

Patient Controlled Health Records Standards and Technical Track

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What are Patient Controlled Health Records?

Each person controls his or her own Personal Health Record and decide who can access which parts of their PHR ... PHRs contain information from all health care providers

– *Proposed Principles for Consumer Empowerment Breakthrough*,
MARKLE FOUNDATION

... the personal health area of the NHII supports individuals in managing their own wellness and healthcare decision making. It includes a personal health record that is created and controlled by the individual or family, ...

– *Letter to Secretary Leavitt*,
NCVHS

The PHR is ...

... owned by an individual or designee.

... linked with, or contains copies of, provider's legal or electronic records.

The PHR is not ...

... owned by any third party.

... a replacement for the legal record or EHR of a provider.

– *The Role of the Personal Health Record in the EHR*, AHIMA



What do Health Records Include?

- Registration and Demographic Data
- Digital Images (e.g., X-Rays, EKGs)
- Documents (e.g., Discharge, Labs, Op Note, Physical Exam)
- Clinical Information
 - Problem Lists
 - Medications
 - Allergies
 - etc.
 - Procedures
 - Encounters
 - Social and Family History
- Personal Information
 - Advance Directives
 - Personal Preferences



What do Standards Define?

Policy

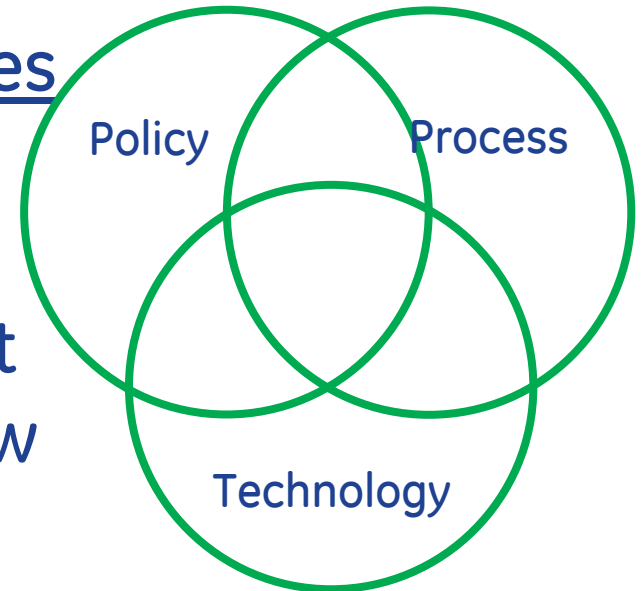
- Driven by business goals
- Informed by Risk Assessments
- Defines rights and responsibilities

Process

- Enforces policy
- How people or organizations act
- who / what / where / when / how

Technology

- Enforces process
- How equipment should act
- Algorithms and data formats



Why are we here?

- September 2005 – PHRs are fairly new, there is little or no sales and usage statistics – NCVHS
- March 2006 – the lack of a proven business case for widespread deployment hinders PHR adoption. *Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption* – JAMIA, Vol 13, #2,
- May 2006 – Personal health records have a long way to go before they catch on with patients, a new survey indicates. – Health Data Management
- July 2006 – Although PHRs have been in existence for nearly a decade, there has been little overall increase in consumer adoption. – Gartner Research
- September 2006 – Federal government ... could play a large role in promoting the use of personal health records, but health literacy could be a significant barrier to PHR adoption ... – Modern Healthcare



What is holding the PHR back?

- Legal and Regulatory **Policy**
 - PHRs are NOT presently legally recognized, and not protected under HIPAA Privacy and Security regulations. Rights and legal/medical responsibilities of patients, providers, PHR suppliers, and other entities have yet to be defined.
- Economics Uncertain
 - Who will pay for a PHR? How much? What is the financial model?
 - Economic benefits have not been studied, proven or quantified.
- Security **Technology**
 - Security concerns abound, mostly around privacy, access control and authentication.
- Communication Standards
 - Standards need to be established to exchange information with and between PHR systems.
- Technology
 - EHR adoption is low, but essential to PHR deployment.



Policy Questions

Technical Certification

- Needs Harmonized Definition and Feature Set
 - HL7 PHR Functional Model
 - Markle Foundation / Connecting for Health
 - AHIMA - Role of the Personal Health Record in the EHR

Certifying Quality of Information

- Professional sources should be identified
- Completeness is measurable
 - Provides Incentive to add more data
- Subjective quality measures are potential disincentives



What is Security?

