

# **June 30<sup>th</sup> Committee Report**

## **For Submission to the EHR Taskforce Steering Committee**

### **Committee: Personalizing Health**

#### **Outcome Oriented Committee Goal**

Promote a secure environment in which all individuals in the State of Illinois have access to a PHR in electronic format that is an integral part of the EHR that emerges in the State.

#### **Committee Objectives**

1. Define Personal Health Record (PHR).
2. Promote and adopt the National Standards for data elements
3. Recommend a certification process that will ensure that service providers of PHRs protect confidentiality, as well as maintain rights to privacy.
4. Suggest policy that will provide financial resources to broaden access to PHR.
5. Promote incentives for sponsorship of PHR.
6. Support a framework that parallels the EHR for secure and reliable health information exchange.
7. Identify and address the barriers to use of the PHR in order to reduce health disparities in the State of IL.
8. Educate consumers about the benefits and value of PHR.
9. Create a business case for PHR adoption by organizations with the State.
10. Identify regulatory barriers to data exchange of PHR providers, individuals and others.
11. Identify and promote key functionalities of PHR.

## Objectives and Corresponding Issues

1. Define PHR
  - a. Should the State adopt its own standard definition of terms or rely on those of another governing organization?
  - b. Is the definition of PHR suggested by the Personalizing Health Committee flexible enough to change, if necessary, to be aligned with the evolving National definition?
  - c. Will the definition of PHR support a National Standard that is likely to evolve?
  - d. Should the State establish a set of guidelines concerning individual rights for PHR such as: the ability of the patient to opt-in or opt-out; the ability to restrict access to their records held by family members and parties to an electronic exchange transaction; ownership rights and responsibilities, etc.
2. Promote and adopt the National Standards for data elements
  - a. What are the advantages and disadvantages of promoting and adopting the national standards?
  - b. Will the national standards be adopted in a timely manner for implementation in Illinois?
  - c. Should the State monitor initiatives other than CCR?
  - d. Should the State monitor other States that are further along and how?
  - e. Should National Standard be phased-in if adopted?
  - f. Which entity will be responsible for compliance of standards being met?
  - g. Would the State governance accept standards less than that which is adopted as the National Standard?
  - h. Should standards be regulated? If yes, how would the State monitor?
3. Recommend a certification process that will ensure threat service providers of PHRs protect confidentiality, as well as maintain rights to privacy.
  - a. Will new Illinois regulations be needed to ensure that the PHR is secure and private?

- b. Should the certification process be managed by an independent third party selected by the State?
  - c. On issues of privacy and confidentiality, what existing or proposed Federal regulations might pre-empt Illinois regulations and/or what additional regulations should Illinois pass?
  - d. What is the extent to Illinois' authority to enforce implementation of a certification process?
  - e. What certification process will be required to certify authenticity of the PHR when requested for legal process?
4. Suggest policy that will provide financial resources to broaden access to PHR.
- a. Does policy currently exist that provides financial resources to broaden PHR access?
  - b. Does current proposed Federal and State legislation provide financial resources?
  - c. Are there private initiatives/funding available to provide financial resources?
5. Promote incentives for sponsorship of PHR
- a. Should the State create tax credits and subsidies for Illinois employers that make PHRs available to employees and if yes, in what form?
  - b. Should the State create tax incentives and direct subsidies to encourage organizations to reach out to medically underserved populations (MUPs) and to individuals in medically underserved areas (MUAs) and health professional shortage area (HPSAs)?
  - c. Are there State regulations that prohibit certain entities from providing hardware/software for EHR systems to independent practitioners, others?
  - d. Should consumers pay to access their PHR, if yes, what forms of payment would be acceptable?
  - e. Could non-identifiable information be sold?
  - f. Should the State regulate how the data can be sold and to whom it could be sold?
  - g. Will payors support the provision of PHR as a health benefit?

6. Support a framework that parallels the EHR for secure and reliable health information exchange.
  - a. What are the key components of the framework?
  - b. How will the State determine which framework to parallel?
  - c. What are the unique PHR issues that should be considered when mirroring the EHR?
  - d. What are the synergies among the TeleHealth initiatives?
7. Identify and address the barriers for use of the PHR that may reduce health disparities in the State of IL.
  - a. What are the characteristics of the health population with disparities?
  - b. What resources are necessary to implement TeleHealth and PHR in these populations and how?
  - c. How can the State continue to promote or enhance TeleHealth activities?
  - e. What resources are necessary to implement MUPs?
8. Educate consumers about the benefits and value of PHR
  - a. What are the benefits of PHR—financial and otherwise?
  - b. What demographic information exists that will enable the State to target communications and develop educational programs?
  - c. If the average consumer needs to understand the content of the PHR, what communication strategies should be implemented to address MUPs who face economic, cultural or linguistic barriers?
  - d. Should the State adopt communication strategies from other communities that are already tried and tested, or contract with existing service providers?
  - e. Should the State be responsible for maintaining knowledge-based resources to educated consumers and providers about PHR?
  - f. What information should be communicated to consumers regarding ownership rights and responsibilities?

9. Create a business case for PHR
  - a. Should a separate business case be developed for each stakeholder?
  - b. What are the costs associated with maintaining the PHR?
  - c. Are data available to demonstrate the value (monetary or otherwise) of PHR?
  - d. What would be the strategic framework for adoption of PHR?
  
10. Identify regulatory barriers to data exchange of PHR providers, individuals and others.
  - a. Does the State need legislation to protect the consumer against loss and abuse of data?
  - b. How do we ensure the barriers are removed?
  - c. Do laws addressing sensitive information pose a barrier to data exchange?
  
11. Identify and promote key functionalities of PHR.
  - a. Should there be an information hot-line for consumers to receive help and interpret data in the PHR?
  - b. Should there be a link to health content references?
  - c. Should the State recommend best practices that will minimize inaccuracies of patient specific data in the PHR?
  - d. What is the relationship of the PHR to the EHR?
  - e. Will the PHR be portable?
  - f. How will inaccuracies in the PHR be minimized? And what will be the process for correcting inaccuracies?
  - g. What data elements can be modified (edited, deleted)?
  - h. Should this be a passive repository of data or personal on-line advisor?
  - i. How would the PHR be adapted for literacy, culture, language and any other potential barriers?