BUSINESS CASE:
The Role of Public Health in National Health Information Technology Standardization
The Public Health Data Standards Consortium (PHDSC, The Consortium) is a national non-profit membership-based organization of federal, state and local health agencies, professional associations, academia, public and private sector organizations, international members, and individuals.

The Consortium is committed to bringing a common voice from the public health community to the national efforts of standardization of health information technology and population health data in order to improve individual and community health.

To fulfill its mission the Consortium:

- **Identifies priorities for new national standards** for population health data;
- **Promotes integrating health-related data systems** to meet the needs of public and private organizations, agencies and individuals;
- **Participates in national and international efforts** to standardize health-related information;
- **Represents public health interests** in standards development organizations, data content committees & standards harmonization entities; and
- **Educates** the public health community about health information technology standards and the health information technology community about public health.

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This document was developed under the Cooperative Agreement with the National Center for Health Marketing, Centers for Disease Control and Prevention (CDC), “Assuring HIT Standards for Public Health”, Grant No.: IU38HM000455-0. The material in this document has not been subject to agency review and approval for publication as a Centers for Disease Control and Prevention (CDC) report. Mention of trade names, products, or services, does not convey, and should not be interpreted as conveying, official CDC approval, endorsement, or recommendation.
CONTRIBUTING ORGANIZATIONS AND ACKNOWLEDGEMENTS

Centers for Disease Control and Prevention (CDC)

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We would like to thank Ms. Marjorie Greenberg and Ms. Missy Jamison, CDC National Center for Health Statistics; Dr. Michael Fitzmaurice, Agency for Healthcare Research and Quality; Ms. Starla Ledbetter, California Office of Statewide Health Planning and Development; Dr. Robert Aseltine, University of Connecticut Health System; Mr. Bill Brand, Public Health Informatics Institute; Dr. Shaun Grannis, Regenstrief Institute; Mr. Brook Dupee, New Hampshire Department of Health, NH; Dr. Alex Hathaway, Dr. Neil Calman, The Institute for Urban Family Health, NYC; Mr. James Golden, Minnesota Department of Health, MN; and Dr. David Ross, Public Health Informatics Institute for the review of the Business Case document and valuable comments. We also would like to thank members of the Consortium’s Data Standards Committee for the review of the document and Glen Freyer for his editorial assistance.
Table of Contents

EXECUTIVE SUMMARY .................................................................................................................. 6

HEALTH IT ADOPTION: CHALLENGES AND OPPORTUNITIES FOR PUBLIC
HEALTH ........................................................................................................................................... 8

  Health Information Technology Adoption in Public Health ................................................ 8
  Toward a Nationwide Health Information Network ......................................................... 9
  Public Health Opportunities in a Nationwide Health Information Network ................. 10

HEALTH IT STANDARDS: CHALLENGES AND OPPORTUNITIES FOR PUBLIC
HEALTH ........................................................................................................................................ 11

  HIT Standards in Public Health ............................................................................................. 13
  Public Health Involvement in HIT Standardization ............................................................ 14
  Public Health in HIT Standardization: Barriers and Opportunities ............................... 18
    Why Participate in National HIT Standardization/Risks of Non-participation .... 19
    Where Should Public Health Participate? .......................................................................... 20
    What Public Health Interests Should be Brought to the Standards Table? ... 20
    Is Public Health Ready to Participate and Who Should Participate? ....................... 22
    How Much Will Participation Cost? ............................................................................... 24
    How Should Public Health Participation be Coordinated? ........................................... 25

ASSURING PUBLIC HEALTH PARTICIPATION IN HEALTH IT
STANDARDIZATION: A BUSINESS STRATEGY ...................................................................... 27

  What Needs to be Accomplished? ....................................................................................... 28
  Who Needs to Participate? .................................................................................................... 28
  Who Can Encourage Public Health Participation in HIT Standardization? .......... 30
  Strategies to Increase Public Health Participation in HIT Standardization .......... 32

CALL TO ACTION: COORDINATED PUBLIC HEALTH ACTION PLAN ON
HEALTH IT STANDARDS ........................................................................................................... 33

APPENDIX: WEB-BASED INTERACTIVE MODEL ON PUBLIC HEALTH IN
HEALTH IT STANDARDIZATION ............................................................................................... 35

REFERENCES: .......................................................................................................................... 36
Section 1

Executive Summary

To date, Health Information Technology (HIT) adoption in public health has been program-specific and jurisdiction-based. This has created – and perpetuated – fragmented, non-interoperable information systems across the public health enterprise. To be effective, public health needs real-time, meaningful data that existing systems cannot easily receive, generate, or exchange. National HIT adoption strategies have created unprecedented interest in using population-level data. Such data can be available if public health information systems successfully interoperate, i.e., receive and send data between clinical information systems – including Electronic Health Record Systems (EHRs) – and across health information systems at all levels of government.

HIT standardization is central to the Department of Health and Human Services (HHS) strategy to achieve health data integration, interchange, and systems interoperability for HIT meaningful use. This creates a unique opportunity for public health to (1) enhance data collection mechanisms via interoperable EHR-Ss; (2) standardize existing stand-alone, fragmented public health information systems to make information systems interoperable within – and across – agencies; and (3) establish bi-directional, real-time exchanges of health information between public health and clinical practices, as well as integrating public health knowledge into the clinical care process.

Today, public health participation in national HIT standardization efforts – especially from state and local public health agencies – has been limited. The voice of state and local public health agencies in that effort is weak and uncoordinated. To build a Coordinated Public Health Voice in national HIT standardization, there is a need for a common understanding and coordinated action within the public health community to define how the interests of programs, agencies, and jurisdictions can all be reflected in the standard-based, interoperable HIT products.

The Public Health Data Standards Consortium (PHDSC) has been actively involved in standards development, harmonization, and certification efforts since its inception in 1999. Working with representatives from local, state and federal public health agencies, various professional associations, private sector organizations, and individuals, PHDSC leadership and members have been firm advocates for public health interests in HIT standards.1,2,3
PHDSC proposes working with local, state and federal public health agencies, professional associations, academia, standards development, harmonization and certification organizations, as well as others in the public and private sector, to establish a process assuring public health a strong, coordinated, and educated voice in national HIT standardization.

This document presents a Business Case for public health participation in the HIT standardization process. The document is targeted at public health leadership, decision makers at the local, state and federal levels, national HIT leaders, leadership of HIT standardization entities, professional associations, academia, and public health and clinical professionals. Our goal is to raise awareness of HIT stakeholders to the critical role of federal, state and local public health agencies in the national HIT standardization process.

