Health Information Exchange: Why Are We Doing It and What Are We Doing?

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Premise

• We are at an inflection point with interoperability
• Some of the responses to “meaningful use” are altering the interoperability landscape
  – How exactly?
Outline

• Motivation for HIE
• History of HIE: 2001-2010
• Current factors influencing approaches to health information exchange
• What are some important considerations going forward?
Roles of clinical data

• Give a more accurate picture of what the patient needs
• Adjust conditional probabilities
• Clinical data is good for other things too
  – Analyses for public health and research
  – Surveillance
Clinical use case

*Data often unavailable*

- In primary care\(^1\)
  - Clinical information missing in 13% of visits
  - Data present in an outside system 52% of time
  - At least somewhat likely to adversely affect care 44% of time

- In emergency setting\(^2\)
  - Information gaps present in 32% of visits
    - More common in sicker patients
  - “Essential to care” 48% of time

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1 – Smith, JAMA, 2005
2 – Stiell, CMAJ, 2003
Current state

Patient → Clinician caring for patient

Data from the clinician’s institution

Site 1, Site 2, Site 3, Site 4, Site N

Data about the patient at other institutions not available to the clinician
The Vision – clinical use case

Data from the clinician’s institution

Regional data interchange

Data about the patient at other institutions
The Vision – add’l use cases

Patient

Clinician Caring for Patient

Regional Data Interchange

Site 1
Site 2
Site 3
Site 4
Site N

Data about the patient at other institutions

Public Health Analytics Quality
1990s – rise of clinical systems

• EHRs, CPOE
  – Regenstrief (Indiana), Partners, Utah, etc.

• Recognition of use cases that “silos” do not support
  – Transitions of care
  – Longitudinal analyses
  – Public health
  – Etc.

• Hurdles to breaking down the silos
  – Structure / coding data
  – Patient matching
  – Privacy
  – Leadership; organizational models
“… comprehensive, knowledge-based system capable of providing information to all who need it to make sound decisions about health.”

“The Committee recommends a strategy that gives [HHS] a key leadership role at the center of a broadly collaborative process for the public and private sectors.”
NHII use cases

Responding rapidly to individual emergencies and local public health threats: 66-year-old Mrs. F. and her sister are camping in a national park. While hiking, she experiences severe stomach and chest pains. She activates her wireless automated medical alert system, which includes a global positioning system. It alerts the closest emergency medical team, which arrives quickly. Simultaneously, Mrs. F.'s own cardiologist, Dr. Y., in another state receives the same alert. The emergency team, which has standing permission to access relevant medical history in patients' online records, rushes Mrs. F. to the closest emergency room. All the...

Table I. NHII Contributions to Healthcare System Improvements

<table>
<thead>
<tr>
<th>Category</th>
<th>Improvements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of care</td>
<td>• More consistent implementation of clinical practice guidelines</td>
</tr>
<tr>
<td></td>
<td>• Improved clinical data collection and analysis at the organizational and national level</td>
</tr>
<tr>
<td></td>
<td>• Portability of patient information across healthcare provider organizations</td>
</tr>
<tr>
<td></td>
<td>• Improved provider-patient communication</td>
</tr>
<tr>
<td></td>
<td>• More accurate and accessible patient records</td>
</tr>
<tr>
<td>Patient Safety</td>
<td>• Fewer drug-drug interactions and medication errors</td>
</tr>
<tr>
<td></td>
<td>• Automated reminders and alerts</td>
</tr>
<tr>
<td></td>
<td>• Continuous event monitoring to detect adverse events</td>
</tr>
<tr>
<td>Cost</td>
<td>• Improved triage to reduce unnecessary office and emergency department visits</td>
</tr>
<tr>
<td></td>
<td>• Improved home care to reduce nursing home and hospital care</td>
</tr>
<tr>
<td></td>
<td>• More robust disease management</td>
</tr>
<tr>
<td>Efficiency</td>
<td>• Reduced paper flow</td>
</tr>
<tr>
<td></td>
<td>• Faster processing of administrative transactions</td>
</tr>
<tr>
<td></td>
<td>• Automated scheduling and prescription refills</td>
</tr>
</tbody>
</table>

Avoiding unnecessary care, cost, and anxiety: Mr. S. flies across the country to start a new job. He has already chosen a medical practice in his new town because it has the same online health support service as his previous doctor, even though it is a different medical plan. He can set up appointments, get prescription refills...

