

Personalizing Health Committee Final Report

November 9, 2006

The purpose of the Personalizing Health Committee was to recommend a strategic framework that will enable consumers in Illinois to participate in the management of their own healthcare through the use of a Personal Health Record (PHR). Studies suggest that well-informed patients are better equipped to actively participate in their own health care and decision-making. Advancements in technology have enabled consumers to have electronic access to their health information and to gather specific information relating to their illnesses, chronic conditions and health characteristics.

The Committee deliberated on several issues before formulating its recommendations. The issues discussed by the Committee related to the following objectives:

1. Defining the characteristics of the PHR and identifying its key functionalities.
2. Promoting and adopting standards for data elements.
3. Recommending a certification process that ensures that PHR service providers will protect confidentiality, as well as maintain rights to privacy.
4. Suggesting policy that provides financial resources to broaden access to PHR.
5. Promoting incentives for sponsorship of PHR.
6. Supporting an infrastructure that mirrors the EHR for secure and reliable health information exchange.
7. Identifying and addressing the barriers for use of the PHR.
8. Educating consumers about the benefits and value of PHR.
9. Creating a business case for PHR
10. Identifying regulatory barriers to data exchange among PHR providers, individuals and others.

The Committee recognized that enhancing consumer choices and promoting the use of Telehealth systems are important issues, however these issues were discussed to a lesser degree because initiatives are already underway in the marketplace to address these matters.

Goal

Promote a secure environment in which all individuals in Illinois have access to a private electronic PHR that is interoperable with other systems for the purpose of broadening access to patient information and health education.

Objective 1.

Promote adoption of Standards for the PHR. Ensure that this objective remains worthy of implementation. Given the number of PHR initiatives throughout the State of Illinois and at the private-sector level, it is not productive for the State to develop a separate definition at this time.

Recommendations for Implementing the Objective:

1. Support the National Standard or other standard PHR that it is likely to evolve. Such standard should include the following characteristics:
 - It is in an electronic format.
 - The consumer has control over its content and rights of access.
 - It includes consumer-generated information in addition to information from healthcare providers, pharmacists and PBMs, health plans and insurance companies.
 - It is private and secure.
 - It combines personal health data and knowledge-based tools.
 - It provides information about consumer rights and responsibilities.
 - It is portable and interoperable.
2. Monitor initiatives that are under consideration that could universally affect the PHR.
 - Given the number of PHR initiatives at the National, State and private sector level, it is not productive for the State to develop separate standards. However, anything offered in the State should meet at least minimum Federal requirements.
 - The State should monitor initiatives at the state and national level for the purpose of influencing a PHR initiative in Illinois and aligning any such initiatives, as needed, with national efforts for the purpose of interoperability.
 - The Authority should monitor the state of PHR development in the marketplace and engage in educating the public regarding PHR availability and adoption.
3. Support a PHR framework that parallels the EHR for secure and reliable health information exchange.

Issues for Further Consideration:

1. The Committee understands that ASTM International (originally known as the American Society for Testing and Materials) through HL7 and X12 has accepted the role of administering a National Standard, therefore the State would not have to assume such responsibilities if it accepts the National Standards.
2. The Committee noted that development of the PHR is on a fast track for individuals with health insurance and those who are Medicare-eligible. The State's major role should be to focus on the uninsured, Medicaid and other State Health Program participants.
3. Although interoperability is currently not available in most PHR systems, it is an important goal in the development of a PHR in Illinois. The Committee recognizes that in the interim development of a PHR system, data transfer is likely to be paper-based.

Objective 2

Reaffirm that existing processes for privacy and security of personal health information are in place and that the appropriate regulatory authorities can monitor non-compliance and breaches.

