

PUBLIC HEALTH DATA
STANDARDS CONSORTIUM

PHDSC

Promoting Standards Through Partnerships



Privacy, Security and Data Exchange Committee Annual Report 2008



Presented at the
PHDSC Annual Meeting

November 12, 2008

PHDSC Home Page ⇨ <http://www.phdsc.org/>
PRISM Web Page ⇨ http://www.phdsc.org/privacy_security/prism.asp



Background and Mission

Mission

- Represent and educate broad public sector health and health services research interests on privacy and security issues
- Focus on priorities related to privacy, security, and data standardization, including implementation of the HIPAA privacy and security rules
- Address balancing the need for individual privacy, confidentiality, and security with the need for use of data for public health and research activities



Accomplishments

- Revise Committee Web Page for improved access to committee products and resources
- Participate in national privacy and security efforts (HISPC and HITSP)
- Privacy projects
 - Further work on and expansion of the PRISM Tools
 - Two reports on Privacy and Security in Public Health Information Exchanges
 - Report on Best Practices in Public Health Information Privacy



Revised Committee Web Page

- Revised Privacy, Security and Data Exchange Committee web page
 - Revised entire website this past year
 - Revised and updated page format and content
 - New committee page at http://www.phdsc.org/privacy_security/default.asp



Participation in National Privacy and Security Efforts

- CCHIT:

- Participate in the Privacy and Compliance Workgroup
- Workgroup defines the certification criteria for Inpatient and Ambulatory EHR products
- This year's focus on Network Service Providers and PHR products



Participation in National Privacy and Security Efforts

- HISPC

- Phase III (April 2008 through March 2009) underway
- Seven Multi-state Collaboratives developing common, replicable multi-state solutions to privacy and security issues
- Most states include direct leadership or active involvement of state public health



Participation in National Privacy and Security Efforts

- HISPC Multi-state Collaboratives

Collaborative	Participating States and Territories	
	N	Abbreviations
Consent 1 - Data Elements	11	IN, ME, MA, MN, NH, NY, OK, RI, UT, VT, WI
Consent 2 - Policy Options	4	CA, IL, NC, OH
Harmonizing Privacy Law	7	FL, KY, KS, MI, MO, NM, TX
Consumer Education and Engagement	8	CO, GA, KS, MA, NY, OR, WA, WV
Provider Education	8	FL, KY, LA, MI, MO, MS, TN, WY
Adoption of Standard Policies	10	AZ, CO, CT, MD, NE, OH, OK, UT, VA, WA
Interorganizational Agreements	7	AK, GU, IA, NJ, NC, PR, SD



Participation in National Privacy and Security Efforts

- HITSP

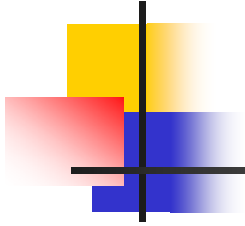
- Leadership roles in the Population Perspective and the Security, Privacy and Infrastructure (SPI) TCs
- Population TC developed 2008 Implementation Specification for PH Case Reporting and Immunization and Response Management Use Cases
- SPI TC developed constructs to address specific public health-related issues, including Anonymization and Pseudonymization, Patient ID Cross-Referencing, Patient Demographic Query, Unstructured Document Exchange, and Non-Patient Notification Alert

- Assist in the ONC National Privacy and Security Framework development



2008 Committee Privacy Projects

- Set of products and documents
 - Project 1 – PRISM Phase II
 - Revisions and update to existing PRISM tool
 - Create PRISM Disclosures TO Public Health
 - Create PRISM LITE
 - Marketing/outreach efforts
 - Project 2 - Reports on Privacy and Security in Public Health Information Exchanges, from HISPC documents
 - Project 3 - Report on Best Practices in Public Health Information Privacy, from direct state interviews



