# Personal Health Records: What We've Heard So Far

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April 26, 2005

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Information for Health: A Strategy for Building the National health Information Infrastructure – November 15, 2001
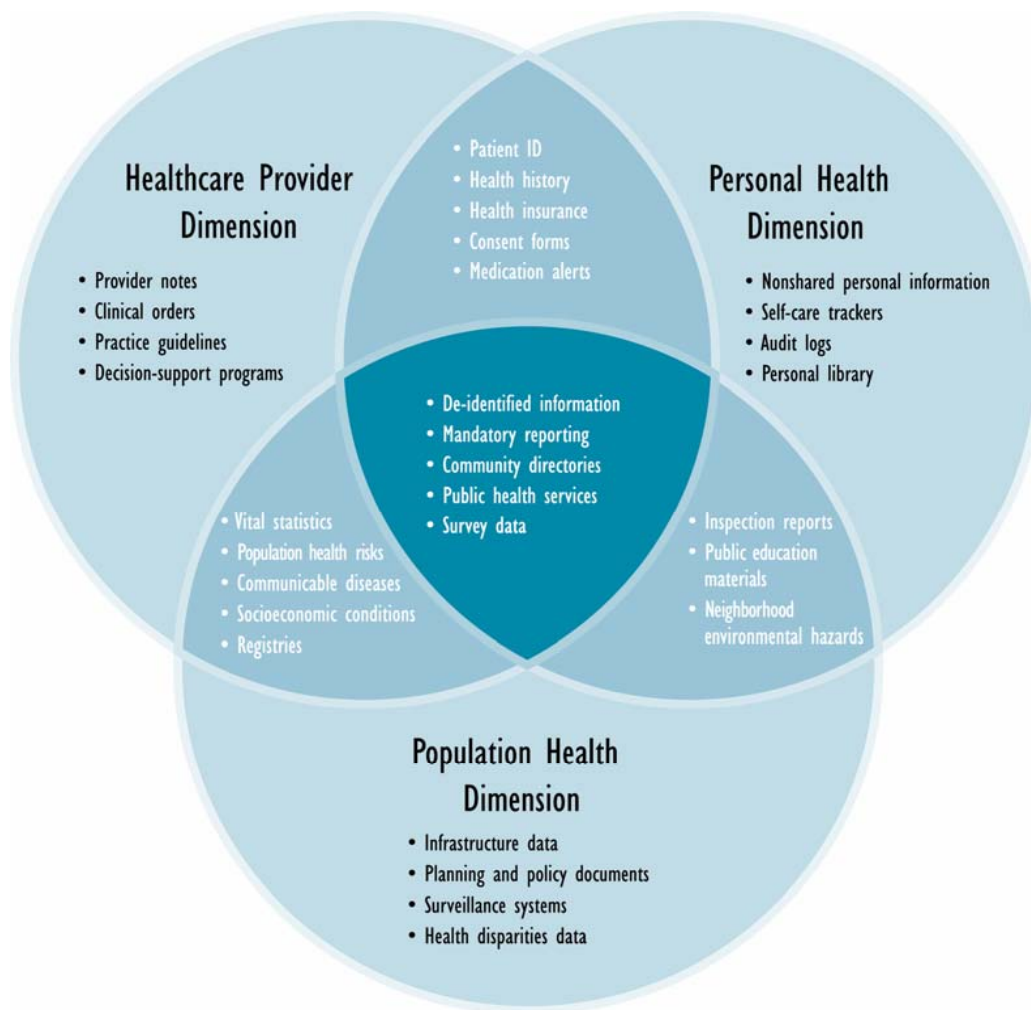
NHII Workgroup Hearings on PHRs

- July 24, 2002: PHR models & issues; Integrating E-mail
- January 27-28, 2003: PHR data sets; standards; identification and authentication
- August 7, 2003: expert/policy views
- November 12, 2004: Federal interests; examples of PHRs, EHR-derived and not
- January 5-6, 2005: Consumer and provider perspectives; business issues

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Full Disclosure!

