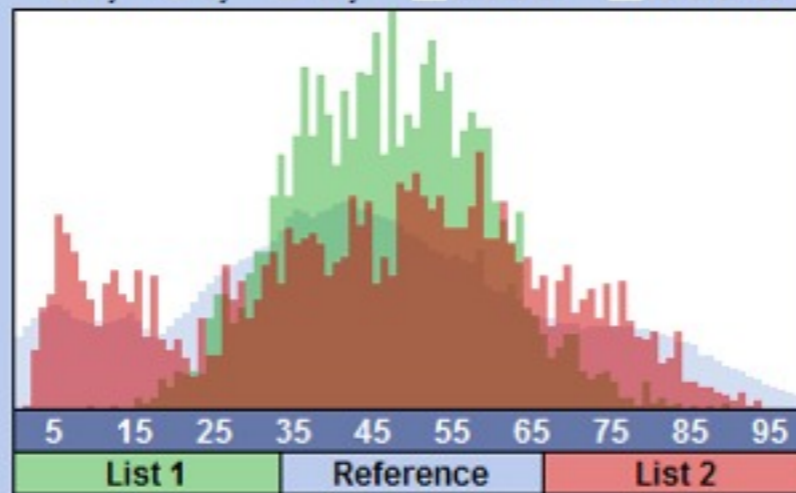
Two List Demographics Comparison

Number of patients in Morbid Obesity = 2829

Number of patients in Allergic Asthma = 2407

Age Comparison

1y    5y    10y    means    reference



Reference list includes all patients in the database.

	List1	List2
Mean	46.52	43.77
StDev	12.21	21.97
n	2829	2407

z-score = 5.467

p-value = 0

# Grand Challenge #5

## Decision Support

- More literature published every year than a clinician can read in a lifetime
- Turning data into information into knowledge into wisdom
- Maintaining the rules

# Decision Support

- Medical Library Role - Decision Support Service Providers, a new form of curation
- Informatics support within clinical departments - pharmacy, pathology, radiology
- Novel forms of social networking to identify experts
- Patient and provider decision support

**Concise Synopsis of evidence-based imaging recommendations.**

Questions or Comments

Please Select the imaging procedure you wish to perform by clicking the checkbox for the procedure's row.

**Current Profile**

Patient coagulopathic

Acute pancreatitis suspected

Allergy to iodine

**Specific attributes of this patient**

**Jaundice**

In patients with new-onset jaundice, the recommended initial imaging modality is abdominal ultrasound. US can distinguish between hepatic parenchymal damage and biliary obstruction. In very obese patients and those with bowel obstruction, US may be unreliable, in which case CT of the abdomen is suggested. In patients with an equivocal US, who do not show biliary duct dilation, and who are coagulopathic, ERCP is a reasonable diagnostic option. If ERCP is contraindicated (e.g., in acute pancreatitis), then magnetic resonance angiography and cholangiopancreatography may be considered. In patients with ductal dilation/obstruction, percutaneous transhepatic cholangiography (PTHC) may be both diagnostic and therapeutic, but may be contraindicated in patients with bleeding diatheses

	Score	Imaging Study	Safety	Risk	mRems	Cost	CoPay	Comment
<input type="checkbox"/>	■ ■ ■ ■ ■	MRCP (MR Abdomen With and Without Contrast)	■ Allergy to iodine	1	0	1112	N/A	perform with MRA with or without contrast.
<input checked="" type="checkbox"/>	■ ■ ■ ■ ■	Ultrasound Abdomen Limited, Single Organ		0	0	136	N/A	N/A
<input type="checkbox"/>	■ ■ ■ ■ ■	CT Abdomen With Contrast	■ Allergy to iodine	3	1800	406	N/A	N/A
<input type="checkbox"/>	■ ■ ■ ■	MRA Abdomen Without Contrast		1	0	574	N/A	perform with MRCP at the same time.
<input type="checkbox"/>	■ ■ ■	ERCP		4	10500	217	N/A	N/A
<input type="checkbox"/>	■ ■ ■	Percutaneous Transhepatic Choleang (PTHC)			000	610	N/A	N/A

