AHIMA Testimony on Personal Health Records

NCVHS Privacy, Confidentiality and Security Subcommittee

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AHIMA
American Health Information Management Association®

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- **Professional society of 53,000 members**
  - **125 job titles in 40 different health care, vendor, government, settings**
  - **Manage, analyze, report, and utilize data for patient care, while making it accessible to healthcare providers and others for secondary data use**
- **Dual Mission**
  - **Advancing the HIM profession through leadership in advocacy, education, certification, and lifelong learning**
  - **Advancing HIM/HIT standards and policy**
- **Quality healthcare through quality information**

Background: Donald T. Mon, PhD

- 30 yrs of health information management & technology, consulting, teaching, research experience
- HIT standards, strategic planning, re-engineering, data warehousing/mining, decision support, outcomes, performance measurement, clinical indicators, program evaluation, benchmarking, administrative & clinical systems

Insights from Industry Activities

- **EHR / PHR**
  - **Health Level Seven (HL7) Co-Chair, EHR Work Group**
  - **HL7 Co-Facilitator, PHR Work Group**
  - **National Alliance for Health Information Technology (NAHIT) Co-Chair, Records Work Group to Define Key Terms - EMR, EHR, PHR**
  - **Expert Panel, Evaluating CMS PHR Demonstration Projects (Assistant Secretary for Planning & Evaluation - ASPE)**
  - **PHR Technical Subcommittee, Connecting for Health**
- **Certification**
  - **AHIMA one of three organizations that founded the Certification Commission for Healthcare Information (CCHIT)**
  - **Industry Liaison, CCHIT**
  - **Member, CCHIT PHR Advisory Task Force**
- **Health Information Exchange (HIE)**
  - **Prime Contractor, State-Level Health Information Exchange (SLHIE) projects**

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Insights from Industry Activities

- **Privacy, Confidentiality and Security**
  - **Subcontractor, Health Information Security & Privacy Collaborative (HISPC)**
- **Standards Harmonization**
  - **AHIMA Representative, Health Information Technology Standards Panel (HITSP)**
- **Other**
  - **Board Member, HL7**
  - **Board Member, Public Health Data Standards Consortium (PHDSC)**
  - **AHIMA Representative, US Technical Advisory Group (US TAG), International Organization for Standardization Technical Committee 215 (ISO TC 215) – Health Informatics**
  - **Member, Business Sustainability Transition Work Group for the AHIC Successor (now the National eHealth Collaborative – NeHC)**
  - **Steering Committee Member, National Quality Forum (NQF) HIT Structural Measures**
  - **AHRQ Expert Panels: Population Health, EHR Safety, Innovative Designs in Data Display**
  - **Testified before AHIC and NCVHS on various topics**

AHIMA's Verbal Testimony

- Supplements our written testimony
- Based on our core health information management, consumer, and standards development experience
- Focuses on key questions received from NCVHS staff
  - Vision of PHRs & patient-facing online services
  - Key differentiators in PHR models
  - Top privacy question: Consumer's ability to modify professionally sourced information
- Not addressing every PHR model

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Problems PHRs Are Trying to Solve

- Problems are well documented and real
- AHIMA supports consumer empowerment principle that PHRs can be used effectively to:
  - Make informed health decisions
  - Facilitate patient-clinician interaction and communication
  - Exchange health information
  - Provide convenience (e.g., scheduling)
- Resulting in increases in quality care, reduced costs, better healthcare experience

Evolving Relationship bet. PHRs/Other HIT

- **Confusion: PHR is one of many, sometimes overlapping, health information technologies involved in the solutions to the same problems**
- **Health information technologies will continue to overlap, all of them:**
  - **Strive to be as patient-centric as they can**
  - **Have (the same) health information as their base**
- **Yet there are key characteristics on which they differ that will help set them apart and define their evolving, inter-related roles**

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Primary Purpose of PHRs

- What is the primary purpose of PHRs?
  - To facilitate health information exchange between patients and their physicians, and/or
  - Merely serve as a record consumers keep for themselves
- In the granular world of records management and standards development, the answers are not as naïve as they appear

Questions relating to the PHR's purpose, incorporating individual participation, and uptake are intertwined

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Incorporating Individual Participation

- Privacy, confidentiality and security
- Making the interaction with the PHR and other patient-facing HIT an engaging experience
- Response to an emotional need
- Convenience (e.g., auto-population)
- Increased value added administrative functionality, capitalizing on advances in technology
  - Microdisk expansion: Possible to put PHRs on devices in two – five years
  - Smart phones & netbooks: Text messaged scheduling
  - Submit data for medical flexible spending reimbursement

These factors will also increase uptake, encourage health information exchange

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Factors Affecting Uptake

- Low rates of adoption for all HIT provides opportunity for them to interact and grow in concert with each other
- Some legacy EHR systems
  - Do not have patient portals, keeping the number of provider-sponsored PHRs artificially depressed, giving an opportunity for other PHR models to grow
  - Are not able to exchange data with PHRs
- Recommendation: Build this functionality into legacy EHR systems over next few years