This Business Case describes the current state of HIT adoption and standards development in public health; the national HIT standardization process and current level of public health involvement; the barriers to state and local public health agencies’ participation; and a proposed business strategy to assure and maximize public health’s future participation. We believe this strategy will mobilize public health to engage in HIT standardization, assuring meaningful development and adoption of interoperable, standard-based HIT products in public health.
Health Information Technology Adoption in Public Health

Public health agencies collect and use data to:

- Provide meaningful information to decision-makers;
- Support public health programs that monitor a population’s overall health;
- Coordinate and deliver healthcare, health education, and prevention services;
- Administer Medicaid/Medicare programs and professional licensure programs; and
- Disseminate information to the public.

Since the 1980's, and in some cases earlier, various information systems have been used to support the diverse data needs of public health agencies. This includes information systems in areas of immunization, vital and health statistics registration, cancer programs, statewide patient discharge data systems, communicable disease surveillance, and others. After September 11, 2001, the boost to improve public health IT infrastructure brought computers and internet connectivity into almost every local public health agency. Public health information systems, electronic communication tools, and specifically designed software products streamlined agency operations, enhanced analytic capabilities, and improved dissemination of health information.

Despite these successes, public health information systems today face several challenges. Developed to serve the needs of individual programs – often with program-specific funding from federal agencies – public health information systems frequently operate as stand-alone “silos” using homegrown applications and non-standard data structures and content. These systems receive much of their data from healthcare providers via paper-based reports, or, in some cases, via program-specific, web-based interfaces. In only very limited cases have electronic information exchanges between providers and public health been established, some using proprietary data content and format ‘standards,’ others using nationally-adopted standards. As a result, providers are often asked to report to different public health information systems the same data on multiple forms and through multiple interfaces, creating costly redundancies. Varying data formats, content, and customized IT products further limit integration with related systems.

Today, public health information systems operate mostly as “silos” that employ various software products, data formats, content and standards. Program-specific federal funding to state and local agencies that does not authorize expenditures for integration with related systems reinforces the “siloed” adoption of HIT in public health. Integration of public health information and information systems can improve the effectiveness of public health programs, the quality of care and the health of the public.
The Nationwide Health Information Network of regional health information exchanges will connect EHR-Ss in clinical practices with other systems required to support the healthcare system. States will play a critical role in determining “meaningful use” of EHR-Ss to ensure that populations with unique needs are addressed.
measures to demonstrate achievement of “meaningful use” parameters. EHR-S technology adopted under these provisions must also be compatible with state or federal administrative management systems.21

Public Health Opportunities in a Nationwide Health Information Network

The Nationwide Health Information Network initiative has brought public health into the center of national HIT adoption efforts. State and local health agencies are participating in building regional and state-wide information exchanges in their jurisdictions,22 defining policies for electronic communication of information within and across jurisdictions,23 working with EHR-S vendors to build interoperable, clinical-public health information systems,24 and in implementing NHIN demonstration projects.25

Public health participation in NHIN initiatives has resulted in improved understanding for other stakeholders (e.g., clinicians, vendors) of public health activities and of program diversity. It has also highlighted public health’s critical role in the larger healthcare community.26 This participation has enabled public health to see itself as a critical partner of the healthcare enterprise whose infrastructure, knowledge, and services are essential, complementary, and irreplaceable in delivering quality care and in protecting the nation’s health.

NHIN development efforts also
have led to a new paradigm in health information use: to view individual healthcare within a context of the health of the community. This becomes an underlying driver for interoperability of clinical and public health information systems that once functioned as stand-alone systems.27

Public health is a critical partner of the healthcare enterprise whose infrastructure, knowledge and services are essential and irreplaceable in delivering quality care and in protecting the nation’s health.
Standards are the rules that define how clinical and public health information systems interact and communicate to support electronic exchanges of health information. They are fundamental to health information systems interoperability and the existence of a NHIN.

Standards are developed by standards development organizations, data content committees, and standardization entities through a consensus-based process. Each standards development organization maintains its own committees, workgroups, tiger teams, special interest groups, and processes to support a full array of standards development efforts.

The HITECH Act calls for government leadership in developing standards that allow for the nationwide electronic exchange and use of health information to improve healthcare quality and coordination of care. The Department of Health and Human Services has adopted the HIT standardization process as central to its strategies of health data integration, data interchange and systems interoperability.

We define the HIT standardization process in six phases:

1. Identify HIT Interoperability Needs and Priorities
2. Develop and Maintain Standards
3. Select and Harmonize Standards
4. Test Standards Interoperability (Trial Implementations)
5. Certify Interoperable HIT Products
6. Deploy Interoperable HIT Products

Various public and private entities have been created to carry out these phases as follows:

<table>
<thead>
<tr>
<th>HIT Standardization Phase</th>
<th>HIT Standardization Entity Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify HIT Interoperability Needs and Priorities</td>
<td>HIT Policy Committee(^{29}) and HIT Standards Committee(^{30}) (formerly AHIC, American Health Information Community(^{31}))</td>
</tr>
<tr>
<td>Develop and Maintain Standards</td>
<td>Health Level Seven (HL7),(^{32}) SNOMED,(^{33}) LOINC,(^{34}) ASC X12(^{35})</td>
</tr>
<tr>
<td>Select and Harmonize Standards</td>
<td>Integrating the Healthcare Enterprise (IHE)(^{36}) (formerly Health Information Technology Standards Panel (HITSP)(^{37}))</td>
</tr>
<tr>
<td>Test Standards Interoperability</td>
<td>Integrating the Healthcare Enterprise (IHE)</td>
</tr>
<tr>
<td>Certify Interoperable HIT Products</td>
<td>Certification Entities (formerly, Certification Commission for HIT (CCHIT)(^{38}))</td>
</tr>
<tr>
<td>Deploy Interoperable HIT Products</td>
<td>Users: Clinical and Public Health Community at Large, NHIN</td>
</tr>
</tbody>
</table>

Each of these entities is working to produce standards-related documents (e.g., use cases, profiles, interoperability specifications, HIT product certification criteria) to ensure systems interoperability. Table 1, below, presents HIT standardization phases, examples of standardization entities and their products.
### Table 1. Health Information Technology Standardization Phases, Products and Entities