- Sampling of key themes/messages
- Neither a true synthesis nor a true random sampling
- Shows scope and flavor
- There's lots there

Consumer attitudes towards PHR

- Consumers are eager to obtain health information online and facilitate transactions
- Consumer concerns about Internet privacy are strong and well-documented
- Users will want to be able to control their PHR as much as possible
- The more educated about PHR, and the more experience consumers have with it, the more open they are to the concept

Privacy Concerns

- Markle 2003
  - Almost all respondents (91 percent) are very concerned about their privacy and keeping their health information secure. However, most people believe that technology provides appropriate protections.
  - People who suffer from chronic illness and/or are frequent health care users are less concerned about privacy and security
- Harris Interactive 2005
  - 48% say benefits of EHRs outweigh risk
  - 47% say risks outweigh benefits

Patient Users

- More office visits
- More chronic problems
- Children of elders
- Age 46 to 64
- Familiar with the Internet

Personal Health Working Group (2003). Connecting for Health: A Public-Private Collaborative.
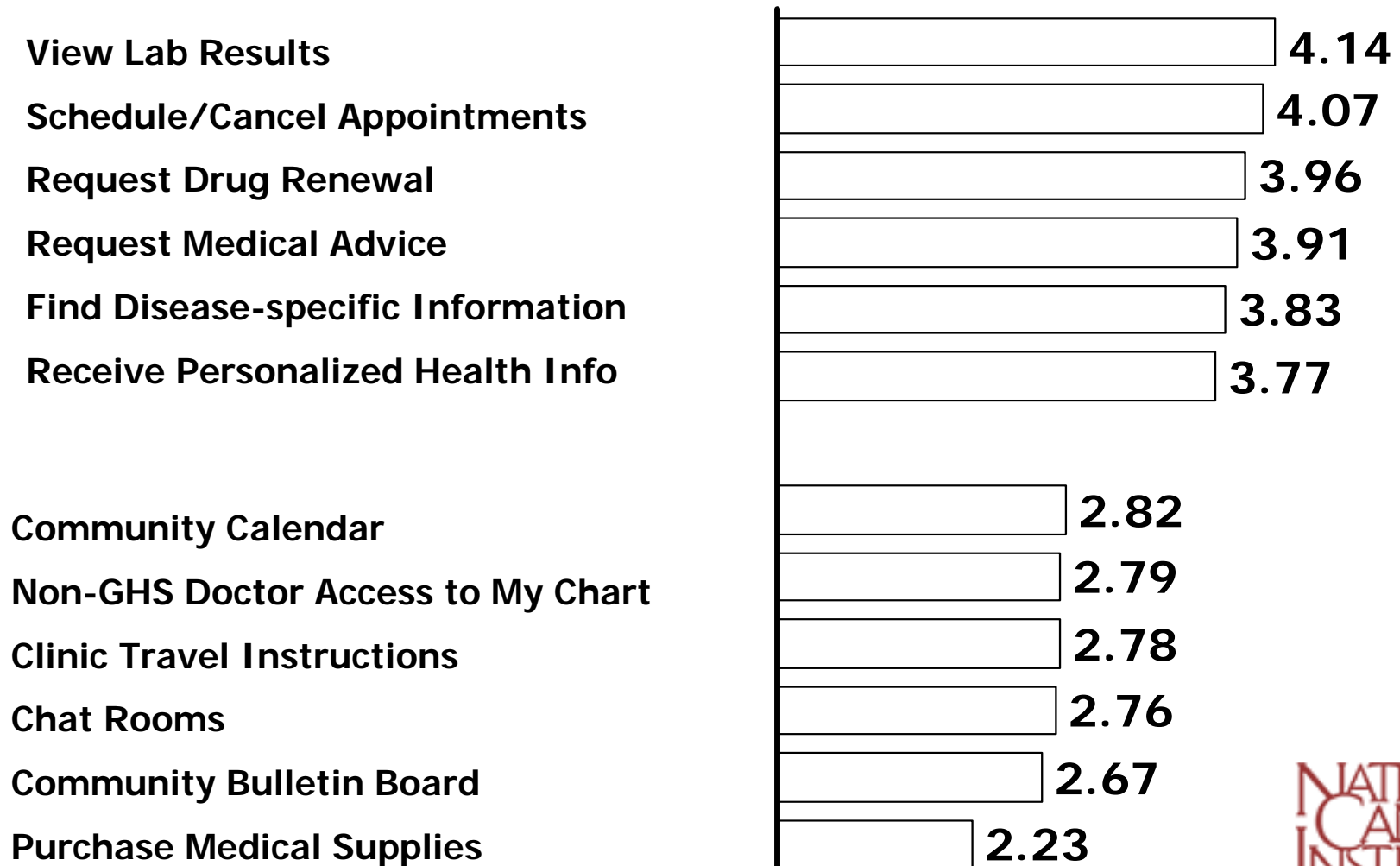
FAACT-Markle Survey, PHR Demand

