PUBLIC HEALTH DATA STANDARDS CONSORTIUM

PHDSC

Promoting Standards Through Partnerships

**Privacy, Security and
Data Exchange (PSDE) Committee**

Health Information Privacy in State Public Health Agencies:

A Review of Past, Present and Future Privacy-Related Issues and Priorities Affecting Public Health Practice

Project Report

December, 2008

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1. Introduction

Background

Significant amount of work has been done over the past five years to understand and document the impact of privacy laws on health care organizations, and in particular the impact that the HIPAA Privacy Rule has had on covered entities. Studies have included such topics as the impact of HIPAA privacy on consumer awareness of privacy, access to patient care, care delivery, quality of care, patient safety, research, and compliance enforcement.

Less information is available about the effect that these and other regulations have had on public health and public health agencies, the data they collect, use and disclose, the services supported by these data, and the current and emerging privacy-related issues that state and local public health agencies face, as more information about the health of individuals and the community is captured, maintained and exchanged electronically through electronic health record systems (EHRS), personal health record systems (PHRS) and health information exchanges (HIEs).

Participation of public health agencies in the emerging Nationwide Health Information Network (NHIN) and in regional and local National Health Information Exchanges (NHIEs) is opening a new frontier of opportunities of more efficient and cost-effective ways to communicate electronically. Yet, these same opportunities are bringing new privacy issues that affect how public health agencies participate in, and ultimately use NHIEs and the NHIN to conduct the business of information exchange.

Public health in general and public health agencies in particular have had a long standing tradition of collecting and strictly protecting health information about individuals. For many years, they have gathered health information, some in individually identifiable form, from providers and other sources. This information includes vital and health records (i.e., births and deaths), communicable disease reports (i.e., TB, HIV/AIDS) and disease-specific information (i.e., cancer registries). Federal, state and local public health agencies are required to strictly abide by laws that protect the confidentiality of such information. And they have established strong technical, physical and administrative protections to the health information they collect and use.

In order to adapt to the new HIPAA Privacy regulations, public health agencies have systematically gone through the process of applicability analysis, impact assessment, gap analysis, remediation, and periodic evaluation.

In 2006, the Association for State and Territorial Health Officers (ASTHO) conducted a survey of state agencies' designation under the HIPAA Privacy Rule. The survey found that 32 states of the 50 respondents (64%) had designated their public health agency as a hybrid organization under the HIPAA Privacy Rule ("hybrid" refers to organizations that have some organizational components that are covered by the HIPAA Privacy Rule and some that are not covered). Fifteen (30%) said their state public health agency was designated as a covered entity under HIPAA, while three states (6%) reported the agency classification as 'other' (not a covered entity, most likely).

Notwithstanding their self-designation decision, most state agencies and many local public health departments have established (or named) a formal office within their organization as the 'Privacy Office', and designated an individual as the 'Privacy Officer' of the organization.

In 2003 the Centers for Disease Control and Prevention (CDC) published "HIPAA Privacy Rule and Public Health" (MMWR, April 11, 2003/Vol. 52), a reference document providing guidance to public health agencies and others on the effect of the HIPAA Privacy Rule on the collection, use and disclosure of health information by public health programs and interpreting public health responsibilities under HIPAA Privacy. The National Institutes of Health has also offered guidance on "Protecting Personal Health Information in Research: Understanding the HIPAA Privacy Rule" (NIH Publication Number 03-5388). Several other agencies within the Department of Health and Human Services has since provided guidance on the applicability of HIPAA Privacy to specific program activities. For example, the Health Resources and Services Administration has provided a privacy rule resource guide for HIV service providers; the CDC's National Immunization Program has provided guidance on the applicability of HIPAA Privacy to immunization registries; the Substance Abuse and Mental Health Services Administration also provided HIPAA guidance related to substance abuse and mental health information (see http://www.hipaa.samhsa.gov/Part2ComparisonCleared.htm) Finally, the Office for Civil Rights at the Department of Health and Human Services has also offered some guidance on the applicability of HIPAA Privacy to public health and research.

At the state level, ASTHO has conducted three other important general assessments related to privacy and public health:

- "HIPAA Privacy Rule Implementation in State Public Health Agencies: Successes, Challenges and Future Needs". A 2005 report on the findings of ASTHO's 2004 survey of state public health agency experiences with HIPAA Privacy. The report highlighted how states agencies designate under HIPAA, their achievements, implementation barriers and how those barriers have been overcome

- "Privacy Issues in Public Health Information Exchange Across State Lines". A 2007 report exploring privacy concerns related to the inter-state experiences with public health information exchange

- "Privacy & State Public Health: Results from the ASTHO 2007 Privacy Survey". A report issued in 2008 discussing the role and responsibilities of privacy officers and the privacy office within state public health agencies

  [ASTHO has published other reports on privacy and public health issues, including public health, law enforcement and privacy; privacy in child health information systems; impact of HIPAA privacy on syndromic surveillance, data sharing with covered entities; and privacy and pandemic flu]

But, what are the recurrent, emerging and new issues faced by public health agencies with respect to privacy of health information today? What are their current privacy-related priorities? What are the privacy issues for public health as it relates to the emerging adoption of health information technologies such as electronic health records (EHRs) and personal health records (PHRs)? What are the privacy issues for public health related to the implementation of local and regional health information exchanges (HIEs) and their participation (and exchange of public health information) via these HIEs? These core questions were the focus of the Public Health Data Standards Consortium's 2008 assessment of privacy practices and priorities in state public health agencies.

Project Overview

During 2008, the Public Health Data Standards Consortium conducted a series of interviews with state public health privacy officers. The main purpose of these interviews was five-fold:

- Identify and document health information privacy issues that state public health agencies faced in the past five-six years, since the implementation of HIPAA Privacy, and how they addressed them

- Identify and discuss ongoing health information privacy issues that agencies are currently facing, and how they are being addressed

- Document and discuss new health information privacy issues that agencies see coming, as more health information is expected to be collected, accessed, used and disclosed electronically, and how they see these issues might be addressed

- Identify and document health information privacy issues that agencies will face and that are associated with their participation in a regional exchange (RHIO) network or other health information exchange (HIE) network, and how they see these issues might be addressed

- Identify and discuss multi-state and national issues related to health information privacy and public health and that agencies considered critical to be addressed, and how they see these issues might be addressed

The assessment was intended to be broad in scope and not limited to HIPAA privacy issues. Still, the focus was on privacy issues that directly affect, are affecting, or will be expected to affect the public health agency's ability to exchange individually identifiable health information. Such issues may be internal to the organization, inter-organizational with private sector organizations (such as with providers, health plans, and others), or inter-agency issues (such as between public health and Medicaid).

The project was implemented under the direction of the Consortium's Privacy, Security and Data Exchange (PSDE) Committee. Funding was provided by the National Center for Health Statistics, Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.

The principal investigator for the project and lead author of this report was Dr. Walter G. Suarez, MD, MPH, President and CEO of the Institute for HIPAA/HIT Education and Research.

2. Methodology

The methodological approach used by the Consortium to complete this project consisted of the following steps:

- Identification, selection and recruitment of participating states
- Development of the state interview guide
- Development of state profiles
- Implementation of state interview process
- Aggregation and analysis of findings

Identification, Selection and Recruitment of Participating States

The first step in completing the project was to identify, select and recruit participating states. Funding and resource considerations set a maximum number of eight states to be included. Criteria used to select states included:

- <u>Geographic diversity</u>: achieve a balanced representation from various regions across the US, as well as a balanced representation of states with large urban and large rural population profiles

- <u>Current state of Health IT and HIE development</u>: identify and select states with more advanced levels of adoption of Health IT and implementation of local, regional or statewide HIEs as documented by national initiatives such as the State Alliance for e-Health, State Level Health Information Exchanges, the Health Information Security and Privacy Collaborative (HISPC) project, and the Nationwide Health Information Network initiative

- <u>Leadership on privacy issues</u>: select states that have demonstrated significant leadership in identifying and addressing privacy issues, as demonstrated by their legislative agendas on health information privacy and leadership involvement in national efforts such as HISPC

Based on these criteria and input from the Consortium's PSDE Committee, the following 8 states were identified, selected and recruited for this project:

- California
- Florida
- Massachusetts
- Michigan
- Minnesota
- Oregon
- Washington
- West Virginia

Development of State Interview Guide

In developing the state interview guide, the project first identified the core topics that needed to be covered during the state interview process. These topics were consistent with the five overall goals of the project, noted above.

Accordingly, the interview guide was organized into the following six core sections:

- Section 1 - Basic Agency Information – including general organizational questions covering basic organization demographic, structure, HIPAA designation, privacy office/officer roles and functions and contact information

- Section 2 - Past Health Information Privacy Issues – and how the agency addressed them

- Section 3 - Current/Ongoing Health Information Privacy Issues – and how the agency is dealing with them

- Section 4 - Future/emerging Health Information Privacy Issues – and how the agency foresees preparing for and being able to address them

- Section 5 - Future/emerging Health Information Privacy Issues Associated with Public Health Participation in Regional Health Information Exchanges (RHIO and/or HIE) – and how the agency intends to address them

- Section 6 - Multi-state and National Health Information Privacy Issues Currently Affecting Public Health – and agency suggestions for addressing them

The interview guide included the ability to document examples of tools, documents and resources developed by the public health agency, which could serve as models, guidance and best practices for other states.

A copy of the state interview guide is provided in Attachment 1.

Development of State Profiles

In order to provide a state reference point for the project and to better understand and document the current status of state Health IT and HIE efforts, a State Profile was created for each of the participating states. The profile included the following information:

- Basic Demographics: including state population demographics, health insurance distribution in the state and state health care expenditures data

- Health IT and HIE Projects in the State: providing a snapshot of current developments in the state's Health IT and HIE arena, including local and statewide HIE efforts; NHIN, CDC and the Agency for Healthcare Research and Quality (AHRQ)-funded Health IT and HIE initiatives (as applicable); Medicaid Health IT projects; and the state's Health Information Security and Privacy Collaborative effort

- Roles of Public Health in Health IT and HIE: summarizing the current roles of the state public health agency in adoption of Health IT and implementation of HIE efforts, including facilitator, convener, funder, participant, data contributor, and other

An attempt was made to provide the most up-to-date, accurate and realistic picture of the various evolving efforts in each state, as well as identify unique market dynamics and environmental factors that have contributed to the current stage of development of these efforts in states.

A copy of the State Profiles is provided in Attachment 2.

Implementation of State Interview Process

As noted above, the project plan was to conduct a series of interviews with state public health privacy officers. Once state contacts where identified and participation confirmed, a state interview was scheduled. Interviews lasted 90-120 minutes. Follow-up was only needed to obtain further documentation cited during the interviews. Interviews and other associated data collection were completed during the months of August and September, 2008.

Aggregation and Analysis of Findings

A series of tables capturing the identified issues by states were created to document and assist in the aggregation and analysis of data. Common themes and related issues highlighted by a majority of states were identified and analyzed. Issues that were noted by a small number of states were also highlighted. Findings are presented in the following sections of this report.

3. Privacy Office/Privacy Officer Roles and Responsibilities

The participating states represented a mix of stand-alone public health agencies (6) and combined public health and human services (Medicaid) agencies (2). One of the states classifies the public health agency as a covered entity, six as hybrid entities and one as a non-covered entity.

All have a designated privacy office (in some instance with expanded functions, such as a data access) that is generally a part of the agency's executive office or no more than two persons removed from directly reporting to the public health officer (commissioner or secretary). In most instances the office resides within the Office of Legal Counsel, the Information Security Office, or the office of the Chief Information Officer.

While these privacy offices were generally established following the HIPAA Privacy Rule, not all of them are considered a 'HIPAA' Privacy Office (or 'HIPAA' Privacy Officer), as their responsibilities, privacy-related and otherwise, have gone beyond HIPAA.

In all the participating states, the privacy officer was considered to be the privacy 'expert' and advisor on privacy issues to the agency and to all its programs. Privacy-related responsibilities often cited included:

- Act as the data practices coordinator of the agency, and assist programs in implementing the state's government data practices regulations

- Serve as the central office and single point of contact for coordination, resolution, awareness and education related to privacy

- Implement all administrative and policy aspects delineated by HIPAA (for covered and hybrid entities), including the Notice of Privacy Practices

- Develop, administer and maintain the agency's privacy policies and procedures

- Convene, facilitate and be a member of internal committees, cross agency committees, and public-private committees responsible for discussing and addressing privacy-related issues

- Be involved in, or in some cases be responsible for drafting and reviewing privacy legislation on behalf of the agency

- Identify, detect, prevent, and address agency breaches

    o Privacy officers had different levels of authority to handle agency breaches

    o In some instances, the privacy office is responsible for maintaining a database on all privacy and security breaches, analyzing data and taking remediation actions

- Maintain and administer a comprehensive set of education and outreach programs and activities to ensure internal workforce is appropriately trained and periodically re-trained

    o Create and maintain an internal portal of information
    o Issue news/briefs periodically to all agency staff
    o Maintain records of training efforts
    o Implement train-the-trainer programs

- Coordinate with privacy officers of other state agencies (where applicable) as well as privacy officers of county and local health departments

- Be involved and advise the agency on privacy issues related to research

    o Participate in the IRB of the state agency
    o Advise researchers on privacy issues
    o Serve as a contact for Human Subjects Review Committee (IRB)
    o Review and confirm access to health information is authorized for research purposes

In one of the states these responsibilities are shared among the Director, Confidential Data Officer and Privacy Officer and are not the responsibility of solely the Privacy Officer. In some states the Attorney General's Office has little to do with the privacy issues related to public health.

In another state, the Governor has created a statewide privacy office that coordinates the privacy-related activities of all agencies, establishes and

administers the statewide privacy framework and works with all agency privacy officers. It also offers a call-center for consumers to address questions about privacy.

Generally, state public health privacy offices do NOT have enforcement authority or responsibilities. This is mostly done via other enforcement mechanisms (licensure, sanctions) as well as legal and law enforcement actions (via the state AGs office) when necessary.

In all participating states, the privacy office is small, with 2-3 full time employees, including the privacy officer, an administrative person and a technical/support person.

Most offices have an external web presence in the agency's website, where they provide information and resources to various audiences including consumers, providers, payers, researchers and others.

4. Health Information Privacy Issues Faced by Public Health Agencies in the Past Five Years

With the implementation of the HIPAA Privacy Rule in 2003, state public health agencies faced a number of issues and challenges. These issues and challenges stemmed primarily from the various administrative provisions of the rule, as well as the confusion that existed among providers and others during the initial transition months regarding the ability to report data to public health agencies.

In preparation for this transition, one of the first priorities cited by state public health privacy officers was to ensure that all programs within the agency would be able to continue to receive the data needed for their operations. All participating state agencies noted the need to prepare and submit letters to providers and others clarifying the classification of public health programs under HIPAA and the Privacy Rule provisions permitting the disclosure of protected health information to public health authorities for public health purposes, and informing them of their ongoing and uninterrupted responsibility to report such data to public health agencies.

Other priority activities undertaken by public health agencies in response to the HIPAA Privacy Rule and consistently cited by all participating states included:

- Determination, documentation and dissemination of the self-designated covered entity status under HIPAA (i.e., covered entity, hybrid, not a covered entity)

- Establishing/designating a privacy office/privacy officer and assigning responsibilities

- Preparing and conducting an in-depth program-by-program analysis of the impact of HIPAA to the collection, use and disclosure of health information by such programs. Programs that showed special circumstances and need for clarification included:

    o Disease registries (i.e., cancer)
    o Immunization registries
    o WIC Program
    o Encounter-level data projects
    o Early Intervention (is under FERPA, not HIPAA)

- School Health and School Based Clinics (HIPAA and FERPA intersection
- Substance Abuse Services (intersection of 42 CFR Part 2 and HIPAA)

- Conducting an analysis of public health laws, particularly those related to the collection of health information, vis-à-vis the HIPAA Privacy Rule

- Identifying those areas where it was necessary to amend regulations to allow for the collection of certain information

- Developing internal privacy (and security) policies and procedures to address specific existing (and new) requirements identified by HIPAA. In this respect, state privacy officers commented that HIPAA helped them identify gaps and holes in their internal policies and elevated the level of documented policies and procedures aimed at addressing privacy issues

- Creating an external communications strategy, including the development of the Notice of Privacy Practices (as applicable) and the availability of other resources for consumers, clients, providers and others. Specifying state regulatory requirements and citations of public health agency authority to collect data was critical for providers

- Initial education and training of the organization's workforce on privacy (and security) issues. This was one of the most prominent (and challenging) roles of the newly appointed privacy officer, as reported by all participating states. In some cases the workforce represented thousands of employees than needed to be trained in a very short amount of time on a complex subject. Retraining and specialized training continues to pose major challenges

- Securing and disseminating specific legal opinions (coming, for the most part, from the state's Attorney General) on the applicability of the HIPAA Privacy Rule to specific public health data projects, including immunization information exchanges, cancer registries (and other chronic condition registries), vital statistics, communicable disease reporting, public health laboratory data exchanges, and others

- Clarifying to external covered entities (data submitters such as providers and payers) that the agency was not and should not be

considered a Business Associate of the covered entity for purposes of such data submissions

- Identifying and addressing public health program initiatives that included collection of individually identifiable health information from providers and for which the agency did not have specific legislative or regulatory authority but was using broad agency data collection powers to support. In some instances the state had to promulgate regulations or pursue a specific legislative authority to avoid the drop in covered entities participating in such initiatives

- Providing guidance to local public health departments (in various forms, including written and in-person training) on agency designation under HIPAA, the impact of HIPAA regulations on data collected by local health departments, and the impact of data being exchanged between state and local agencies

- Conducting, facilitating, or participating in the development of comprehensive state preemption analyses, particularly in states where state privacy laws where more comprehensive and stringent

- Addressing concerns from providers regarding wrongly perceived privacy restrictions on disclosures of health information when dealing with public health investigations that required review of records

- Beginning to identify and address risks associated with portable devices used by agency personnel (laptops, portable hard drives), establishing a balanced, yet strong and strict policy around these issues, and educating staff and enforcing compliance with policy

- Identifying the 'true' business associates of the agency (if agency had self-designated as a covered entity or a hybrid entity)

5. Current and Ongoing Health Information Privacy Issues Reported by Public Health Agencies

Once the initial wave of concerns, problems and challenges for public health agencies that emanated from HIPAA subsided, several new issues emerged. Among them:

- **<u>Data linkages and Data De-identification</u>**

  These two opposing and somewhat contradicting issues continue to pose challenges to public health agencies.