<table>
<thead>
<tr>
<th>HIT Standardization Phases</th>
<th>Needs &amp; Priorities</th>
<th>Development &amp; Maintenance</th>
<th>Selection &amp; Harmonization</th>
<th>Trial Implementation</th>
<th>Certification</th>
<th>Deployment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goals</strong></td>
<td>What should be accomplished?</td>
<td>What are the standards?</td>
<td>What standards to use?</td>
<td>Show what can be accomplished</td>
<td>Certify standards-based products</td>
<td>Deploy standards-based products</td>
</tr>
<tr>
<td><strong>HIT Standardization Entities</strong></td>
<td>HIT Policy Committee</td>
<td>HIT Standards Committee (Formerly AHIC, to be superseded pending ONC decisions)</td>
<td>SDOs (e.g., HL7, SNOMED (IHTSDO), LOINC, ASC X12)</td>
<td>IHE (Formerly HITSP, to be superseded pending ONC decision)</td>
<td>NHIN IHE</td>
<td>Certification Entities (Formerly CCHIT, to be superseded pending ONC decisions)</td>
</tr>
<tr>
<td>Standards Documents</td>
<td>Use Cases (Description of the health information exchanges)</td>
<td>Standards</td>
<td>Interoperability Specifications Technical Frameworks Integration Profiles</td>
<td>Implementation Reports</td>
<td>Certification Criteria</td>
<td>Deployment Reports</td>
</tr>
</tbody>
</table>
The HIT standardization process focuses on the following categories of standards:

1. Data Standards (vocabularies and terminologies)
2. Information Standards (reference information models)
3. Information Exchange Standards (message-based and structured document-based)
4. Identifier Standards (e.g., National Provider Identifier (NPI))
5. Privacy and Security Standards (e.g., access control, audit, electronic consent)
6. Functional Standards (e.g., work processes, workflow and dataflow models)
7. Other Standards (e.g., Internet standards, etc.)

Before the NHIN initiative, HIT standardization’s main focus was on data and messaging standards. This included defining (1) data sets and their supporting vocabularies and terminologies (e.g., clinical terminology (SNOMED), laboratory data (LOINC), administrative data (ASC X12)) and (2) ways to send data from one information system to another (HL7). NHIN activities revealed the need to standardize other critical elements of health information exchanges to achieve seamless interoperability between systems such as matching patients’ records (identifier standards), assuring confidentiality of health information (privacy and security standards), and understanding work processes of stakeholders involved in information exchanges (functional standards).

The HITECH Act calls for government leadership to develop and adopt standards that allow interoperable nationwide electronic exchange of health information to improve quality and coordination of care. The Department of Health and Human Services has adopted the HIT standardization process as central to its strategy of addressing the issues of data integration, interchange and systems interoperability.

HIT Standards in Public Health

As an early adopter of health information technology, public health has long been involved in HIT standardization efforts. Nevertheless, HIT standards used today in public health are insufficient to support integration/interoperability of public health information systems within an agency, across agencies, and between clinical and public health information systems.

Public health faces four principal challenges regarding HIT standards:

1. **Program-Specific Standards** – Program-specific adoption of HIT has resulted in program-specific standards (e.g., standards for immunization, cancer, maternal and child health, and communicable diseases). Standardization efforts in these programs are often led by professional associations and/or expert groups.
(2) **Proprietary Standards** – Some public health programs use proprietary standards (e.g., data collection forms, vocabularies, etc.) for their systems;\(^5^2\)

(3) **Jurisdiction-Specific Standards** – Various jurisdictions have developed standards that are mandatory for public health programs in those jurisdictions;\(^5^3\) and

(4) **Federal Agency-Focused Standards** – Federal agencies lead many program-specific standardization efforts, (e.g., Centers for Disease Control and Prevention (CDC) in immunization, cancer, communicable diseases, vital statistics; Health Resources and Services Administration (HRSA) in maternal and child health; Agency for Healthcare Research and Quality (AHRQ) in healthcare quality reporting). In addition to being program-specific, federal standards often focus on aggregate-level data (population-level) reported to federal agencies rather than on individual patient-level data needed by state and local health departments for case investigation and management, care coordination, and health education.

**Public Health Involvement in HIT Standardization**

To be interoperable, HIT applications need effective standards that support **all** stakeholders participating in information exchanges, i.e., clinicians, public health agencies, laboratories, pharmacies, and others. Public health must examine its role and HIT standards needs within the broader context of the continuum of care, as well as, public health’s functions and services across various programs and levels of government. This is fundamental to “ensure that public health business and operating needs are taken into account when developing interoperable standards; and, therefore, to ensure that public health information systems can interoperate with other systems within public health and healthcare, in general.”\(^5^4\)

“Coordinated, collective action is required at almost every level of the healthcare system to realize the full benefits of HIT. This makes it unlikely that individual actors, pursuing their own self-interests, would be able to take the full advantage of HIT. The importance of **collective action** is most apparent in securing effective communication – so-called interoperability – across providers of care in the United States” – David Blumenthal, National Coordinator for HIT.\(^5^5\)
Public health needs can only be communicated effectively to standards developers, and, in turn, built into standards, if public health professionals who know these needs participate in the HIT standardization process. To date, public health professionals have achieved significant success advocating inclusion of public health needs and priorities in the national HIT agenda. Specifically, participation of public health professional associations (the Association of State & Territorial Health Officers (ASTHO), the National Association of City & County Health Officers (NACCHO), the American Public Health Laboratory Association (APHL) and the Council for State and Territorial Epidemiologists (CSTE)) at the American Health Information Community during 2005-2008 helped develop several national public health Use Cases such as 

- Bio-surveillance, Immunization and Emergency Response,
- Public Health Case Reporting,
- Newborn Screening and Maternal and Child Health.  

These national Use Cases serve as a common description of health information exchange needs across public health programs and clinical care, and, accordingly, lay the groundwork for developing interoperable, standardized HIT products.

The selection of interoperable HIT standards for these public health use cases at the Health Information Technology Standards Panel (HITSP) demonstrated that, in addition to an advocacy role, there is a critical need for public health professionals – especially those from state and local agencies – to be directly involved in the downstream of HIT standards selection, harmonization and trial implementation; development of the certification criteria for interoperable HIT products; and deployment of standards-based HIT applications (Table 1). While a number of public health professionals have consistently participated in HITSP activities, public health, especially at the state and local level, continues to be under-represented in these efforts.