Over 70 percent of respondents would use one or more features of the PHR:

Email my doctor	75 percent
Track immunizations	69 percent
Note mistakes in my record	69 percent
Transfer information to new doctors	65 percent
Get and track my test results	63 percent

Thirty five percent of respondents would use seven or more features of a PHR today if it were available.

Geisinger Study: Patient Drivers

View Lab Results	4.14
Schedule/Cancel Appointments	4.07
Request Drug Renewal	3.96
Request Medical Advice	3.91
Find Disease-specific Information	3.83
Receive Personalized Health Info	3.77
Community Calendar	2.82
Non-GHS Doctor Access to My Chart	2.79
Clinic Travel Instructions	2.78
Chat Rooms	2.76
Community Bulletin Board	2.67
Purchase Medical Supplies	2.23

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Patient Satisfaction

- "More, More, Faster, Faster."
- Age secondary.
- Pediatric access critical.
- Adult children assist their parents.
- Usability critical.
- "Other things equal, I would prefer to go to a doctor who provides it."
- "It provides the information I need."
- "It is easy to find the information I need."

Hassol, A., J. M. Walker, et al. (2004). "Patient Experiences and Attitudes about Access to a Patient Electronic Healthcare Record and Linked Web Messaging." J Am Med Inform Assoc **11**: 505-13.

Key Features of a Patient-Centric PHR (System)

- Data
  - Structured Data
    - Conditions, Medications, Allergies, Test Results, Health Risks, Surgeries, Symptoms, Clinical Findings, Care Plans, etc
  - Unstructured Data
    - Journal entries, feedback about care, unstructured messages
- Patient-Centric Portability and Shareability
  - Emergency Record Summaries
  - Paper, Fax, Electronic, Phone, Smart Card integration
  - Interoperability with electronic data with other systems
- Other Bundled Features
  - Secure Messaging
  - Automated Feedback
  - Faxable, Printable Reports
  - Health Risk Assessments/Health Behavior Programs

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Attributes of a Patient-Centric Personal Health Record