Factors Affecting Uptake

- **Desire for the longitudinal record & record retention policies**
  - **Provider-sponsored PHRs are longitudinal to degree that consumer has received care from that provider over a period of time, but are not birth to death**
  - **Not known how long how long community hospitals, small doctors offices, abiding by their risk assessment and record retention policies, will keep patient data**
  - **Places more importance on non-sponsored PHRs to act as the longitudinal, perhaps birth to death, record**
  - **Health information will need to be exchanged at the end of every visit/encounter or as soon thereafter (an "automatic deposit")**

This factor encourages the PHR to be a record consumers keep for themselves

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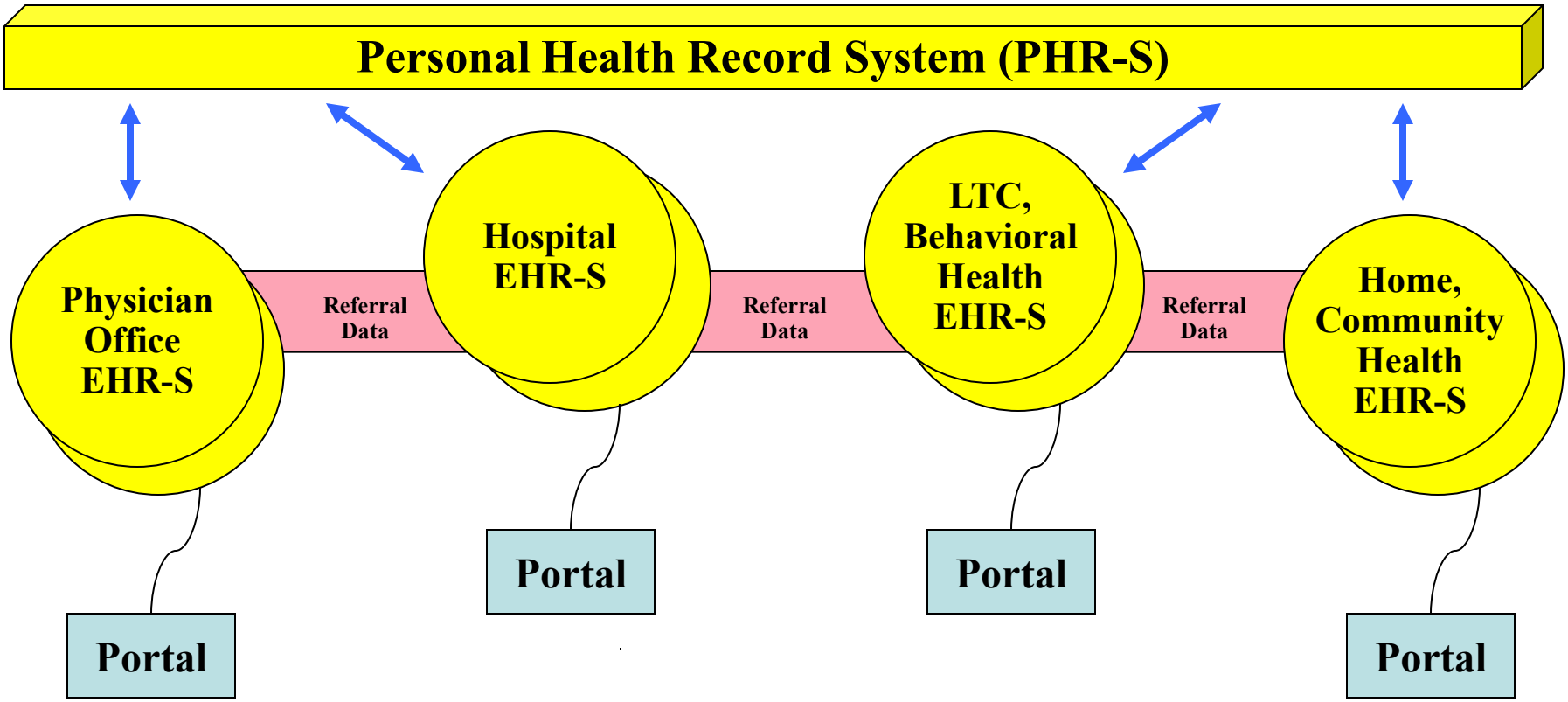
Provider-Sponsored vs. Standalone PHRs



Pros

- Pre-populated data
- Convenience
- Lower maintenance

Cons

- Episodic, not lifelong
- Which one to use?