Table 2 and Figure 2 illustrate the current level of public health participation in the HIT standardization process.
**Table 2. Public Health Participation in HIT Standardization**

<table>
<thead>
<tr>
<th>HIT Standardization Phase</th>
<th>HIT Standardization Entity</th>
<th>Total Number of Organizations, N</th>
<th>Public Health Organizations, N (%)</th>
<th>Number of Persons by Public Health Organization, N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Needs Identification &amp; Priorities Setting</strong></td>
<td>HIT Policy Committee**</td>
<td>20</td>
<td>2 (10)</td>
<td>Federal Agencies 1, State Public Health 0, Local Public Health 1, Prof. Associations 0, Academia*** 1</td>
</tr>
<tr>
<td></td>
<td>HIT Standards Committee</td>
<td>23</td>
<td>1 (4)</td>
<td>Federal Agencies 0, State Public Health 0, Local Public Health 0, Prof. Associations 1, Academia 0</td>
</tr>
<tr>
<td><strong>Standards Development &amp; Maintenance</strong></td>
<td>Health Level Seven (HL7)</td>
<td>503</td>
<td>27 (5)</td>
<td>Federal Agencies 7, State Public Health 12, Local Public Health 5, Prof. Associations 3, Academia 0</td>
</tr>
<tr>
<td></td>
<td>Health Information Technology Standards Panel (HITSP)</td>
<td>641</td>
<td>30 (5)</td>
<td>Federal Agencies 10, State Public Health 4, Local Public Health 3, Prof. Associations 7, Academia 6</td>
</tr>
<tr>
<td><strong>Standards Selection &amp; Harmonization</strong></td>
<td>Integrating the Healthcare Enterprise (IHE)</td>
<td>251</td>
<td>7 (3)</td>
<td>Federal Agencies 1, State Public Health 3, Local Public Health 0, Prof. Associations 3, Academia 0</td>
</tr>
<tr>
<td><strong>Standards Trial Implementation</strong></td>
<td>Certification Commission for Health Information Technology (CCHIT)</td>
<td>341</td>
<td>3 (1)</td>
<td>Federal Agencies 0, State Public Health 1, Local Public Health 0, Prof. Associations 2, Academia 0</td>
</tr>
<tr>
<td><strong>Total Number of Organizations</strong></td>
<td></td>
<td>1780</td>
<td>70 (4)</td>
<td>Federal Agencies 18, State Public Health 20, Local Public Health 9, Prof. Associations 16, Academia 7</td>
</tr>
</tbody>
</table>

* Based on the total number of participating organizations as of December 1, 2009.

** In addition to two public health professionals (I-Local public health; I-Academia) - members of the HIT Policy Committee, two more public health professionals (I-Local and I-State public health) participate in the HIT Policy Committee Working Groups.

*** Academia refers to Schools of Public Health only.
The public health voice in the national HIT standardization continues to be weak and un-coordinated, representing the needs of only a particular program or organization that often conflict with those of the other programs and organizations. Lack of broader public health representation and coordination in the HIT standardization delays interoperable standards or creates standards that do not serve public health needs at large.

Today, the total number of public health organizations involved is 69, or just 4% of all participating organizations (N=1779). For example:

- Only one local public health representative participates in the HIT Policy Committee. Only one public health representative participates in the HIT Standards Committee – national committees that set policy and standards priorities for HIT;
- Twelve state and five local public health agencies (24% of all state and 0.2% of all local public health agencies) have a representative in HL7, an organization that develops

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**The public health voice in the national HIT standardization continues to be weak and un-coordinated. Lack of broader public health representation and coordination in the HIT standardization delays interoperable standards or creates standards that do not serve public health needs.**

**Coordinated participation of public health representatives in the national HIT standardization entities is critical to assure that public health needs are met in the standards-based interoperable HIT products.**
health information exchange standards (messaging standards and others). HL7 maintains 46 various committees. At best, the 17 participating state and local public health agencies delegate 1-2 persons per agency to attend the meetings. This means one public health professional per about 3 committees;

- Four state public health agencies (8% of state public health agencies) and three local public health agencies (0.1% of local public health agencies) participate in HITSP – the national HIT standards harmonization entity; and
- One state public health agency (2% of state public health agencies) and none of the local public health agencies participate in CCHIT – the national HIT product certification entity.

Those who participate in the HIT standardization process usually have detailed knowledge in a particular public health program or area and may not effectively represent the entire scope of public health needs/interests.

Lack of participation of state and local public health representatives in national HIT standardization efforts (Table 2) ultimately means that public health’s needs for interoperable information systems may not be met in standards-based HIT products. Standards developers will not know or consider public health’s needs when developing HIT standards and standards-based HIT products.

**Public Health in HIT Standardization: Barriers and Opportunities**

To assure representation from state and local public health agencies in national HIT standardization, it is important to address barriers to public health’s participation and the risks of non-participation. We have identified five barriers to participation:

- **Lack of awareness** of the benefits of participating in HIT standardization efforts/entities;
- **Difficulty in identifying standardization entities** that provide the greatest opportunity for addressing state and local public health needs;
- **Limited ability to be involved** in national efforts as state and local agencies serve particular jurisdictions or reflect limited knowledge of needs in other jurisdictions, programs, and levels of public health;
- **Lack of technical knowledge and informatics skills** to participate in the technical dialogue and to effectively translate public health needs into technical HIT standards;
- **Lack of funding** to support basic participation, such as travel to meetings.

HIT standards are **complex** (numerous standards developed by numerous standard development entities), **technically-challenging** (it’s an advanced computer science field) and **political** (standards serve needs of those who develop them).
Public health agencies must decide how best to navigate this challenging world and decide:

(1) Why participate?
(2) Where should public health participate?
(3) What interests should be brought to the HIT standardization table(s)?
(4) Is public health prepared to participate and who should participate?
(5) How much will participation cost and how should it be funded?
(6) How should public health participation be coordinated?

By answering these questions below we propose ways to overcome the five barriers to state and local public health participation in HIT standardization, thus helping to harmonize HIT standards for public health information systems and to integrate those systems into regional and nationwide health information exchanges under a NHIN.

Why Participate in National HIT Standardization/Risks of Non-participation

Limited or non-participation by state and local public health representatives in national HIT standardization ultimately means that public health needs for interoperable clinical and information systems are not served in the standards-based certified HIT products. This, in turn:

♦ Threatens public health data gathering activities as fragmented public health information systems are unable to receive data electronically from EHR systems;
♦ Diminishes effectiveness of public health interventions as underreporting – caused by the inability to receive/exchange data electronically – reduces timeliness and effectiveness of public health services and responses, negatively affecting public safety;
♦ Diminishes efficiency of public health operations due to continued redundancy of data gathering across programs and encourages outdated information technology;
♦ Reduces ability to communicate public health information back to clinicians electronically in real-time to inform clinical decisions (e.g., population health status and disease surveillance reports; information about public health resources; public health guidelines and recommendations; health educational materials);
♦ Jeopardizes adoption of modern interoperable HIT applications in public health, as these applications lack functionality needed to address public health needs;
♦ Jeopardizes achieving NHIN population-level goals as public health lacks the capacity to participate in electronic regional and nationwide health information exchanges with clinicians and cannot effectively provide population health information;
♦ Minimizes the potential of state and local public health entities to receive funding from federal and other sources that will likely mandate use of interoperable HIT products.