- Enables each person to control his or her own PHR;
- Contains information from one's entire lifetime;
- Contains information from all health care providers;
- Is accessible from any place at any time;
- Is private and secure;
- Is transparent. Individuals can see who entered each piece of data, where it was transferred from and who has viewed it;
- Permits easy exchange of information with other health information systems and health professionals.
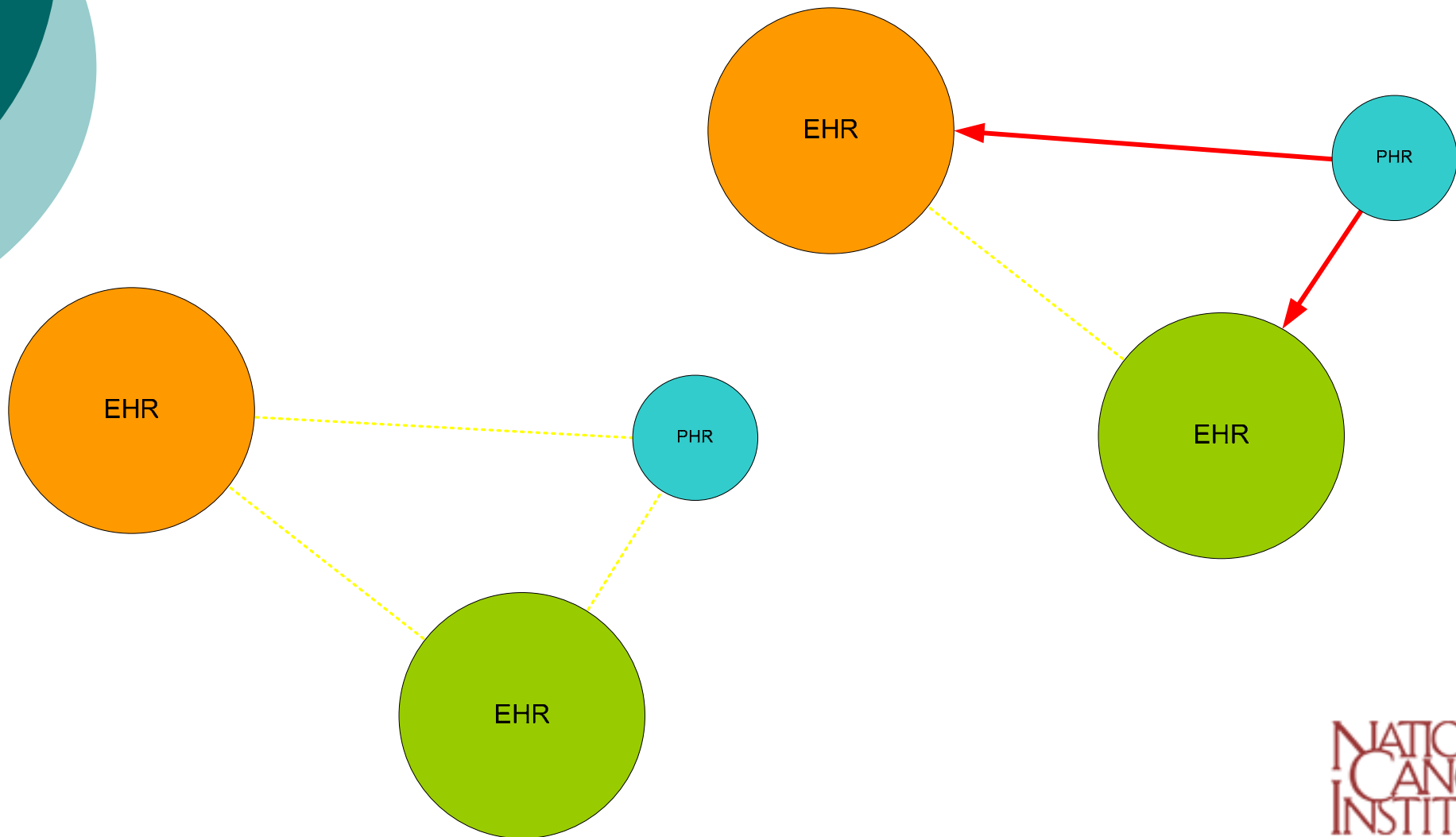
EHR-Derived:Layered Functionality

- A layer on the enterprise EHRS
- Access
  - To information
  - To services
  - Filtered access to clinical data
- Communication
  - Providers
  - Customer service
  - Payors