Project 1

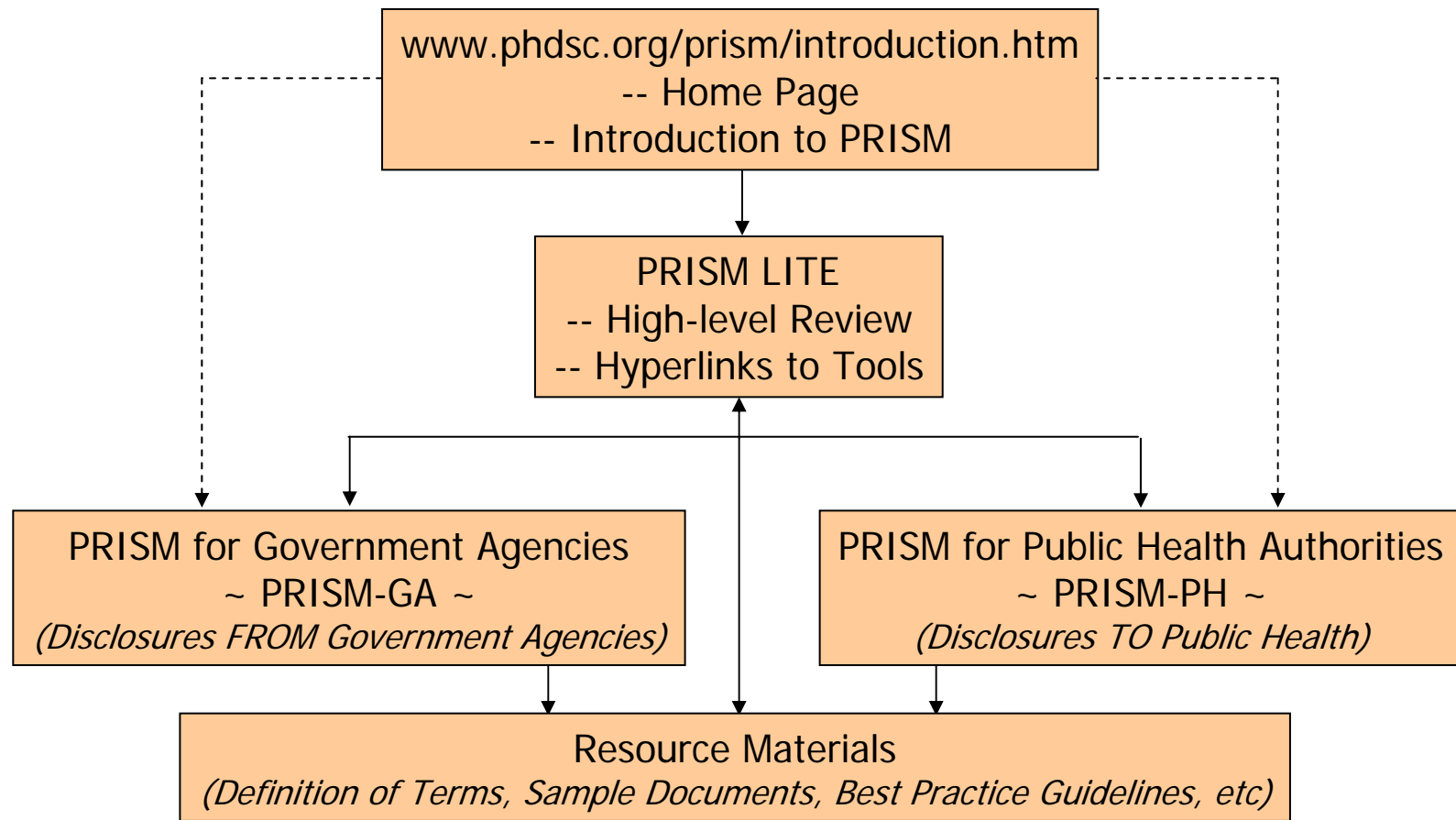
PRISM Phase II



Revision and Expansion of PRISM

- Created the PRISM Family of Privacy Tools
- Four Components
 - Updated Current PRISM Tables
 - Created PRISM for Public Health Agencies (Disclosures TO)
 - Created PRISM Lite ®
 - Expanded PRISM Education and Outreach efforts