Public health needs can only be communicated effectively to standards developers, and, in turn, built into standards, if public health professionals who know these needs participate in the HIT standardization.
Where Should Public Health Participate?

The following HIT standardization entities (Table 1) are critical for state and local public health participation to assure that public health needs are addressed in national standards:

- **HIT Policy Committee** – recommends policies to the Office of National Coordinator (ONC) for the development and adoption of NHIN
- **HIT Standards Committee** – defines national HIT standards priorities
- **ASC X12, SNOMED (IHTSDO), LOINC** and others – defines data standards
- **Health Level Seven (HL7)** – defines information exchange standards
- **Health Information Technology Standards Panel (HITSP)** – selects and harmonizes standards
- **Integrating the Healthcare Enterprise (IHE)** – harmonizes standards and demonstrates standards-based HIT solutions (trial implementation), and
- **Certification Commission for Health Information Technology (CCHIT)** and other certification bodies as they emerge – certifies standards-based HIT products.

What Public Health Interests Should be Brought to the Standards Table?

**Addressing Jurisdictional Needs**

State and local public health agencies serve populations of particular jurisdictions that create their own healthcare laws, regulations, policies, and practices resulting in state-specific reporting requirements to public health agencies and varying levels of health information privacy protection. This, in turn, affects how HIT is used within jurisdictions. Only if standards developers are aware of jurisdiction-specific differences can they develop suitable technical solutions to ensure systems interoperability. Standards developed by federal agencies, for example, may not work at state and local levels if they do not reflect jurisdiction-specific needs.

Participation in national HIT standardization efforts currently may be viewed as “outside” the interests and authority of state and local governments. However, only through their participation can standards developers meet jurisdiction-specific public health’s needs in standards-based “meaningful” EHR-Ss.
Addressing Program-Specific Needs
State and local public health agencies serve populations through various programs (e.g., immunization, vital registration, communicable disease surveillance) each with specific data needs supported by programmatic information systems (e.g., immunization information systems, vital registries, communicable diseases registries). Today, when public health agencies are actively involved in planning and building regional health information exchanges, they are under pressure to decide how various programmatic information systems can interoperate with each other and regional health information exchanges.

National HIT standards harmonization efforts at HITSP, and international efforts at IHE, are aimed at addressing the same issues of non-interoperability across healthcare information systems (e.g., clinical systems, laboratory systems, pharmacy systems, payor systems and other). Learning about interoperability challenges in healthcare systems and the ways those challenges are being overcome can help public health prevent costly and ineffective implementations, as well as help transition public health from proprietary, program-specific standards to interoperable HIT standards within its agencies.

Public health professional associations have played a critical role in HIT standardization efforts in their program-specific interest areas.

Some examples include:
- Immunization
  - American Immunization Registry Association (AIRA)
- Laboratory
  - Association of Public Health Laboratories (APHL)
- Epidemiology & Disease Reporting
  - Council for State and Territorial Epidemiologists (CSTE)
- Cancer
  - North-American Association of Central Cancer Registries (NAACCR)
- Vital Statistics
  - National Association for Public Health Statistics and Information Systems (NAPHSIS)
- Healthcare Management
  - National Association of Health Data Organizations (NAHDO)
  - American Health Information Management Association (AHIMA)

These organizations help state and local public health programs develop common data sets and information exchange standards for programmatic public health information systems across the United States. They also play an important role in coordinating state and local needs with those of federal agencies in their area of interest.
To further serve their constituents, several professional associations have sought to harmonize program-specific standards with the nationally-adopted interoperability standards by participating in HITSP and IHE\textsuperscript{61} (Table 2).

The existing opportunity is to take jurisdiction-specific and program-specific needs and harmonize them across public health, within an agency and between public health agencies across jurisdictions.

Participation of state and local public health agencies in HIT standardization entities helps inform these entities about jurisdiction-specific and program-specific needs and challenges related to adoption of national interoperability standards, thus helping the national process become more robust and responsive to state and local needs, assuring broader adoption of “meaningful” standards-based HIT products. Only then can EHR-Ss be interoperable truly with public health information systems, such that systems support the needs of both clinicians and public health practitioners in local, state, and nationwide health information exchanges.

**Is Public Health Ready to Participate and Who Should Participate?**

Standards are developed by highly-trained IT professionals, mostly HIT vendors. For example, 215 vendor organizations (43% of total) participate in developing standards at HL7 compared to 27 public health organizations (5%).\textsuperscript{62} Public health professionals involved in national HIT standardization efforts are expected to explain public health needs for interoperable information systems. They are expected to fully participate in the development and review of vastly technical standards documents (e.g., use cases, technical frameworks, technical specifications, integration profiles, and interoperability specifications), even though these public health professionals come from non-IT backgrounds. They are expected to understand, speak, and critique the IT “language” of these documents comprised of diagrams, models, and acronyms often foreign to non-IT audiences.

During the last decade, public health professionals have become more active in developing the discipline of Public Health Informatics – a newly emerging field that deals with the use of data, information, and knowledge in public health.\textsuperscript{63,64} Schools of public health have been developing informatics training courses and programs to expand professional expertise.\textsuperscript{65} CDC Public Health Informatics Training\textsuperscript{66} and CDC Centers for Excellence in Public Health Informatics\textsuperscript{67} also have been advancing public health informatics curricula. Though the number of graduates from these programs is growing, the demand for informaticians capable to participate in HIT standardization is largely unmet.
It should also be noted that participation in HIT standardization entities requires a high-level of understanding of public health practices, which may not be expected from new graduates of public health informatics programs. These individuals may lack technical or practical knowledge/skills on HIT standards as well. While HIT standards topics are included in CDC Public Health Informatics Core Competencies, and might be covered in some lectures under courses offered by academic programs, today, only the Johns Hopkins Public Health Informatics program offers a course on HIT standards for a non-IT audience.

Several professional organizations offer educational webinars on HIT standards (e.g., CDC Vocabulary and Messaging Community of Practice, HITSP, PHDSC and others). However, educational webinars are infrequent and usually focus on a particular HIT standardization activity (e.g., standards development, harmonization, or certification). Until academic educational efforts “catch up”, most public health professionals are left the difficult task of becoming HIT standards experts and learning technical IT language through direct participation in the HIT standardization process.