Recommendations for Implementing the Objective:

1. Establish a set of protocols and procedures to enable payers, stakeholders, and consumers to report breaches of privacy and security.
2. Ensure that complaints relating to privacy and security are handled by the Illinois Attorney General's office and/or the Division of Insurance, Department of Financial and Professional Regulation.
3. The Committee determined that privacy and security guidelines already exist under HIPAA and existing State law. While existing guidelines and laws may address privacy and security issues, the Committee defers to the findings and recommendations of Health Information Security and Privacy Collaboration (HISPC) regarding privacy and security guidelines.

Issues for Further Consideration:

1. New Illinois regulation may be needed in the absence of any federal regulations, relating to privacy and security non-compliance. Defer to the findings of the HISPC Project.
2. Recognizing that non-identifiable data may and can be sold, the Committee suggests that the State regulate who should have access to non-identifiable data for research and marketing but not regulate how data can be sold.

Objective 3

Encourage PHR vendors wishing to do business with the State to adhere to industry standards relating to technology, security, confidentiality, privacy, and governance.

Recommendations for Implementing the Objective:

1. PHR service providers wishing to provide services in the State according to approved standards must meet industry-wide certification requirements identified by the Authority.
2. The Authority should delegate or identify a certifying body that will certify PHR service providers wishing to provide services in the State according to approved standards.
3. The Authority should create a list of PHR service providers that have met industry wide certification standards and make the list available to the public.

Issues for Further Consideration:

1. The Authority should consider establishing a list of certifying bodies that are recognized by the Authority.
2. The Committee recognizes that certifying bodies do not exist at this time, but anticipates that such bodies will exist in the future.

Objective 4

Suggest policy that will provide financial resources to broaden access to PHR.

Recommendations for Implementing the Objective:

1. Ensure that the financial resources will be made available for PHR for the uninsured, Medicaid and other recipients of State programs, individuals in medically underserved areas (MUAs) and health professional shortage areas (HPSAs).
2. Ensure that appropriate financial resources are dedicated to adoption of PHRs and education of consumer and provider groups regarding the benefits of the PHR.

Issues for Further Consideration:

1. The Committee acknowledges that the employers and health plans will play an important role in making PHRs available to employees and their family members,

therefore State resources would not be directed to those populations where PHR is available.

2. The Committee urges the State to address what happens to the PHRs of individuals who lose health coverage and/or access to a PHR vendor when they are no longer employed.
3. The Committee discussed issues relating to fees for an electronic PHR, but ultimately decided that the decision regarding fees should not be determined by the State, but rather the State should allow the market to drive whether there should or should not be fees for access.
4. The Committee agreed that the State should not create any tax credits or subsidies to broaden access of PHR.
5. The Committee held several discussions as to the status of PHRs with regard to health benefit plans and specifically as to whether PHRs should be considered a “health benefit” or a “program enhancement.” The Committee determined that considering PHRs to be a “health benefit” had regulatory, as well as tax implications, for consumers and employers sponsoring PHRs. Therefore, the Committee determined that PHRs should be considered as a “program enhancement” for the purpose of this project.

Objective 5

Identify and address the barriers that can limit access to PHRs for individuals in medically underserved communities to limit health disparities in Illinois.

Recommendations for Implementing the Objective:

1. The Committee recognizes that the PHR combined with technology results in a powerful telehealth medical tool. Healthcare consumers can easily communicate with providers while also participating in their own healthcare. The State should promote and enhance telehealth activities by working with providers to educate, train, support and finance telehealth medicine opportunities in communities where it is deemed appropriate.
2. The State should develop strategies to ensure that all consumers in the State have access to a PHR and consumer information about benefits, rights, and responsibilities.
3. The State should explore opportunities to develop and distribute PHRs in collaboration with existing State programs.

Issues for Further Consideration:

1. The State should identify all government and other authorized websites and agencies involved in Health Advisory that will support PHR.
2. PHRs will bridge communication between the healthcare consumer and the provider. The Committee believes that as health care consumers take more responsibility for their own health and begin to take part in decisions regarding their treatment, there exists a potential for improvement in the quality and efficiency of the care provided.