PRISM Family of Privacy Tools





PRISM Family of Privacy Tools

PRISM Update

- PRISM for Government Agencies (PRISM-GA)
 - Revisions and updates to the original tool (completed in 2007)
 - Focus on Disclosures FROM Government Agencies
 - Revisions include edits and text corrections, harmonizing tables, additional table clean-up



PRISM Family of Privacy Tools

Disclosures TO PH

- PRISM for Public Health Authorities (PRISM-PH)
 - New tool identifying principles and practices related to the disclosure of identifiable health information TO Public Health by various sources
 - Overall structure similar to original PRISM
 - Purposes for disclosures to public health (Required by Law, others), plus
 - Type of information being disclosed (vital statistics, immunizations, HIV, medical record information, etc)



PRISM Family of Privacy Tools

PRISM Lite

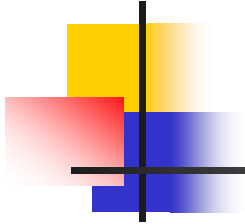
- PRISM "LITE"
 - A simplified summary of privacy principles and practices
 - Extracted core elements, common components and guidance from the larger PRISM Tables
 - Summary presented in a matrix with higher-level concepts and principles



PRISM Family of Privacy Tools

PRISM Education/Outreach

- Expanded PRISM Education/Outreach
 - A comprehensive plan developed and underway
 - Focuses on the following activities:
 - PRISM Webinars
 - PHDSC Newsletter
 - Market New PRISM
 - Expanded PRISM Website
 - Articles on PRISM
 - Sessions at National Events
 - PRISM 101 Tutorial
 - Special-Topic One-Pagers



Project 2

Privacy and Security for Interoperable Public Health Information Exchanges



Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

- Purpose: to review state privacy and security variations, solutions and implementation plans affecting public health
- Process: Extract data from the Health Information Security and Privacy Collaborative (HISPC) Reports related to Public Health



Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

- Outcomes:
 - Summary report with State Variations on Privacy and Security Laws, Policies and Practices Affecting Public Health (June 1, 2008) – *Committee Review*
 - Summary report with State Solutions and Implementation Plans to address the variations on Privacy and Security Laws, Policies and Practices Affecting Public Health (June 15, 2008) – *Committee Review*

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges



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

Assessment of Variations in Privacy and Security Policies, Practices and State Laws Affecting the Interoperability of Public Health Information Exchanges

A Review of State Findings from the Health Information Security and Privacy Collaboration Project

Project Report (1 of 2)

September 2008



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

Analysis of Solutions and Implementation Plans Proposed by States to Address Privacy and Security Issues Affecting the Interoperability of Public Health Information Exchanges