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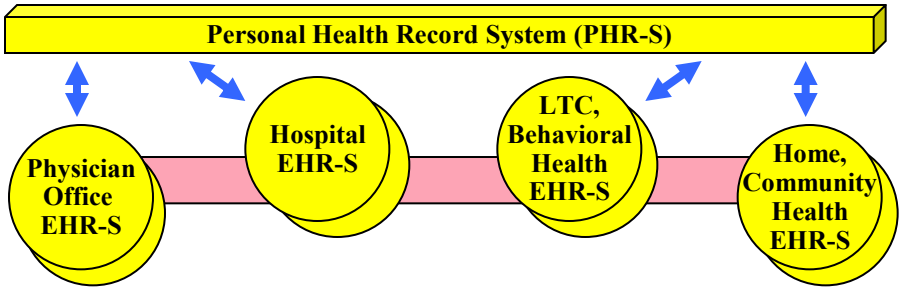
Factors Affecting Uptake

- **The PHR as a pointer & record retention policies**
  - **Model: PHR does not store the actual data, but knows the location of them and is able to present the data in a coherent view**
  - **Worthwhile concept, technically challenging to implement**
  - **Not known how long how long community hospitals, small doctors offices, abiding by their risk assessment and record retention policies, will keep patient data**
  - **May affect the adoption of this model**

Consumer's Ability to Modify Data

- Depends on type of data
- Depends on source
  - Externally sourced
    - Professionally sourced
    - Other: Devices
  - Patient sourced
- Depends on PHR model
  - Provider-sponsored PHR: Underlying record is an EHR and serves as a legal record for business and disclosure purposes (single most important differentiator by model, country)
  - Non-provider-sponsored EHR: Underlying record is not a legal record



Controversy is around clinical, professionally sourced data, not all data

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Types/Methods of Data Modification

- Add
  - Appropriate administrative data (demographics, insurance, provider, etc.)
  - Journal, diary
  - To externally sourced data through annotation
- Request provider to correct data at the source (EHR) and then send an update to the consumer's PHR
- Withholding data

May require ability to modify, attribute modification of data, at the data element, not just the document or record, level

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Consumer Can Withhold Data By:

- Not entering data into the record in the first place
- Selecting only certain portions of professionally sourced data to import into the record
- Limiting or revoking system access to data to certain individuals (including the physician)
- Masking the data (showing that data is present, but has a mask over it)
- Hiding the data (the data is contained in the record but does not appear to the physician to be present)
- Deleting professionally sourced data with or without audit traceability
- Modifying professionally sourced data with or without audit traceability
- Modifying professionally sourced data with a change in attribution (it's now the patient providing the information, not a clinician from previous care)
- Controlling the export of health information from the PHR (what data is exported and who it is exported to)

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Change in Attribution

- Professionally sourced data is imported into the consumer's PHR
- Is attributed to (explicitly labeled as) data coming professional source
- When patient modifies professionally sourced data, the data is immediately attributed to the patient, no longer the professional source
- No audit trail of the modification
- Appears to the physician the next time he/she views the record as patient sourced information and regards it the same way he/she has regarded such information in the past
- Patient has no way of modifying the source attribution back to the physician

Source of truth vs. truth of source affect trust in the data and thereby adoption

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Conclusion

- There are definite problems in which the PHR can solve
- Privacy and confidentiality remain the top issue to solve before PHRs can proliferate
- PHRs and other patient-facing technologies will evolve together
- Factors such as convenience, making interaction with the PHR engaging, etc. must be addressed
- Will take time and investment

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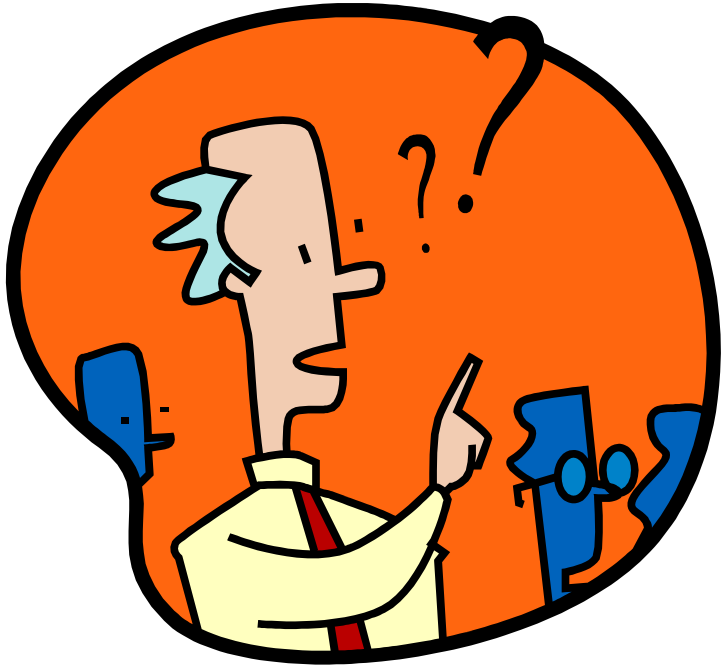

Thank you!

Questions?