  On the one hand, public health benefits greatly from the ability to look at information longitudinally, linking data across disparate systems to create a more complete, longitudinal record of an individual. This is particularly valuable across health and human services agencies (public health and Medicaid) to assist with early intervention programs and activities.

  On the other hand, public health agencies are concerned about the increasing risk and apparent ease with which data disclosed by the agency as de-identified is now being re-identified, by using advanced record linkage capabilities.

  In addition to this, the difficulty of defining de-identification per-se remains a major issue. Different statutes (federal and state) have different definitions. Even if identifiers are removed, there is still a need to make sure that the remaining data do not inadvertently identify an individual.

  Public health agencies identified the need for a standardized way to ensure data de-identification and secure and reliable methods for data linkages across multiple databases as these issues continue to pose challenges to public health agencies.

- **<u>Handling Data Breaches and Identity Theft</u>**

  This was one of the single most commonly cited priority issue from participating privacy officers. With the advent of more information collected and maintained electronically, an increasing amount of identifiable information and enhanced capabilities for record linkages,

the need to prevent, monitor, identify, detect, manage and remediate breaches has become one of the more important functions of privacy officers.   Some of the more important issues related to data breaches noted by participating states included:

- o Data mobility and the portability of data devices must be handled appropriately. Establishing strong policies on things like laptop encryption, transport security, and others is paramount

- o New and emerging state legislation (consumer protection laws, data breaches, identity theft) that imposes strict requirements on breach notification and applies both to the private sector and to state agencies. For example, in one of the states the breach notification law applies to an individual's name along with a SSN, drivers' license numbers, and financial account or credit card numbers; however, it does not apply to protected health information without one of the above

- o Working together with security officers and IT staff to establish security mechanisms that assist in preventing, monitoring, reporting and documenting breaches and data exposures

- o With respect to data breaches from entities regulated by public health, a need to strengthen the enforcement capabilities of public health agencies

- o Aligning data breach policies with new and emerging identity theft protection regulations

- o Creating a 'breach prevention' culture and workforce that emphasizes prevention, early detection and timely reporting of breaches, regardless of size or perceived significance of exposed data. Fostering reporting of 'near misses' and 'close calls' is necessary to identify systemic issues in the handling and processing of information. On this point, one of the states noted that a major challenge they face is that many people in public health believe they have always taken great care with the privacy of personal data. This is a barrier to their paying attention to new policies and technologies, as they believe they already follow best practices, even though they may not. Moreover, they believe it takes time away from their core public health mission to focus on privacy and security. It is hard to

convince employees that the privacy and security of public health data are part of the core public health mission.

- o Challenges with newer technologies such as wireless, hand-held devices

- **<u>Privacy of Genetic Information</u>**

With the increasing amount of genetic information about individuals being collected and stored in health records, there was an impending need to establish a strong national policy protection framework. This was somewhat addressed with the passage of the Genetic Information Nondiscrimination Act (GINA) of 2008 (Public Law 110-223).

Nonetheless, states are investigating the need to further strengthen these regulations with more stringent laws. At the same time, privacy officers were cautious about possible unintended effects of more restrictive regulations, particularly when it comes to the impact that certain genetic information may have in selecting and recommending specific treatment options.

- **<u>Ongoing Education and Training of the Workforce</u>**

Privacy officers continue to experience challenges when it comes to ensuring appropriate privacy and security-related training and education of the workforce. Availability of adequate resources; efficient methods of delivering context-sensitive training to the right staff at the right time; and updating and expanding training efforts in an increasingly complex data security environment were three of the issues most commonly cited.

One of the privacy officers noted that *"… privacy is relatively easy here – Security is the problem. That is where the challenges exist…"*.

This was one of the areas where privacy officers are in agreement. There are significant amounts of information and techniques available for workforce training. The challenge is the degree to which the content of the training must be sensitive and specific to the laws, regulations, and policies and procedures applicable to a specific jurisdiction and state and local agency

■ **Enforcement**

Privacy officers agree that they have little to no external enforcement authority on privacy, and that the most they have is internal authority to oversee and handle privacy-related issues in the agency.

Most privacy-related violations are handled by the federal Department of Health and Human Services Office for Civil Rights, specifically those related to HIPAA and committed by covered entities. States do have defined enforcement and compliance roles, particularly in light of the emerging consumer protection laws, and they mostly fall under the jurisdiction of the state's Attorney General Office. The state public health agencies do have specific oversight responsibilities and enforcement action capabilities over licensed and regulated entities, but most of them do not relate to health information privacy violations. Further clarification on this authority and responsibility was recognized as a needed priority for states.

■ **Selected Topics**

A number of additional topics, including state-specific issues, were noted by participating privacy officers, including:

o Need to update outdated statutes related to basic/brief substance abuse screenings in primary care settings and the determination that such screenings are protected under substance abuse federal laws. The issue some states have had with this brief screening intervention is two fold. First, is it also subject to 42 CFR Part 2, in addition to HIPAA? This likely depends on who conducts the brief intervention. If it is a staff person hired for this purpose and it is his or her primary responsibility, then it appears to be covered. If it is the physician, who does not have this function as his or her primary responsibility then it is not covered. This is where the amendment of federal law would assist. Second, as a public health agency funding these projects, the agency would like to collect these data and follow these clients longitudinally to ascertain the effectiveness of early interventions. This generally requires client consent, which would likely undermine the screening.

- New federal requirements to report HIV/AIDS data to the states (not CDC) with identifiable information including, specifically, the name of the individual, which requires amendment of regulations and assurances to consumers that these data will be adequately protected

- HIV/AIDS testing now has a specific billing code that can easily show in encounter-level data

- There are similar issues for billing substance abuse screening in a primary care setting

- One of the participating states is implementing a Personal Health Record Data Bank project, which poses a significant number of privacy concerns and challenges

- Privacy needs and considerations of the state Refugee Health Assistance Program, including the need to translate the Notice of Privacy Practices into over 400 different languages

- New Real ID Regulations and the impact on matching driver license records with birth certificate data

- Privacy considerations related to the exchange of health information for emergency preparedness and bioterrorism events, particularly across state boundaries. This same issue arises with respect to communicable diseases and newborn hearing and metabolic screening and sharing data across state borders. Several states noted that while there is guidance available on these topics, some confusion still exists among providers. There has been, for example, conflicting directions from the federal government related to the ability to publish lists of names on emergency shelters

- The impact of federal laws such as the Patriot Act on access to health information by some agencies (such as Homeland Security) being held by HHS and other federal and state agencies

- Ability of state laws to address the protection of student records under the Family Education Rights and Privacy Act (FERPA) and the restrictions to access, when such information is essential for

public health purposes such as immunizations, communicable disease outbreaks, environmental risks and lead exposure prevention

6. New and Emerging Health Information Privacy Issues Identified by Public Health Agencies

State public health privacy officers participating in this project noted that most of the issues they already identified as current will continue to evolve and exist in the coming months. Issues around data breaches, linkages of data sets, emergency preparedness and genetic privacy were mentioned here as well.

Most of the new and emerging issues noted by privacy officers related to the adoption and use of new and emerging health information technologies, such as electronic health records, personal health records, health record banks, and the increased ability to share and create virtual longitudinal records of individuals across communities and nationwide.

Notwithstanding the issues identified by privacy officers as emerging and that relate to health information exchanges (discussed in the next section of this report), the following are the most significant new issues privacy officers expect to face into the future:

- **Need to Develop a State Public Health Privacy Framework**

    Privacy officers agree on the need to develop a robust and comprehensive public health privacy framework at the state level that simplifies the understanding and documentation of privacy regulations applicable to the reporting of health information by providers (and others) to public health and the disclosure of health information by public health agencies.

- **Need to Standardize Definition of Sensitive Health Information**

    As consumers are increasingly being offered the ability to exercise privacy controls over their health information via electronic consent systems used in electronic health records, personal health records and health information exchanges, the need to categorize in a simplified manner different types of health information will become critical.

- **Impact of Personal Health Records on Public Health**

    Although personal health records are still evolving, the potential impact on public health information systems and programs can be

significant. Privacy officers agreed on the need to monitor and study the relationships between these tools and public health, particularly the privacy and security aspects of accessing and exchanging information between the two.

- **Consent Standard**

  Privacy officers agreed there is a need to develop a standardized consent form, even within a state, to advance the harmonization of consumer consent requirements and expectations. One of the states has already established a standard form and others commented on the value that such standard form will have on their own state efforts to achieve a similar goal.

- **Telecommuting Policy and Continuity of Operations**

  Public health agencies continue to adapt to increasing demands and requirements for telecommuting among their employees. This brings additional needs to establish secure mechanisms for allowing employees to connect and communicate remotely. Strong policies on what data can be kept locally/remotely and what procedures employees should follow to ensure the integrity and confidentiality of the information are needed. This also requires an auditing component that is beyond most agencies' current resources.

- **Transferring of Responsibilities to New Privacy Officer**

  Given that most privacy offices are very small and that significant amount of the historical knowledge and information about the office, state policies, and privacy operations lies within the privacy officer, transferring such knowledge and responsibilities to a new person when the time comes will be a significant challenge.

- **Research and Privacy**

  Privacy officers expect an increasing demand for identifiable information for research purposes, as agencies collect and maintain larger and more detailed data and information in electronic form. This will also bring increased opportunities to link databases to create a more complete, longitudinal view of an individual's experience with the health care system. Both will bring more complex privacy issues to be handled by IRBs of state agencies and open the broader ethical issue

of balancing increased access for research with increased concerns and sensitivity about privacy.

There is also a recurring challenge around collaborations between public health and academic institutions or other contractors in research projects.

- **Need for Increased Resources for Privacy Officers**

Privacy officers expect to see an increased demand for their services, and there will be a need to secure additional resources to continue to fulfill the duties and responsibilities of the office. There is also the opportunity to establish a more formal network of public health privacy officers to share experiences, issues, challenges and develop common approaches to resolve them.

7. Health Information Privacy Issues Related to the Participation of Public Health in State, Local and Regional Health Information Exchanges

Public health agencies have often been at the forefront of the development and deployment of local and state health information exchanges. In most states they have played a leadership role serving as a neutral convener, facilitator and funder (through state appropriated funds) of such efforts. Still, most public health agencies do not participate actively as data contributors or exchange health information with their 'exchange partners' via these regional HIEs.

Nonetheless, privacy officers did identify the following privacy-related issues specific to public health and HIEs:

- **Lack of Integration of the State's Public Health Information Infrastructure with State's HIE efforts**

  As noted, state public health information infrastructures continue to exist in parallel silos with emerging HIEs in states. Little or no connections exist yet between these systems. Data flows continue to be achieved via customized connections, some utilizing secure Internet file transfer sites.

- **Lack of a Roadmap for Public Health Participation in HIEs**

  A roadmap for public health participation would help systematically organize the way by which public health networks and databases, such as the state's Public Health Information Network, Electronic Disease Surveillance System, Health Alert Network, BioSense connections (where applicable), Public Health Laboratory system, Immunization Registry, Cancer Registry (and other chronic disease registry systems) will be linked to state or local HIEs.

  As more provider organizations join and begin exchanging information via an HIE, they will expect to be able to communicate and report to the state public health agency in a similar fashion the type of information they are required to report for public health purposes.

- **Lack of a Regulatory Framework for HIEs in States**

  At this point only a few states have began to develop a regulatory framework for the implementation of HIEs in the state, including the way privacy will be protected and maintained in such HIEs, consistent with state laws and regulations. How consumers agree to have their information exchanged and made available through HIEs is a critical step. Will there be an 'Opt-In' or an 'Opt-Out' option? Would consumers be able to control their health information at a more granular level than an all-or-nothing option? These are the types of privacy policy issues that states must address. Currently there are only very few states that have established laws around how consent will operate in an HIE, let alone developed a comprehensive regulatory framework.

- **Lack of a Public Health Privacy Framework for HIE Participation**

  Defining the privacy framework under which public health will participate in HIEs will be critical to ensure the adequate protection of health information exchanged by HIE participants with public health agencies.

8. Multi-State and National Health Information Privacy Issues Affecting Public Health

A number of multi-state and national-level privacy issues affecting public health were identified by participating states. Some issues are similar to those at the state level. They include:

- **Need for a Federal-level Public Health Privacy Framework**

    As with the need to develop state public health privacy frameworks, a federal public health privacy framework would be beneficial to help build a consistent understanding of the privacy of public health information exchanged between state and local public health and various federal agencies.

- **Lack of Inter-Jurisdictional Portability of Privacy**

    State privacy officers recognized the lack of portability of privacy across state boundaries as a major challenge for the implementation of HIEs. The need to address this lack of cross-state portability via inter-state agreements (in light of the fact that a national 'ceiling' regulation is unrealistic at this point) was noted.

- **National Privacy Framework for Privacy in Cross-state Emergency Situations**

    While privacy laws allow the exchange of information during natural and man-made disaster events, privacy officers felt there was a need to create and offer a uniform national framework on how to share data between and across states during such events.

- **Re-release of Information Across States and by Federal Government**

    Significant concerns exist among privacy officers on the issue of re-release of information provided from one state to another, or by a state to the federal government.

■ **<u>Need to Standardize Definition of Sensitive Health Information</u>**

As noted earlier, privacy officers agreed that there is a need to address at the federal level the variations in definition, interpretation, protection and implementation of so-called 'sensitive' health information. Such information generally includes mental health, substance abuse, sexually transmitted diseases, reproductive health, genetic information, and others.

■ **<u>FERPA Restrictions on Access to School Records</u>**

FERPA continues to impose restrictions on public health's ability to access health information on school records that would be beneficial for purposes such as child immunizations and lead exposure prevention, as well as for analysis of asthma, childhood leukemia and developmental disabilities due to environmental exposure.

■ **<u>Specific Cross-border Privacy Issues</u>**

Privacy officers noted specific challenges for cross-border exchange of information under certain public health programs. These included:

o Newborn Hearing Screening and Newborn Metabolic Screening – Babies born in one state that live in another state – how is the data being shared or reported? What can be shared with other state public health agencies? There is a need to develop inter-state agreements to ensure consistent implementation of these exchanges

o For acute communicable diseases, it seems there is broad authority on state public health agencies to share data for the benefit of a community to prevent the spread of diseases. Still, it wasn't clear whether these broad powers are being used consistently when exchanging communicable disease information across states

o Sharing of immunization registry data across states appears to be possible to be done, but there is a lack of common understanding and a standard inter-state agreement that would facilitate such exchanges.

9. Concluding Themes and Possible Roles, Opportunities and Areas of Work for the Consortium

This report summarizes the results and findings of a series of interviews conducted by the Public Health Data Standards Consortium in 2008 with a group of public health privacy officers from selected states.

In the five years since the implementation of the HIPAA Privacy Rule, public health privacy officers (and their respective Privacy Offices) have become invaluable resources within state agencies, consolidating their roles as lead 'experts' on the interpretation and applicability of privacy regulations to public health programs. In doing so, they have created a wealth of information, documentation, tools and resources, most of which are publicly available.

The findings presented in this report highlight a series of priority issues and challenges that, together, represent a unique agenda of opportunities for the advancement of public health information privacy in the US.

In addition to the various recommendations for action presented in the previous sections of the report, there are four possible opportunities and areas of work for the Consortium.

- **Convene a Public Health Privacy Officers Community of Practice**

  Privacy officers have found significant value on the possibility of continuing to get together to share information and issues with others. The Community of Practice would serve such convening role. It would be open to federal, state and local privacy officers.

- **Explore the Possibility of Conducting a More Comprehensive Survey**

  Gathering information from a much larger group of states and including local public health privacy officers would serve as a comprehensive nationwide baseline for top priority privacy issues faced by state and local public health agencies.

- **<u>Conduct a Similar Survey of Public Health Security Officers and Explore the Possibility of Convening a Public Health Security Officers Community of Practice</u>**

  The current project focused primarily on public health privacy issues. Nevertheless, participating privacy officers consistently noted the need to work closely with their Information Security counterparts.

- **<u>Explore the Possibility of Establishing a Web-based Public Health Privacy and Security Resource Center</u>**

  As has been noted in this report and through the work of the Consortium, there is a wealth of information, documentation, model forms, templates, and other resources that state public health agencies have created over the past several years and that can be catalogued, organized and made available to others via a web-based resource center.

Over the next few months the Consortium will evaluate these and other priorities and opportunities and consider launching a comprehensive public health privacy and security project agenda for 2009.

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Health Information Privacy in State Public Health Agencies:

*A Review of Past, Present and Future Privacy-Related
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Attachment 1
State Interview Guide

Project Report

December, 2008

Background

The Public Health Data Standards Consortium is implementing a series of projects to identify and document current and emerging health information privacy-related issues that affect state and local public health agencies, and collect and disseminate a series of best practices from states addressing these issues.