Organic Evolution of a PHR
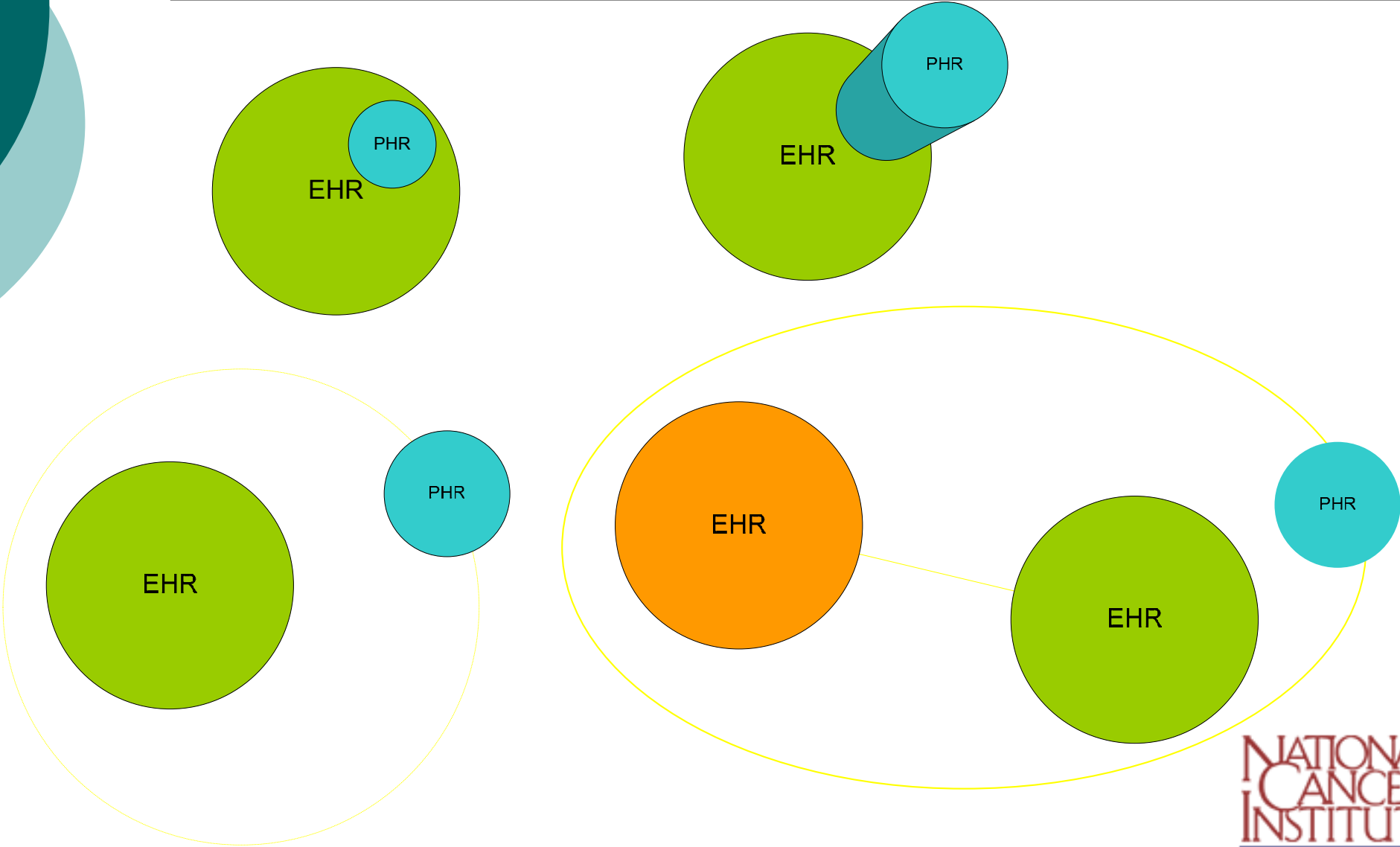
PHR as Special Case of EHR

Business Models

- Subscription
- Tiered services
- Transactional
- Payor sponsored

Barriers (Provider Perspective)

- Lack of EHRs designed to support it
- Lack of effectiveness evidence
- Physicians' cost of change
- Patient acceptance
- Much of the medical record is jargon (unusable as is)
- Legal complexity (pediatric access)

Business Case for Information Management

- A major cause of medical errors and suboptimal quality in the US is the lack of proactive population management, chronic disease management, and care coordination
  - These activities are all made possible and easier with HIT
  - There is NO evidence that adoption of HIT without a concomitant business case for population / disease management / care coordination will lead to these quality enhancements
  - Basis for pay-for-performance "incentives"
- Widespread EHR adoption (without reimbursement changes that reward desired use / targets) will <u>not</u> result in the four major goals laid out by Dr. Brailer – but rather "digitized dysfunction"
- Widespread PHR adoption (without reimburse-ment reform) will likely result in similar waste of technologic potential

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What Standards Have Been / Should be Discussed?

- Minimum data sets to facilitate data sharing
- Interoperability between electronic systems
- Patient control and privacy standards
- Authentication standards
- Consumer terminologies

PHR Minimum Data Sets

A minimum PII data set accessible by patients could ensure that the minimum amount of data is available to guide care decisions, cost prediction, and self management.

