

Patient Privacy and Patient Safety – Conflicting Interests?

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“The sorrow that has no vent in tears may make other organs weep.”

Dr. Henry Maudsley, MD (1835-1918)

Patient Privacy Protection

- Inherent conflicts/challenges
 - Patient rights
 - Patient safety
 - Improved if patients divulge sensitive information
 - Compromised if provider access is limited
 - Demand
 - Feasibility
 - Anonymization (de-identification) of data
 - Cost
- Privacy and Security Tiger Team Meeting
 - Consumer Choice Technologies – June 29, 2010

Examples of Current “Segmentation” of Protected Health Information

- Clinical Management for Behavioral Health Services Consent Model (Behavioral Health Integrated Provider System)
 - Network of 250 substance abuse providers in Texas
- “Discloser provider” (owner of clinical records) fills in consent form
- The patient can decide the receiving provider, type of clinical documents, document date range, and the expiration date
- Described as HITSP Manage Consent Directives Transaction Package (TP 30) compatible

Segmentation of Protected Health Information

- Technically feasible but many issues remain:
 - Example
 - Patient with a history of AIDS
 - AIDs diagnosis can be “segmented”
 - Supporting information (e.g., AIDs specific medications) could also be segmented
 - Associated labs are more challenging to block...

Segmenting Clinical Context

- Example (continued)
 - Suppress all labs that would be confirmatory of an AIDs diagnoses - possible
 - Labs, medications and procedures *suggestive* of an underlying diagnosis of AIDs could also be automatically suppressed
 - E.g., Spinal fluid results in a patient who requires serial lumbar punctures due to Cryptococcus infection
 - Safety issues may occur when segmentation of associated data is automated
 - Granular segmentation in this case may require patient/healthcare provider interaction

Additional Challenges

- What level of medical sophistication is needed to make informed choices?
 - Context of care settings may be myriad and evolve over time
 - Patients may not be aware of consequences of suppressing information
 - E.g., Viagra use and nitroglycerin
 - Potential role of medically trained patient advocates
 - Cost and training issues

Additional Challenges

- A fair amount of standards work has been completed but more needed
 - Semantic interoperability of segmented data and associated metadata
- Ease of implementation and use in EHR/PHR/Portal
- Provider and consumer demand and support for segmentation

Workflow Considerations

- Impact of consumer segmentation tools on workflow and cost
 - Clinic and/or vendor staff needed to support patient's use of tools
 - Ideally patients would perform this at home, but many will wait until arrival
 - Even basic opt-in/opt-out may impact workflow
 - Cost issues
 - Development and testing of segmentation tools
 - Training of providers/patients
 - Regulatory oversight

Content Challenges

- The number of clinical concepts that need protection potentially very large
 - Diseases, medications, procedures, devices
- Mapping of related concepts (that might suggest the patient has a disorder) would be an enormous undertaking
- Would require a high level of medical sophistication
- Patient safety issues would need to be addressed given the complex ensuing scenarios

Consumer Education Issues

- Sources of accurate information needed about disclosures
- Use of granular consent controls:
 - Decision making process may be difficult for some patients
- Educational process could create healthcare utilization concerns
- Need to make patients aware of potential value of data in improving healthcare

Technical Issues

- Anonymization
 - Can it truly be achieved?
- Disclosure challenges
 - Large systems may have difficulty processing disclosure reports
- Prioritization for vendors
 - Federal requirements emerging
 - State requirements will likely change in response

Recommendations

- Further research is needed
 - Manage access in rapidly changing medical domains
 - Consistency of consent policies across different healthcare domains
 - Patient safety and quality of care
 - Workflow impact
 - Impact on costs
 - Ease of use for providers and patients
 - How to address previously disclosed electronic information
 - Provider and consumer education

- Thank You

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