NCVHS NHII – PHR Taxonomy

Task:

Are there existing names for PHR's that we should be using?

Linda Fischetti RN MS

NCVHS NHII - April 26 2005

Call for PHR Definitions

- HL7 International Working Group Meeting
- International – via personal communication
- AHIMA
- HL7 EHR TC Working Group

  - ☐ Disclaimer:
    - Not comprehensive
    - Personal Communication
    - Observation

ISO 20514

4.8 The personal health record (PHR)

The key features of the PHR are that it is under the control of the subject of care and that the information it contains is at least partly entered by the subject (consumer, patient).

There is a widespread misapprehension in the community, including among health professionals, that the PHR must be a completely different entity from the EHR if it is to meet the requirements of patients/consumers to create, enter, maintain, and retrieve data in a form meaningful to them and to control their own health record. This is not correct. There is no reason why the PHR cannot have exactly the same record architecture (i.e. standard information model) as the health provider EHR and still meet all of the patient/consumer requirements listed above. In fact there is every reason to ensure that a standardised architecture is used for all forms of EHRs (but certainly the ICEHR), to enable sharing of information between them as and when appropriate, under the control of the patient/consumer.

The PHR can then be considered in at least four different forms:

a. A self-contained EHR, maintained and controlled by the patient/consumer,

b. The same as a. but maintained by a third party such as a web service provider,

c. A component of an ICEHR maintained by a health provider (e.g. a GP) and controlled at least partially (i.e. the PHR component as a minimum) by the patient/consumer, or

d. The same as c. but maintained and controlled completely by the patient/consumer.

Australia

There is really very little interest in the PHR as a separate entity (ie separate from the shared EHR) in Australia.

□ I would strongly urge that any US definition should include or be accompanied by mention of the need/desirability for the PHR to have the same architecture as the broader EHR so that relevant parts of it can at least potentially be shareable with the patient's care team. This of course should be under the control of the PHR's owner. - Peter Schloeffel

England

- No formal and preferably ratified definitions of personal/patient/citizen held records.
  - used NCVHS definition

ASSURING A HEALTH DIMENSION FOR THE NATIONAL INFORMATION INFRASTRUCTURE

A Concept Paper by the National Committee on Vital and Health Statistics Presented to the U.S. Department of Health and Human Services Data Council

October 14, 1998

- Personal CHRs are personal health records for individual use, including assessment of health status and linkage with physicians' records. Some refer to these as consumer-oriented health records.

Canada

- EHR is the current focus. At this time they have not done definitional work for PHR.
  - Attributes (personal communication)
    - Patient view into comprehensive health record
    - Presentation data able to be understood by lay person.
    - Contains data entered by patient
    - Access by healthcare providers controlled by patient
    - Easily transportable (print, browse online, memory stick etc)

Netherlands

- Patient Experience Dossier
  - Funded by government through non-profit
  - Patient entered data
  - Web based

AHIMA's Definition of the PHR

The Personal Health Record (PHR) is an electronic, ubiquitous, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.

AHIMA: PHR Issues & Activities

- **PHR is a separate record from the legal EHR's of various providers**
  - □ **PHR not a legal record, but providers' EHRs are**
  - □ **Though it may be incomplete, the PHR is in a better position to be longitudinal, containing information across providers (if diligently maintained by the individual)**
- **Consumer education is greatly needed**
  - □ **www.myPHR.com**
  - □ **Community-based public education campaign**

HL7 Electronic Health Record Technical Committee – Personal Health Record work group

HL7 PHR work group.

- (1) run through the various permutations from stand alone PHR to fully tethered PHR, and
- (2) stated that from a standards perspective, the issue of tethering vs. untethered doesn't matter.

Findings

- A PHR should be interoperable with more than one EHRs no matter what the permutation of EHR it exchanges health information with.

Findings

- No standardized Taxonomy for the 'types' of PHR's

Observation

PHR Core Definition similar but with variability by axis

- Axis:: Type of information (personal vs. educational vs. benefits)

- Axis:: Source(s) of information

- Axis:: Ownership/Custodianship/stewardship

- Axis:: Authority   Least Variability

- Axis:: Interoperability

- Axis:: Sponsorship

Observation

PHR Core Definition

Axis:: Type of information (personal vs. educational vs. benefits)

Axis:: Source(s) of information

Axis::Ownership/Custodianship/Stewardship

Axis:: Authority

Axis:: Interoperability

Axis:: Sponsorship

'Tethered vs. Untethered' places focus on Interoperability

PHR Core Definition

Axis:: Type of information (personal vs. educational vs. benefits)

Axis:: Source(s) of information

Axis::Ownership/Custodianship/Stewardship

Axis:: Authority

Axis:: Interoperability

Axis:: Sponsorship

Terms should emphasize Ownership/Custodianship/Steward

PHR Core Definition

Axis:: Type of information (personal vs. educational vs. benefits)

Axis:: Source(s) of information

Axis::Ownership/Custodianship/Stewardship

Axis:: Authority

Axis:: Interoperability

Axis:: Sponsorship

Observation
Record vs. Record System

- **electronic health record (EHR)**
  - a repository of information regarding the health status of a subject of care, in computer processable form
- **EHR system**
  - a system for recording, retrieving, and manipulating information in electronic health records

Summary

- No existing taxonomy that solves the NHII communication issue.

- Observations
  - Authority never wavers
  - Emphasis on Ownership
  - Distinguish between record and record-system