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Panel Discussion

Patient Driven Access Control

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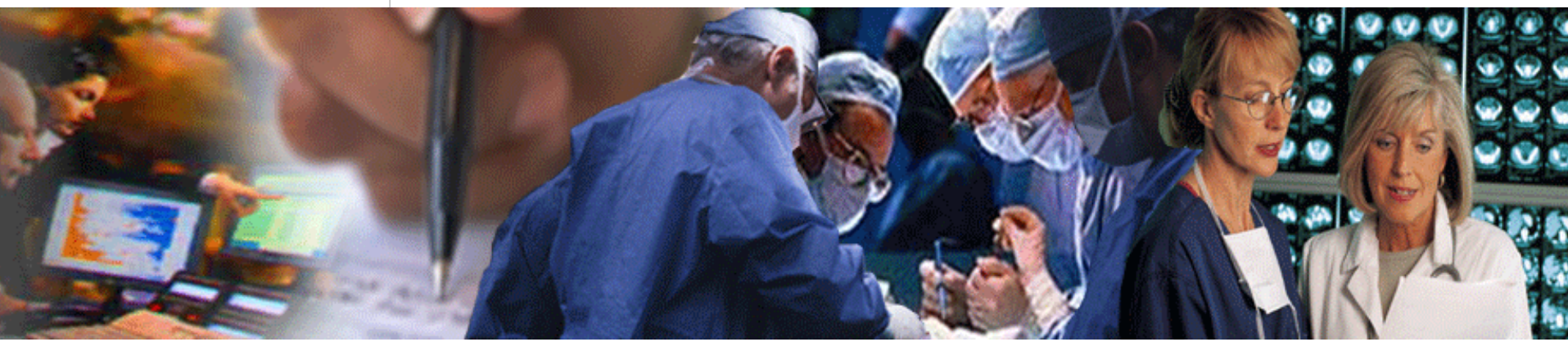

EXPERIENCE. RESULTS.

Patient Driven Access Control

Patient Control of Access to their own Healthcare Data

- **PROS**
  - Presumed *sine qua non* of 'consumer-centered' health information networks
  - Patient has reasonable expectations of confidentiality and care in the handling of their data, and should be able to ask that data be shared:
    - » only with other organizations that have a legitimate need for, and right to, the data.
    - » with someone acting as their proxy, and that they can later revoke that access.
    - » with a clinician or organization, but that those organizations be denied access in the future.

Patient Driven Access Control

Patient Control of Access to their own Healthcare Data

- **CONS**
  - Adding consumer control of the data is
    - Technologically challenging
    - Expensive
    - Proper use requires savvy consumer
    - Challenges in integrating with provider workflows
  - Current systems and network architectures not conducive to
    - granular partitioning of data
    - per-access consent
    - revocable data
    - complex rule-based access
  - Are consumers equipped to handle access control responsibilities?
    - Do they have insight into implications (informed consent?)
    - Consumers don't know enough about the data to make choices at a granular level
    - Chronic care patients have shown little interest in access control – higher priority on providers having access to all relevant data

Patient Driven Access Control

Types of Data Consumers Want to Control Access of

- **Average consumer expected to want to control**
  - Mental health related data
    - Need to be careful not to define this too broadly or you begin to erode the utility of clinical data in general
  - HIV data
- **CONS**
  - Medical data is multi-faceted and semi-structured
    - Impossible to partition "facts" about a patient
  - HIV status can be derived from declaration of status, current drug regime; chief complaint; diagnostics; planned tests; or doctors notes
  - Partitioning strategies can only be applied to categories (types of providers, or drugs), and only on data that is both clean and well organized
  - Early patient controlled health records have tried to be proactive
    - PatientSite waits one week before notifying patients of cancer / HIV results, allowing care giver to communicate first
    - Restricted access to progress notes

Patient Driven Access Control

Propagation of User Preferences across Network

- **PROs**
  - Distributed data requires distributed management (complex)
  - Effective patient driven access control calls for propagation of control to all locations where data exists
- **CONS**
  - Data once released from primary source cannot be really be controlled without data management investment that is proportional to scale of the network
    - Clinical and regulatory practice prevents a data-holder from deleting it
      - » Cannot implement revocability in current environment
  - Control is effected through applications and not ‘encapsulated’ with the data
      - » You can control applications not data
  - Media industry has spent $billions on Digital Rights Management to little lasting effect

Patient Driven Access Control

Steps/Levels where Preferences could be Implemented

- **Patient management of access control may occur at many places in network**
  - Control is best effected through applications at the edges and not “in the network”
  - PHRs / Patient portals offers logical choice as primary point of control
  - Current EMRs do not allow direct patient access, but contain the most healthcare data
- **CONs**
  - Need to propagate access control information
    - Propagating access control results in significant complexity
    - Once information has been “released” in compliance with the patient’s desired access controls then its disposition becomes governed by other rules and regulations
  - Mechanics of patient assigning permissions to individual providers require means to identify roles / individual providers
  - Individual providers practically almost impossible to enumerate or even know in advance

Patient Driven Access Control

Data Exchanges Necessary to Implement Access Controls

- **Full access control capability requires sharing of**
  - Subjects: Individual and Organizational Providers, Roles
  - Resources: Patient data, Data types and domains
  - Actions: Read / Write / Update
  - Rules: Permit / deny based on conditions
- **PROs**
  - Distributed access control management across network nodes
- **CONs**
  - High complexity solution requiring significant synchronization of security architectures across multiple enterprises
  - Likely too complicated to implement in reasonable time frame

Patient Driven Access Control

Minimizing Impact on Providers delivering Patient care

- **PROs**
  - Authority resides with ultimate information owner/steward of information, who has the most interest in it
  - Focusing the control points to the source where the patient and provider can have a shared dialog about access control is ideal

- **CONs**
  - Consumers unaware of potential impact on their own healthcare of controlling (denying) care givers access to their health information
  - As copies proliferate, impossible to locate all versions of data pertaining to a particular patient, or all copies of a particular piece of data
  - Without 'Break-the-glass' function can be hazardous to healthcare in the foreseeable future