Avoiding adverse events: Concerned about his persistent cough, Mr. A. visits his doctor, Dr. Z. At the end of the visit, Dr. Z. advises Mr. A. that she will transmit an electronic prescription to the pharmacy. Dr. Z. enters the medication choice in Mr. A.'s electronic medical record, which is integrated with a prescription alert system, and receives a warning that, after taking this same medication, some patients have experienced adverse events...

Improving individuals' ability to self-manage chronic conditions: With the help of a multimedia home information center, a 50-year-old mother, Mrs. M., manages her family's health. She receives automatic alerts and e-mails from her own doctors and her daughter's, and she also receives health information tailored to her specifications. For example, the last time her daughter had an asthma attack, Mrs. M. was able to e-mail information about her daughter's...
2004 – Federal HIT strategy

• Formation of ONC
• 4 part Strategic Framework
  – EHRs, Connected Care, Personalized Care, Public Health
• Little direct government funding for EHRs
• HIE central to EHR adoption strategy
  – Have access to data that others have entered
  – EHRs become a window into the world of data
  – Data exchange increases the value of EHRs
• Heartening examples of interoperability
  – Indiana, Santa Barbara (for a while)
2004 (continued)

- Related initiatives
  - American Health Information Community
    - Make recommendations, including identifying use cases
  - CCHIT – Certification of EHRs
  - HITSP – “Harmonize” standards
- “LHIIs” -> RHIOs
  - Goal: Leverage interoperability to improve care
  - Address governance, technical, privacy, business, legal, etc.
  - Encouraged by Office of the National Coordinator
  - AHRQ – 5 State and Regional Demonstration projects
    - By 2008, 130; 42 operational (eHealthInitiative)
- Nationwide Health Information Network prototype project ($18.6M)
  - Prototype architectures
  - Each had to demonstrate interconnection of 3 communities
Key results of NHIN 1

• Can do a nationwide health information network without a national patient identifier
  – Can query for patients across communities
• There are architectures that support heterogeneous technologies
• There are models for an NHIN do not require central operations
• There are migration paths that do not require wholesale updating
NHIN model
“Network of networks”

Population needs
- Reporting
- Other data uses

Individuals
- Personal health records and tools

NHIE

Hospitals and ambulatory care organizations -- EHRs
NHIN “Operational” (Core) Services

Services an HIE needs to provide to be an NHIE

Most implemented as interfaces between cooperating NHIEs

<table>
<thead>
<tr>
<th>Core Services and Capabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data Services</strong></td>
</tr>
<tr>
<td>■ Secure data delivery and confirmation of delivery, to EHRs, PHRs, other systems and networks</td>
</tr>
<tr>
<td>■ Data lock-up, retrieval and data location registries</td>
</tr>
<tr>
<td>■ Support for notification of the availability of new or updated data</td>
</tr>
<tr>
<td>■ Subject-data matching capabilities</td>
</tr>
<tr>
<td>■ Summary patient record exchange</td>
</tr>
<tr>
<td>■ Data integrity and non-repudiation checking</td>
</tr>
<tr>
<td>■ Audit logging and error handling for data access and exchange</td>
</tr>
<tr>
<td>■ Support for secondary use of clinical data including data provisioning and distribution of data transmission parameters</td>
</tr>
<tr>
<td>■ Data anonymization and re-identification as well as HIPAA de-identification</td>
</tr>
<tr>
<td><strong>Consumer Services</strong></td>
</tr>
<tr>
<td>■ Management of consumer-identified locations for the storage of their personal health records</td>
</tr>
<tr>
<td>■ Support of consumer information location requests and data routing to consumer-identified personal health records</td>
</tr>
<tr>
<td>■ Management of consumer-controlled providers of care and access permissions information</td>
</tr>
<tr>
<td>■ Management of consumer choices to not participate in network services</td>
</tr>
<tr>
<td>■ Consumer access to audit logging and disclosure information for PHR and HIE data</td>
</tr>
<tr>
<td>■ Routing of consumer requests for data corrections</td>
</tr>
<tr>
<td><strong>User and Subject Identity Management Services</strong></td>
</tr>
<tr>
<td>■ User identity proofing and/or attestation of third-party identity proofing for those connected through that HIE</td>
</tr>
<tr>
<td>■ User authentication and/or attestation of third-party authentication for those connected through that HIE</td>
</tr>
<tr>
<td>■ Subject and user identity arbitration with like identities from other HIEs</td>
</tr>
<tr>
<td>■ Management of user credentialing information (including medical credentials as needed to inform network roles)</td>
</tr>
<tr>
<td>■ Support of an HIE-level, non-redundant methodology for managed identities</td>
</tr>
<tr>
<td><strong>Management Services</strong></td>
</tr>
<tr>
<td>■ Management of available capabilities and services information for connected users and other HIEs</td>
</tr>
<tr>
<td>■ HIE system security including perimeter protection, system management and timely cross-HIE issue resolution</td>
</tr>
<tr>
<td>■ Temporary and permanent de-authorization of direct and third-party users when necessary</td>
</tr>
<tr>
<td>■ Emergency access capabilities to support appropriate individual and population emergency access needs</td>
</tr>
</tbody>
</table>
2007 -- NHIN 2