The purpose of this questionnaire is to elicit the following:

- Health Information Privacy issues that your agency faced in the past five-six years, since the implementation of HIPAA Privacy, and how your agency addressed them

- Ongoing health information privacy issues that your agency is currently facing

- New health information privacy issues you see coming, as more health information is expected to be collected, accessed, used and disclosed electronically

- Health information privacy issues you see associated with participation in a regional exchange (RHIO) network or other health information exchange (HIE) network

- Multi-state and national issues related to health information privacy and public health that you consider critical to be addressed

Please note this is a broad health information privacy assessment and should not be construed to only focus on HIPAA Privacy-related issues.

Also note that the focus of this assessment is on privacy issues that directly affect, are affecting, or will affect the public health agency's ability to exchange individually identifiable health information. Issues may be internal to the organization, inter-organizational with private sector organizations (such as providers, health plans, others), or inter-agency issues (such as between health and Medicaid, if applicable). This should be used as the context for all the questions that follow.

How is the Instrument Organized

The questionnaire is divided into six core sections:

- Section 1 - Basic Agency Information – including general organizational questions covering basic organization demographic, structure, classification, as well as contact information of the responder
- Section 2 - Past Health Information Privacy Issues and how your agency addressed them
- Section 3 - Current/Ongoing Health Information Privacy Issues and how your agency is dealing with them
- Section 4 - Future/upcoming general Health Information Privacy Issues and how your agency foresee them being addressed
- Section 5 - Future/upcoming Health Information Privacy Issues specifically associated with agency's participation in a regional exchange (RHIO) network or other health information exchange (HIE) network and how your agency foresee them being addressed
- Section 6 - Multi-state and National Health Information Privacy Issues affecting your public health agency

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Disclaimer: Participation in this interview is voluntary. Summary of the results of the interview will be provided to participant prior to publication. Results will be published in an aggregate manner. Permission will be requested from the state contact prior to publishing any non-public information from the state gathered during the interview process.

Part 1 – Basic Organization Information

- Name of agency/division:

- Brief description of agency/division (mission, organization, size (staff), overall health information role and activities)

- Name of Contact (including job title, email, other contact information)

- Type of organization:

  _____ Stand-alone public health agency
  _____ Combined Public Health and Human Services (Medicaid) agency
  _____ Other (please describe)_____

- Please briefly describe your agency's privacy office (role, mission, activities, staffing, website, major successes/accomplishments, major challenges)

Part 2 – <u>Past</u> Health Information Privacy Issues

2.1   What were the top five (5) health information privacy-related issues that your agency faced since the implementation of HIPAA Privacy?

2.1 Top Five Privacy-related Issues your agency faced since the implementation of HIPAA Privacy	2.2 How did you address them? Were your solutions successful?	2.3 Can you provide examples (i.e., letters, written policies, practices, reports, legal opinions, communications, other) of materials you used to address these issues? (*)	2.4 What was most helpful in addressing these issues?
Issue 1:			
Issue 2:			
Issue 3:			
Issue 4:			
Issue 5:			

(*) Please send electronic files (if available) via email or if non-electronic materials via fax/mail.

2.5 Please identify and briefly describe one or two privacy-related issues your agency has faced, if any, since implementation of HIPAA Privacy related to each of the following specific health information topics/areas, if any:

    2.5.1   <u>Vital and Health Statistics data</u>
                Issue 1:
                Issue 2:

    2.5.2   <u>Notifiable/Reportable Conditions data</u>
                Issue 1:
                Issue 2:

    2.5.3   <u>AIDS/HIV Data</u>
                Issue 1:
                Issue 2:

    2.5.4   <u>Mental Health/Chemical Dependency Data</u>
                Issue 1:
                Issue 2:

    2.5.5   <u>Adolescent Health Data (i.e., reproductive health)</u>
                Issue 1:
                Issue 2:

    2.5.6   <u>Disease Registries</u>
                Issue 1:
                Issue 2:

    2.5.7   <u>Discharge data/Encounter data</u>

Issue 1:
Issue 2:

2.5.8   Patient Safety
Issue 1:
Issue 2:

2.5.9   Research
Issue 1:
Issue 2:

2.5.10   General data sharing
Issue 1:
Issue 2:

2.5.11   Other
Issue 1:
Issue 2:

Part 3 – <u>Current/Ongoing</u> Health Information Privacy Issues for Public Health

3.1 What are the top five (5) health information privacy-related issues that your agency is currently facing?

3.1 Top Five Privacy-related Issues your agency is <u>currently facing</u>	3.2 What are you doing to address them? Are your solutions being successful?	3.3 Can you provide examples (i.e., letters, written policies, practices, reports, legal opinions, communications, other) of materials you used to address these issues? (*)	3.4 What has been most helpful in addressing these issues?
Issue 1:			
Issue 2:			
Issue 3:			
Issue 4:			
Issue 5:			

(*) Please send electronic files (if available) via email or if non-electronic materials via fax/mail.

3.5 Please describe one or two privacy-related issues, if any, that your agency is <u>currently facing</u> related to each of the following specific health information topics/areas, if any:

    3.5.1   <u>Vital and Health Statistics data</u>
        Issue 1:
        Issue 2:

    3.5.2   <u>Notifiable/Reportable Conditions data</u>
        Issue 1:
        Issue 2:

    3.5.3   <u>AIDS/HIV Data</u>
        Issue 1:
        Issue 2:

    3.5.4   <u>Mental Health/Chemical Dependency Data</u>
        Issue 1:
        Issue 2:

    3.5.5   <u>Adolescent Health Data (i.e., reproductive health)</u>
        Issue 1:
        Issue 2:

    3.5.6   <u>Disease Registries</u>
        Issue 1:
        Issue 2:

    3.5.7   <u>Discharge data/Encounter data</u>
        Issue 1:

Issue 2:

3.5.8   Patient Safety
Issue 1:
Issue 2:

3.5.9   Research
Issue 1:
Issue 2:

3.5.10   General data sharing
Issue 1:
Issue 2:

3.5.11   Other
Issue 1:
Issue 2:

3.6   What are the **current top five health information privacy-related priorities for the state** (i.e.,
consumer consent, privacy breaches, etc) and how are you addressing them?

Issue 1:
Issue 2:
Issue 3:
Issue 4:
Issue 5:

Part 4 – <u>Future/Upcoming</u> General Health Information Privacy Issues for Public Health

4.1   What do you foresee are going to be the top five (5) health information privacy-related issues that you believe your agency will face in the future?

4.1 Top Five Privacy-related Issues you believe your agency <u>will face in the future</u>	4.2 Do you have any plans to address them? How do you think they will be best addressed?	4.3 What do you think would be most helpful in addressing these issues
Issue 1:		
Issue 2:		
Issue 3:		
Issue 4:		
Issue 5:		

4.2   Please describe one or two privacy-related issues you foresee your agency <u>facing in the coming years</u>, if any, related to each of the following specific health information topics/areas:

4.2.1   Vital and Health Statistics
         Issue 1:
         Issue 2:

4.2.2   Notifiable/Reportable Conditions
         Issue 1:
         Issue 2:

4.2.3   AIDS/HIV Data
         Issue 1:
         Issue 2:

4.2.4   Mental Health/Chemical Dependency Data
         Issue 1:
         Issue 2:

4.2.5   Adolescent Health Data (i.e., reproductive health)
         Issue 1:
         Issue 2:

4.2.6   Disease Registries
         Issue 1:
         Issue 2:

4.2.7   Discharge data/Encounter data
         Issue 1:
         Issue 2:

4.2.8   Patient Safety

Issue 1:
Issue 2:

4.2.9   Research
         Issue 1:
         Issue 2:

4.2.10   General data sharing
         Issue 1:
         Issue 2:

4.2.11   Other
         Issue 1:
         Issue 2:

4.3   What do you foresee will be the top **general five health information privacy-related priorities for the state over the next few years** (i.e., privacy of health information exchanges, breaches, enforcement) and how do you see them being addressed?

       Issue 1:
       Issue 2:
       Issue 3:
       Issue 4:
       Issue 5:

Part 5 – Future/Upcoming Health Information Privacy Issues Specifically Related to the Agency's Participation in Local or State RHIOs and/or HIEs

5.1   Are there any statewide health information exchange [1] initiatives currently underway in the state? If so, please briefly describe

5.2   What role(s) is/are your agency playing in such effort(s)

_____ Facilitator/convener
_____ Funder
_____ Data contributor
_____ Data exchange participant
_____ Policy/regulatory role
_____ Member of board overseeing effort
_____ Member of planning committees
_____ Member of implementation committees
_____ Other (please explain)

5.3   Is your agency currently exchanging health information via a regional or statewide health information exchange (HIE)? If so, what type of information is your agency exchanging via the HIE?

5.4   What privacy issues do you see related to health information exchange?

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[1] By Health Information Exchange (HIE) Initiative we mean the sharing of clinical and administrative health information electronically among independent health care organizations through an organized, multi-organization regional or state network.

5.5   How do you think these issues can be addressed?

5.6   What would help your agency address the issues?

Part 6 – Multi-State and National Issues Health Information Privacy Issues Affecting Public Health

6.1   What do you believe are the top five current multi-state and national privacy related issues affecting public health?

        Issue 1:
        Issue 2:
        Issue 3:
        Issue 4:
        Issue 5:

6.2   How do you see them being addressed?

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Attachment 2
Participating State Profiles

Project Report

December, 2008

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Introduction

- **States Involved in Project**

- **Topics Covered in State Profiles**

    o **Basic Demographics**
    o **Health IT and HIE Projects in the State**
    o **Roles of Public Health in Health IT and HIE**

- **Data Sources**

State Profiles

Introduction

This document contains a series of profiles from states that participated in the 2008 Public Health Data Standards Consortium's "Assessment of Privacy Issues and Priorities for Public Health Practices" project.

States Involved in Project

States that participated in the Consortium's project included:

- California
- Florida
- Massachusetts
- Michigan
- Minnesota
- Oregon
- Washington
- West Virginia

Topics Covered in State Profiles

The state profiles include information on the following core topics:

- Basic demographics
- Health IT and HIE in the State
- Roles of Public Health in Health IT and HIE

Data Sources

Information gathered for these profiles came from five major sources:

- State contacts (including public information available from the state's websites)

- Health Information Security and Privacy Collaborative (HISCP) Project Reports – http://privacysecurity.rti.org/

- Agency for Healthcare Research and Quality (AHRQ) National Resource Center for Health Information Technology – http://healthit.ahrq.gov/portal/server.pt?open=512&objID=650&PageID=0&parentname=ObjMgr&parentid=106&mode=2&dummy=

- Health Information Management System Society (HIMSS) State Dashboard - http://www.himss.org/statedashboard/MapPage.aspx

- State Level Health Information Exchange (SLHIE) – http://www.slhie.org/efforts.asp

- Kaiser Family Foundation - http://www.statehealthfacts.kff.org/

1. California

<mark>Basic Demographics</mark>

General Demographics	State #	State %	US #	US %
Total	36,163,342	100%	298,215,356	100%
Metro	35,540,245	98%	249,589,926	84%
Non-Metro	623,097	2%	48,625,430	16%
<19 years	10,035,692	28%	78,645,221	26%
19-64	22,254,972	62%	182,781,246	61%
65-74	2,041,236	6%	19,587,238	7%
75+	1,831,443	5%	17,201,650	6%
Female	18,204,795	50%	152,167,024	51%
Male	17,958,548	50%	146,048,331	49%
White	15,579,846	43%	196,128,707	66%
Black	2,242,188	6%	36,259,715	12%
Hispanic	13,230,020	37%	45,949,214	15%
Other	5,111,288	14%	19,877,720	7%
Median Income	$55,864.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	17,772,178	49%	159,311,384	53%
Individual	2,420,619	7%	14,541,782	5%
Medicaid	5,793,999	16%	39,296,423	13%
Medicare	3,200,361	9%	36,155,452	12%
Other Public	274,296	1%	3,253,122	1%
Uninsured	6,701,890	19%	45,657,193	15%
Total	36,163,342	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$166,236		$1,551,255	
Hospital Care	$57,805	35%	$566,886	38%
Physician and Prof Services	$55,595	33%	$446,349	28%
Drugs and Nondurable Medications	$20,799	13%	$222,412	14%
Nursing Home Care	$8,424	5%	$115,015	7%
Dental Services	$11,625	7%	$81,476	5%
Home Health Care	$5,537	3%	$42,710	2%
Total Gov. Expenditures	$171,181		$1,340,034	
Gov. Health Expenditures	$38,575		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

In 2007, the state of California reorganized its existing Department of Health Services into two separate department-level agencies:

- The California Department of Health Care Services – responsible for financing and delivering health care services to Californians, including administering the California Medical Assistance Program – Medi-Cal

- The California Department of Public Health – focusing on creating, maintaining and administering the state's public health infrastructure

The state also renamed the California Office of HIPAA Implementation (CalOHI) to the California Office of Health Information Integrity (CalOHII). The new office is the lead state office on Health IT adoption and HIE Implementation. It is working with a wide spectrum of healthcare stakeholders including providers, consumers, health care industry representatives and privacy and security advocates to enable the adoption and application of Health IT and HIE in the state. In addition, CalOHII is also working on a number of items on the administration's health information

technology agenda, including the expansion of broadband initiative, telemedicine, and Health Information Technology Financing study. Many of the activities done in support of these projects involve other state and government partners and are well beyond the original scope of the office.

- **California Health Information Law Identification Project**

    The California Health Information Law Identification Project (CHILI) will identify and organize provisions of the Constitution of the State of California and all codified State statutes (or subdivisions thereof) that relate to the privacy or security of health information, e.g., every provision of State law that has one or any combination of the following specific purposes:

    - Regulating the collection of health information;
    - Regulating the use of health information;
    - Regulating the disclosure of health information;
    - Regulating the privacy of health information;
    - Regulating the security of health information;
    - Regulating the storage or retention of health information;

    or, the statute otherwise affects the regulation of health information in a "direct, clear, and substantial way."

    The CHILI reference tool will be an interactive tool available to search by keyword, HIPAA regulation number or California statute number and will enable the user to quickly identify the provisions of California law that regulate the use of health information or health records, as well as correlating the California provisions that resonate with the privacy and security requirements of the federal HIPAA provisions. The CHILI will also provide a link to the OHI's HIPAA preemption analysis, where applicable.

- **Health Information Technology Financing Advisory Commission**

    The purpose of this Commission is to determine the extent to which access to capital impedes the implementation of Health Information Technology in various health care sectors; if impediments exist, determine whether the state should be involved in addressing these impediments, and suggest how that involvement might be most effectively implemented.

- **California Privacy and Security Advisory Board (CalPSAB)**

    Privacy and security of health information is a cornerstone to the success of the electronic exchange of health information. In October, 2007, the Secretary of the California Health and Human Services Agency announced the formation of the new CalPSAB. The Advisory Board is the arena where the interactions of the law, privacy, security and the education of consumers and providers can be strategically explored and addressed. The goal is to work though the business variations and legal impediments found within California so that we can be in a position to pilot the exchange of electronic health information with other states.

The CalPSAB is a private and public collaboration which makes recommendations regarding privacy and security standards, policies, model documents and law changes. The Advisory Board oversees four Committees; Privacy, IT Security, Legal, and Education. The Committees research and analyze issues, develop and evaluate the effectiveness of alternative solutions, and present recommendations to the CalPSAB. Public comment is being gathered around the Advisory Board's mission statement, vision statement and objectives, scope of work, strategic approach and principles and definitions.

In addition to the state agency's efforts, California is home to several Health IT and HIE initiatives, including:

- **California Regional Health Information Organization (CalRHIO)**

  The California Regional Health Information Organization - CalRHIO - is a collaborative effort to incrementally build the structure and capabilities necessary for a secure statewide health information exchange system that enables California's health care providers and patients to access vital medical information at the time and place it is needed. An independent organization, CalRHIO brings together health plans, providers, hospitals, consumers, government and public health agencies, researchers, policy leaders, and others around a shared vision: using information technology to make health care safer and more efficient throughout California. CalRHIO is currently working on two major initiatives:

    o **CalRHIO HIE Utility Service:** A statewide health information exchange utility service offers California health care providers and patients secure electronic access to patient medical records, where and when needed.

    o **Safety Net: Advancing HIE in the Community:** Supported by a grant from Blue Shield of California Foundation, CalRHIO is helping safety net providers and their communities plan and deploy health information exchange (HIE) projects.

  CalRHIO also maintains an inventory of HIE initiatives in the state, organized by state region (northern, central, southern). All in all, a total of 11 regional initiatives are identified.

- **NHIN Trial Implementations and CDC Regional HIE Related Grants**

  Two NHIN trial implementations are taking place in California:

    o Long Beach Network for Health
    o Kaiser Permanente

- **AHRQ-Funded Health IT and HIE Projects**

  Fourteen AHRQ-funded Health IT projects are currently underway in California, including:

- o Patient-Centered Online Disease Management Using a Personal Health Record System
- o Pilot Testing of Electronic Prescribing Standards
- o El Dorado County Safety Net Technology Project
- o Crossing the Quality Chasm in Eastern Rural County
- o IT Systems for Rural Indian Clinic Health Care

■ **Other Health IT and HIE Projects**

In addition to the AHRQ-funded projects, there are a number of other Health IT-related projects undertaken by health care organizations across the state and funded through a variety of sources, including:

- o San Diego Medical Information Network Exchange (SD MINE)
- o Northern Sierra Rural Health Network
- o Alliance for Rural Community Health HIE

■ **Medicaid Health IT Projects**

While not a recipient of a Medicaid Transformation Grant (Phase 1 or Phase 2), California Medicaid has several Health IT projects underway, including:

- o MMIS/MITA – California is beginning the process to completely replace the existing 30-year old MMIS (a system that processes 220 million health care claims a year)
- o One-e-Apps – the next generation of Health-e-Apps, an expedited enrollment process for Medicaid and SCHIP customers

■ **Health Information Security and Privacy Collaboration/California [1]**

The statewide collaboration and engagement with stakeholders that occurred during the Privacy and Security Solutions project has become the foundation for the recently established California Privacy and Security Advisory Board (CalPSAB). It was established to provide a governance structure to facilitate and guide the privacy and security decisions faced by the designated RHIOs and other state government and education models in California. CalPSAB's mission is to establish security standards, develop privacy principles and policies, and, in general, continue the privacy and security efforts begun under the Privacy and Security Solutions project. The board has established 4 committees: the Privacy Committee, the IT Security Committee, the Legal Committee, and the Education Committee.