It is important to emphasize that the complexity of HIT standardization efforts, and the need for senior-level expertise with deep knowledge of public health practices as relates to information exchanges, require senior public health program staff and public health informatics staff to participate in HIT standardization activities. Several state and local public health agencies – usually larger ones – have established divisions of, or positions for, public health informaticians who dedicate part of their duties to monitoring and participating in national HIT advisory bodies (i.e., the former American Health Information Community to help advance public health’s agenda via national use cases). Some of these individuals are now also involved in the HIT Policy Committee. However, in general, the number of trained informaticians working at state and local health departments is very low. Many local agencies are located in parts of the country where recruitment of informaticians and highly-skilled IT staff is difficult.

Public health IT professionals working at the state and local program or agency level (i.e., chief information officers, directors of information technology, and others), with a deep understanding of public health practices, could be engaged in representing agency interests in national HIT standardization entities.

Professional associations engaged in HIT standardization efforts may also play a significant role in representing state and local...
public health interests at the national level, particularly as relates to their programmatic interests. It is important to point out, however, that not all professional associations have dedicated professional staff with sufficient expertise to participate in HIT standardization efforts. Therefore, additional educational and recruitment efforts are needed to bring HIT standards-savvy staff to these organizations.

How Much Will Participation Cost?

Today, participation in HIT standardization efforts is overwhelming for many involved stakeholders (e.g., vendors and domain experts such as clinicians and public health professionals) in terms of time, resources, funding, and technical expertise.

All HIT standardization entities rely heavily on volunteers to develop, harmonize, and certify standards. Voluntary participation means that standardization entities do not pay participants for their work in developing/harmonizing/certifying standards, but expect that the participating organizations bear the cost of employee work hours spent on conference calls, attending meetings, developing/reviewing documents and traveling. HIT vendors cover their employees' costs of participation because it is in the vendor's interest to influence development of standards in ways that enhance their products' competitive advantage. Federal agencies also bear the cost of their representatives while only a few state and local public health agencies are able to do so.

Proper resources have to be allocated to support public health participation in the national HIT standardization process. Based on participation of PHDSC representatives at HL7, ASC X12, HITSP, and IHE, we estimated that voluntary participation in any one entity requires on average up to 10 hours per week (about 25% FTE) to take part in conference calls, conduct document review, and attend 3-5-day-long quarterly face-to-face meetings. Considering that ongoing participation of an individual is needed for consistency, and that people capable of contributing to highly technical discussions must work at a senior level, PHDSC estimates the cost of participating at $25,000-30,000 per person per entity per year.

In addition to time allocation, resources are needed for travel to meetings. Standardization entities usually hold quarterly or trimester meetings, so we estimate that $8,000 is needed per person per entity per year to attend meetings. Lastly, we estimate that on average $1,500 per person per year is needed for continuing education in HIT standards-related topics. Accordingly, direct costs of participating for one individual in one HIT standardization entity are $39,500 per year.
How Should Public Health Participation be Coordinated?

Public health needs to speak with a strong, coordinated voice to HIT standardization entities. This voice has to reflect the needs/interests of local, state, and federal public health together, because successful HIT adoption cannot be achieved if HIT products fail to support the needs of all stakeholders. This voice must also be coordinated across the various public health programs and activities.

To build a coordinated public health voice in HIT standardization, there must be coordinated action within the public health community to define how its various program, agency, and jurisdictional interests can all be reflected in the resulting outcome. This action should occur on two levels of efforts – the advocacy level and the technical level.

Public health has succeeded in establishing its place at the “national HIT table” due to the advocacy efforts of several public health professional associations, e.g., ASTHO, NACCHO, CSTE, and APHL at AHIC for public health use cases; PHDSC at HL7, ASC X12, National Uniform Billing Committee (NUBC), and National Uniform Claim Committee (NUCC) for data content and information exchanges. The Joint Public Health Informatics Taskforce (JPHIT) – formed by the above mentioned, and several other public health professional associations – is aimed at coordinating public health advocacy efforts on HIT adoption.

The challenge today is that, after succeeding in advocating for public health in the HIT agenda, meaningful participation of public health representatives in the technical HIT standardization process (standards development, harmonization, certification), especially from state and local public health agencies, does not occur to the extent needed. Without input from state and local public health communities into technical decision-making about HIT standards, all the hard work upstream of public health advocacy and use-case development is for naught. This problem is particularly poignant at a time when vendors are seeking technical public health input, due to marketplace demands they expect in the future.

“Coordinated, collective action is required at almost every level of the healthcare system to realize the full benefits of HIT. This makes it unlikely that individual actors, pursuing their own self-interests, would be able to take the full advantage of HIT.

The importance of collective action is most apparent in securing effective communication – so-called interoperability – across providers of care in the United States” – David Blumenthal, National Coordinator for HIT.
PHDSC strives to work with local, state, and federal public health agencies, and public health professional associations, to develop a process to assure public health has a strong, coordinated, unified voice to develop, harmonize, certify, and deploy national HIT standards.

The Public Health Data Standards Consortium has been involved in standards development, harmonization, and certification efforts under all national HIT initiatives. Working with representatives from local, state, and federal public health, and various professional associations, PHDSC leadership and members have been firm activists for public health interests in technical HIT standards and in helping public health develop a unified voice.

PHDSC strives to work with local, state, and federal public health agencies, and public health professional associations, to develop a process to assure public health has a strong, coordinated voice in the technical efforts to develop, harmonize, certify, and deploy national HIT standards.

PHDSC proposes a business strategy for Assuring Public Health Participation in HIT Standardization as described below.
The National HIT standardization process requires collective input from public health on what public health issues need to be addressed in national interoperable HIT standards. This input needs to be collaboratively developed, put through the national HIT standardization process and uniformly implemented. Public health’s “Coordinated Voice on HIT Standards” will have to take on a character reflective of this reality.

We define public health’s Coordinated Voice on HIT Standards as an open, transparent, participatory process of harmonizing program-specific and jurisdictional needs with national HIT interoperability standards by working with HIT standardization entities on various phases of HIT standardization.

Participation in the HIT standardization process is becoming a key for assuring that public health needs are met in national HIT standards.

We propose a business strategy which (a) maximizes the impact of those who can participate on behalf of public health in the national HIT standardization process, and (b) informs, educates and obtains input, as best as possible, from those who cannot.

Through this joint public health effort, we could achieve meaningful interoperability across public health information systems as well as between public health and clinical information systems.
**What Needs to be Accomplished?**

There is a need to increase participation of representatives from state and local public health in national HIT standardization activities, so that national interoperable HIT standards and certified standards-based HIT products will sustain data needs for public health decision support and services delivery.

Additionally, a strong, coordinated public health voice needs to be built to help ensure that HIT products developed as a result of HIT standardization efforts will meet the needs of all stakeholders.