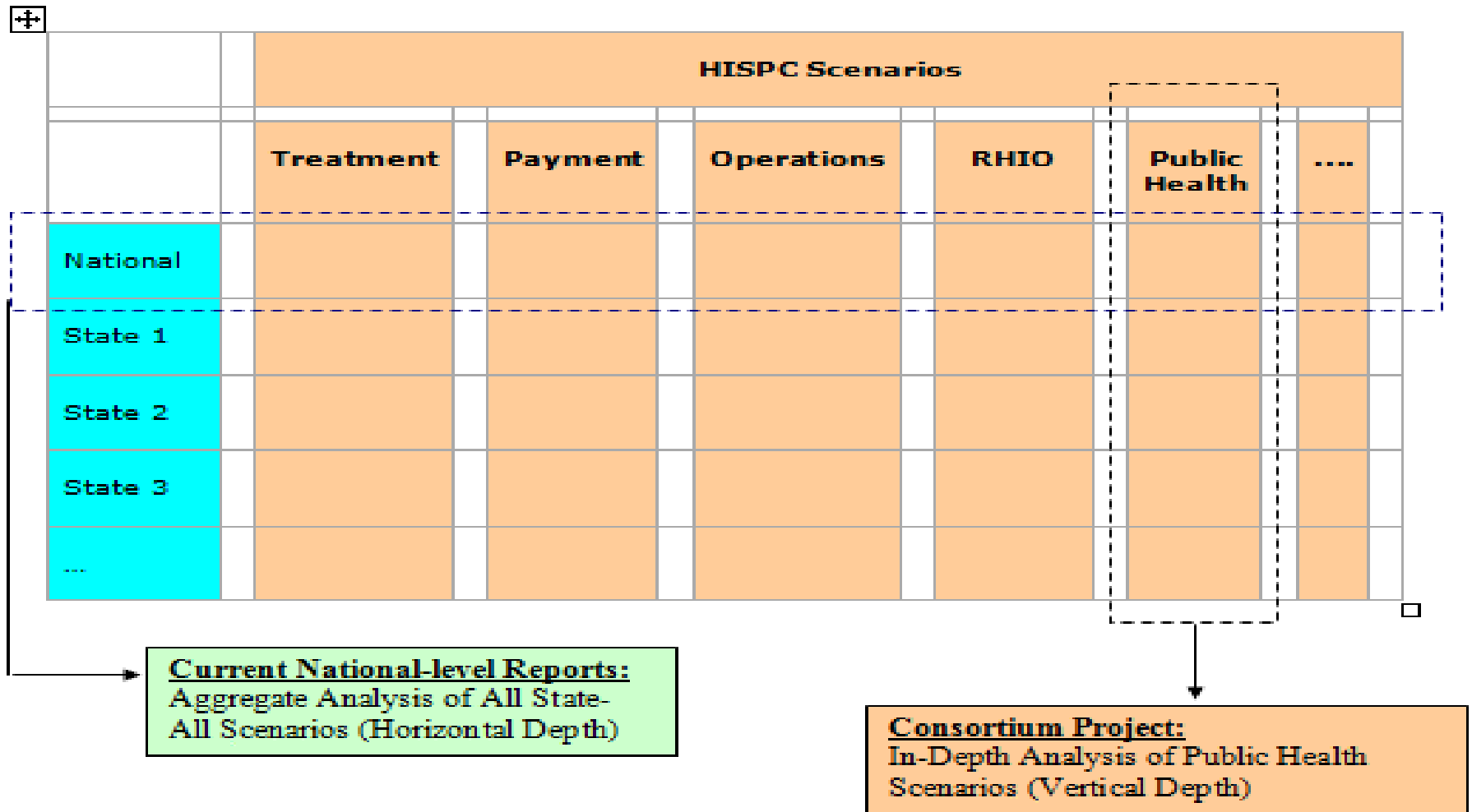
A Review of State Findings from the Health Information Security and Privacy Collaboration Project

Project Report (2 of 2)

September, 2008

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

Fig. 1
Horizontal and Vertical HISPC Scenario Analysis:
National HISPC Project and PHDSC Project Domain Depths



Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

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September 2008

Table of Contents

1. Introduction

- a. Overview of Project
- b. Purpose of Report

2. Methodology

- a. Research and Collect Document Sources
- b. Identify, Select and Extraction Public Health Related Information
- c. Aggregate and Analyze Findings

3. HISPC Public Health Scenarios and Privacy and Security Domains Used by States to Conduct Assessment of Variations

- a. Public Health Scenarios
- b. Privacy and Security Domains

4. Summary of State-level Issues – Variations in Privacy and Security Business Practices, Policies and State Laws Affecting Public Health Information Exchanges

- a. Analysis of Top State Issues

5. Summary of Multi-State and National level Issues - Variations in Privacy and Security Business Practices, Policies and State Laws Affecting Public Health Information Exchanges

- a. Analysis of Top Multi-State and National Level Issues

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

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

Table 1
Themes, Identified State and National Issues and Possible Roles, Opportunities and Areas of Work For the Consortium