When California began to participate in the Privacy and Security Solutions project, very little collaboration existed between the private and government sectors of the state's health care industry. The first statewide private/public collaboration was established under the auspices of the project.

From the project's initial assessment of variations in business practices and policies, it was clear that an environment for health information exchange

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[1] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

would require a formal collaborative process led by the state. In October of 2007, the Secretary of California Health Human Services Agency (CHHS) convened the first CalPSAB, composed of representatives from the major statewide health industry associations and government entities, and assigned the task to develop and recommend to the Secretary the privacy and security standards necessary to enable safe and secure health information exchange in California.

Subsequently, 3 of its 4 committees held their first meetings: the privacy committee, the security committee, and the legal committee. The first meeting of the education committee will take place in January 2009.

As part of the process to implement the CalPSAB effort, the following tools were developed:

- An issue management process specific to privacy and security demonstrates the logical procedure to address the issues identified in Phase I of the Privacy and Security Solutions project and blends them with the areas of HIPAA that allow flexibility to entities
- Initial project schedules allow appropriate and timely interaction as proposed solutions are developed between the committees and the board
- Communication charts demonstrate the flow of communication among the many parties involved in supporting the CalPSAB and its committees
- A flow chart illustrates the issue analysis flow, describing what steps are necessary to conduct a deliberative analysis of an issue
- New forms support the issue analysis process document, a deliberative procedure of identifying, analyzing and proposing potential solutions, including implementation challenges. In addition, lists of criteria are provided that may be utilized to brainstorm alternative solutions and for weighing those alternatives
- A description is provided of the communication suite established to enable transparent statewide discussions by the committees, task groups, and the CalPSAB

The Privacy and Security Solutions project has been a catalyst for awareness of privacy and security issues in California and, in particular, the importance of collaborating with consumers. Consumers recognize that advancements in technology alone are not sufficient to achieve interoperability. In terms of interstate and regional collaboration, California's Privacy and Security Solutions project efforts have been closely coordinated with New York's efforts. California anticipates sharing information about privacy policies and security standards with Oregon and Washington. California has also shared results with 16 other project states during the project.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), California is participating in the "Consent 2 – Policy Options" Collaborative focusing on identifying the different consent approaches within and between states with the intent to propose policy approaches for consent that facilitate interstate electronic health information exchange. The Collaborative will research the technological, public policy, and legal aspects of intrastate and

interstate consent issues, produce tools for other states to use as they develop strategies for adopting consent policies, and provide policy recommendations for nationwide consideration.

<mark>Roles of Public Health in Health IT and HIE</mark>

As noted above, the state's public health agency, through the Office of Health Information Integrity (CalOHII) is actively involved in health IT and HIE activities. It's main roles include:

- Facilitate and convene Health IT and HIE efforts in the state
- Coordination/support of the California Privacy and Security Advisory Board
- Disseminate information about Health IT and HIE initiatives
- Support the implementation of a study on Health Information Technology Financing
- Support the implementation of the California Health Information Law Identification project
- Coordinate and provide advice and support to other state agencies in matters related to Health IT and HIE

While the Department is not yet participating in specific HIEs as a data exchange partner, several of the goals in the Department's 2008-2010 strategic plan are aimed at improving the efficient exchange of population-based data, including the collection, use and exchange of information necessary to achieve the Department's mission and objectives.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

2. Florida

General Demographics	State #	State %	US #	US %
Total	18,029,898	100%	298,215,356	100%
Metro	17,234,651	96%	249,589,926	84%
Non-Metro	795,246	4%	48,625,430	16%
<19 years	4,331,505	24%	78,645,221	26%
19-64	10,767,308	60%	182,781,246	61%
65-74	1,508,663	8%	19,587,238	7%
75+	1,422,422	8%	17,201,650	6%
Female	9,221,748	51%	152,167,024	51%
Male	8,808,149	49%	146,048,331	49%
White	10,938,360	61%	196,128,707	66%
Black	2,642,939	15%	36,259,715	12%
Hispanic	3,876,070	22%	45,949,214	15%
Other	572,529	3%	19,877,720	7%
Median Income	$46,142.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	8,500,588	47%	159,311,384	53%
Individual	950,809	5%	14,541,782	5%
Medicaid	1,727,980	10%	39,296,423	13%
Medicare	2,889,417	16%	36,155,452	12%
Other Public	222,872	1%	3,253,122	1%
Uninsured	3,738,230	21%	45,657,193	15%
Total	36,163,342	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$95,223		$1,551,255	
Hospital Care	$31,494	33%	$566,886	38%
Physician and Prof Services	$29,968	31%	$446,349	28%
Drugs and Nondurable Medications	$15,545	16%	$222,412	14%
Nursing Home Care	$6,503	7%	$115,015	7%
Dental Services	$4,494	5%	$81,476	5%
Home Health Care	$2,876	3%	$42,710	2%
Total Gov. Expenditures	$61,597		$1,340,034	
Gov. Health Expenditures	$15,397		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

Florida has been very active in pursuing statewide and regional implementation of HIE initiatives, with significant support and involvement from the state's Agency for Health Care Administration (AHCA), designated by the Governor as the lead agency in the state's efforts to improved Health IT adoption and HIE implementation.
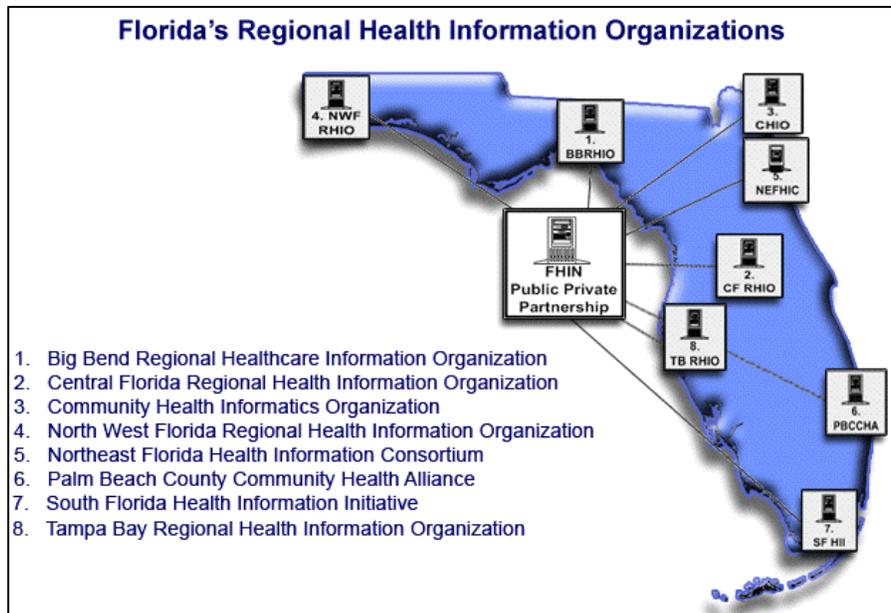
In 2004, the Governor established the Health Information Infrastructure Advisory Board, which recommended the creation of the Florida Health Information Network (FHIN), a statewide collaboration between AHCA and regional health information organizations. Over the past several years the state has allocated significant funding to support the establishment of regional HIEs and Health IT adoption projects. The grants program has been administered by AHCA.

The Florida Health Information Network vision calls for integrating clinical health information exchange in Florida through a statewide health information network that will empower physicians to access timely and accurate medical records in order to deliver the highest quality medical care for their patients. The Florida Health Information Network is being built from the local community up. An essential

element of the strategic plan is to empower local stakeholder collaborations focused on health information exchange.

The driver of this plan began with the FHIN Grants Program and continues with the Regional Health Information Organizations in local communities around Florida, efforts by the Agency for Health Care Administration and the new Point of Care Model Electronic Health Records Grants Program. The final goal of the Florida Health Information Network is to integrate Florida's Regional Health Information Networks in a seamless health information exchange. The success of the statewide network depends on the long term sustainability of each local RHIO, and their collective ability to work together to achieve a common goal of exchanging medical records for the benefit of patients across the state.

The state now includes eight regional health information organizations in different stages of development:

Florida's Regional Health Information Organizations

1. Big Bend Regional Healthcare Information Organization
2. Central Florida Regional Health Information Organization
3. Community Health Informatics Organization
4. North West Florida Regional Health Information Organization
5. Northeast Florida Health Information Consortium
6. Palm Beach County Community Health Alliance
7. South Florida Health Information Initiative
8. Tampa Bay Regional Health Information Organization

In addition, AHCA is also implementing a series of Health IT projects in support of health information exchanges:

■ **Health Information Exchange Coordinating Committee**

The Health Information Exchange Coordinating Committee was organized by the Florida Agency for Health Care Administration during the fall of 2007 to advise and support the Agency in developing and implementing a strategy to establish a privacy-protected, secure, and integrated statewide network for the exchange of electronic health records among authorized physicians.

The HIE Committee provides guidance for the Regional Health Information Organizations operating in Florida to ensure the privacy and security of health information and recommends technical standards to ensure the

interconnectivity of all health care providers and to establish and maintain the security for electronic health information. The HIE Committee reviews and evaluates applicant proposals to the Florida Health Information Network Grants Program and makes funding recommendations to the Agency Secretary through the State Consumer Health Information and Policy Advisory Council. The HIE Committee also assists the Agency as it develops and implements specific programs for the creation of a statewide network, adoption of electronic medical record systems and development of health information exchange at the local level.

- **Florida e-Prescribing Clearinghouse - www.fhin.net/eprescribe/**

The creation of the **Florida ePrescribe Clearinghouse** website was a joint effort among employees of the Office of Health Information Technology located within the Agency for Health Care Administration, Florida Center for Health information and Policy Analysis. Information contained in this website is a result of the generous cooperation, participation, and guidance from members of the Florida Electronic Prescribing Advisory Panel, ePrescribe Florida, SureScripts, RxHub and other numerous associations, organizations, programs, news sources, and vendors.

The mission of the Florida ePrescribe Clearinghouse is to provide information that contributes to the promotion and implementation of electronic prescribing by health care practitioners, health care facilities, and pharmacies in order to prevent prescription drug abuse, improve patient safety, and reduce unnecessary prescriptions.

- **Point of Care Model Electronic Health Records**

The Agency for Health Care Administration announced earlier in 2008 the Point of Care Model Electronic Health Record Grants Program. The purpose of the program is to provide assistance to eligible organizations to implement outpatient clinic information technology emphasizing case management. Grant projects must demonstrate a model health information technology solution that provides access to patient medical records for case management, demonstrate and evaluate the cost-effectiveness of the software deployed in supporting case management of patients, encourage appropriate utilization of outpatient clinic services resulting in a reduction of emergency department visits, and demonstrate a reduction of health care costs. Applicants should demonstrate that the recommended technology has a record of proven success in case management and health care cost reduction resulting from operating in outpatient clinics.

- **Adding Clinical Data to Statewide Administrative Data**

The Agency for Health Care Administration, Florida Center for Health Information and Policy Analysis, was awarded a contract from the Agency for Healthcare Research and Quality (AHRQ) that runs through September 2009 for a pilot project to study new ways to approach hospital quality measures. The pilot project funding is provided to add clinical laboratory data to the hospital administrative data already collected by AHCA under statutory authority. By adding clinical data to administrative data, AHRQ hopes to

develop better predictors for hospital quality indicators. One purpose of the pilot project is to demonstrate and evaluate the process required to 1) standardize laboratory data into a common nomenclature; 2) merge clinical data with hospital administrative data; 3) complete a statistical analysis of the merged dataset; 4) assess the added value of using clinical data to evaluate the quality of patient care within hospitals; 5) and describe all findings in a Final Report.

- **FCC Rural Health Care Pilot Project – Providing Broadband Telecommunications to Hospitals in the Florida Panhandle**

  In November 2007, the Federal Communication Commission awarded $9.6 million to the Big Bend Regional Healthcare Information Organization, in partnership with the Agency for Health Care Administration, to build a gigabit fiber network to nine rural hospitals and surrounding clinics in the Florida Panhandle. The funding was provided as part of a nationwide program to connect rural hospitals to a broadband telecommunication backbone.

  Big Bend RHIO will construct gigabit fiber facilities from Florida LambdaRail interface points, to a constructed point of presence in each of the eight counties, and then run broadband last mile connections to the nine rural hospitals in the project. Once the network connections are complete, the hospitals will be online with the Big Bend RHIO, which will provide secure messaging services and facilitate the transmission of large imaging files such as x-rays, MRIs, CAT scans from fixed or mobile imaging units and other digital files between the rural and urban specialty providers in their network.

- **Personal Health Record Toolkit - www.fhin.net/PHR/index.shtml**

  One of the first of such toolkits in the nation to be offered by a state agency, the PHR Toolkit provides basic information about PHRs to consumers. It includes such features as:

  - The importance of ePHRs (including a description of the benefits for Hurricane Preparedness)
  - ePHR Basics
  - ePHR Feature
  - The Content of ePHRs
  - Privacy and Security of ePHRs
  - The importance of ePHR Interoperability
  - Additional Resources including PHR Videos, Health Plan PHRs, Free PHR Forms and a PHR Checklist

- **AHRQ-Funded Health IT and HIE Projects**

  Two AHRQ-funded Health IT projects are currently underway in Florida, including:

  - Promoting Patient Safety with Web-based Patient Profiles
  - Health IT for Medication Safety in Critical Access Hospitals

- **Medicaid Health IT Projects**

  Florida was the recipient of a Medicaid Transformation Grant which focuses on improving/expanding the adoption of ePrescribing among Medicaid providers. In addition, Florida Medicaid has several Health IT projects underway, including:

  o MMIS/MITA – Florida is currently in a 5-year plan (that started March 1, 2008) to develop a new MMIS in partnership with a new Fiscal Agent

  o Health Information Exchange Collaboration with Medicaid Participation: The purpose of this project is to offer health care providers at the point of care access to a longitudinal claims-based electronic patient medical record for all Medicaid enrollees. The Medicaid claims-based EHR will include encounter history including clinical information (procedure codes and notes), medication history, financial and administrative (claims) information, coverage and eligibility information. Medicaid would like to see this serve as the kernel for adding other payers information, so a more complete longitudinal record across payers can be offered to providers (Medicaid patients come off and on into Medicaid at a rate of 20%). It will be accessed via a web portal so all the providers will need is a computer and web access. In the future they would like to include lab results as well. A Request for Information is being issued (will send as soon as it is published). The intent is to request proposals from technology partners who will be willing to develop the base system at no cost to Medicaid or to providers

  o Medicaid e-Prescribing Incentives Program: This is a new project that is building on the current e-Prescribing pilot implemented by Medicaid. It is currently in planning mode, with initial implementation to start in 2010. The pilot, called e-EmpowerX - Gold Standard Program - included about 1,500 providers who were given a PDA system to do e-Prescriptions. It ended in June. The pilot demostrated successfully the savings that can be achieved by using e-Prescribing. Still, there was the issue of moving providers to adopt e-Prescribing. This new program offers a 2% of claims incentive directly back to Medicaid providers for adopting e-Prescribing. The main purpose of the new Program is to widely expand the use of e-Prescribing among Medicaid providers. The interest is to use it as a springboard for other payers and other providers to also adopt e-Prescribing. The level of the incentive would change over time and eventually be phased out. The use of the technology would not be limited to Medicaid providers however, the incentive would be limited to Medicaid providers. Florida has several other efforts around e-Prescribing: 1) GenRx - this is the Medicaid Transformation Grant to promote the use of Generic Prescribing Drugs; 2) e-Prescribe Florida (now e-Prescribe America) - a clearinghouse of e-prescribing information for providers

- **Health Information Security and Privacy Collaboration/Florida [2]**

  Florida, like many other states, has struggled in balancing the concerns for privacy and security with the potential benefits of electronic health information exchange as a solution to the inefficiencies and patient safety issues that exists in the health care system. Prior to engaging in the Privacy and Security Solutions project, Florida had not hosted any activities specifically related to examining privacy and security issues in health information exchange.

  The community was quite aware of the issues and concerns about building and maintaining a private and secure health information exchange, as well as the barriers to the adoption and utilization of electronic health records among health care providers, but was unaware of the actual drivers behind the reluctance to share health information. The Privacy and Security Solutions project allowed Florida to bring together numerous stakeholders to discuss the problems associated with health information exchange and to devise potential solutions.

  As a result of the work conducted under the Privacy and Security Solutions project, several products and tools have been developed and are available for use in the state, including:

  - **Florida Privacy and Security Resource Center**
    http://www.fhin.net/PSresourceCtr/index.shtml

    The Agency for Health Care Administration created this website as an educational resource for health care providers, health information organizations, and consumers that have questions and would like to learn more about the privacy and security of electronic health records.

