Data Segmentation for Privacy (DS4P) Introduction to Panel Discussion

Wes Rishel

Twitter: @wrishel

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Agenda

- Short introductory remarks (ad lib)
 - Deven McGraw, definition and policy issues
 - Wes Rishel, proposed technical approach
 - Chris Chute, provider's point of view
 - Mark Frisse, ACO/HIE point of view
 - Marc Overhage, vendor's point of view
 - Rim Cothren, emerging technologies
- Audience Q&A/Comments (Limit comments to 2 minutes)



Data Segmentation

"Process of <u>sequestering from capture</u>, <u>access or view</u> certain data elements that are perceived by a legal entity, institution, organization or individual as being undesirable to share."

"Data Segmentation in Electronic Health Information Exchange: Policy Considerations and Analysis" Goldstein, Rein 29 Sep 2010 retrieved 21 Jul 2013.

A valuable information source:

Coleman, Singerenau and Weinstein "Report to the HITSC Privacy and Security Work Group, S&I Framework Data Segmentation for Privacy Initiative, 3/20/2013"

http://www.healthit.gov/sites/default/files/hitsc_spwg_update_3_2-2013_final.pptx



S&I Framework Focused on These Federal Laws

- 42 CFR Part 2: Federal Confidentiality of Alcohol and Drug Abuse Patient Records regulations protect specific health information from exchange without patient consent.
- <u>Title 38, Section 7332, USC</u>: Laws protecting certain types of health data coming from covered Department of Veterans Affairs facilities and programs. Types of data include sickle cell anemia, HIV, and substance abuse information.
- 45 CFR §164.522(a)(1)(iv): Effective 3/26/2013, this final rule describes how patients may withhold any health information from health plans for services they received and paid for out-of-pocket.*

^{*} May be useful, but patient, not provider, has responsibility for ensuring that downstream recipients know that patient is requesting restriction.



Application to Interoperability

(Receiver

becomes

sender)

Sending System

Identify Information that is further restricted

Verify the patient's privacy consent allows the disclosure of protected information

Add privacy metadata to health information to be disclosed to other organization

SENDING SYSTEM: Provider/Healthcare Organization A

Receiving System

Process privacy
metadata associated with
health information
received from other
organizations

Identify third-party protected information before re-disclosure

Verify patient's consent before redisclosure of protected health information

RECEIVING SYSTEM: Provider/Healthcare Organization B

Applicable to Other State and Federal laws

- Mental Health
- Data Regarding Minors
- Intimate Partner Violence and Sexual Violence
- Genetic Information
- HIV Related Information.

Possible Technical Approaches

Reports are Sequestered

- Reports categorized at the highest level of sensitivity by sender
- Standards work to clarify metadata for current use cases
- "Pull" interactions include assertion of intended use
- Reports may contain structured data

Data Items are Sequestered

- Structured data categorized by data item
- Items categorized automatically when feasible, manually otherwise.
- Standards work to include metadata at data item level in C-CDA.
- Reports are composed by sender according to data sensitivity and intended use



Possible Technical Approaches: Pluses, Minuses and Interabangs

Reports are Sequestered

- + Follows current paper practices
- + Consent "Kabuki dance" clearer to patient"
- Difficult to use privileged data for decision support
- Difficult to extract nonprivileged info into general record

Data Items are Sequestered

- + Easier to extract non-privileged data into the general record
- ? Easier to use privileged data in decision support?
- Consent "Kabuki dance" requires patient counseling
- Substantial workflow impact for tagging
- Workflow impacted by autotagging
- Changes to internals of EHR draw attention from other innovations, raises cost



Current Meaningful Use Regulatory Status

- Nothing is announced.
- S&I Framework presentations include sequestration by data item.
- HL7 is working on modifying its standards to support sequestration by data item.

5 Pilots Reported by S&I Framework (1 Federal, 4 Industry)

- VA/SAMHSA (Demonstrated at HIMSS 2013 Interop Showcase)
- NETSMART (Demonstrated at HIMSS 2013 Interop Showcase)
- Software and Technology Vendors' Association (SATVA) [ONC]
- Jericho / University of Texas
- Greater New Orleans Health Information Exchange (GNOHIE) [Beacon Community]





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Some thoughts about pilots

- Demos at best demonstrate technical compatibility
- Operational pilots can find or overlook workflow issues
- These pilots are mostly focused on document sequestration.
- They aren't over until they're over

More detail:



Possible Regulatory Scenarios

Whimper

- Pilots do not show workability of data element sequestration
- Continued lobbying on both sides
- 3. No proposed or final regulatory requirement for data element sequestration through Stage 4

Bang

- 1. Pilots do not show workability of data element sequestration
- Continued lobbying on both sides
- 3. Proposed regulatory requirement for data element sequestration in stages 3 or 4.
- Proposal dropped or certification and attestation requirements are watered down.

<u>Miracle</u>

- 1. Pilots <u>do</u> show workability of data element sequestration
- Continued lobbying on both sides
- 3. Regulatory requirement for data element sequestration in stage 4.
- 4. Nominal compliance in stage 4 proves workable, leads to further adoption and requirements.

