

Public Health Data Standards Consortium Education Strategy

Draft Report for Distribution at March Meeting

Prepared for:

National Center for Health Statistics

March 2, 2001

Prepared by:

**The Lewin Group, Inc. and The National Association of Health Data
Organizations, in conjunction with the Public Health Data
Standards Consortium Education Work Group**

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EXECUTIVE SUMMARY

Introduction

The transformations occurring in our society around information and communication technologies offer tremendous potential to support health and health care. Information is the cornerstone of the science behind both care delivery and public health. Unlike other sectors of the economy such as financial services, the clinical care delivery and public health systems have been slow to move into the information age. One of the critical enablers to entering this age is a comprehensive set of standards for all health data. Uniform data standards are methods, protocols, or terminologies agreed to by an industry to allow disparate information systems to operate successfully with one another.¹

Enacted in 1996, the Administrative Simplification (AS) provisions of The Health Insurance Portability and Accountability Act (HIPAA) require the Secretary of Health and Human Services (the Secretary) to adopt standards to support electronic data interchange for a variety of transactions involving health care data. HIPAA-AS is focused on the interchange of data among health insurers and providers including public health providers who seek reimbursement. Although, HIPAA-AS standards are not mandated for many other public health related data transactions, these standards will have important implications for public health.

The health care encounter is the source of a significant portion of public health data. Lack of adoption of standards will make it more difficult to communicate with the clinical care delivery system especially for those data systems that rely heavily on administrative data (e.g., hospital discharge data sets). HIPAA also requires adoption of standards for claims attachments and directs the National Committee on Vital and Health Statistics to study issues and make recommendations on uniform data standards for patient medical record information. The claims attachment represents the bridge between administrative/financial information and clinical information. The medical record is a primary source of data for disease registries, reportable disease tracking and immunization registries and provides information for birth and death statistics and many other public health databases. The adoption of clinical data standards for both care delivery and public health will facilitate the electronic interchange of data which is now primarily paper-based. Electronic interchange will improve the efficiency, accuracy, and timeliness of reporting.

HIPAA also mandates the development of unique identifiers for individuals, employers, providers, and health care plans, and stipulates that the Secretary must develop standards to protect the privacy and security of data. While unique identifiers will greatly enhance

¹ National Committee on Vital and Health Statistics. (July 6, 2000) [Uniform Data Standards for Patient Medical Record Information](#). Report by the National Committee on Vital and Health Statistics to the Secretary of the U.S. Department of Health and Human Services.



the ability to link data across encounters and sites of care to support research, privacy standards will have important implications for access to data and how these data are collected, transmitted, and stored.

Data standards are not only necessary to support the interface with the private sector, standards are also critical to support the flow of information across public health programs and levels of government. Developed largely through categorical funding, the systems that support public health are fragmented with different systems across programs and across jurisdictions. Public health is beginning to realize the value of integration and standardization. In some cases, standards development and implementation and data integration efforts are underway including the CDC's National Electronic Disease Surveillance System (NEDSS) and immunization registries. In other cases, there is a mature process for national standards development, including The North American Association of Central Cancer Registries (NAACCR).

In January 1999, the Public Health Data Standards Consortium (the Consortium) was established to serve as a mechanism for ongoing representation of public health and health services research in the implementation of HIPAA Administrative Simplification and other data standards setting processes relevant to public health.

The Consortium's initial focus has been on the HIPAA transaction standards and tangible results in this arena will be important to build the Consortium's credibility in public health and with relevant standards development organizations. As the Consortium develops critical mass, the intent is for it to broaden its efforts beyond encounter data to support the full array of public health data standards needs. This educational plan will support this goal.