- $22M
- Demonstrate interoperable and secure health information exchange based on common specifications among operational health information exchange
- Core services demonstrations
  - Look-up and retrieve data across HIEs
  - Deliver a summary record across HIEs
  - Exchange consumer access permissions
  - Support delivery of data for population uses
- Support for specific use cases
NHIN 2 Use Cases

1. EHR-Lab Results – *Electronic sharing of new lab results with ordering clinicians and other providers*
2. Emergency responder -- *Clinician access to data in an emergency scenario*
3. Medication management – *Medication reconciliation / access to medication and allergy data in outpatient setting*
4. Quality – *Communication of quality related information from a provider organization to a reporting entity*
5. Social security administration (SSA) – *Data for disability benefits determination*
6. Biosurveillance -- *Collect data to support situational awareness, event detection, outbreak management, etc.*
7. Consumer access to clinical information -- *Consumer access to their data via a PHR*
8. Consumer empowerment: registration / medication history – *The consumer authorizes provider to have a view of his or her data*
“Interoperability specification” (EHR-lab)

Figure 1.0-2  EHR Interoperability Specification

Note: For readability, not all composite standards (e.g. Unified Code for Units of Measure (UCUM)) or other regulatory mandates, such as HIPAA and CLIA, are included in Figure 1.0-2.
NHIN Trials Implementation – Initial Participants

Eventually 20 participants

- Long Beach Network for Health
- Lovelace Clinic Foundation
- CareSpark
- NCHICA
- NYeC
- MedVirginia
- WV HIN
- Indiana University
- Delaware

Map showing locations of initial participants.
NHIN 2 -- Products

• Services
  – “Do you know my patient”? (Subject discovery)
  – “Send me the patient’s data” (Query for documents)
  – Security services (audit trails, authorization)
  – Consent services (patient permissions)

• Content -- Continuity of Care Document (CCD)*
  – 17 modules
  – 155 data elements; 48 with specified terminology

*Developing Content Specifications for the NHIN Trial Implementations, Kuperman JAMIA 2010 Jan-Feb;17(1):6-12
## Summary of Data Elements for CCD, XDS-Lab, and XDS-MS Discharge Summaries

<table>
<thead>
<tr>
<th>Data Element ID</th>
<th>Data Element</th>
<th>Opt/Repeat</th>
<th>Data Source</th>
<th>Additional Specification and/or Constraint</th>
<th>Additional Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.01</td>
<td>Language</td>
<td>R/Y</td>
<td>cda:recordTarget/cda:patientRole/cda:patient/cda:languageCommunication</td>
<td></td>
<td>2.2.1.3.1</td>
</tr>
</tbody>
</table>

### Support Module

See the HL7 Continuity of Care Document section 3.3 for constraints applicable to this module. OID=2.16.840.1.113883.3.88.11.32.3. A patient may have multiple support modules.

<table>
<thead>
<tr>
<th>SUPPORT</th>
<th>R2/Y</th>
<th>/cda:ClinicalDocument/cda:participant</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>3.01</td>
<td>Date</td>
<td>R/N</td>
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<td>cdatime</td>
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### CONTACT

See the HL7 Continuity of Care Document section 3.14 for constraints applicable to this module.