    For providers that are considering the implementation of electronic health records in their office practice or the participation in a health information network, this site provides basic information about certification of vendor products, security risk assessments, and laws governing the release of health records.

    Consumers can learn about their privacy rights through the information and links to other resources presented on this site.

    The site also contains information about the activities of the Florida Health Information Security and Privacy Collaboration (HISPC) project.

  - **The AHCA Self Assessment and Educational Tools**: including the AHCA Risk Assessment Tool (Privacy and Security) and other national resources

  - **Analysis of Florida Health Records Law**: including a series of reports produced during the HISPC Phase I project\

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[2] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Florida is participating in two Collaboratives:

- o The "Harmonizing Privacy Laws" Collaborative: to advance the ability of states and territories to analyze and reform, if appropriate, their existing laws related to health information exchange

- o The "Provider Education" Collaborative: aimed at creating a toolkit to introduce electronic health information exchange to providers and increasing their awareness of the privacy and security benefits and challenges of electronic health information exchange

Roles of Public Health in Health IT and HIE

In Florida, the Department of Health is an agency independent from the Florida Agency for Health Care Administration. AHCA is responsible, among other things, for administering Florida's Medicaid program.

While the Department of Health is not directly responsible for Florida's Health IT and HIE initiatives, it works closely with, and participates in the activities that ACHA is involved with. The Department is not yet engaged in specific HIEs as a data exchange partner.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

3. Massachusetts

General Demographics	State #	State %	US #	US %
Total	6,335,555	100%	298,215,356	100%
Metro	6,177,099	98%	249,589,926	84%
Non-Metro	158,456	3%	48,625,430	16%
<19 years	1,549,313	25%	78,645,221	26%
19-64	3,946,524	62%	182,781,246	61%
65-74	413,383	7%	19,587,238	7%
75+	426,335	7%	17,201,650	6%
Female	3,278,246	52%	152,167,024	51%
Male	3,057,309	48%	146,048,331	49%
White	5,077,489	80%	196,128,707	66%
Black	402,934	6%	36,259,715	12%
Hispanic	428,294	7%	45,949,214	15%
Other	426,838	7%	19,877,720	7%
Median Income	$58,286.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	3,777,434	60%	159,311,384	53%
Individual	280,693	4%	14,541,782	5%
Medicaid	979,539	15%	39,296,423	13%
Medicare	786,682	12%	36,155,452	12%
Other Public	12,756	0%	3,253,122	1%
Uninsured	498,451	8%	45,657,193	15%
Total	6,335,555	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$43,009		$1,551,255	
Hospital Care	$16,865	39%	$566,886	38%
Physician and Prof Services	$10,406	24%	$446,349	28%
Drugs and Nondurable Medications	$5,462	13%	$222,412	14%
Nursing Home Care	$4,124	10%	$115,015	7%
Dental Services	$2,276	5%	$81,476	5%
Home Health Care	$1,743	4%	$42,710	2%
Total Gov. Expenditures	$39,207		$1,340,034	
Gov. Health Expenditures	$7,743		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

Massachusetts is the home state for several of the leading health care delivery and educational institutions in the country and the world. The state also has a long history of public-private collaborative initiatives towards the adoption of Health IT and implementation of HIE. Today, the state's Health IT and HIE landscape is being shaped by organizations such as:

- **The Massachusetts Health Data Consortium (MHDC)** – founded in1978, it continues to play a central role as a catalyst for cooperative dynamic discussion and action on critical health information issues. Several initiatives over the past few years have advanced the adoption of Health IT in the state, including:

    o Leadership forums, such as Privacy Officers Forum, Security Officers Forum, Data Managers and Users Forum, and the Internet Professionals Forum

- o The CIO Forum (formerly the Affiliated Health Information Networks of New England)

- o MA-SHARE (Simplifying Healthcare Among Regional Entities) – a regional collaborative initiative operated by MHDC to promote the inter-organizational exchange of healthcare data using information technology and standards, so that accurate health information is available wherever needed in an efficient, cost-effective, timely and safe manner. Projects implemented under MA-SHARE included:

  - ▪ e-Prescribing Gateway and Education
  - ▪ MedsInfo-ED for exchanging medication information with Emergency Departments
  - ▪ Secure E-mail

- o An extensive resource center and library with documentation and information about several local, state and national health information initiatives and topics

- o A promoter and organizer of forums and events

- o MHDC also maintains the state's inpatient databases, observation stay databases, emergency department databases and physician licensure databases and provides access to data and data analysis services

- ◼ **Massachusetts eHealth Collaborative (MAeHC)**: The Massachusetts eHealth Collaborative was formed in 2004 as an initiative of the physician community to bring together the state's major health care stakeholders for the purpose of establishing an EHR system that would enhance the quality, efficiency and safety of care in Massachusetts. MAaEC endeavors to transform the deliver of health care using electronic health records and health information exchange. The Collaborative received a $50 million commitment from Blue Cross Blue Shield of Massachusetts to fund its demonstration project phase.

  The Collaborative has established several working groups covering several areas including clinical requirements, data exchange standards, quality measurement and evaluation, privacy and security, legal and regulatory, and financing and reimbursement.

  MAeHC's two main project areas are:

  - o Adoption of EHRs – A pilot project involving 130 medical practices to test the implementation of interoperable EHRs

  - o Regional HIEs – MAeHC has selected three communities for the first demonstration project testing community-wide implementation of electronic health records in Massachusetts

- **New England Healthcare EDI Network (NEHEN)**: Sponsored originally by the MHDC in 1998, NEHEN is a consortium of regional payers and providers that have designed and implemented a secure and innovative electronic-commerce solution for reducing administrative costs in health care

  NEHEN provides a collaborative, payer- and provider-owned solution for connectivity and administrative simplification that transports HIPAA-compliant transactions, has a low-cost of ownership, delivers a close-to "all-player" solution to connectivity, makes the most of the participating organizations' investment in existing "legacy" systems and shortens the elapsed time to achieve EDI at an appropriate transaction volume level.

- **MassPRO**: Through the DOQ-IT (Doctors Office Quality – Information Technology) Project, the Massachusetts Quality Improvement Organization (MassPRO) is working with small-to-medium sized physician practices (1-8 doctors per practice) to support the adoption and use of EHRs

- **Boston Community Health Information Improvement (CHII) Project**: CHII goal is to integrate data from 11 ambulatory care electronic medical record (EMR) databases. The initiative aims to use the data to establish a longitudinal clinical data warehouse for chronic diseases and prevention. The primary components of the project include clinically driven metrics, optimized models for clinical reporting, practice-based reporting, and integration with administrative data (registration, billing, pharmacy systems). The initiative supports collaboration among the participating health organizations and the Boston Medical Center (BMC)

- **Southeastern Massachusetts RHIO (SEMRHIO)**: A regional collaboration of hospitals in South Eastern Massachusetts formed for the purpose of connecting physicians and patients electronically. The vision of SEMRHIO is to foster clinical connectivity from the source of the clinical data, hospitals, labs, radiology facilities, to the doctor's desktop and smartphones, which will enable the right clinical decision to be made based on the most accurate and timely data

- **eRX Collaborative**: A joint effort of Blue Cross Blue Shield of Massachusetts, Tufts Health Plan, Neighborhood Health Plan, and their technology partners DrFirst and Zix Corporation, to promote ePrescribing adoption in Massachusetts. The goals of the eRx Collaborative are to enhance patient safety, reduce healthcare spending, and deliver a robust, secure e-prescribing system with the following characteristics: streamline workflow with all-in-one device; certified with RxHub; 128-bit encryption for full confidentiality; HIPAA compliant

In addition to these collaborative efforts, the state government is implementing a number of Health IT initiatives, including:

- **Enabling e-Prescribing and Enhanced Management of Controlled Medications**: A project from the MA Department of Public Health to expand the adoption and diffusion of electronic prescribing and improve medication management by ambulatory care clinicians at the point-of-care. Expansion of

e-prescribing to cover federally controlled substances (e.g., narcotics, stimulants, sedatives) will also increase needed access to and reduce risks of dangerous pharmaceuticals, particularly for patients with chronic medical conditions who are frequently prescribed such medications.

- **Medicaid Health IT Projects**

  Massachusetts was the recipient of a Medicaid Transformation Grant which they focused on the secure verification of citizenship through the automation of vital health records.   The primary goals of the project were 1) to digitize what are currently primarily paper-based birth and death records; 2) to implement an electronic verification of vital events system (EVVE); 3) to reduce fraud by obtaining citizenship information directly from the governmental source; and 4) to reduce waste by rapidly identifying deceased individuals.

  Other Health IT projects being undertaken by Massachusetts Medicaid include:

  - MMIS/MITA – Massachusetts recently launched (October, 2008) its new MMIS system replacing its old state-run MMIS with a new full-featured system developed by an external vendor/fiscal agent.
  - Electronic Health Record initiative
  - ePrescribing project

Other Health IT and HIE projects in the state include:

- **AHRQ-Funded Health IT and HIE Projects**

  Twenty one AHRQ-funded Health IT projects are currently underway in Massachusetts, including:

  - Value of Imaging-Related Information Technology
  - Statewide Implementation of Electronic Health Records
  - Improving Safety and Quality with Outpatient Order Entry
  - Evaluating Smart Forms and Quality Dashboards in an EHR
  - Parent Link: Better and Safer Emergency Care for Children
  - Improving Pediatric Safety and Quality with Health Care IT

- **Health Information Security and Privacy Collaboration/Massachusetts [3]**

  In Massachusetts, the first phase of the Privacy and Security Solutions project identified legal and operational barriers to electronic health information exchange, proposed solutions, and provided a recommended 24-month implementation plan. As a result of the review of barriers, the Massachusetts steering committee concluded that 2 important, yet often understated, challenges to electronic and paper health information exchange exist. First, there is confusion among health care personnel, patients, and consumers about what protected health information and situations require application of

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[3] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

federal and/or state privacy laws. The second issue concerns when, how, and where the laws, regulations and entity preferences are applied (particularly those involving sensitive health information). An additional complication is the varying ability of health care provider entities to manage the collection, storage, decision making, and transmission of patient privacy consent information. Accordingly, the steering committee authorized the commencement of the consent management implementation project (CMP). The CMP addresses improvements in electronic clinical data exchange interoperability by identifying the privacy processes, issues, requirements and preferences that drive the decision making to collect, use, and disclose patient information.

The key outcomes of the CMP process included a use case collection template; use case elements matrix; an online tool for stakeholders to review and comment on use cases; a series of process information flow diagrams that include sensitive health information and public health decision loops; a summary of laws governing sensitive health information in Massachusetts; and a working glossary of defined key terms. These tools will be shared broadly across the Massachusetts health care community and can also be used by other states who wish to follow a similar process.

With respect to governance and leadership, the Massachusetts Health Data Consortium (MHDC, the state-designated participant in the Privacy and Security Solutions project) has become more visible in the role of convener for privacy and security issues.

One of the major outcomes of this project has been on stakeholder knowledge and education. The project brought greater clarity about the legal requirements for numerous relevant health information exchange scenarios, and a detailed analysis of current practices and opportunities for standards and/or harmonization in managing patient consent. It also prompted the Massachusetts team to create a consumer and professional educational resource area on a project website to address privacy and security issues around data sharing. The learning that has taken place among stakeholders will support future health information exchange.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Massachusetts is participating in the "Consent 1 – Data Elements" Collaborative charged with establishing a model for identifying and resolving patient consent and information disclosure requirements across states and developing a foundational reference guide that describes and compares the requirements mandated by state law and any known regional or local consent policies and practices in each participating state. Massachusetts is also participating in the "Consumer Education and Engagement" Collaborative focusing on developing a series of coordinated, state-specific projects that focus on targeted population groups to describe the risks and benefits of health information exchange, educating consumers about privacy and security regarding health information exchange, and developing messages to address consumer privacy and security concerns.

<mark>Roles of Public Health in Health IT and HIE</mark>

The Department is involved in several of the regional public-private partnerships, as a member of oversight bodies or Board of Directors.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)

    o MDPH is currently replacing the legacy system with a system that will have true electronic exchange with hospitals utilizing public health standards

- Electronic Laboratory Reporting (ELR) system

    o Currently 25 hospitals in MA are submitting reportable communicable diseases electronically.

- Immunization Registry

    o This registry has been developed, but currently it is not active. Once resources are identified for roll-out electronic exchanges are intended.

- Encounter-level data reporting (inpatient and outpatient)

    o EIM/ESM (Enterprise Invoice Management and Enterprise System Management) Through ESM the Bureau of Substance Abuse Services receives electronic reporting of data from all licensed substance abuse treatment programs in the state.
    o Erwin Hirsh State Trauma Registry – hospitals report to MDPH specified trauma data elements through the INET application discussed below.
    o Hospital Case Mix data (inpatient discharge/emergency department/ outpatient observation data) are reported to the Division of Health Care Finance and Policy through INET [The Division of Health Care Finance and Policy is a different agency from MDPH].
    o MATRIS (Massachusetts Ambulance Trip Reporting Information System) – Licensed ambulance services report EMS minimum data set electronically to MDPH.

- State (Electronic) Disease Surveillance System and communicable disease reporting

    o MAVIN – Electronic Laboratory Reporting data are combined with data from electronic medical records. This project implements electronic surveillance by searching EMRs to fill needed fields for case findings. These data are electronically shared with authorized local board of health representatives.

- o AEGIS – Syndromic Surveillance project - A real time public health surveillance system based on a prediction model utilizing emergency department historic free text chief complaint and diagnostic codes data. The system analyzes submitted data nightly to identify clusters of disease and reports findings back to participating hospitals.

- State Public Health Information Network (PHIN)

  - o Includes MAVIN, AEGIS, ELR and the HAN.

- State Health Alert Network

  - o Among other things, it is integrated with AEGIS such that it provides summary, not identifiable information, and notifies of outbreaks.

- Disease-specific registry systems (such as Cancer Registry)

  - o No electronic reporting at this point

- Birth Certificate Matching Web Service – electronic interface between MDPH birth records and Medicaid to verify the citizenship of MassHealth and Commonwealth Care applicants required as part of Medicaid's eligibility review. Permits a query of MDPH to ascertain whether a Massachusetts birth certificate exists for a particular applicant.

- Documentum – Electronic scanning of old birth records. Records can also be used as part of electronic matching in the Birth Certificate Matching Web Service.

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

4. Michigan

Basic Demographics

General Demographics	State #	State %	US #	US %
Total	9,940,234	100%	298,215,356	100%
Metro	8,388,818	84%	249,589,926	84%
Non-Metro	1,551,416	16%	48,625,430	16%
<19 years	2,579,251	26%	78,645,221	26%
19-64	6,054,238	61%	182,781,246	61%
65-74	679,876	7%	19,587,238	7%
75+	626,869	6%	17,201,650	6%
Female	5,070,396	51%	152,167,024	51%
Male	4,869,838	49%	146,048,331	49%
White	7,755,788	78%	196,128,707	66%
Black	1,384,425	14%	36,259,715	12%
Hispanic	366,976	4%	45,949,214	15%
Other	433,046	4%	19,877,720	7%
Median Income	$49,394.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	5,761,698	58%	159,311,384	53%
Individual	379,262	4%	14,541,782	5%
Medicaid	1,279,096	13%	39,296,423	13%
Medicare	1,378,958	14%	36,155,452	12%
Other Public	44,400	0%	3,253,122	1%
Uninsured	1,096,821	11%	45,657,193	15%
Total	9,940,235	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$51,048		$1,551,255	
Hospital Care	$20,206	40%	$566,886	38%
Physician and Prof Services	$13,653	27%	$446,349	28%
Drugs and Nondurable Medications	$7,790	15%	$222,412	14%
Nursing Home Care	$3,193	6%	$115,015	7%
Dental Services	$3,147	6%	$81,476	5%
Home Health Care	$1,326	3%	$42,710	2%
Total Gov. Expenditures	$41,718		$1,340,034	
Gov. Health Expenditures	$11,558		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

The government of the State of Michigan, through the leadership of the Governor and the Departments of Community Health (MDCH) and Information Technology (MDIT) has placed over the past four years a high priority on the adoption of Health IT and implementation of regional HIEs to drive quality improvements and efficiency in the state's health care system.

In 2006, the Michigan Health Information Network (MiHIN) was officially created as a 6-month effort to convene multiple stakeholders to speed the adoption of Health IT and promote HIEs. A report *"Michigan Health Information Network: Conduit to Care"* was issued at the end of 2006 establishing a vision and roadmap for Michigan's Health Information Network. MiHIN focuses on the HIE side, while others are focusing on the Adoption of Health IT. The following four guiding principles were developed and endorsed by the community-based consensus building process:

- Consumer privacy, security and confidentiality are paramount

- Clinical data will only be utilizied for the clinical care process
- Delivery of health care is local; HIEs at the regional level are critical
- Multi-stakeholder collaboration is needed to implement achievable and measureable initiatives to show early progress and value

The role of state government was set to include:

- Legal interpretation and consensus
- Standard setting and technical support
- Statewide coordination
- Fundraising and administration of statewide funding
- Education and marketing

In 2006 also, the Michigan Health Information Technology Commission was created with the support from MDCH and a detailed analysis of Michigan's 'Medical Trading Areas' (MTA) was conducted to understand the patterns of service utilization and referrals in various parts of the state and proposed potential 'boundaries' for MTAs.