**Who Needs to Participate?**

**State and Local Public Health Agencies**

Participation in HIT standardization on behalf of public health requires individuals who have both on-the-ground public health expertise as well as some degree of IT knowledge. To be effective, public health must build an HIT-standards-savvy workforce through informatics training. Until then, it must rely on senior public health program staff, senior public health informaticians and IT professionals currently employed by public health agencies.

To overcome the lack of specialized public health workforce training, public health agencies can employ several strategies, including:

- **Recognize HIT standardization efforts as a distinct role** for senior program staff, senior informaticians and/or IT professionals, incorporating these additional tasks into existing staff duties;
- **For larger agencies, train and explicitly devote one or more staff members**, e.g., informaticians, IT staff – especially if they are in a leadership position with respect to one or more programs – to carry out an agency’s HIT standardization activities;
- **For smaller agencies, outsource HIT standardization efforts** where possible to expert consultants with extensive knowledge of public health, HIT standards and informatics to participate on the agency’s behalf;
- **Recognize the need for continuing education** in public health informatics and HIT standards for an agency’s workforce;
- **Band together within a region** (i.e., various local public health agencies within a state) and share costs associated with deployment of one or more public health professionals to represent the region in HIT standardization;
- **Participate in and leverage memberships in public health professional associations** involved in standardization activities as a way to provide input into the process;
- **Participate in** building public health’s Coordinated Voice on HIT Standards.
**Professional Associations**

Public health professional associations are in a strong position to provide leadership and coordination for HIT standardization input, especially for particular public health programs (e.g., immunization, communicable diseases, vital statistics, newborn screening, and cancer). Through various workgroups and committees, these organizations can channel program-specific standards toward national HIT standardization activities. Through an association's broader membership, they can disseminate information, facilitate discussion, and generate consensus and support for HIT standards. These associations can further coordinate the education process necessary for standards promulgation and adoption. While representing interests of a particular program, professional associations also need to be involved in harmonization of their programmatic standards with those from other programs, through collaboration with other associations, thus forming a public health's Coordinated Voice on HIT Standards.

**Coordinating Entity**

Due to the broad spectrum of public health interests (local, state and federal) in HIT standardization activities, and the wide variety of HIT standardization efforts (development, harmonization, certification, deployment) in which to get involved, there is a need for an entity to coordinate public health activities in HIT standardization and to build public health’s Coordinated Voice on HIT Standards.

The Coordinating Entity could:

- **Facilitate** public health involvement in various HIT standardization entities;
- **Coordinate** activities of professional organizations and their constituents;
- **Assist** local, state, and federal agencies in identifying appropriate HIT standardization entities and professional organizations in which to communicate their needs;
- **Identify** new areas of public health for developing standards and carry out activities needed to initiate standards development efforts in these areas;
- **Conduct** outreach activities regarding public health participation in HIT standardization and educate the public health workforce on HIT standards via sessions at public health meetings, through on-line resources and by participating in development and delivery of HIT standards courses for academic programs/continuing professional education; and
- **Identify** and secure resources needed to support the participation of public health professionals in HIT standardization entities.
Who Can Encourage Public Health Participation in HIT Standardization?

State and federal governments, academia, and the private sector can all help enable public health participation in the national HIT standardization process as each of these stakeholders can also benefit from public health’s participation.

Role of Federal Government

The federal government will benefit from state and local public health participation in the national HIT standardization process because interoperable standards-based local and state public health information systems will ensure the successful and meaningful implementation of electronic health information exchanges under the NHIN.

To foster public health participation in the HIT standardization process, the federal government could implement several options:

- **Require and support** public health participation in the HIT standardization process as a condition of being involved in, and funded by, federal programs;76
- **Directly fund participation** of state and local public health representatives in HIT standardization entities;
- **Fund** (a) coordination of local, state and federal public health interests in the HIT standardization process, and (b) professional education on HIT standards;
- **Support public health efforts** in developing a public health’s Coordinated Voice on HIT Standards and a common approach ensuring public health participation.

Role of State Government

The state government will benefit from state and local public health participation in the national HIT standardization process because currently fragmented state and local public health information systems will become interoperable. This will ensure real-time collection and exchange of data for decision-making and provision of quality care and public health services in their jurisdictions.

State governments can stimulate participation by:

- **Funding** involvement of representatives from state and local public health in the national HIT standardization process to advocate for state needs at the national level;
- **Launching** statewide HIT standardization awareness efforts;
- **Supporting** the training of a public health workforce on HIT standards;
- **Leveraging** federal funding aimed at supporting such participation and training.

Necessary funds could also be made available by leveraging additional resources provided by non-public health entities (e.g., foundations, hospital systems, government and private sector).77
Role of Academia
Universities can stimulate public health participation in national HIT standardization by creating in-class and online courses on HIT standards, and – through their partnership with public health agencies and professional associations – delivering these courses to the public health workforce. Such courses should be included in public health informatics curricula of schools of public health. Faculty from other schools and programs such as information systems, computer sciences, medicine, and business should be invited to participate in the development and delivery of HIT standards courses because broader expertise is needed to define their content. These courses also could be offered to IT professionals, thus assuring their understanding of public health needs in HIT standardization. In addition, sponsored research conducted in academia could be useful to the HIT standardization process.

Role of Private Sector
While federal and state governments can play important roles in increasing public health participation in the standardization process, effective implementation of these standards lies predominantly with the private sector. Only the private sector can ensure that the products they develop address public health needs. Thus the private sector continues to seek public health involvement in the HIT standardization process. Close collaboration between the private sector and public health during the HIT standardization process minimizes the private sector burden to address these issues at a later time after product development. The private sector can also encourage public health participation at various standardization entities by sponsoring participation of state and local agency representatives in those entities, viewing them as domain experts who inform the development of “meaningful” HIT products.
**Strategies to Increase Public Health Participation in HIT Standardization**

The following are proposed strategies to increase public health participation in HIT standardization:

- **Develop and gain consensus** on a clear, shared public health vision for HIT adoption and participation in the HIT standardization process;
- **Ensure** that every public health agency (about 3,000 local and 50 state) realizes the need for participation and identifies ways to get involved or at least stay informed;
- **Identify sources of funding** to create and maintain positions of staff members or expert consultants to represent agency interests in the national HIT standardization process; to support travel expenses; and to support training of the public health workforce;
- **Establish fellowships for public health professionals** from state and local public health agencies to allow them to be assigned to HIT standardization efforts and entities to promote in-depth, hands-on experiences for a number of individuals each year;
- **Establish an open and transparent process** for soliciting public health needs for HIT standards and ensure these needs are met in HIT products through collaboration of local, state and federal public health agencies, professional associations, academia, and the private sector;
- **Identify a core group of public health professionals** that are actively engaged in the HIT standardization process and develop a network of extended public health professionals to whom the core group can send inquiries and receive input for HIT standards;
- **Develop web-based tools** (e.g., web-sites, webinars, and online educational programs) to support participation of public health representatives, train public health professionals in HIT standardization issues, and raise general awareness about HIT standardization activities and outcomes (see Appendix);
- **Increase the number of attendees** in formal public health informatics programs at colleges and universities and ensure that HIT standardization is part of the core curriculum;
- **Increase the number of HIT and HIT standardization-related sessions** offered at public health conferences and meetings that are *not* primarily focused on IT, informatics, or standards. While these may be of limited interest initially, over time HIT will become an expected presence at these events.
- **Conduct a pilot program for implementing these strategies** with a representative number of state and local public health agencies (municipal, county, state) refining the proposed strategy to assure public health participation in HIT standardization.