Core Themes	Summary of Identified State and National Issues	Possible Consortium Roles, Opportunities and Areas of Work
Need to Develop a Public Health Privacy and Security Framework	<ul style="list-style-type: none"> ■ Lack of a privacy and security framework that would apply to public health participation in RHIOs and local, state, regional and national health information exchanges 	<ul style="list-style-type: none"> ■ Convene a multi-stakeholder workgroup to develop such framework ■ Facilitate the convening of public health privacy officers, in partnership with ASTHO, NACCHO and others
Need to Advance Health IT Adoption in Public Health	<ul style="list-style-type: none"> ■ Significant continued reliance on paper-based processes for public health information exchanges was common across states 	<ul style="list-style-type: none"> ■ Identify opportunities where state and local public health can move from paper to electronic
Need to Address Variations in Privacy and Security Policies and Practices Related to the Collection, Use and Disclosure of Health Information by Public Health	<ul style="list-style-type: none"> ■ Variations around the reporting of communicable <u>diseases/notifiable conditions</u> ■ Variations in the definition of 'Sensitive' health information ■ Level of access by public health agencies to health information during emergency, bioterrorism ■ Variations in the exchange of data with health oversight agencies when broad statutory authority exists 	<ul style="list-style-type: none"> ■ Prioritize areas of work (from list of identified items) and convene workgroup(s) to address the issues

Core Themes	Summary of Identified State and National Issues	Possible Consortium Roles, Opportunities and Areas of Work
	<ul style="list-style-type: none"> ■ Variability of re-disclosure policies and practices applicable to public health agencies within state and across states 	
Need to Advance the Adoption of Data Standards Related to the Collection, Use and Disclosure of Health Information by Public Health	<ul style="list-style-type: none"> ■ In areas such as communicable disease reporting, disease registries, 'sensitive' information 	<ul style="list-style-type: none"> ■ Identify data standardization priorities and opportunities and work with Consortium's Data Standards Committee to address them
Need for Continued Education and Outreach	<ul style="list-style-type: none"> ■ On a public health privacy and security framework ■ On the advancement of health IT adoption by public health ■ On the adoption of data standard and harmonized policies and practices related to the collection, use and disclosure of health information by public health ■ On the differences between voluntary vs. authorized vs. mandated exchanges of health information with public health agencies ■ On the interactions between federal and state laws affecting public health information exchanges ■ On targeted issues, such as how to address FERPA limitations to allow sharing of immunization data collected by schools 	<ul style="list-style-type: none"> ■ Prioritize and implement education and outreach activities through the Consortium's Education Committee

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

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

Analysis of Solutions and Implementation Plans Proposed by States to Address Privacy and Security Issues Affecting the Interoperability of Public Health Information Exchanges

*A Review of State Findings from the Health Information
Security and Privacy Collaboration Project*

Project Report (2 of 2)

September, 2008

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- 4. Summary of State-level Solutions and Implementation Plans Proposed by States to Address Variations in Public Health Related Privacy and Security Business Practices, Policies and State Laws**
 - a. State-level Solutions**
 - i. Reducing Variations – Practice or Policy Solutions**
 - ii. Legal or Regulatory Issues**
 - iii. Technology and Standards**
 - iv. Education**
 - v. Implementation and Governance of Privacy and Security Solutions**
 - vi. Ancillary Issues and Solutions**
 - b. State-level Implementation Plans**
 - i. Leadership and Governance**
 - ii. Practice and Policy**
 - iii. Legal and Regulatory**
 - iv. Technical and Standards**
 - v. Education and Outreach**
- 5. Summary of Multi-State and National level Solutions and Implementation Plans Proposed by States to Address Variations in Public Health Related Privacy and Security Business Practices, Policies and State Laws**
 - a. Analysis of Top Multi-State and National Solutions**
- 6. Concluding Themes and Possible Roles, Opportunities and Areas of Work for the Consortium**

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

Table 1
State-level categories of solutions and implementation plans and Possible Roles and Opportunities for the Consortium