- Demographic Information
- Insurance and Provider Information
- Contact Information
- Current Conditions (condition, provider, date diagnosed, severity)
- Current Medications (med, dose, frequency, prescriber, date prescribed)
- Pertinent Test Results (test, date, results, trends, measurer)
- Allergies
- Immunization History
- Surgical History
- Current Health Risks and Family History

Rethinking Medical Documentation

- Medical records "bloat"
  - Average note is 3-5 times longer than it needs be
    - Compliance with E/M coding guidelines
    - Misconception that ↑ verbiage protects against errors / malpractice
  - ↑ sharing of these bloated "textblobs" with patients via PHRs
    - Cause of MD concern
    - Not particularly useful
- However, if the current "problem oriented medical record" → "quality-oriented shareable record"
  - Shorter notes containing more structured elements
  - Focused on documenting only what is necessary, no incentives for verbosity
  - Focused on improving quality
  - Focused on (where appropriate) longitudinal care rather than documentation of episodic care
  - Focused on share-ability

Consumer Vocabularies

- Web portal searches
- Translate from professional to consumer
  - Clinical notes
  - Discharge summaries
  - Explanation of Benefits
- Translate from consumer to professional
  - Personal health records
  - On-line consultations

Consumer Vocabularies

- True "Interface" Terminologies
  - Provide the ability to interface patients to complex terms and concepts at a specified reading level (Example: "Diabetes Mellitus with ophthalmic manifestations" translated to "Diabetes with eye problems)
  - Provide the ability to translate colloquialisms and common phrases into medically-valid concepts

- Examples
  - WellMed: consumer preferred terms to all 12,000 ICD9 codes and 14000 SNOMED codes
  - Apelon number of terms and mappings 2002
    - 15k total terms
    - 10k algorithmically mapped
    - 4k human mapped
    - 1k unable to be mapped

Ownership / Control of the Record

- Medical record currently has three functions
  - Record of complaints, findings, diagnoses, medications, etc
  - Basis for payment (defense against claims of billing fraud)
  - Defense against future malpractice claims
- Unless we make radical and concomitant changes in reimbursement and liability – use of the PHR can <u>not</u> alter the physician's record, or control of the record (at least for purposes of payment and establishment of defense against malpractice)
- Implications:
  - MDs own / control their EHR
  - (Hopefully) information within EHRs is formatted (or "formattable") in such a way as to make data exchange easy, inexpensive (free?), and accurate
  - Tethered PHRs are owned / controlled by MD (maybe ok)
  - Untethered PHRs are owned / controlled by patient

  (certainly ok)

Patient Control, Privacy and Authorization Standards: Do we need anything new?

- HIPAA provides general expectation for protecting privacy (the "floor")
- Standards for Authorization /Permission will become increasingly important
  - Systems that maintain patient-viewable data should comply with baseline permissions standards (e.g. A patient should be able to withhold data that they consider sensitive, or enable read-only access)
  - "Sensitive" data is different for every patient, so enabling patients to establish item-by-item permissions is important
- Audit Trail information standards applied to all systems that maintain patient viewable data would support privacy
  - "Who accessed or edited what data when?"

Authorization and Control

- PHR designers must anticipate implications of patient, caregiver, consumer "control":
  - Selective release of information
  - Release to selected providers
  - Possibility of inconsistency, error across sources
  - Mechanism for user correction of data
  - Mechanism for user annotation of data
- People will use PHR as they choose!!
- Education on the implications of authorizing/ withholding information is essential
- Possibility of multi-tiered approach

Interoperability

- Enablers
  - Standards allow for source system independence
  - Standards and modular approach solutions to fit into multiple PHR models
  - Patient centric solutions vs. provider/care setting centric
- Barriers
  - Provider willingness to share patient data
  - MPI resolution
  - Alignment among diverse solution vendors
  - Lack of final standards

What we're just beginning to hear: Personal Health Information Banks

- Third-party host for PHI
- Authorization and access management as distinct function
- Implicit business model? "There's gold in them thar PHI"
  - Value of de-identified PHI for secondary use (pharma; population health)
  - Possible reimbursement to patients for consent to share

Some Recommendations

- Support standards for common data fields stored and shared between PHRs and EHRs
- Support standards/incentives for sharing data
- Support creation of set of 'best practices' for information authorization, control and security
- Support PHRs for government employees and CMS beneficiaries