<table>
<thead>
<tr>
<th>CONTACT</th>
<th>R2/Y</th>
<th>cda:associatedPerson/cda:guardian or cda:patientRole/cda:patient/cda:guardian</th>
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<th></th>
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</thead>
<tbody>
<tr>
<td>3.02</td>
<td>Contact Type</td>
<td>R/N</td>
<td>@classCode</td>
<td>2.2.1.4.1</td>
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<tr>
<td>3.03</td>
<td>Contact Relationship</td>
<td>R2/N</td>
<td>cda:code</td>
<td>2.2.1.4.2</td>
</tr>
<tr>
<td>3.04</td>
<td>Contact Address</td>
<td>R2/Y</td>
<td>cda:addr</td>
<td></td>
</tr>
<tr>
<td>3.05</td>
<td>Contact Phone/Email/URL</td>
<td>R2/Y</td>
<td>cdatelco.com</td>
<td></td>
</tr>
<tr>
<td>3.06</td>
<td>Contact Name</td>
<td>R/Y</td>
<td>cda:assignedEntity</td>
<td></td>
</tr>
</tbody>
</table>

### Healthcare Provider Module

See the HL7 Continuity of Care Document section 3.17 for constraints applicable to this module. If no healthcare providers are supplied, the reason shall be supplied as free text in the narrative block.

<table>
<thead>
<tr>
<th>PROVIDER</th>
<th>R2/Y</th>
<th>/cda:ClinicalDocument/cda:documentationOf/cda:serviceEvent/cda:performer</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4.01</td>
<td>Date Range</td>
<td>R/N</td>
<td></td>
<td>cdatime</td>
</tr>
<tr>
<td>4.02</td>
<td>Provider Role Coded</td>
<td>R2/N</td>
<td>cda:functionCode</td>
<td>2.2.1.3.1</td>
</tr>
<tr>
<td>4.03</td>
<td>Provider Role Free Text</td>
<td>R2/N</td>
<td>cda:originalText</td>
<td>2.2.1.3.2</td>
</tr>
</tbody>
</table>

### PROVIDER ENTITY

<table>
<thead>
<tr>
<th>PROVIDER ENTITY</th>
<th>R/Y</th>
<th>cda:assignedEntity</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4.04</td>
<td>Provider Type</td>
<td>R2/N</td>
<td>cda:code</td>
<td>2.2.1.3.3</td>
</tr>
<tr>
<td>4.05</td>
<td>Provider Address</td>
<td>R2/Y</td>
<td>cda:addr</td>
<td></td>
</tr>
<tr>
<td>4.06</td>
<td>Provider Phone/Email/URL</td>
<td>R2/Y</td>
<td>cdatelco.com</td>
<td></td>
</tr>
</tbody>
</table>
NHIN 2 – Final product

• Demonstration event 9/08 and 12/08
• Electronic patient data were exchanged among Cooperative members using NHIN-conformant specifications
  – Operational systems, however mock data
  – Scenario – heart attack at a football game
• Success!
2009

- Incentive funding for EHRs
- Interoperability secondary to adoption
- Meaningful use includes “Care Coordination”
HIE in HITECH

ONC programs ($2B)

Incentive funds for EHRs (~$27B)

State HIE Cooperative Agreements

Regional extension centers

Beacon, SHARP, educational programs

Loan programs, etc.

“In effect, you can see the entire $14-$27 billion as support for HIE because …meaningful use has to emphasize HIE”

-- David Blumenthal, Health Affairs, April 2010
HIT-Enabled Health Reform

Achieving Meaningful Use

2009

HIT-Enabled Health Reform

HITECH Policies

2011

2011 Criteria
Capture/share data

2013

2013 Criteria
Advanced care processes with decision support

2015

2015 Criteria
Improved Outcomes

Meaningful use criteria

Clearer………………..……………..Vaguer

26
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality / safety</td>
<td>CPOE (10%), drug-drug, key data elts (problems, meds, etc.), quality measures, eRx, 5 CDS rules, integrate labs, submit claims electronically</td>
<td>CPOE (all), order sets, CDS at point of care, eMAR, bar code, clin doc, care plans</td>
<td>Outcome, efficiency, safety</td>
</tr>
<tr>
<td>Engage patients</td>
<td>Provide patients with access to data, educational resources</td>
<td>Access to a PHR populated in real-time</td>
<td>Quality measures related to patient engagement</td>
</tr>
<tr>
<td>Coordinate care</td>
<td>Capability to exchange key clinical information among providers</td>
<td>Retrieve / act on medication fill history, produce summary</td>
<td>Exchange data with all available sources</td>
</tr>
<tr>
<td>Population health</td>
<td>Capability to submit immunization data to registries, syndromic surveillance data to DOH</td>
<td>Receive immunization data, receive public health alerts, have ability to link data</td>
<td>Real-time public health surveillance</td>
</tr>
<tr>
<td>Privacy</td>
<td>Compliance w/ HITECH regulations</td>
<td>Provide anonymized data for public health</td>
<td>Timely accounting of disclosures</td>
</tr>
</tbody>
</table>
NHIN Connect / Limited Production