Category	Summary of Solutions	Possible Consortium Roles and Opportunities
Public Health Reporting Policy	<ul style="list-style-type: none"> Conduct a comprehensive review of state privacy and security laws and regulations affecting public health. Facilitate the integration of state public health data systems into health information exchanges Develop a roadmap for how public health can participate on an HIE 	<ul style="list-style-type: none"> Develop a template/tool for states to use when assessing the state privacy and security laws affecting public health Facilitate the development of a roadmap for public health participation in HIEs
Privacy Policy	<ul style="list-style-type: none"> Develop, change, update, and integrate/consolidate state privacy policies and laws, particularly those related to patient consent. Special areas of interest to public health include: Medicaid regulations on privacy, additional state protections for 'sensitive' health information (such as HIV/AIDS, mental health, substance abuse, genetic information), and sharing of information related to minors. Establish the statutory parameters for collecting, documenting and reporting patient consent electronically, including standards for accepting digital signatures. 	<ul style="list-style-type: none"> Research and document emerging state privacy policies, particularly those related to patient consent, opt-in/opt-out for HIEs, sensitive health information, and other topics.

Category	Summary of Solutions	Possible Consortium Roles and Opportunities
Security and Technical Standards	<ul style="list-style-type: none"> Establish a framework and a common set of interoperable policies and technical requirements to address Authorization, Authentication, Access Control and Audit. Adopt health information exchange standards to enable a uniform anonymization and pseudonymization processes. 	<ul style="list-style-type: none"> Facilitate the development of a security framework for public health on issues such as authentication, authorization, access control and audit Help develop/promote a standard approach for anonymization and pseudonymization
RHIO/HIE-Enabling Policy	<ul style="list-style-type: none"> Introduce and adopt legislation to create a state Health Information Network Establish a state Health Information Technology and Exchange entity which will serve as a collaborative forum to promote HIT/HIE use and the adoption of a common HIT/HIE framework and principles. 	<ul style="list-style-type: none"> Monitor and document state legislation establishing/promoting local, regional and state HIEs and the participation of public health in them
Sensitive Health Information	<ul style="list-style-type: none"> Address the variability in the use and implementation of the term 'sensitive' health information. 	<ul style="list-style-type: none"> Facilitate the development of a standardized approach to sensitive health information
Ancillary Issues	<ul style="list-style-type: none"> Address issues related to: <ul style="list-style-type: none"> Use of health information for Quality, Research, Public Health and Other Purposes Breaches and Identity Theft Privacy and security of genetic-related information Enforcement of privacy and security regulations Handling of non-covered entities 	<ul style="list-style-type: none"> Prioritize and facilitate and/or participate in working groups to address the various ancillary issues identified by states
Education and Outreach	<ul style="list-style-type: none"> Health information exchange education and outreach was a fundamental component of all state solutions and implementation plans. Public health was specially referenced in many states as a source, a facilitator, the subject for, and the target of such initiatives. 	<ul style="list-style-type: none"> Be actively engaged in regional and national education and outreach efforts Develop templates and tools to assist states with education and outreach efforts

Project 2: Privacy and Security for Interoperable Public Health Information Exchanges

Table 2
National-level categories of solutions and implementation plans and Possible Roles and Opportunities for the Consortium

