

NCVHS Privacy and Confidentiality Subcommittee
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Health Record Banks Enable Privacy in Health Information Infrastructure

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Outline

- **Requirements for Community Health Information Infrastructure**
- **Health Record Banking Model**
- **Privacy Implications**
- **Policy Recommendations**

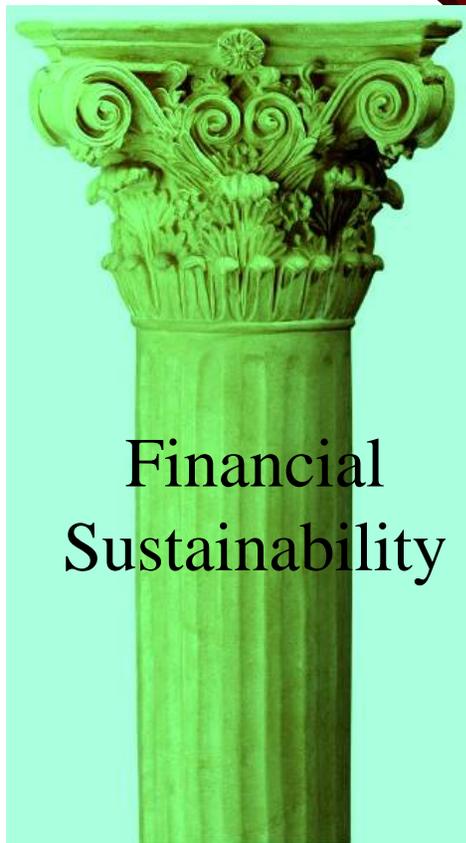
Components of a
Community Health
Information Infrastructure



**Complete
Electronic
Patient
Information**



Stakeholder
cooperation



Financial
Sustainability



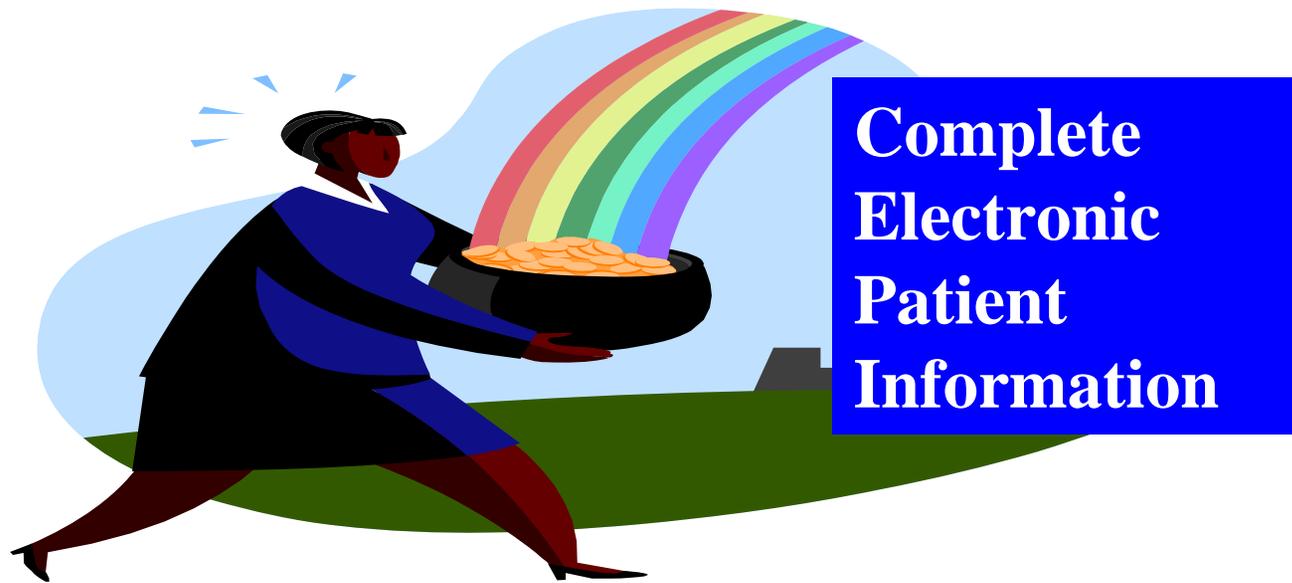
Public
Trust



- Most information is already electronic: Labs, Medications, Images, Hospital Records
- Outpatient records are mostly paper
 - Only 10-15% of physicians have EHRs
 - Business case for outpatient EHRs weak
- For outpatient information to be electronic, need financial incentives to ensure that physicians acquire and use EHRs
- **Requirement #1:** Financial incentives to create good business case for outpatient EHRs



- **Need single access point for electronic information**
- **Option 1: Gather data when needed (scattered model)**
 - **Pro: 1) data stays in current location; 2) no duplication of storage**
 - **Con: 1) all systems must be available for query 24/7/365; 2) each system incurs added costs of queries (initial & ongoing); 3) slow response time; 4) searching not practical; 5) huge interoperability challenge (entire U.S.); 6) records only complete if every possible data source is operational**