**Safety considerations – automatically based on known patient data, including lab values**

**Evidence-based efficacy score (what is the best test for this patient?)**

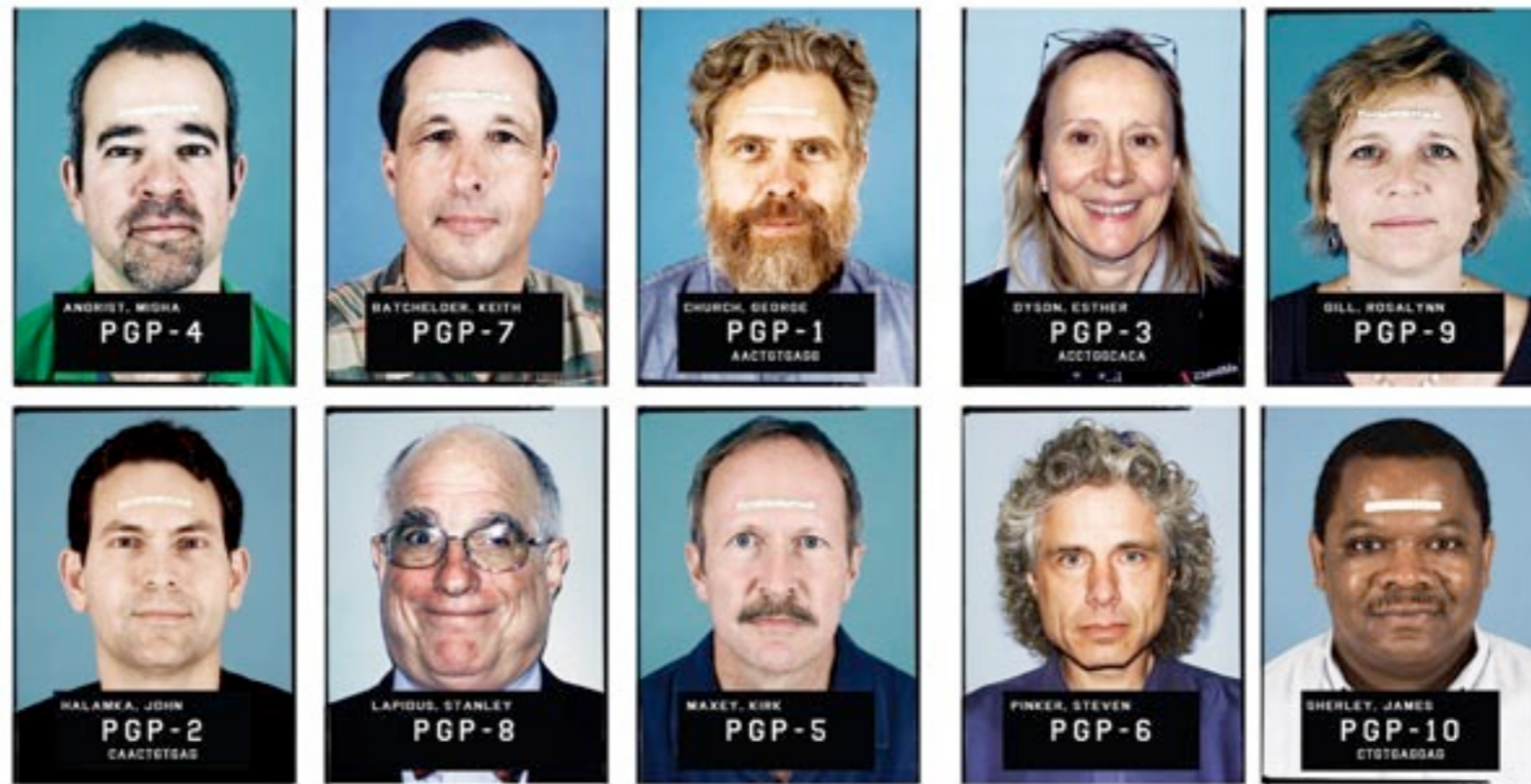
**Cost and Patient Co-Pay and Insurer Realtime Authorization of Imaging Test**

highest value, to one square, the lowest value.  
 and "Without" mean with and without contrast.  
 the procedure or intervention. 5 highest risk (e.g. coronary angiogram), 0 low  
 relative warnings and red items are absolute warnings.  
 usage for this particular imaging study.  
 retail cost for this procedure.

**CoPay.** Estimated insurance cost to patient, if available.  
**Comment.** Any additional information regarding this scenario.

Back Order Test

# Decision Support The Genome



# Decision Support My Genome

- Charcot Marie Tooth IV
- Severe Combined Immunodeficiency
- Susceptibility to Tuberculosis
- 2x risk of Prostate Cancer
- Negative Kell Antigen
- Glaucoma

# Questions?

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