The report recommendations (which still provides the guiding vision for the state HIE efforts) called for the creation of nine regional HIEs in an equal number of defined MTAs in the state.
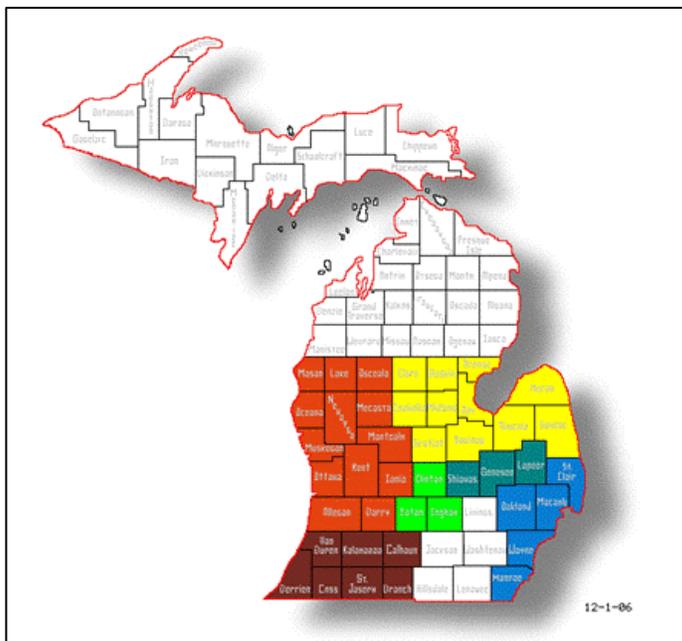
Michigan HIE Regions

HIE	Sponsoring Organization
Upper Peninsula	Marquette General Health System
Northern Lower Peninsula	North Central Council of the MHA
Central Michigan	Central Michigan University
West Michigan	Alliance For Health
Capital Area	Capital Area Health Alliance
Genesee Area	Greater Flint Health Coalition
Southeastern Michigan	Altarum Institute
Southwestern Michigan	TBA
South Central Michigan	TBA

The Michigan regional HIE grant program was established and funding was made available to support the planning and implementation of HIEs in the state, consistent with the guiding principles developed by MiHIN. The MiHIN Resource Center was also created in 2007 to develop strategies, advice the state and provide technical assistance to regional HIEs being formed. In 2007 seven regional HIEs were awarded planning grants (5) and implementation grants (2).
Currently, the first round of HIE grants are ending and deliverables, including a sustainable business plan for HIE operations, are due.

- **Michigan's FCC Rural Health Care Pilot Project**

  In addition to these HIE efforts, Michigan is implementing a large-scale connectivity project through a $20.9 million grant from the FCC received in late 2007 to support broadband connections to rural health care systems. The purpose of this grant is to enhance public and non-profit health care providers' access to advanced telecommunications and information services. The Michigan Public Health Institute is serving as the primary point of contact and is overseeing the project.

In addition to the state agency's efforts, Michigan is home to several Health IT and HIE initiatives, including:

- **AHRQ-Funded Health IT and HIE Projects**

  Five AHRQ-funded Health IT projects are currently underway in Michigan, including:

  - Health IT Support for Safe Nursing Care
  - Health IT Planning for a Critical Access Hospital Partnership
  - Implementation of a Regional Health IT Network by ten Critical Access Hospitals
  - Bar Coding for Patient Safety in Northern Michigan

- **Other Health IT and HIE Projects**

  In addition to the AHRQ-funded projects, there are a number of other Health IT-related project undertaken by health care organizations across the state and funded through a variety of sources, including:

  - CLEAN – Communities Leveraging e-Health for Asthma Needs
  - Implementing Interorganizational EMR to Improve Care for Disadvantaged Populations
  - Southeast Michigan e-Prescribing Initiative

- **Medicaid Health IT Projects**

  Michigan's Medicaid Transformation Grant (MTG) for Round 1 - "Michigan Expansion of Vital Records Automation and Integration into Medicaid Michigan One Source Credentialing" focuses on improving the vital records database (clean-up, enter, update, etc) and improving the linkage of the vital records database with the Medicaid system to enhance the ability of case workers to perform citizenship validations.

  In Round 2 of the MTGs, the state will develop the "Michigan OneSource Credentialing" system to improve the efficiency of credentialing providers by using standard interfaces and cross-organization integration technologies that will allow real-time exchange of information and help eliminate payments to sanctioned providers and fraudulent payments.

In addition, Michigan Medicaid has several Health IT projects underway, including:

- o MMIS/MITA – Current mainframe-based 30-year old MMIS system is being replaced by CHAMPS – Community Health Automated Medicaid Processing System. Initial roll-out include a new secure, web-based Medicaid enrollment system that allows providers to enroll and update data quickly and efficiently

- **Health Information Security and Privacy Collaboration/Michigan [4]**

The barriers to health information exchange identified during the assessment stage by Michigan's HISCP Phase 1 project included fragmented, conflicting and scattered state privacy and security laws and state laws that are not applicable to health information exchange. The MiHIN Resource Center was chosen as a centralized body to support and guide the implementation of privacy and security measures in the development of regional health information exchange, a critical component of health care efficiency.

The Phase 1 primary goal was to develop a list of priorities, including privacy and security that the state would address to facilitate health information exchange. In conjunction with providing centralized support to the developing regions, the state also recognized the urgent need for guidance in relation to privacy and security issues surrounding the development of health information exchange. Through the MiHIN Conduit to Care Process, and the first portion of the Privacy and Security Solutions project, Michigan already had a highly effective and cohesive privacy and security working group in place.

The Michigan Privacy and Security Solutions project has seamlessly incorporated the privacy and security discussion into the health information exchange development process in Michigan. The governance structure originally created for MiHIN is now the coordinating process for all health information exchange-related activities, regardless of the source. Thus, the project has helped create an enduring governance structure and has made privacy and security issues a seamless part of the planning of all health information exchange-related initiatives.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Michigan is participating in two Collaboratives:

- o The "Harmonizing Privacy Laws" Collaborative: to advance the ability of states and territories to analyze and reform, if appropriate, their existing laws related to health information exchange

- o The "Provider Education" Collaborative: aimed at creating a toolkit to introduce electronic health information exchange to providers and increasing their awareness of the privacy and security benefits and challenges of electronic health information exchange

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[4] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

<mark>Roles of Public Health in Health IT and HIE</mark>

The Michigan Department of Community Health has been a strong leader, advocate, facilitator, and funder of major HIE initiatives in the state. The Department plays a key role as a neutral facilitator in continuing to advance its agenda and the work of the Michigan Health Information Network.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

5. Minnesota

Basic Demographics

General Demographics	State #	State %	US #	US %
Total	5,164,919	100%	298,215,356	100%
Metro	3,773,198	73%	249,589,926	84%
Non-Metro	1,391,721	27%	48,625,430	16%
<19 years	1,327,486	26%	78,645,221	26%
19-64	3,215,469	62%	182,781,246	61%
65-74	318,016	6%	19,587,238	7%
75+	303,948	6%	17,201,650	6%
Female	2,585,138	50%	152,167,024	51%
Male	2,579,781	50%	146,048,331	49%
White	4,413,658	86%	196,128,707	66%
Black	215,423	4%	36,259,715	12%
Hispanic	232,686	5%	45,949,214	15%
Other	303,151	6%	19,877,720	7%
Median Income	$57,815.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	3,154,070	61%	159,311,384	53%
Individual	325,149	6%	14,541,782	5%
Medicaid	581,320	11%	39,296,423	13%
Medicare	626,320	12%	36,155,452	12%
Other Public	24,515	0%	3,253,122	1%
Uninsured	453,544	9%	45,657,193	15%
Total	5,164,919	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$29,524		$1,551,255	
Hospital Care	$10,009	34%	$566,886	38%
Physician and Prof Services	$8,762	30%	$446,349	28%
Drugs and Nondurable Medications	$3,639	12%	$222,412	14%
Nursing Home Care	$2,367	8%	$115,015	7%
Dental Services	$1,678	6%	$81,476	5%
Home Health Care	$679	2%	$42,710	2%
Total Gov. Expenditures	$25,753		$1,340,034	
Gov. Health Expenditures	$6,987		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

Minnesota has been at the forefront of Health IT standardization and implementation of HIEs since the 1990s. The state, with the leadership and support of the Minnesota Department of Health, has work with the health care industry to advance the adoption of EHRs and the creation of self-sustaining health information exchanges.

Through a combination of state regulations and public-private partnership initiatives, the state now has one of the most robust policy and technical infrastructures in the nation.

In 2004, the Department established the Minnesota e-Health Initiative to serve as the focal point for guiding and facilitating the adoption of Health IT in the state. The Initiative is a public-private collaborative whose vision is to accelerate the adoption and use of Health IT in order to improve health care quality, increase patient safety, reduce health care costs and improve public health. The purpose of the initiative is to:

- **Empower Consumers** with information to make informed health and medical decisions
- **Inform and Connect Healthcare Providers** by promoting the adoption and use of interoperable Electronic Health Records and electronic health information exchange
- **Protect Communities and Improve Public Health** by advancing efforts to make public health systems interoperable and modernized
- **Enhance the Infrastructure** through:

  - Adoption of standards for health information exchange
  - Instituting policies for strong privacy and security protection of health information
  - Increasing funding and other resources for implementation
  - Assessing and monitoring progress on adoption, use and interoperability

The state was the first in the nation to pass a law requiring the adoption of standards for electronic transactions (Minnesota Health Care Administrative Simplification Act of 1994), two years ahead of HIPAA. The state is also one of the first in the nation to pass laws requiring:

- The adoption of state uniform companion guides for use with HIPAA transactions (eliminating proprietary companion guides)
- All health care providers and hospitals in the state to have an interoperable EHR system by 2015
- All EHRs acquired by health care providers to be certified by the national Certification Commission for Healthcare Information Technology (CCHIT) (if certified product for the provider's particular setting is available)
- Establishing of uniform health data standards by 2009 (including EHRs, Medication Management, Laboratory Results Reporting, Immunization Information Exchange)
- All health care providers and payers establish and use an e-prescribing system by January, 2011

The Department's e-Health Initiative efforts currently include:

- Advisory Committee and Workgroups on topics such as e-Prescribing, Standards, Effective Use of EHRs, Communications and Education, Privacy and Security, Assessment and Evaluation, Population Health
- Administration of Grants and Loans to support adoption of Health IT
- An extensive web-based resource center on e-Health information and resources

Over the past three years, the state has issued close to $15 million in grants to support the adoption and implementation of health IT at health care provider settings across the state.

In addition to the state agency's efforts, Minnesota is home to more than close to 50 Health IT and HIE initiatives. A detailed profile listing all these initiatives was prepared by the Department in late 2007, and included:

  - Community Health Information Collaborative (CHIC) – see below

- o DOQ-IT Project – Minnesota
- o E-Prescribing in the Medicaid Program - see below
- o Itasca County Health Network
- o Lac qui Parle Health Network
- o Minnesota Health Care Connection Project
- o Neighborhood Health Care Network
- o Medicaid's State Operated Services EHR – see below

■ **Minnesota Health Information Exchange (MN-HIE)**

The Minnesota Health Information Exchange (MN HIE) is a not-for-profit organization established by the state's leading health plans, hospitals and clinics and the state of Minnesota. MN HIE improves safety and efficiency by providing doctors across the state with secure electronic access to vital medical information needed to treat patients during a medical emergency or for routine care. To protect patient privacy in accordance with state and federal law, patients must grant permission before doctors or other health care providers can access information. Several large health care systems and programs are now participating in this effort.

■ **NHIN Trial Implementations and CDC Regional HIE Related Grants**

One NHIN trial implementation is taking place in Minnesota:

- o **Community Health Information Collaborative (CHIC)**:
  Headquartered in Duluth, MN, CHIC is dedicated to initiating projects that promote health information exchanges across settings, to share costs, best practices, improve and standardize electronic communication among its growing members. CHIC was recently added to the regional initiatives that are part of the Nationwide Health Information Network (NHIN) project sponsored by the Office of the National Coordinator for Health Information Technology.

■ **AHRQ-Funded Health IT and HIE Projects**

Seven AHRQ-funded Health IT projects are currently underway in Minnesota, including:

- o Health IT Strategic Plan of Southwestern Minnesota
- o Community-shared Clinical Abstract to Improve Care
- o Health IT-based Regional Medication Management Pharmacy System
- o Long Term Care e-Prescribing Standards Pilot Study
- o E-Health Records to Improve Dental Care for Patients with Chronic Illness

■ **Medicaid Health IT Projects**

Minnesota is implementing a Medicaid Transformation Grant focusing on 1) re-establishment of the primary care physician office as a true 'medical home' for the coordination of care for Medicaid clients with complex health care needs; and 2) creation of an interoperable, user-friendly, web-based system, built behind the state's current MN-ITS system, that will enhance and

empower this process. The project is called "Minnesota Communication and Accountability for Primary Care Systems (CAPS)".

In addition, Minnesota Medicaid has other Health IT projects underway, including:

- o E-Prescribing in the Medicaid Program – to provide physicians at the point of care with real time recipient eligibility, formulary information and aggregated medication history
- o State Operated Services' Electronic Health Record – to meet clinical, fiscal, regulatory and strategic planning needs for mental health (adult and child), TBI, CD, Forensic and Nursing Home populations
- o While not currently revamping its MMIS-II (created in 1994), the state is moving towards the implementation of the new Medicaid Information Technology Architecture (MITA)
- o Minnesota Medicaid is also developing a comprehensive, automated eligibility determination system – HealthMatch – to streamline eligibility determination for all health care programs
- o The Medicaid agency is also actively participating in the development of a public-private partnership to create and maintain the Minnesota Health Information Exchange (MN-HIE), a statewide interoperable health data exchange to serve all Minnesotans

- ■ **Health Information Security and Privacy Collaboration/Minnesota** [5]

Minnesota has a long and rich history of health data privacy protections, extending back to 1977. The Minnesota Health Records Act (Minnesota Statutes §§ 144.291–.298) requires patient consent for the disclosure of patient information. Compared to the HIPAA Privacy Rule, and most states, Minnesota law requires written consent even for purposes of treatment, with exceptions existing only for medical emergencies and for disclosures among facilities within an integrated care system. Patient consent generally expires within 1 year.

The focus of the Minnesota Privacy and Security Solutions project during Phase I was to update the Minnesota Health Records Act to reflect an electronic age. As this law had been amended over time, it became increasingly more difficult to read, had an increasing number of undefined or ambiguous terms, and needed to be updated to reflect needs in an electronic age. For these and other reasons, provider organizations were not always clear on when and how patient consent was to be obtained to disclose health information.

Phase I of the project included these results and recommendations:

- o recodified the Minnesota Health Records Act to be more readable;
- o provided definitions for new and existing terms such as "health record," "medical emergency," and "record locator service;"

[5] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

- o defined privacy protections and security requirements for a record locator service;
- o authorized "representation of consent" so that a provider requesting patient information can attest to the patient's written consent;
- o extended liability to a requesting organization that inappropriately request patients' health information (previous liability pertained to the disclosing organization only); and
- o required the Commissioner of Health to develop a standardized, universal consent form for a patient to disclose health information, which must be completed by January 1, 2008.

These changes represented the most significant changes to Minnesota's privacy laws in 25 years. The Minnesota Privacy and Security Solutions project team was able to work out over 95% of the privacy issues in the state and incorporate them into the newly recodified and revised Minnesota Health Records Act.

During this phase, Minnesota also developed a series of Security Principles to be used in guiding the development of policies for HIE initiatives.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Minnesota is participating in the "Consent 1 – Data Elements" Collaborative focusing on establish a model for identifying and resolving patient consent and information disclosure requirements across states and developing a foundational reference guide that describes and compares the requirements mandated by state law and any known regional or local consent policies and practices in each participating state.

Roles of Public Health in Health IT and HIE

As noted above, the state's public health agency, through the Minnesota e-Health Initiative is actively involved in a very significant way in the support, deployment and maintenance of health IT and HIE activities.

In addition, Minnesota has created a state-local Minnesota Public Health Information Network (MN-PHIN) steering committee charged with creating the infrastructure and policies that enable timely, accurate, and statewide exchange of public health information. Such a network will enable public health professionals, policy makers, and community partners to respond efficiently and effectively to community health threats, protect the public from serious but preventable diseases or injury, carry out their responsibilities to make Minnesota communities healthier places to live, and enable consumers to access the public health and prevention information they need to make informed health decisions.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system

- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

6. Oregon

Basic Demographics

General Demographics	State #	State %	US #	US %
Total	3,728,717	100%	298,215,356	100%
Metro	2,872,892	77%	249,589,926	84%
Non-Metro	855,825	23%	48,625,430	16%
<19 years	915,925	25%	78,645,221	26%
19-64	2,347,035	63%	182,781,246	61%
65-74	237,477	6%	19,587,238	7%
75+	228,280	6%	17,201,650	6%
Female	1,875,651	50%	152,167,024	51%
Male	1,853,065	50%	146,048,331	49%
White	3,017,034	81%	196,128,707	66%
Black	66,350	2%	36,259,715	12%
Hispanic	354,293	10%	45,949,214	15%
Other	291,040	8%	19,877,720	7%
Median Income	$48,521.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	1,943,329	52%	159,311,384	53%
Individual	231,049	6%	14,541,782	5%
Medicaid	410,084	11%	39,296,423	13%
Medicare	457,012	12%	36,155,452	12%
Other Public	39,072	1%	3,253,122	1%
Uninsured	648,169	17%	45,657,193	15%
Total	3,728,717	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$17,516		$1,551,255	
Hospital Care	$5,998	34%	$566,886	38%
Physician and Prof Services	$5,857	33%	$446,349	28%
Drugs and Nondurable Medications	$2,042	12%	$222,412	14%
Nursing Home Care	$897	5%	$115,015	7%
Dental Services	$1,269	7%	$81,476	5%
Home Health Care	$201	1%	$42,710	2%
Total Gov. Expenditures	$20,215		$1,340,034	
Gov. Health Expenditures	$3,842		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

While Oregon has a long history of advanced and innovative health care delivery and financing efforts, the state has been relatively slow in moving forward with state-led Health IT and HIE initiatives.

