

# Getting to the Right Health Information Public Policies

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# Public Policy is Crucial

- It's the organizing principle
  - Envisioned benefits
  - Public policy framework
  - Operational design
- Public policy
  - Establishes parameters that operational designs must accommodate
  - Key determinant for probability of achieving desired benefits

# Privacy and Security

- Privacy and security rules and procedures flow from policy determinations of ownership and control.
- Policy development starts with choosing the basic premise.
  - Assume existing arrangements?
  - Design better arrangements?

# Implicit Issues

- Ownership determines how information is protected
  - Legally (privacy)
  - Physically (security)
- Ownership determines how information is used
  - Control over storage and access
  - Receipt of economic benefits

# Consideration - 1

## Property Rights

- Legal recognition and enforcement of property rights:
  - Creates incentive for owners to protect assets (privacy, security).
  - Establishes precondition for commerce in assets.
  - Necessitates development of rules and mechanisms.

# Consideration - 2

## Type of Asset

- Characteristics of health records
  - Intangible
  - Replicable
  - Wide contextual variation in value
  - No inherent production limits
- A form of intellectual property
  - Patents - some similarity
  - Copyrights - more commonality

# Consideration - 3

## Types of Rights

- To use
- To alter
- To transfer
- To lease
- To encumber
- To duplicate
- To destroy
- Limitations on exercise of rights

# Consideration - 3

## Types of Use

- Primary uses
- Secondary uses
- Inclusionary uses
- Exclusionary uses

# Consideration - 4

## Forms of Ownership

- Absolute
- Conditional
- Joint
- Proportionate

# Consideration - 5

## Agency

- Owner can authorize agent to manage asset.
- Agent has fiduciary obligation to owner.
- Government can regulate relationship between owner and agent.

# Consideration - 6

## Commercial

- Ownership recordation
- Dispute resolution
- Standardize contracts
- Aggregate sellers and/or buyers
- Reveal, realize and distribute latent value

# IHRB Approach

- Independent
  - Neutral repository and manager
  - Multiple, competing
- Health Record
  - Substantially complete
  - Lifetime
- Bank (Trust)
  - Agent/fiduciary subject to government laws/oversight

# IHRB Features

- Consumer ownership and governance
  - Examples: Credit union, mutual insurer
- Agent/fiduciary for information owner
- Also agent/fiduciary for associated rights recognized in law as inherent to others (providers, payers).
- Administers information storage, retrieval, security, access, permission, commercial transactions.
- Contracts with vendors for technological services.

# IHRB Policy Elements

- Statute specifying ownership rights
- Statute specifying IHRB obligations, responsibilities, and operating standards
- Select agency to vest with oversight authority and specify scope of authority
- Establish chartering mechanism
- Establish dispute resolution mechanism
- Create incentives for participation

# Status

- Current debate focused on ‘technical’ issues (interoperability, data standards).
- Need to shift debate to issue of underlying policy framework.
- First version of IHRB legislation (Brownback-Ryan, S.3454 and H.R.5559).
- Needs further clarification of health information property rights.
- Explore possibility of a state acting first.
- Privacy and security rules will flow from decisions about ownership and control.