Role of the Education Work Group and Goals of the Education Strategy

A primary role of the Consortium is to educate the public health and health services research communities on data standards issues. In support of this role, the Consortium created the Education Work Group to develop, facilitate, and oversee the implementation of an education strategy. As a first step, the Work Group contracted with The Lewin Group, Inc. (The Lewin Group) in collaboration with the National Association of Health Data Organizations (NAHDO) to develop an education strategy to guide the initial efforts of the Work Group. The goals of the education strategy are to:

- Articulate why public health data bases should migrate to existing data standards, possibly beginning with HIPAA transaction standards, and why public health needs to engage in standards setting activities for the benefit of public health clients and public health organizations;
- Identify the multiple audiences for educational outreach;
- Identify possible collaborators and experts needed to develop educational content and implement the education plan;



- Identify relevant data bases at the state level and the types of standards that apply;
- Identify and prioritize the types of educational products that are needed, including evaluation tools that provide valuable feedback to the Consortium and its Education Work Group on their success;
- Formulate a plan for developing and delivering educational messages and materials, which may include tutorials, teleconferences, newsletters, exhibits, presentations, listservs, and websites; and
- Serve as a vehicle to attract organizational and financial support to implement the plan.

Rationale for Data Standards in Public Health

Unlike providers and insurers, much of the public health community faces no clear federal mandate to adopt HIPAA standards and the rationale for such action has not been widely communicated. As such, the public health and health services research communities have not actively participated in national standards discussions or implemented standards at the state or local level. A critical component of this educational plan will be to communicate a compelling rationale to motivate these communities to take action. Key messages include:

- The business case supports data standards in public health. Standardization reduces costs, supports the electronic flow of information, increases efficiency, improves data quality and utility, supports performance measurement, and enhances public health's ability to perform key functions.
- An electronic environment is emerging in the health sector; public health risks being left out.
- Data standards support integration across public health programs and between the public and private sectors.
- Not adopting standards places public health data and relationships at risk. Public health may lose access to data and the lack of integrated data systems places the health of the public at risk.

Key Audiences for Educational Outreach

Discussions with Education Work Group members and interviewees identified five audience types for educational outreach--defined by their different roles with respect to public health data and information. These include:

Decision-makers: Decision-makers are senior level government officials in health and human services agencies at both the state and federal level who make decisions about cross-program initiatives and funding priorities related to public health. This initial



education strategy will focus on state decision-makers as the Consortium's first priority. Federal decision-makers will be discussed in their role as funders and partners.

Funders: The Consortium's work will require substantial resources at each stage. Potential funders for data standardization efforts include state legislatures, federal agencies, and foundations.

Collectors: Data collectors are the individuals that collect, compile, and maintain public health data. Data collectors include a wide array of federal, state, and local public health agency staff as well as health services researchers. These individuals might be licensing or certification directors, registrars, epidemiologists, statisticians, or other types of professionals. This group will be the primary audience for implementation and will require the most intensive educational support.

Users: Users are groups or individuals that use public health data. Users include public health agency staff at all levels of government who use this data to perform core functions of public health, health services researchers, private organizations, consumers, or the media. Many collectors of data are also users. This Education Strategy will identify activities for the Consortium to implement to make sure the needs of the first two groups are met in standards related efforts.

Suppliers: Suppliers of information are the organizations that report information to public health entities. These include hospitals, laboratories, physicians, and other providers as well as payors and funeral directors. We also include in this group other organizations that are involved in the supply chain of health care information including data clearinghouses, vendors that build and support their information systems and create capacity for electronic data interchange (EDI), and the standards setting organizations.

Partners

The Consortium will need to expand its current set of partnerships to leverage its resources and develop the critical mass it needs to reach out to various parts of the public health community and make its voice heard. Partnership goes beyond membership or subscription to the Consortium listserv. Partners will play an active role in the implementation of the education strategy. Roles may include:

- Representing the interests of various stakeholder groups in the further development and implementation of this education strategy;
- Providing access to key audiences of the education strategy;
- Collaborating in the development and dissemination of educational materials;
- Representing the interests of public health on standards setting bodies;
- Providing financial support for carrying out the education strategy;



- Taking responsibility for components of the education strategy.

