



Role of Privacy in HIT Standards-Setting Efforts

Institute of Medicine

**Committee on the Review of the Adoption and
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Joy Pritts, JD

Research Associate Professor

Health Policy Institute, Georgetown University

jpg@georgetown.edu



Importance of Protecting Privacy

Fosters trust among

- i Consumers
- i Providers and others who exchange health information



HITSP Role

“It’s not the role of HITSP to make privacy policy.”

John Halamka, HITSP Chair June 2007

Kathryn Foxhall, “A Big Headache Cured? Making a Standard Medication List a Reality,” *For The Record* (Aug. 20, 2007)



Federal Privacy Policies

- i **Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule**
- i **Medicaid and Medicare Confidentiality Standards**
- i **Alcohol and Drug Abuse Treatment Confidentiality Standards**
(42 CFR Part 2)



HIPAA: Limited Scope

“Covered entities”

- i Health plans
- i Health care clearinghouses
- i Health care providers who transmit health claims-related information electronically

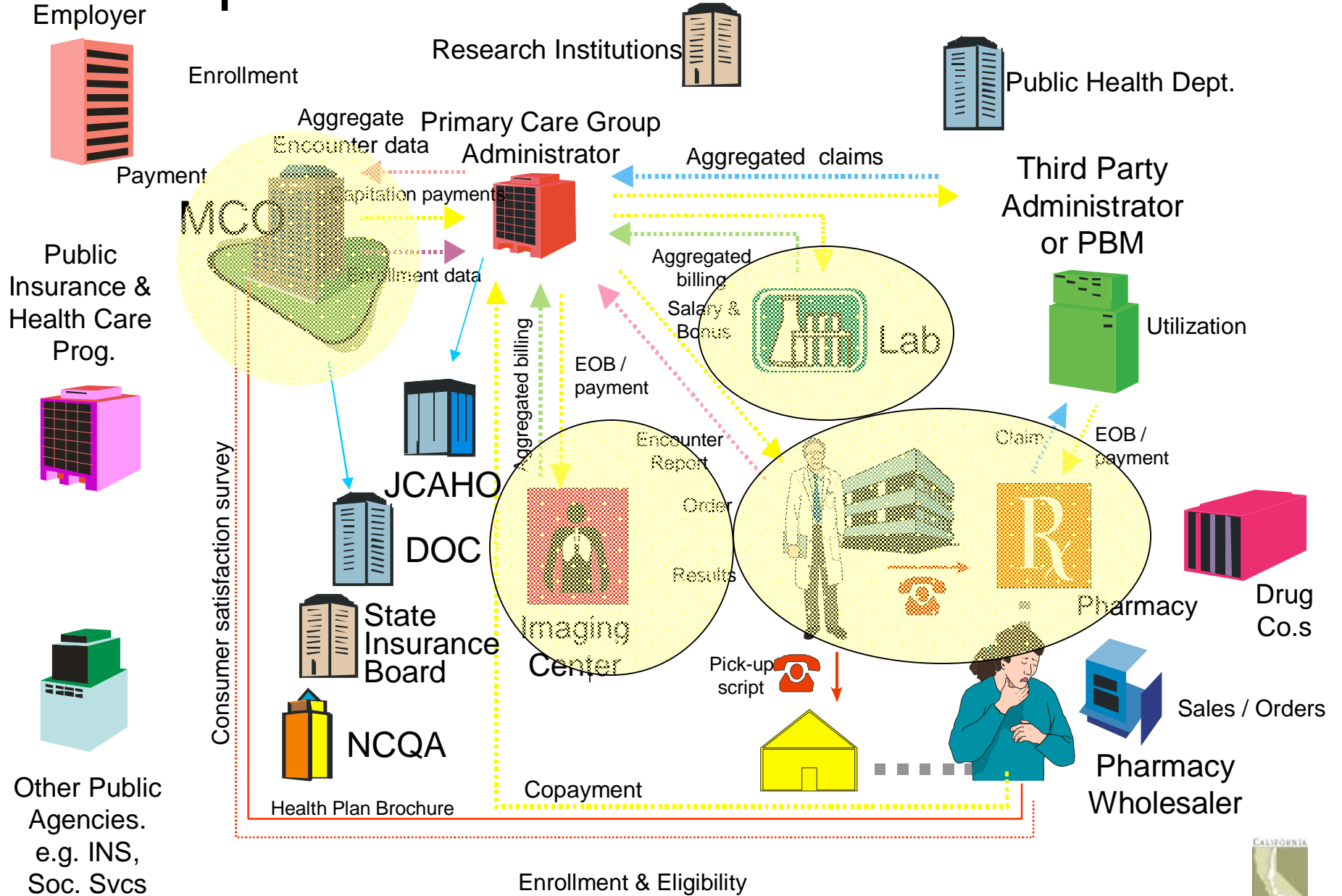


HIPAA: Gaps

Does not directly regulate
emerging eHIE models

- i Regional health information networks
- i Personal Health Records

"Simple" Data Flow





HIPAA: “Ambiguous” Rules

- i Meant to be scalable and flexible
- i Practical matter-source of great variability
- i E.g., Minimum necessary



HIPAA: Minimum Privacy Standards

- i “Floor” of privacy protections
- i More stringent state laws remain in place
- i Patient consent-one of the main issues



Implications

- i Cannot base effective technical standards solely on Federal Privacy Laws
 - | HIPAA doesn't apply to many data holders
 - | Regulations are not clear
 - | Standards would only apply in states where there are no "more stringent" state health privacy law (<5)

Basing tech. standards solely on existing federal privacy laws would be like building a house on sand.





Federal Privacy Initiatives

AHIC Confidentiality, Privacy and Security Workgroup

- i Make actionable confidentiality, privacy, and security recommendations to the Community on specific policies that best balance the needs between appropriate information protection and access to support, and accelerate the implementation of the consumer empowerment, chronic care, and electronic health record related breakthroughs.



