Unlocking Patient Data

Pulling the Linchpin of Data Exchange and Patient Empowerment

December 5, 2018

A Briefing from AMIA and AHIMA

Digital Program at

amiahill-18patientaccess.strikingly.com

HIPAA

The "P" Stands for Portability

- 1996 Law
- Bestows Individual Right of Access
  - An individual has the right to access their protected health information in one or more "designated record sets" maintained by a covered entity in the form, format, and manner requested, if readily producible.
- Creates Scope with Covered Entities (CEs) and Business Associates (BAs)

HITECH

- $37B for hospitals / clinicians to adopt EHRs
- Created Office of National Coordinator for Health IT (ONC)
- Amended HIPAA right of access to include electronic copies of information and extends right to BAs
- Led to Meaningful Use regulations
  - Patient Portals (view, download, transmit)
  - Common Clinical Data Set
  - Patient-facing APIs

21st Century Cures

- Cures defines interoperability in the context of health IT that
  - (1) enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the user;
  - (2) allows for complete access, exchange, and use of all electronically accessible health information for authorized use under applicable State or Federal law; and
  - (3) does not constitute information blocking.
- CCDS to become US Core Data for Interoperability
- NIH All of Us Research program leads to Sync4Science initiative

Core Challenges to Address

- HIPAA provides a solid foundation through its "right of access," but operationalizing this right has been elusive
  - Broad definitions = variable interpretation = fragmented access and inconsistent application
- There is no strategy to marry HIPAA right of access to ONC Certification and no clear tactics to begin the effort
  - Where's my "EASY BUTTON"?
- Health data is no longer confined to CEs and BAs
  - mHealth technologies and health social media applications fall outside HIPAA as "Non-Covered Entities," or NCEs

Modernize HIPAA

- <u>**Rec 1:**</u> Converge HIPAA with Health IT Certification
  - <u>**a:**</u> Establish a new term, "Health Data Set"
    - Includes all clinical, biomedical, and claims data maintained by or for a CE or BA
    - Supported through ONC's Certification Program
    - Enables view, download, or transmit to a third party and access via API
  - <u>**b:**</u> Revise and clarify HIPAA Designated Record Set definition
    - Require ONC Certification to provide amended DRS to patients electronically while maintaining computability
- <u>**Rec 2:**</u> Extend the HIPAA right of access to NCEs
  - Establish uniformity of health data access policy, regardless of covered entity, business associate, or other commercial status

Additional Recommendations

- <u>**Rec 3:**</u> Encourage note sharing with patients in real-time
  - Such as OpenNotes
  - Medicare and Medicaid payment programs
    - Merit-based Incentive Payment System

- <u>**Rec 4**</u>: Clarify existing regulatory guidance on third-party access to patient data
  - Third-party legal requests that seek information without appropriate patient-direction and beyond what is part of the DRS

Panel of Experts

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20 Years After HIPAA

Patient Experience & Provider Realities

Paper-based Policy In a Data-Centric World

Reactions to HIPAA Modernization Recommendations

AMIA / AHIMA Recommendations

1. Converge HIPAA with Certification
   - Establish a new term, "Health Data Set," or
   - Revise and clarify HIPAA Designated Record Set definition
2. Extend the HIPAA right of access to NCEs
3. Encourage note sharing with patients
4. Clarify existing regulatory guidance

Future Directions for Federal Policy

Audience Q&A

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