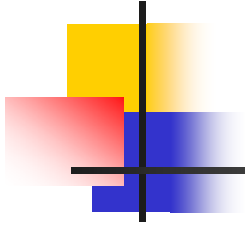
Category	Summary of Solutions	Possible Consortium Roles and Opportunities
National Public Health Reporting Standards	<ul style="list-style-type: none"> Develop a framework for sharing individually identifiable health information across states in the event of emergencies, disasters and bioterrorism 	<ul style="list-style-type: none"> Assist in coordinating the development of framework
Inter-state Coordination and Agreements	<ul style="list-style-type: none"> Establish national and regional multi-state task forces to develop standardized HIE policies and procedures for public health information exchanges between states. Develop standard inter-state agreements that support the exchange of public health and other health-related information. 	<ul style="list-style-type: none"> Facilitate the formation of such multi-state working groups Work with other national initiatives to develop standard inter-state agreements
HIPAA Regulatory Changes	<ul style="list-style-type: none"> Address the following issues: <ul style="list-style-type: none"> Business Associate Agreement Minimum Necessary Accounting of Disclosure De-identification, Limited Data Sets, Designated Record Set Non-Covered Entities 	<ul style="list-style-type: none"> Prioritize and work on addressing the identified issues
Changes in Other Federal Laws	<ul style="list-style-type: none"> Address issues related to the following federal laws and regulations: <ul style="list-style-type: none"> Substance Abuse FERPA CLIA STARK 	<ul style="list-style-type: none"> Prioritize and work on addressing the identified issues
Sensitive Health Information	<ul style="list-style-type: none"> Address at the federal level the variations in definition, interpretation, protection and implementation of so- 	<ul style="list-style-type: none"> Assist the federal government in developing a common

Category	Summary of Solutions	Possible Consortium Roles and Opportunities
	called 'sensitive' health information.	approach to sensitive health information.
Addressing RHIO/HIE Status	<ul style="list-style-type: none"> Address the legal status of RHIOs, including whether they should be considered Covered Entities, Business Associates or something else. Develop a framework for liability that addresses the role of the state level HIE organization/RHIO and the interaction of federal and state level regulatory frameworks. Develop model consent forms for loading information (routine and/or specially protected information) into a HIE. 	<ul style="list-style-type: none"> Work with the federal government to address the legal status of RHIOs and other similar organizations involved in HIEs.
Security and Technical Standards	<ul style="list-style-type: none"> Develop national standard policies and practices for Authentication, Authorization, Access Controls and Audits. Utilize federal bridge to register, enroll, and integrate state based digital identity services. Promote the establishment of a national standard patient identification process/algorithm. National standards defining security breaches exist (NIST, ISO, etc.) but could be clarified in terms of their relationship to electronic HIE. 	<ul style="list-style-type: none"> Work with partners to develop national standard policies and practices on security issues such as authentication, authorization, access control and audit.
Education and Outreach	<ul style="list-style-type: none"> Create national standardized consumer education programs regarding secure and private use of individually identifiable health information. Implement a public awareness campaign that will help the public understand what they stand to gain with increased exchange of health information and how their health information will be protected. 	<ul style="list-style-type: none"> Work with ONC and others to coordinate a national consumer education campaign regarding secure and private use and disclosure of individually identifiable health information.



Next Steps

- Publication and dissemination of report and findings
- Discuss and address identified opportunities for Consortium through PSDE Committee
- Explore possibility of creating a clearinghouse of information covering privacy and security issues for public health agencies participating in local, state and regional health information exchanges



Project 3

State Best Practices on Privacy and Security Related to Public Health



Project 3: State Best Practices on Privacy and Security Related to Public Health

- Purpose: to identify a series of state best practices on privacy and security related to public health
- Process:
 - Select 8-9 states with active public health involvement in planning/implementation of HIEs (partly based on HISPC report analysis)
 - Interview state officials to identify priority privacy issues for public health, best practices
 - Document and publish best practices



Project 3: State Best Practices on Privacy and Security Related to Public Health

- Outcomes:
 - Summary of state health information exchange initiatives involving public health and their privacy and security policies and practices (October, 2008) – *Committee Review*
 - Summary of multi-state and national-level issues and recommended approaches related to public health and privacy/security (October, 2008) – *Committee Review*
 - Best Practices report – identifying a series of best practices from states on privacy and security related to public health information exchanges (November, 2008) – *Committee Review*



Project 3: State Best Practices on Privacy and Security Related to Public Health

- Status:

- ☑ Identified and selected states
- ☑ Developed interview guide
- ☑ Completed interviews of 8 states
- Creating summary profiles of states (Nov 15)
- Review/analysis of data (Nov 15)
- Prepare draft report (Nov 15)
- Review draft report with PSDE Committee (Nov 25)
- Prepare and deliver final report (Nov 30)