Federal Initiatives—State Health Privacy Policies

Health Information Security and Privacy Collaborative

- i Funded by ONC & AHRQ
- i Phase I
 - | 33 states and 1 territory assessed health information privacy policies and practices to identify potential “barriers” to eHIE and solutionsPhase
- i Phase II
 - | Potential state collaboratives on certain topics identified as barriers



Federal Initiatives—State Health Privacy Policies

State Alliance for e-Health

- i Funded by ONC
- i Staffed by National Governors Assoc.
- i Charge:
 - | From a state-specific perspective, address barriers to health information exchange and adoption of health IT, while preserving privacy, security, and consumer protections.
 - | Build consensus in seeking the harmonization of the variations in state policies, regulations, and laws, where appropriate, and develop standards and/or guidance for modifying such policies, regulations, or laws.



State Privacy Policy Work Product to Date

- i Focus on laws governing “sensitive” health information
- i HISPC identified laws within states but did not compile laws/policies
- i State Alliance – sampled 25 states
- i No inventory of state privacy policies across the board on any one topic



Implications

We do not have a detailed catalogue of state privacy policies/requirements upon which to base technical standards.



Interaction of Privacy and Standards-Setting Initiatives

- i Some overlapping membership/participation HISPC State Alliance and HITSP
- i Technical initiatives have made presentations to privacy policy initiatives (e.g., CCHIT has presented to State Alliance)



Implications

Intersection of

- i HITSP and State Alliance with AHIC
 - | State policy with federal policy

- i HITSP and State Alliance with HITSP
 - | State policy with technical standards

Has not been clearly articulated



Conclusion

- i Current federal privacy policies are inadequate base for technical standards
- i Insufficient knowledge of state privacy policies to set technical standards
- i Unclear how Federal initiatives to address these privacy issues intersect with HIT standards-setting activity



The End