To implement these strategies PHDSC proposes launching a **Coordinated Public Health Action Plan on HIT Standards** – a joint HIT standardization awareness effort of local, state and federal agencies, professional associations, academia and the private sector as further described below.
The PHDSC proposes to work with local, state and federal public health agencies, public health professional associations, academia, and the public and private sector to set an open, transparent, participatory process assuring that public health has a strong, coordinated voice in the national HIT standardization process.

The following steps are needed to establish a **Coordinated Public Health Action Plan on HIT Standards**:

- **Work with senior leadership at state and local public health agencies** (e.g., Health Commissioners or Secretaries) to assure their support for (1) designating agency representatives to participate in the national HIT standardization process in collaboration with other public health organizations and (2) identifying and securing funding for their participation and training needs.

- **Work with senior program and informatics staff and IT leadership at state and local public health agencies** (e.g., directors of public health informatics, chief information officers (CIOs)) to assure their support of agency representatives to participate in national HIT standardization and to adopt interoperable HIT standards across an agency’s information systems. Coordinate CIOs’ efforts in HIT standards adoption and representation of public health IT interests in regional, state, and nationwide health information exchanges through the National Association for Public Health Information Technology (NAPHIT).

- **Work with public health professional associations to coordinate cross-program interests and needs in identifying priorities and setting policies on HIT standards** for local, state and nationwide health information exchanges through collaboration of appropriate public health professional associations:
  - Representing local interests – National Association of City and County Health Officers (NACCHO)
  - Representing state interests – Association of State and Territorial Health Officers (ASTHO)
  - Representing public health informatics interests – Joint Public Health Informatics Task Force (JPHIT)

We propose a business strategy which (a) maximizes the impact of those who can participate on behalf of public health in the national HIT standardization process, and (b) informs/educates and obtains input, as best as possible, from those who cannot. Through this joint public health effort, we could achieve meaningful interoperability across public health information systems as well as between public health and clinical information systems.
Work with public health professional associations to coordinate program-specific efforts on HIT standardization at the local, state and federal levels, for example:

- Immunization
  - American Immunization Registry Association (AIRA) and CDC National Center for Immunization & Respiratory Diseases
- Laboratory
  - Association of Public Health Laboratories (APHL) and CDC Offices of Surveillance, Epidemiology, Informatics, Laboratory Science, and Career Development
- Epidemiology & Disease Reporting
  - Council for State and Territorial Epidemiologists (CSTE) and CDC Offices of Surveillance, Epidemiology, Informatics, Laboratory Science, and Career Development
- Cancer
  - North-American Association of Central Cancer Registries (NAACCR) and CDC National Center for Chronic Disease Prevention and Health Promotion
- Vital Statistics
  - National Association for Public Health Statistics and Information Systems (NAPHSIS) and CDC National Center for Health Statistics
- Newborn Screening
  - Public Health Informatics Institute, Maternal and Child Health Bureau, HRSA and CDC National Center on Birth Defects and Developmental Disabilities
- Healthcare Management
  - National Association of Health Data Organization (NAHDO) and American Health Information Management Association (AHIMA)

Work with academia to develop educational programs and tools on HIT standardization for public health professionals to assure that representatives from public health agencies and professional associations possess the necessary skills and expertise to participate in technical discussions with vendors in the HIT standardization process. Collaborate with schools of public health to include HIT standards training in their public health informatics curricula both for academic and continuing education training of public health professionals.

Identify a public health organization to carry out a Coordinated Public Health Action Plan on HIT Standards including:

- Facilitate coordination between public health agencies, professional associations, academia and the private sector in meeting public health needs in the national HIT standardization process;
- Identify and secure funding for participation of state and local agency representatives in the national HIT standardization process;
- Provide informational and educational resources to the public health workforce on the HIT standardization process; and
- Conduct outreach activities on the role of public health in HIT standardization for a broad public health audience.

The Public Health Data Standards Consortium, with appropriate resources, is ready, willing, and able to assume this role.
To monitor implementation of the **Coordinated Public Health Action Plan on HIT Standards**, PHDSC has been developing a web-based **Interactive Model on Public Health in HIT Standardization**.

The goals of the *Interactive Model* are to:

- Monitor and coordinate public health participation in the HIT standardization process,
- Assure that public health professionals involved in HIT standardization are equipped with proper knowledge and skills,
- Disseminate information to the broader public health community about HIT standards developed by national HIT standardization entities,
- Disseminate information about adoption of standards-based HIT products in public health, and
- Solicit public health needs for new HIT standards.

The *Interactive Model* will serve as a web-based informational and educational resource for public health, HIT leadership and decision-makers, public health program leadership, public health practitioners, clinicians, and researchers.

The *Interactive Model* consists of four modules designed to address barriers for public health participation in HIT standardization as follows:

**Module 1: HIT Standards Resource Center** - Provides informational resources regarding HIT standards, the standardization process and its entities. This Module was launched in June 2009.  

**Module 2: HIT Adoption Stories** - Conveys current experience with implementation of public health information systems. Anticipated release date: May 2010.

**Module 3: Public Health Needs for HIT Standards and Projects** - Collects functional requirements for new information exchange projects from public health and clinical professionals via an on-line questionnaire. This will help identify and prioritize public health HIT needs and the needs for new standards. Anticipated release date: December 2010.

**Module 4: Public Health Participation in HIT Standardization Process** - Tracks public health involvement in HIT standardization, participants’ experiences/lessons learned during participation and HIT adoption in public health. This module will also include a cost-benefit comparison to track costs and funding sources for participation of public health professionals in HIT standardization, as well as costs and benefits of implementing standards-based HIT products. Anticipated release date: May 2010.
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