- **Need single access point for electronic information**
- **Option 2: Central repository**
 - **Pro: fast response time, no interoperability between communities, easy searching, reliability depends only on central system, security can be controlled in one location, completeness of record assured, low cost**
 - **Con: public trust challenging, duplicate storage (but storage is inexpensive)**

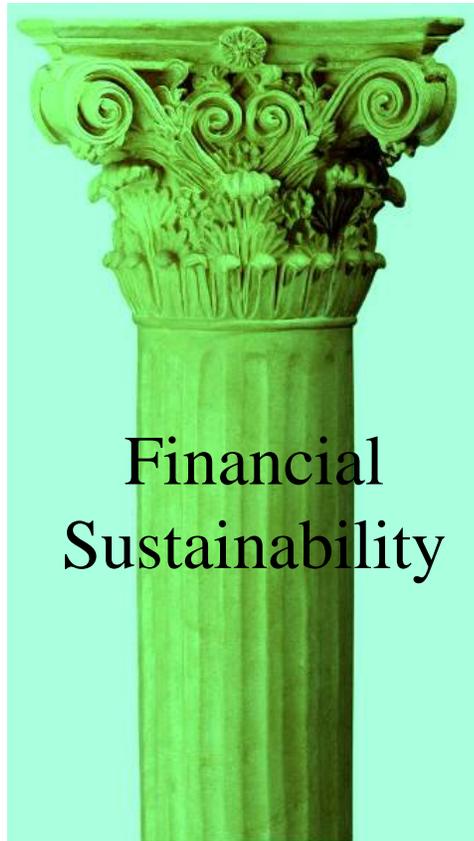


- Need single access point for electronic information
- **Requirement #2:** Central repository for storage



Stakeholder
cooperation

- Voluntary ➡ Impractical
- Financial incentives
 - Where find \$\$\$\$\$?
- Mandates
 - New ➡ Impractical
 - Existing
 - HIPAA requires information to be provided on patient request
- **Requirement #3: Patients must request their own information**



Financial
Sustainability

- **Funding options**
 - **Government**
 - **Federal: unlikely**
 - **State: unlikely**
 - **Startup funds at best**
 - **Healthcare Stakeholders**
 - **Paid for giving care**
 - **New investments or transaction costs difficult**
 - **Payers/Purchasers**
 - **Skeptical about benefits**
 - **Free rider/first mover effects**
 - **Consumers**
 - **72% support electronic records**
 - **52% willing to pay \geq \$5/month**
- **Requirement #4: Solution must appeal to consumers so they will pay**



A. Public Trust = Patient Control of Information

- **Requirement #5: Patients must control all access to their information**



B. Trusted Institution

- Via regulation (like banks) ➡ impractical ??
- Self-regulated
 - Community-owned non-profit
 - Board with all key stakeholders
 - Independent privacy oversight
 - Open & transparent
- **Requirement #6:** Governing institution must be self-regulating community-owned non-profit



C. Trustworthy Technical Architecture

- Prevent large-scale information loss
 - Searchable database offline
 - Carefully screen all employees
- Prevent inappropriate access to individual records
 - State-of-the-art computer security
 - Strong authentication
 - No searching capability
 - Secure operating system
 - Easier to secure central repository: efforts focus on one place
- **Requirement #7:** Technical architecture must prevent information loss and misuse

Health Record Banking Model

- All information for a patient stored in Health Record Bank (HRB) account
- Patient (or designee) controls all access to account information [copies of original records held elsewhere]
- Each HRB has three interfaces:
 - Withdrawal window - record access
 - Deposit window - receives new info
 - Search window - authorized requests
- When care received, new records sent to HRB for deposit in patient's account
- All data sources contribute at patient request (per HIPAA)

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Health Record Banking



Clinician's Bank

Patient data delivered to Clinician

SECURE PATIENT HEALTH DATA FILES

Optional payment

Encounter data sent to Health Record Bank



Clinician EHR System

Encounter Data Entered in EHR



Clinical Encounter

Clinician Inquiry

Patient Permission?

YES

NO

DATA NOT SENT

Health Record Bank



Privacy Implications

- **Essential elements of privacy protection**
 - **Consumer control of information release**
 - **Each consumer customizes their own privacy policy**
- **Health record banks facilitate privacy through consumer control**
 - **Granularity of control limited to information visible at control point**
 - **Scattered model makes such control more difficult since only locations of information are known centrally**

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Policy Recommendations (1 of 2)

1. **Consumer has complete legal ownership and control of health record bank information**
 - **No exceptions needed as copies of information are elsewhere**
 - **Information protected from**
 - **Change in ownership**
 - **Failure of customer payment**
 - **Bankruptcy**
2. **All holders of electronic medical information required to provide it within 24 hours of creation at no charge (on patient request)**

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Policy Recommendations (2 of 2)

3. **Include health record banks as covered entities under HIPAA**
 - **Cover personal health information in all locations**
4. **Require independent privacy & confidentiality audits of health record banks**
 - **Certification of auditing entities**
 - **Public disclosure of audits**
5. **Require security procedures sufficient to enforce privacy & confidentiality policies**

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Questions?

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