In 2004, the Oregon Health Policy Commission formed a Subcommittee on Electronic Health Records and Data Connectivity to develop recommendations for (1) fostering the adoption of EHR in Oregon's health care delivery systems and (2) developing the infrastructure for the secure exchange of electronic health data between systems. The subcommittee report, completed in March 2005, recommended the state's role in fostering the use of interoperable EHRs. The Joint Legislative Committee on Information Management and Technology has been closely following the work of the subcommittee and has supported EHR adoption and interoperability efforts. As a result of the committee work, the Oregon Office of Health Policy and Research has committed resources for creation of a position for health IT coordination.

The Oregon Healthcare Quality Corporation (Quality Corp) and the Oregon Business Council (OBC) have a shared long-term vision for secure health information exchange. The OBC leadership group is composed of the chief executive officers of some of the largest health systems, health plans, employers, and physician groups in the state. These leaders committed a small amount of resources to assist Quality Corp in delineating first steps for health data exchange for Oregon. This work facilitated completion in 2005 of Quality Corp's strategic plan, which proposes a governance structure for a RHIO and incremental implementation through pilot projects. Legislative initiatives proposed in response to the recommendations from the report died during the 2005 legislature.

In 2006 a health information technology coordination position was created at the Office for Oregon Health Policy and Research. An EHR inventory/survey was completed showing an EHR adoption rate among clinics surveyed of 59%. During this year the Oregon Business Council Health Information Exchange Options report was issued, calling for several short-term project opportunities including a Results and Reports Viewing and Retrieval System, a Community Medication List and a Financial Claim Processing system. A separate report called for the creation of the Metropolitan Portland Health Information Exchange (MP-HIE). This same year, the Oregon Health Information Security and Privacy Collaboration project started.

In 2007, the MP-HIE mobilization plan was issued. The state Medicaid agency also received a two-year $5.5 million Medicaid Transformation Grant to create the Health Record Bank of Oregon, am online health record database for the state's more than 400,000 Medicaid beneficiaries, and a building block of Oregon's HIE initiatives.

The Oregon Health Fund Board created in 2007 by the state legislature is currently completing a comprehensive health reform plan to ensure affordable quality health care for every Oregonian.

More recently, in 2008, the Governor signed an Executive Order establishing the Governor's Health Information Infrastructure Advisory Committee. The Committee issued a series of initial recommendations to the Health Fund Board in October, 2008, including:

- The establishment of a mechanism to stimulate, coordinate and support as a priority statewide efforts to increase the adoption and use of interoperable Health IT, including bringing together stakeholders to develop a strategic Health IT plan and provide oversight for the implementation of the plan. The Advisory Committee also recommended to set specific goals for the adoption of EHRs, PHRs, decision support tools, e-prescribing and other technologies as well as the establishment of a system for state health information exchange

- Accelerate widespread, effective use of Health IT by health care providers and patients/consumers to improve health outcomes and quality of care, by restructuring reimbursement systems to provide incentives for use of Health IT and creating a public-private purchasing collaborative (or other similar mechanisms) to help providers obtain affordable high quality EHRs

- Have by 2012 a statewide system for electronic HIE by supporting the use of the Medicaid's Health Record Bank as a building block of the statewide system and facilitating ongoing planning for the development of the statewide system

- Ensure the highest level of privacy and security protections for Oregonian's personal health information in an electronic HIE environment to promote widespread participation by providers and patients

In addition to these activities, a series of Health IT and HIE initiatives are currently underway in Oregon, including:

- **A series of community HIEs initiated through the AHRQ state health information exchange grant:**

    o Improving the Quality of Healthcare in Central Oregon—Bend
    o Bay Area Community Informatics Project—Coos Bay
    o Using IT to Improve Medication Safety for Rural Elders—Lincoln City
    o Medication Management: A Closed Computerized Loop—Grants Pass
    o Improving Safety and Quality With Integrated Technology—Portland

- **Oregon Community Health Information Network (OCHIN)**

    OCHIN is a non-profit collaboration of public and private health systems in Oregon. OCHIN's mission is to improve access to care and quality of care for Oregonians served by Community Health Centers and other health clinics serving vulnerable populations by supporting physician practice adoption of electronic health records. The network went through a rigorous process to select and contract Epic in 2001 and has successfully implemented Epicâ€™s practice management system in over 100 community health centers and local health departments in the last five years. Capitalizing on the success of practice management implementations, OCHIN was awarded two Integrated Services Development Initiative (ISDI) grants and a Shared Integrated Management Information Systems (SIMIS) grant that have enabled the network to further integrate its information systems operations and implement EMR systems for its partner organizations. Building upon its successful Community Health Record, OCHIN will: Focus on growth in California; create a high-quality, consistent customer experience; and develop value-based partnerships with health plans, health delivery systems, researchers, and foundations. This will support funding, development of best practices, and the realignment of financial incentives to make deployment of a Community Health Record possible for Community Health Centers as a tool for transformation of the fragmented West Coast health care delivery system.

- **Metropolitan Portland HIE**

    This private-sector health information exchange effort in the Portland metro area is currently on hold, although some smaller rural efforts are moving forward with AHRQ funding. There is a heightened awareness of patient control issues in terms of privacy and security. A state-designated body, the Health Information Infrastructure Advisory Committee (HIIAC), is expected to create wider harmony on issues that are dividing stakeholders in the state, such as the potential for increased focus on privacy and security issues beyond HIPAA.

- **AHRQ-Funded Health IT and HIE Projects**

In addition to the Community HIE projects listed above, five other AHRQ-funded Health IT projects are currently underway in Oregon, including:

- o RxSafe: Shared Medication Management and Decision Support for Rural Clinicians
- o Automating Assessment of Asthma Care Quality
- o Improving Quality in Cancer Screening

■ **Medicaid Health IT Projects**

As noted above, Oregon received a Medicaid Transformation Grant to develop the Health Record Bank of Oregon. In addition to this, Oregon Medicaid has a number of other Health IT projects underway, including:

- o MMIS/MITA – Oregon just went live earlier this year with its new MMIS system.

■ **Health Information Security and Privacy Collaboration/Oregon [6]**

The Privacy and Security Solutions project helped to stimulate the creation, advancement, and endorsement of HIEs in Oregon. For example, the Health Policy Commission report devoted a section on health information exchange and privacy/security, which spurred a set of recommendations. Although the Metro Portland HIE was started before the Privacy and Security Solutions project began, the project informed the initiative about privacy and security issues.

The Privacy and Security Solutions project has been a catalyst for privacy and security leadership and governance in Oregon. For example, the Metro Portland HIE project predated the Privacy and Security Solutions project, but the work emanating from the project informed the Metro HIE project with respect to privacy and security issues. The transition of the project's steering committee to an HIIAC was also precipitated by the project findings.

There is now a heightened awareness of patient control issues in terms of privacy and security. However, there is little agreement among individuals about the comprehensibility of HIPAA—some believe HIPAA sufficiently covers the privacy and security issues of health IT and health information exchange, while others do not. The Privacy and Security Solutions project has facilitated an informed discussion on HIPAA among the interested groups and has also provided the impetus for legislative action. The project has aided understanding of the complexity of privacy and security issues and allowed stakeholders to form a more realistic view of issues that need to be discussed before data are exchanged. The project has also encouraged some collaborative efforts across states boundaries with Alaska, California, and Washington. Some of these efforts are addressing similar issues about the interpretation and application of HIPAA.

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[6] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Oregon is participating in the "Consumer Education and Engagement" Collaborative focusing on developing a series of coordinated, state-specific projects that focus on targeted population groups to describe the risks and benefits of health information exchange, educating consumers about privacy and security regarding health information exchange, and developing messages to address consumer privacy and security concerns.

Roles of Public Health in Health IT and HIE

The Oregon Office of Health Policy and Research has been the lead agency within the Department of Human Services (under which the state Public Health Division resides) for the Health IT and HIE efforts in Oregon, supporting the Governor's Advisory Committee, the Health Fund Board, the Health Information Privacy and Security project, and the Health Policy Commission.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

7. Washington

General Demographics	State #	State %	US #	US %
Total	6,359,764	100%	298,215,356	100%
Metro	5,861,974	92%	249,589,926	84%
Non-Metro	497,790	8%	48,625,430	16%
<19 years	1,622,729	26%	78,645,221	26%
19-64	4,028,545	63%	182,781,246	61%
65-74	375,229	6%	19,587,238	7%
75+	333,261	5%	17,201,650	6%
Female	3,227,076	51%	152,167,024	51%
Male	3,132,688	49%	146,048,331	49%
White	4,866,559	77%	196,128,707	66%
Black	209,767	3%	36,259,715	12%
Hispanic	545,996	9%	45,949,214	15%
Other	737,442	12%	19,877,720	7%
Median Income	$56,049.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	3,636,450	57%	159,311,384	53%
Individual	328,871	5%	14,541,782	5%
Medicaid	800,480	13%	39,296,423	13%
Medicare	717,922	11%	36,155,452	12%
Other Public	134,592	2%	3,253,122	1%
Uninsured	741,450	12%	45,657,193	15%
Total	6,359,764	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$31,600		$1,551,255	
Hospital Care	$10,702	34%	$566,886	38%
Physician and Prof Services	$10,367	33%	$446,349	28%
Drugs and Nondurable Medications	$3,792	12%	$222,412	14%
Nursing Home Care	$1,860	6%	$115,015	7%
Dental Services	$2,505	8%	$81,476	5%
Home Health Care	$823	3%	$42,710	2%
Total Gov. Expenditures	$27,839		$1,340,034	
Gov. Health Expenditures	$7,759		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

In 2005, the Washington State legislature passed a bill (Substitute Senate Bill 5064) requiring the development of a state strategy for the adoption and use of EMRs and health IT to be consistent with emerging national standards and promote interoperability of health information systems.

The Washington State Health Care Authority (HCA) convened a Health Information Infrastructure Advisory Board (HIIAB) to develop this strategy. The HIIAB was charged with making specific recommendations to the legislature for a strategy and plan designed to (a) encourage greater adoption and use of EMRs and health IT among the state's health care providers and (b) reduce medical errors and enable patients to make better decisions about their own health care by promoting access to medical records. The legislature called for the identification of obstacles to an effective health information infrastructure in the state, provision of policy recommendations to remove or minimize these obstacles, and development of health care purchasing strategies that would provide incentives to providers and organizations to adopt effective health IT.

Governor Gregoire developed a 5-point strategy for increasing quality and reducing the cost of health care purchased by state programs in Washington. One of the

points in the strategy focuses on making better use of health IT. Specifically, the governor has set a goal for implementation of EMR systems in all of the state's hospitals by 2012, has directed the HCA to implement pilot projects for reimbursement incentives to providers and organizations that adopt health IT, and is planning the launch of a public employee health plan that will serve as a model for the state on electronic data interchange.

A number of organizations and initiatives were established to address various aspects of electronic health information exchange, including the following:

- The Puget Sound Health Alliance was formed in December 2004 as a public-private partnership of more than 160 organizations and has created a sustainable leadership coalition among patients, providers, purchasers, and health plans to improve quality and reduce the cost of health care across King, Kitsap, Pierce, Snohomish, and Thurston counties

- In 1996, the Community Health Information Technology Alliance (CHITA) was formed to help facilitate collaborative health IT planning initiatives in the region. CHITA members include providers, health IT vendors, health plans, and government agencies. CHITA is a program of the Foundation for Health Care Quality. CHITA has engaged in a number of projects relevant to health IT privacy and security

- The Washington Healthcare Forum is a coalition of health plans, physicians, hospitals, and purchasers that has joined together to improve the health care system. The forum's contributions to health system improvements include development of guidelines for administrative simplification, creation of local implementation guides for national standards, development of quality measures, and creation of OneHealthPort. OneHealthPort provides health care professionals a single and secure way to sign on to local health care sites and online services

- As part of its Medicare Quality Improvement Organization contract, Qualis Health is assisting nearly 100 physicians in Washington in selecting and implementing EMRs. One goal of this project is to contribute to an infrastructure that will support interoperable health information exchange by assisting practices with capturing and sending patient information through EMRs to a centralized data repository on a set number of quality measures

- The South Sound Health Communication Network is a RHIO being formed in Tacoma, Washington, that is sponsored by Northwest Physician Network and the Pierce County Medical Society

- PeaceHealth, a 6-hospital network based in Bellevue, Washington, has developed a community health record over the past 10 years that enables independent medical groups in Alaska, Oregon, and Washington to access patient data. This network also links laboratory services and competing hospitals in Eugene, Oregon, and Longview, Washington

The next tables describe the progression of Health IT and HIE initiatives in Washington and projections through 2011.

APPENDIX L: Health Information Infrastructure Vision and Target—A Roadmap for Washington State

Roadmap Milestones	Washington State Leadership and Health IT Vision	Private Sector and Government Activity to Support the Vision
May 2005– December 2006 Washington "Lead and Explore"	**Pass legislation SSB 5064 and project funding ($360,000)** • Appoint Health Information Infrastructure Advisory Board (Board) and Stakeholder Advisory Committee • Develop HIIAB infrastructure, framework, values, target statement, and scope • Explore and research • Develop requirements and assessment criteria **Coordinate efforts between state and congressional delegation** **Assess and determine strategies** **Stakeholder feedback and input** **Submit final report with recommendations and "roadmap"** **Implement interim Health IT and adoption strategies** • Governor's 5 point health care strategy • Washington State Health Information Collaborative economic investment assistance to promote and expedite Health IT and EMR adoption • SHB 2573 – Encourage Health IT by 2012 • Blue Ribbon Commission • Puget Sound Health Alliance	**State programs Health IT and strategy alignment** • Align Health IT activities, Board framework • Coordinate and align activity on Governor's 5 point health care strategy • Explore how to expedite and promote Health IT alignment with private sector **Public – private sector conveners informed and support Board framework, Governor's 5 point health care strategy, Puget Sound Health Alliance (PSHA) efforts, Blue Ribbon Commission** **Share information; participate in local, regional, state, and federal Health IT initiatives** **Marketplace builds and deploys products and solutions** **Secure grant and other funding opportunities and resources to support HIIAB framework such as the Health Information Security Privacy Collaborative Grant (HISPC)** **Explore and participate in public – private partnerships and other strategies to promote and expedite local and regional Health IT and EMR adoption**
January– June 2007 Washington "Adopt the Vision"	**Receive final report, recommendations, and "roadmap"** **Adopt and fund recommendations ($8 – 11 million) for health information infrastructure development and first health record banks (HRBs)** **Explore and identify venture partners** **Adopt legislation and executive orders to expedite coordination and alignment of Health IT activities, Board framework, and recommendations** • Incentives for providers (tax credits, economic investment assistance) • Align financial incentives pilots • Evidence-based medicine	**State programs model and align activity on:** Governor's 5 point health care strategy; Health IT needs, Board framework, and recommendations; business case and WSHII participation **Identify partnerships and statewide strategies to leverage resources, knowledge, and strategies for Board recommendations, roadmap and supporting activities.** **"Bottom up" meets "top down":** Coordinate, build, and deploy market solutions for strategies and recommendations; harness and drive market synergy and alignment **Public - private sectors coordinate and deploy provider and consumer education strategies and campaigns** **Seek funding opportunities and share resources to support recommendations and specific roadmap activities** **Expand public - private partnerships to increase Health IT and EMR adoption towards critical mass adoption**

APPENDIX L: Health Information Infrastructure Vision and Target—A Roadmap for Washington State

Roadmap Milestones	Washington State Leadership and Health IT Vision	Private Sector and Government Activity to Support the Vision

July 2007– June 2009
 	
Washington "Test and Learn"
	Appoint interim Board - Create implementation plan/design work, functions, and committees
	• Staffing and budget
	• Organization and governance
	  o Governance, core functions, outreach processes/programs, privacy policies, liability research and risk assessment, audit, charter compliance, and enforcement mechanisms
	• Technical architecture ("construction drawings")
	  o Transaction architecture (withdrawal, deposit, search), content, and standards
	• Establish and assess performance measures; initial and sustainable financing model
	• Consumer and provider engagement processes, programs, and policies
	  o Privacy and security, education and outreach; provider information and education
	  o Personal health record (PHR) requirements, standards, and functions
	• Research and development of the HRB initial implementation sites
	  o Assess – expand Washington Health Information Collaborative economic development assistance to promote and expedite Health IT and EMR adoption
	  o Operational requirements for HRBs; RFP for pilot participation and charter HRB pilots
	• Mitigate risks
	• Model payment/reimbursement incentives
	• Develop state policy and legislative issues for action on: health record banking, strategies, and incentives for Health IT and EMRs
	
	Coordinate and integrate efforts with regional, other states, and federal activities
		Improve state programs' health information infrastructure
		
		Develop and implement state - private sector consumer and provider engagement plans; participate in pilot charter activities
		
		Promote and utilize standardized and certified products
		
		Collaborate with interim Board
		• Engage with health information technology charter pilot programs; continue EMR implementation and adoption initiatives
		• Expand transparency, incentive realignment, performance measures, and standards
		
		"Bottom up" meets "top down"
		• Build - deploy solutions for strategies and recommendations that expand Health IT, EMR adoption, and information exchange
		• Deploy and utilize PHRs towards critical mass goals; consumer tools for care management, preventive care, and wellness activities
		• Leverage existing investments/resources in the marketplace towards "testing and learning labs"
		• Partner with the public sector and local communities on converging needs, continued innovations, and building solutions
		