- Identity Proofing – Establishing the Identity of Persons
- Authentication – Logging in to the System
- Consent – Consumers consent to access
- Access Control – Controlling Access to Information
- Integrity – Information is preserved and transmitted correctly
- Confidentiality – Information is not disclosed inappropriately
- Privacy – Only necessary information is disclosed
- Accountability – Disclosures are tracked
- Non-Repudiation – Ensures information is from a specific party



Security Standards

Area	Policy/Process	Technology
Identity Proofing	Under Review by AHIC, mostly a policy and process issue.	
Authentication	FIPS 190-1 FIPS 196-1 ASTM E-1985	Kerberos, IHE EUA, LDAP, SAML, <i>WS-Security, IHE XUA</i>
Certificates	ASTM E-2212	X.509, LDAP
Consent	ASTM E-2211	IHE BPPC, <i>HL7 Consents</i>
Access Control	ASTM E-1985	LDAP, <i>HL7 RBAC, ISO PMAC, XACML</i>
Integrity		FIPS 180-1 (NIST SHA-1), RFC-1321 (MD5)
Confidentiality	ASTM E-2085 ASTM E-2086	RFC-2246 (TLS), SSL, RSA, Triple-DES, FIPS-197 (AES), IHE ATNA
Accountability	ASTM-2147	RFC-3164 (SysLog), RFC-3881, IHE ATNA
Non-Repudiation	ISO-17090	FIPS 186-2, ISO 17090, ASTM E-2084, ASTM E-1762, XADES, <i>IHE DSG</i>



