Improving Population Health Committee
DRAFT - Final Report

November 2, 2006

One of the critically valuable deliverables of the exchange of Electronic Health Records is the ability to improve the health of individuals, communities, state, and nation by ongoing disease surveillance systems, accelerating the speed of clinical research, and improving quality of care.

Background Information
Improving population health can be accomplished through a variety of public and private initiatives. Some of these initiatives may include bio-surveillance, disease tracking, clinical research studies, clinical performance measurement, and environmental assessment of services and access to care.

For ongoing public health activity governed by state law or regulation, government agencies could request providers to submit required information on a nightly basis to a public health agency's repository. Similarly, organizations that participate in Health Information Exchange (HIE) with the written authorization of the patient and organizational participant may establish a non-patient specific identifiable repository for usage by the organization at their own expense.

For clinical research and other studies, special requests would be submitted to the governing HIE governing body for consideration. Special studies would utilize the record locator service (RLS) approach to identify and link non-patient identifiable data for this purpose. Clinical research and other studies would adhere to the strict patient privacy and security provisions and be responsible for charges incurred in utilizing a RLS approach. The exception for special studies in which a public health agency would need no permission to act would be an emergency request by government public health services to monitor emergency activity or urgent disease conditions.

Goal

Support a patient privacy protected, streamlined approach for access to population health information to advance bio-surveillance capabilities; increase quality and outcomes of patient care; and propel clinical knowledge from the time of discovery to practice implementation.

Objectives

1. Ensure protection of patient privacy and confidentiality of information remains a top priority and consideration in every population health initiative.

Recommendations for Implementing the Objective:

The committee recommends the creation of a state authority to establish a public-private state health information exchange and to foster the development of local health information exchanges. Furthermore, this authority must promulgate rules governing those entities connecting to the state health information exchange and researchers using the exchange data. These rules must follow federal and state patient privacy and confidentiality protections and adhere to access rules developed by the state authority.

The committee also recommends that all organizations connecting to the state health information exchange provide assurances that it:

- complies with federal and state laws and regulations on patient privacy and health information confidentiality;
- has privacy and security protocols and operational guidelines in place; and
- reports instances of non-compliance with privacy and confidentiality guidelines to federal and state authorities.

The Committee recommends that the authority, in collaboration with public and private organizations, educate the public on their patient privacy rights and the privacy and protection of their information under EHRs and HIE exchanges.

Issues for Further Consideration:

2. Ensure that an internal board reviews special study applications for the use of state health information exchange data.

   Recommendations for Implementing the Objective:

   The committee recommends that all requests to the authority for research be reviewed by an internal review board appointed or designated by the authority or governor.

   Issues for Further Consideration:

3. Develop a multi-level approach for secure access to population health that protects patient privacy.

   Recommendations for Implementing the Objective:

The committee recommends that the authority identify regulatory and legislative barriers to accessing population health information based upon State of Illinois HIPAA Pre-emption Analysis and HISPC – Illinois Project.

Issues for Further Consideration:

The authority should look at establishing security access levels for different types of applications. This review should include:

- an information analysis of application types;
- the credentials required of an applicant for different applications;
- distinguish between ongoing and special studies; and
- whether patient identifiable repositories, such as in public health or public health related government organizations, should have access controls and audit trails.

4. Develop a stream-lined approach for secure, approved access to population health information.

Recommendations for Implementing the Objective:

The committee recommends that the authority's design of the state health information exchange include a mechanism to capture population health information and to permit non-patient identifiable research by approved researchers following privacy and security guidelines.

Issues for Further Consideration:

The taskforce has adopted the "federated" model with respect to general patient records. Under that model, health care providers retain the records, but upload patient index information to an RLS. However, there is nothing to preclude the State of Illinois under state law and regulation to require reporting of data to the State to fulfill their regulatory and oversight responsibilities.

Authority staff should also look at RLS, or RLS Plus Tag, architecture to determine its effectiveness in collecting population health data (i.e. bio-surveillance, mandated public health reporting requirements) or for use in research. Related issues to be considered include:

- the cost and ownership of establishing and maintaining population health and a State of Illinois non-identified patient data repository; and

- the management of duplicate patient occurrences (i.e. one patient with multiple occurrences due to submission by physician, hospital, clinic, laboratory, etc.)

5. While patient information and reporting to public health is currently included and covered under HIPAA, an approach for inclusion of patient information for other studies needs to be addressed.

   Recommendations for Implementing the Objective:

   The committee recommends that the authority review the issue of including patient information for other studies.

6. Encourage and enhance "quality" research involving the quality of care and patient outcomes.

   Quality and patient outcomes can be used to:
   - Identify gaps in delivery of care and best practice outcomes
   - Patient and consumer decision-making for consumer guides, report cards, etc.
   - Payment decisions
   - Published studies
   - Regulatory and Quasi-regulatory oversight
   - Identify disparities in health care

   Organizations needing this information may include:
   - Providers
   - Health Plans
   - Regulators
   - Consumer Groups
   - Researchers
   - Employers
   - Media

   Recommendations for Implementing the Objective:

   The committee recommends that the authority work closely with the Department of Public Health's Division of Patient Safety on the design of the state health information exchange to ensure that it captures quality data to address patient errors and other safety issues.

   The committee also recommends the authority should establish a committee to provide and maintain guidelines on the quality of the health

care information maintained by the state health information exchange so that patients, providers, and researchers can be assured of the integrity of the data that is utilized.

To encourage greater participation in research, the committee recommends that providers be notified of any potential patient candidates for clinical studies.

Issues for Further Consideration:

The authority needs to consider methodologies for the removal of duplicate information utilized for both population health/non-identified patient data repositories and studies. This review should address who bears the cost of assembling necessary data and managing duplicate patient occurrences.

Furthermore, the authority will establish time frames and quality reporting requirements and develop participation or suspensions mechanisms for non-compliance.

7. Clinical and medical studies and practice knowledge will rapidly increase with access to EHRs for approved studies. This information needs to be shared with organizations where it will have the most positive impact.

Recommendations for Implementing the Objective:

The committee recommends that in developing its rules regarding research, the authority should take in consideration how the results will be disseminated.

The authority must work cooperatively with the Division of Patient Safety, other offices within the Department of Public Health, the Department of Healthcare and Family Services, the Department of Human Services, and various provider organizations to ensure that needed information is shared with its constituency groups.

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