		Utilize grant and other funding opportunities and resources to support recommendations and specific roadmap activities

July 2009– June 2011 Washington "Prove and Build"	**Review Washington State Health Information Infrastructure (WSHII) organization** • Measure, analyze, and adjust performance; assess operational effectiveness; monitor/ evaluate health record bank compliance; monitor risks and manage mitigation strategies • Test, implement, and assess financing and sustainment model/methods • Identify and develop policy and legislative framework and requirements related to health record banking and electronic medical records • "Broaden the Dialogue" - public education programs; provider and consumer campaigns • Partner with private sector - increase transparency, adopt performance measures, and realign incentives for use of Health IT; assess methodology to demonstrate impact/ benefits of Health IT • Transition from interim Board for statewide HRB implementation **Expand charter pilot program** • Assess 2007 -2009 pilots ; adapt and restate performance measures against established baseline **Expand Washington State Health Information Collaborative investment strategy for Health IT - EMR adoption beyond critical mass** **"LEAD and CHANGE" – A transformed high performance health care system**	**State programs: expanded support of WSHII participation and in pilot programs; assess results and transform health care programs as result of strategy coordination** **Implement public - private high performance health care and transformation activities with private sector participating in pilot programs** • Participate in "green field" pilots • Increase adoption of EMRs in marketplace in tandem with WSHII activity **Build and deploy market solutions that result in high performance health care delivery** **Increase: Health IT and EMR use to majority adoption; connect communities with WSHII beyond critical mass; PHR product availability and choice beyond critical mass** **"Sustain the Dialogue" with providers and consumers through effective engagement strategies**

In addition to these activities, a series of Health IT and HIE initiatives are currently underway in Washington, including:

- **NHIN Trial Implementations and CDC Regional HIE Related Grants**

  One CDC Regional HIE grant is being implemented in the Pacific Northwest (including Washington):

  - The Northwest Public Health Information Exchange involving both Washington and Idaho

- **AHRQ-Funded Health IT and HIE Projects**

  Three AHRQ-funded Health IT projects are currently underway in Washington, including:

  - Evaluating the Impact of an ACPOE/CDS System on Outcomes
  - A Rural Health IT Cooperative to Promote Clinical Improvement
  - Patient-Provider Electronic Messenger in Chronic Illness

- **Other Health IT and HIE Projects**

  In addition to the AHRQ-funded projects, there are a number of other Health IT-related project undertaken by health care organizations across the state and funded through a variety of sources, including:

  - Inland Northwest Health Services (see above CDC grant)
  - Whatcom Health Information Network – e-Prescribing Project
  - The Electronic Laboratory Based Reporting System (by CHITA)
  - North Central Washington Medical Wide Area Network (MedWan)
  - Nothwest Health Information Network (NWHIN)
  - Spokane WA Community Based Diabetes Health Network
  - Washington Health Information Collaborative

- **Electronic Health Record Bank**

  As part of the efforts of the HIIAB, the Washington Healthcare Authority is supporting the creation of Consumer-managed Health Record Banks in three pilot communities in early 2009. Once a consumer creates an HRB account, it will be populated with copies of key health information like prescriptions, allergies, lab results and immunizations from providers' records or other institutions that have this information.

- **Medicaid Health IT Projects**

  Washington is implementing a Medicaid Transformation Grant focusing on a "Second Generation Fraus and Abuse Detection System". In addition, the Medicaid agency is replacing its current25-year old MMIS with a new payment processing system named ProviderOne. When fully operational (2009), the system is expected to process payments of close to 100,000 providers serving 1 million people.

- **Health Information Security and Privacy Collaboration/Washington [7]**

The HISPC Phase 1 Privacy and Security Solutions project stimulated the creation, advancement, or endorsement of HIEs in Washington in the following ways:

- The government has been offering grants as part of the governor's 5-point strategy to encourage EHR adoption.
- Qualis Health has a contract with CMS to help smaller physician offices adopt and implement EHRs in Washington.
- By working within the Authentication and Consumer Engagement Collaborative work groups, the project team members can offer some information and knowledge that might be helpful to health information exchange projects across states.
- At the last HIIAB meeting, members discussed the point that all of the technical issues require consumer/stakeholder buy-in. This project is the best tool for ensuring that the configuration, policies, and procedures of health information exchange in Washington are in line with consumers' needs.

In October 2007, another $1 million in grants was awarded by the Washington Health Information Collaborative, a public-private partnership promoting greater use of health IT, to small physician practices and critical access and rural hospitals. Since 2005, the collaborative's awards to health care providers totaled $2.2 million for acquiring, implementing, and expanding health IT to improve health care efficiency and effectiveness. In 2007, funding for the awards was provided by two $500,000 contributions from First Choice Health and the Washington State Health Care Authority. Also participating in the collaborative are Qualis Health and the Puget Sound Health Alliance.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), Washington is participating in two Collaboratives:

- o The "Consumer Education and Engagement" Collaborative: to develop a series of coordinated, state-specific projects that focus on targeted population groups to describe the risks and benefits of health information exchange, educate consumers about privacy and security regarding health information exchange, and develop messaging to address consumer privacy and security concerns.

- o The "Adoption of Standard Policies" Collaborative: aimed at developing a set of basic policy requirements for authentication and audit and • defining an implementation strategy to help states and territories adopt agreed-upon policies.

Roles of Public Health in Health IT and HIE

The Washington Department of Health is independent from the Washington Healthcare Authority. While not directly leading the major state Health IT and HIE initiatives, the Department is actively involved through participation and

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[7] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

representation in the State's Health Information Infrastructure Advisory Committee to assure that public health data can be integrated and used in conjunction with the clinical data that is the major driver of the system.

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting
- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.

8.   West Virginia

<mark>Basic Demographics</mark>

General Demographics	State #	State %	US #	US %
Total	1,801,922	100%	298,215,356	100%
Metro	1,036,467	57%	249,589,926	84%
Non-Metro	765,455	43%	48,625,430	16%
<19 years	422,466	23%	78,645,221	26%
19-64	1,138,605	63%	182,781,246	61%
65-74	129,765	7%	19,587,238	7%
75+	111,085	6%	17,201,650	6%
Female	915,369	51%	152,167,024	51%
Male	886,552	49%	146,048,331	49%
White	1,706,091	95%	196,128,707	66%
Black	57,124	3%	36,259,715	12%
Hispanic	7,464	0%	45,949,214	15%
Other	31,242	2%	19,877,720	7%
Median Income	$40,103.00		$49,901.00	

Source: Kaiser Family Foundation's State Health Facts; US Bureau of the Census Current Population Survey, 2007

Health Insurance	State #	State %	US #	US %
Employer	915,965	51%	159,311,384	53%
Individual	36,304	2%	14,541,782	5%
Medicaid	295,357	16%	39,296,423	13%
Medicare	283,410	16%	36,155,452	12%
Other Public	21,501	1%	3,253,122	1%
Uninsured	249,384	14%	45,657,193	15%
Total	1,801,922	100%	298,215,356	100%

Source: Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on the Census Bureau's March 2007 and 2008 Current Population Survey.

Health Expenditures (Millions)	State $	State %	US $	US %
Total Health Expenditures	$10,783		$1,551,255	
Hospital Care	$4,432	41%	$566,886	38%
Physician and Prof Services	$2,805	26%	$446,349	28%
Drugs and Nondurable Medications	$1,627	15%	$222,412	14%
Nursing Home Care	$716	7%	$115,015	7%
Dental Services	$384	4%	$81,476	5%
Home Health Care	$197	2%	$42,710	2%
Total Gov. Expenditures	$20,403		$1,340,034	
Gov. Health Expenditures	$2,263		$357,765	

Source: 2004 Health Expenditure Data, Health Expenditures by State of Residence, Centers for Medicare and Medicaid Services, Office of the Actuary, National Health Statistics Group, released September 2007;

Health IT and HIE Projects in the State

In 2006, the West Virginia Health Information Network (WVHIN) was established by the Legislature, at the request of the Governor, as a public-private partnership to promote the design, implementation, operation and maintenance of a fully interoperable statewide network that would facilitate public and private use of health care information in the state while ensuring the privacy and security of patient health care information. The WVHIN has also taken on the role of convener/collaborator, with the goal of aligning the multiple HIT/HIE initiatives going on within the state of West Virginia.

The main goal is to support physicians and other health care providers in providing the best patient care by delivering medical data at the point of care. The network is expected to be operational in July, 2009.

Earlier in 2008, a Health Information Exchange RFI was issued by the WVHIN requesting proposals to identify solutions for the implementation of an interoperable health information exchange framework throughout the state. RFI submissions have identified multiple alternative approaches to the delivery of functionality and

technical architectures and, thus, WVHIN was able to develop a framework technology plan based on RFI responses. The WVHIN plans to issue a RFP in February 2009 and choose a vendor in April 2009.

The network is envisioned to support and facilitate the following types of electronic transactions, activities and systems:

- Secure electronic access to the results of laboratory, X-ray, or other diagnostic examinations and medical record information transfer to medical providers with the patient's consent
- Disease management and disease surveillance and reporting
- Health alert systems and other applications related to homeland security
- Registries for vital statistics, cancer, case management, immunizations and other public health registries
- Educational offerings for health care providers including links to evidence-based medical practice and patient educational materials
- Physician order entry, prescription drug tracking, drug and allergy interaction alerts, and secure electronic consultations between providers and patients; e-Prescribing
- Single-source insurance credentialing system for health care providers; Electronic health care claims submission and processing; and any other electronic transactions or activities as determined by the legislature

The network will support Direct Patient Care with Decision Support for automatic drug-drug interaction and allergy alerts, automatic preventive medicine alerts, and electronic access to the results of laboratory, x-ray, or other diagnostic examinations. It will also support Care Management and Disease management which include the following: medical record information transfer to other providers with the patient's consent, physician order entry, prescription drug tracking, and secured electronic consultation between providers and patients. The network complies with HIPAA regulations.

In 2007, the WVHIN received one of the Nationwide Health Information Network (NHIN) Trial Implementation grants from the Office of the National Coordinator for Health Information Technology.

In addition to this statewide effort, West Virginia is home to several other Health IT and regional/local HIE initiatives including:

- **West Virginia eHealth Initiative:** A coalition of representatives from health care, business and state government organized to promote the broad adoption, use and coordination of Health IT in health care in the state

- **Community Health Network of West Virginia**: The Community Health Network of West Virginia (Network) is a non-profit, health-center controlled collaborative of 20 member community health centers utilizing technology for improved clinical outcomes, efficiencies and economies of scale. The Network member health centers provide a wide range of preventive and chronic disease health care services to over 150,000 patients in rural communities of West Virginia

- **West Virginia State Electronic Health Record (EHR) Project**: The West Virginia State Electronic Health Record (EHR) Project is an ongoing project by the Department of Health and Human Resources (DHHR) that is uniting all of

West Virginia's state-run healthcare facilities through a contiguous electronic repository of patient information. Medsphere Systems has successfully implemented its OpenVista electronic health record (EHR) at Lakin Hospital, Welch Community Hospital, William R. Sharpe Jr. Hospital, Mildred Mitchell-Bateman Hospital, and Hopemont Hospita. Pinecrest Hospital and the John Manchin Sr. Healthcare Center, the two remaining facilities in the program, were connected earlier this year. OpenVista is a commercialized version of the VistA EHR system created by the US Department of Veteran Affairs. The DHHR electronic health records initiative includes both a clinical package for patient care and an operations component. Once the install is complete at its seven acute, psychiatric and long-term care facilities, West Virginia DHHR will evaluate integrating its EHR system with various community health centers and clinics, further extending the availability of patient records for treatment purposes

- **AHRQ-Funded Health IT and HIE Projects**

  Two AHRQ-funded Health IT projects are currently underway in West Virginia, including:

  - o Partnering to Improve Patient Safety in Rural WV
  - o Boone County Community Care Network

- **Medicaid Health IT Projects**

  West Virginia received a Medicaid Transformation Grant (MTG) in Phase 1 to implement a four-prong project: 1) Healthier Medicaid Members through Personal Responsibility; 2) Healthier Medicaid Members through a Stronger Medicaid Program; 3) Healthier Medicaid Members through Health Systems Improvement, and 4) Healthier Medicaid Members through Applied Technology. West Virginia also received a Phase 2 MTG to implement a fifth component of its Health Medicaid series: Healthier Medicaid Members through Enhanced Medication Management.

  In addition to these projects, WV Medicaid has a number of other Health IT projects underway, including:

  - o MMIS/MITA – WV Medicaid's MMIS system has been operated by Unisys since 2003. A one-year extension was given to Unisys in 2007 to continue to manage and process Medicaid claims via its health care payer administration solution known as Health PAS – the only federally certified MMIS solution made up of commercial off-the-shelf (COTS) software

  - o Community health Network of West Virginia is working in partnership with WV Medicaid to help improve the health of Medicaid enrollees by delivering evidence-based medical care and managing care with their electronic clinical system, MedLynks

- **WV Telehealth Alliance**

  The WV Telehealth Alliance is a not-for-profit organization began in 2007 to provide advanced telecommunication and information services by connecting

approximately 290 facilities with the goal of improving connectivity for rural health centers. The WV Telehealth Alliance is sustained by a FCC grant ($8.4 million over a 3-year period) where monies would be used for broadband connectivity and implementation. The organization focuses its efforts on regions of the state with historically high concentrations of poor and elderly individuals suffering from chronic medical conditions. In particular, those served by the WV Telehealth Alliance include primary care centers, local health departments, free clinics, not-for-profit hospitals, etc.

- **The Roadmap to Health Project**

   Four work groups were established by the legislature in May 2008 for The Roadmap to Health Project. The Project is focusing on how to build a state-of-the-art health care delivery system in WV. Focus areas include: administrative simplification, chronic care information systems, health system redesign, wellness and health promotion. The Project is particularly concerned with how HIT and HIE can contribute to health care reform.

- **Health Information Security and Privacy Collaboration/West Virginia** [8]

   WVHIN acts as the governance body in West Virginia and has integrated the Privacy and Security Solutions project into the WVeHI Executive Board as part of a formal privacy governance structure.

   In West Virginia, the Privacy and Security Solutions project provided an impetus to the introduction of enhanced privacy and security procedures across the legislative branch. The West Virginia legislature recently enacted 2 of the project's high-priority legislative proposals, including a bill to amend an existing state statute by providing greater flexibility in the disclosure of confidential mental health information. The project was also instrumental in introducing the state to a group of initiatives being sponsored in other states that focused on the privacy and security aspect of health information exchange.

   In their findings from Phase I of the Privacy and Security Solutions project, the West Virginia project team recommended that West Virginia create additional opportunities to educate consumer stakeholder groups concerning health information exchange privacy and security concerns. West Virginia's population is dominated by a high percentage of low income elderly, rural Medicare and Medicaid recipients with numerous chronic conditions that make them frequent users of health care. The West Virginia team thought it necessary to delve into how to work with this unique population, information that may not be obtained from other states with younger more urban residents.

   The West Virginia team reported that the Privacy and Security Solutions project helped them to formulate their implementation plan into action and educate their consumers so that they can develop a sustainable plan for West Virginia's security and privacy concerns for the future. West Virginia intends to fully implement the plan in 2008, in conjunction with WVHIN and the

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[8] Source: Impact Analysis Report – Privacy and Security Solutions for Interoperable Health Information Exchange – Health Information Security and Privacy Collaboration (HISPC), December 20, 2007

multistate collaborative that is focusing on consumer education, outreach, and dissemination.

Based on recommendations of the West Virginia project, the West Virginia legislature passed 2 bills during the last session. These include West Virginia HB 3184, a bill to amend an existing state statute by providing greater flexibility regarding the disclosure of confidential mental health information, and West Virginia SB 1001, a bill to amend an existing state statute by adding a new section relating generally to the authorization of electronic prescribing.

The executive branch of West Virginia state government recently accepted a statement of 6 privacy principles that will be used to frame the discussion on privacy for health information exchange activity. In the near future, a set of security principles will be enacted. The knowledge base acquired through Privacy and Security Solutions project has also framed consumer education research and outreach activities. These experiences, in turn, will support developing consumer messaging that directly speaks to the concerns the public voiced about health information exchange and health IT.

During the 2008-2009 HISPC Multi-State Collaborative Phase (Phase III), West Virginia, through the West Virginia Medical Institute and the WVHIN is participating in the "Consumer Education and Engagement" Collaborative focusing on developing a series of coordinated, state-specific projects that focus on targeted population groups to describe the risks and benefits of health information exchange, educating consumers about privacy and security regarding health information exchange, and developing messages to address consumer privacy and security concerns. As part of this project, the West Virginia Medical Institute has created "eHealthWV" a web-based resource center (www.ehealthwv.org) to disseminate information to consumers about electronic health records, health information exchanges, and other relevant information. The site also includes content directed to providers and the media.

Roles of Public Health in Health IT and HIE

While the West Virginia Bureau of Public Health, a division of the West Virginia Department of Health and Human Resources, is not the lead agency within the state on Health IT and HIE matters, it is actively involved in several of the statewide projects, including the implementation of a WV State EHR project (see above).

As with other state public health departments, several agency divisions and programs within the Department are actively engaged in electronic exchanges of information, albeit not necessarily through the state HIE initiatives. These programs include:

- Vital and health statistics (i.e., electronic birth records)
- Public Health Laboratory reporting system
- Immunization Registry
- Encounter-level data reporting (inpatient and outpatient)
- State (Electronic) Disease Surveillance System and communicable disease reporting

- State Public Health Information Network (PHIN)
- State Health Alert Network
- Disease-specific registry systems (such as Cancer Registry)

These systems utilize health IT and a variety of standards to collect specific information from providers and other sources.