Project 3: State Best Practices on Privacy and Security Related to Public Health

- States Completed (Privacy Officer):

- ✓ Massachusetts (Tracy Miller)
- ✓ Florida (Rodney Johnson)
- ✓ Minnesota (Dave Orren)
- ✓ Michigan (Denise Chrysler)
- ✓ Washington (Kathy Stout)
- ✓ California (Steve Stuart)
- ✓ West Virginia (Sally)
- ✓ Oregon (Jane Alm)

- Alternate States:

- Indiana
- Rhode Island
- Colorado
- Vermont
- New York
- Wisconsin
- Utah
- Arizona



Project 3: State Best Practices on Privacy and Security Related to Public Health

- Interview Purpose – to identify and document:
 - Health information privacy issues agency faced since implementation of HIPAA Privacy, and how they were addressed
 - Ongoing health information privacy issues agency is facing
 - New health information privacy issues agency sees coming, as more public health information is collected, accessed, used and disclosed electronically
 - Health information privacy issues associated with public health participation in RHIOs and HIEs
 - Multi-state and national issues related to health information privacy and public health that agency considers critical to be addressed



Preliminary Findings (1)

- Privacy Issues Faced at the Start of HIPAA
 - Ensuring Public Health Continued to Get its Health Information Without Disruption
 - Determining Covered Entity Status of Public Health Agency
 - Development of Agency's Privacy Policies and Procedures
 - Completing an Analysis of HIPAA vis-à-vis other Federal and State Privacy Laws Affecting Public Health
 - Dealing with the Variety of Public Health Programs and Understanding the impact of HIPAA and other laws



Preliminary Findings (2)

- Privacy Issues Faced at the Start of HIPAA
 - Addressing De-identification Issues
 - Privacy Training of Staff
 - Addressing Confusion about Role of Public Health vis-à-vis a Business Associate
 - Handling Confusion Regarding 'Authorized' vs. 'Required' disclosures to Public Health
 - Increased Information Security Across the Board



Preliminary Findings (3)

- Current and Emerging Privacy Issues
 - Data linkage and data de-identification – lack of standardized approaches and policies
 - Continue interpreting and de-coding complex and overlapping privacy laws
 - Data breaches (public health and others)
 - Identify theft
 - Emergency preparedness and privacy protections
 - Data ownership - as identified health information is disclosed and re-disclosed
 - Enforcement of privacy requirements and regulations at state level



Preliminary Findings (4)

- Current and Emerging Privacy Issues
 - Small-cell issue and how to consistently address it
 - Continued challenging (the lack of understanding of) the need for population health data
 - Newborn Screening
 - Privacy of Genetic Information
 - Staff training
 - Research – Concerns about capabilities to continue doing research within privacy
 - Security protections of health information



Preliminary Findings (5)

- HIEs/NHIN and Privacy Issues for Public Health
 - Consent
 - Lack of State Regulations Defining Regional HIEs
 - Portability of Data Protections of Public Health Data into HIEs
 - Interoperability of Public Health data systems and regional HIEs (i.e., NEDDS, PHIN, HANs, BioSense, etc)



Preliminary Findings (6)

- Multi-State/National Privacy Issues for Public Health
 - Consent
 - Emergency preparedness and privacy across states
 - Portability of privacy consents across state boundaries
 - Re-release of information across states
 - Lack of common terminology/definitions



Next Steps

- Publication and dissemination of report and findings
- Possibility of expanding state assessment to more states, to cast a wider net of issues
- Opportunity to create a Web-based Clearinghouse on Privacy Issues for Public Health Privacy Officer
- Possibility of convening public health privacy officers into a national forum (in partnership with ASTHO, NACCHO and others)



Future Committee Activity

- Submitted a proposal for further development of the PRISM tool
 - Adding state specific information on selected items
- Additional marketing/outreach for PRISM tools
- Development and presentation of regular webinars on privacy and security related topics
- Continue to seek national involvement in privacy/security efforts
- Development of ideas for security projects



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