- Follow on to NHIN Trials Implementation
- Exchanging live data
- Social Security Administration, DOD, Kaiser, VA, MedVirginia
- Passed testing
- Signed trust agreements
NHIN Direct overview
(Feb/March 2010)

• Goal: Support Stage 1 meaningful use
• Approach
  – Push data to a known recipient
• Requirements
  – Patient identity known
  – Recipient’s “address” known
  – Consent / legal authorization for the information transfer exists
• Automate “HIE” currently being handled by paper or other communication following existing trust models
  – E.g., fax, courier, mail, portal view, etc.

http://nhindirect.org
NHIN Direct -- push model

- Prescription
- Lab results
- Referral request
- Referral response
- Etc.

+ address of recipient

Patient ID
Patient data

NHIN Direct Services

Recipient’s system
Primary care provider refers patient to specialist including summary care record

Primary care provider refers patient to hospital including summary care record

Specialist sends summary care information back to referring provider

Hospital sends discharge information to referring provider

Laboratory sends lab results to ordering provider

Transaction sender receives delivery receipt

Provider sends and receives data with minimal HIT technology

Provider sends patient health information to the patient

Hospital sends patient health information to the patient

Provider sends a clinical summary of an office visit to the patient

Hospital sends a clinical summary at discharge to the patient

Provider sends reminder for preventive or follow-up care to the patient

Primary care provider sends patient immunization data to public health
Why NHIN Direct?

• May be easier
  – Don’t need “subject discovery” / “query for documents”
    • Just need the recipient’s “address” and a secure transport mechanism
  – Less complex than NHIN Connect
  – Content requirements may be light (plain text)
  – Could have “open source” software; easy for vendors to adopt

• Meets Stage 1 meaningful use requirements
  – Suitable for the vast majority of the country

• Gets the vendors engaged
  – Not clear they want to do the heavy NHIN work, nor do they think there is a market for it

• Plan – demonstration by October
Questions

• Is it really easier?
  – Need an address book (central authority)
  – Need authorization scheme
  – Need auditing
  – Need agreed upon security standards
  – Need governance to create policies
  – Need compliance to assure policies followed

• How well does it work for large organizations?
  – Putting an incoming lab result in the right chart
Questions (con’t)

• How much of the problem does it solve?
  – “Push” vs. “pull”
  – Important use cases left out
    • Patient in ED
    • “Get me all the patient’s data”?
  – To what extent will it be used effectively?
  – Complementary to NHIN Connect
NHIN 2 Use Cases

Y  1. EHR-Lab Results – *Electronic sharing of new lab results with ordering clinicians and other providers*

N  2. Emergency responder -- *Clinician access to data in an emergency scenario*

?  3. Medication management – *Medication reconciliation / access to medication and allergy data in outpatient setting*

Y  4. Quality – *Communication of quality related information from a provider organization to a reporting entity*

N  5. Social security administration (SSA) – *Data for disability benefits determination*

Y?  6. Biosurveillance -- *Collect data to support situational awareness, event detection, outbreak management, etc.*

 +/- 7. Consumer access to clinical information -- *Consumer access to their data via a PHR*

Y  8. Consumer empowerment: registration / medication history – *The consumer authorizes provider to have a view of his or her data*
Questions

• “Sending messages” vs. “Information Retrieval”
  – You need both; would like to be sure you’ve gotten everything
  – What does each give you?
• Getting information when the other person wants to send it rather than when you want it
  – E-mail model
• Does it enable the innovative care models envisioned by the payment reform pilots?
  – Will it distract from more desirable eventual models?
• It’s expeditious, but is that a problem?
• Does this reduce the importance of RHIOs in the near term?
• What’s the migration plan to more sophisticated HIE?
• Will it last?