* Letters not used in standards on this slide include: J, Q, V and Z



Security Issues

1. Define the Functionality
2. Assess the Risk

Fine Grained Access Control in a PHR

- No established standards
- Not applicable to HIPAA covered entities

Back End Encryption

- Benefits must be weighed against cost

Interoperable Audit Logs

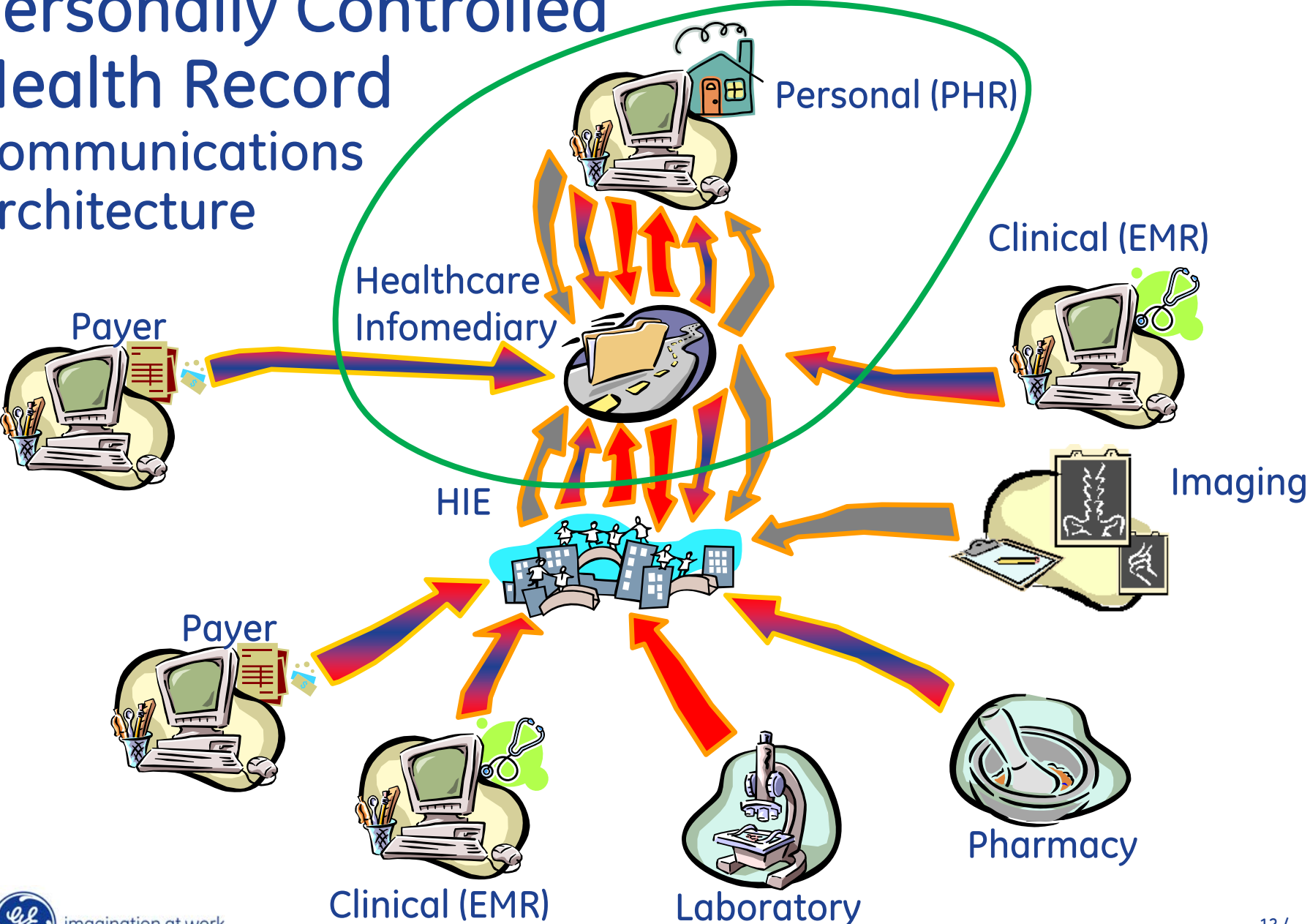
- See RFC-3881

Authentication Infrastructure

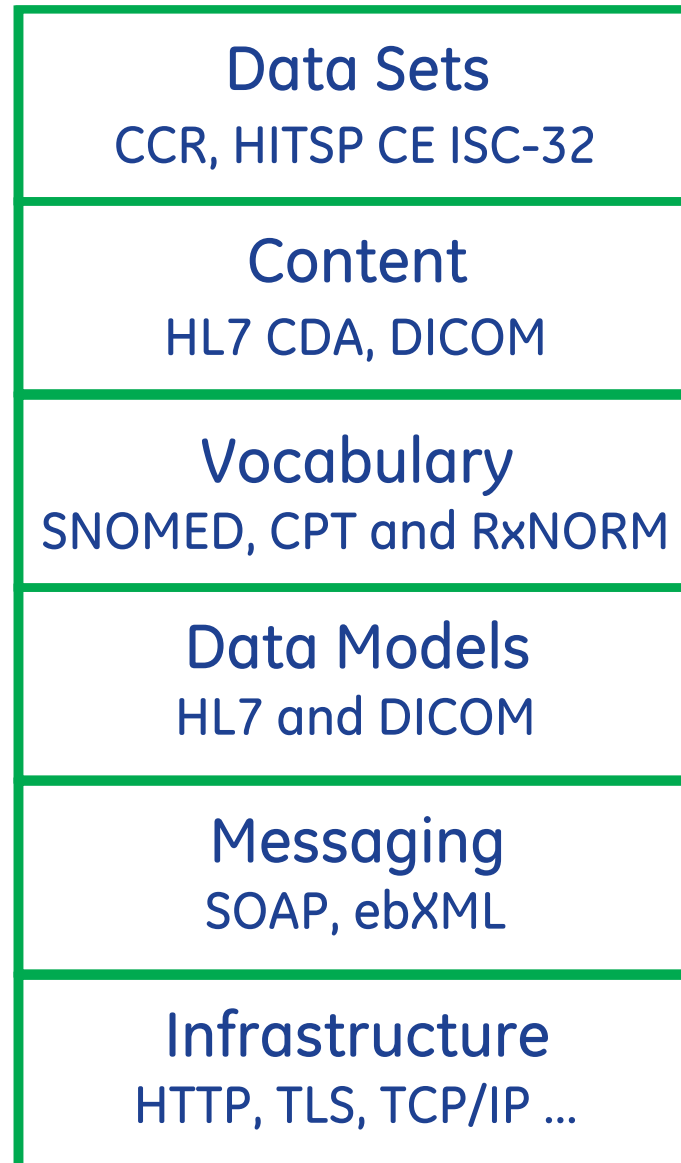
- Learn from other industries (e.g., Banking)
- Decentralize



Personally Controlled Health Record Communications Architecture



Standards and Technology Stack



Why are Documents Important?

- Most of the patient record is in document form.
- Documents are part of the existing provider workflow.
- Patient and Provider rights and responsibilities are well established.
- Complete context is present.
- The longevity of PHR is the patient lifetime.
- Access control is feasible.



Bridging the Gaps

Use Standards

Participate with Others

- Standards Development
- Healthcare Initiatives
- Industry Demonstrations

Provide and Use Open Source



Thank you!