Exhibit E-1 lists examples of the organizations with which the Consortium might partner. The list is divided into three categories. “Extensive” denotes those organizations that should play a central role in the overall implementation of this strategy. These organizations will provide critical linkages to key audiences including state and local health officials and health services researchers. “Targeted” includes organizations that are involved in standards setting activities and offer the potential for coordination on specific activities. “Limited” indicates organizations that might work with the Consortium on a more limited set of discrete strategies. Many of the organizations across all categories are already represented on the Consortium and several already play active roles. Organizations may move across categories of involvement over time.

Exhibit E-1: Partners

| Extensive | Targeted | Limited |
|---|--|--|
| <ul style="list-style-type: none"> • DHHS, Centers for Disease Control <ul style="list-style-type: none"> – National Center for Health Statistics – National Electronic Disease Surveillance System • Association of State and Territorial Health Officials • Association of Public Health Laboratories • Council of State and Territorial Epidemiologists • National Association of County and City Health Officials • National Association of Health Data Organizations • National Association for Public Health Statistics and Information Systems • Academy for Health Services Research and Health Policy | <ul style="list-style-type: none"> • The National Committee on Vital and Health Statistics • The American Medical Informatics Association • Southern HIPAA Administrative Regional Process • Government Information Value Exchange for States • Workgroup for Electronic Data Interchange • North American Association of Central Cancer Registries • The Massachusetts Health Data Consortium • New York State Department of Health, Statewide Planning and Research Cooperative System • The Minnesota Health Data Institute • Utah Health Information Network | <ul style="list-style-type: none"> • The Health Care Financing Administration • The Agency for Healthcare Research and Quality • Health Resources and Services Administration • Assistant Secretary for Planning and Evaluation • The American Public Health Association • The National Committee for Quality Assurance • Vendors of information systems • American National Standards Institute-Healthcare Informatics Standards Board • Standards Development Organizations |

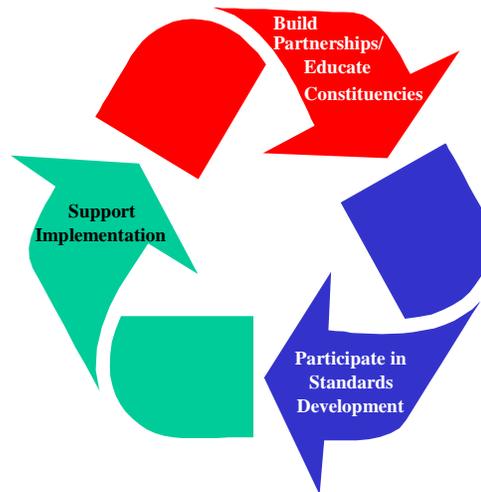
Education Strategy

The work of the Consortium involves an ongoing and repeating process that we have divided into three major stages of effort: building partnerships/educating constituencies; participating in the development of national standards; and supporting implementation. (See Exhibit E-2.) While these stages are progressive with regard to each standards



related issue that the Consortium takes on, at any given point in time there will likely be efforts occurring across all three stages.

Exhibit E-2: Framework for Consortium Support of Data Standards in Public Health



The Consortium’s role may vary in its implementation of each phase of the education strategy. The Consortium is an organization of member organizations and intends to compliment and support, not duplicate, compete with, or reinvent the work of its members. While data standards and data integration are integrally linked, the Consortium’s role will primarily relate to data standards development and implementation not to the full array of activities necessary to support data integration in public health. We have identified the following roles that the Consortium may play:

- Advocate: Articulate the rationale for standards; build momentum for change;
- Convener: Bring together the diverse constituencies within public health and research;
- Voice: Represent the voice of public health and research in standards development; and
- Education and support resource: Support implementation of data standards at the state and local levels.

Phase 1: Build Partnerships/Educate Constituencies

In order to meet its mission, the Consortium will need extensive involvement of the public health and health services research community and support from the various entities that fund the practice of public health and research like legislative bodies, governmental agencies, and foundations. One role of education during this phase will be to reach out to others in the public health and research communities and motivate them to get actively involved in the Consortium’s work. A second role of education during the



constituency building phase of the work will be to reach out to potential funders to make them aware of the critical nature of the Consortium’s work and convince them to supply resources. Finally, the Consortium will have to motivate the public health community to take action at the state, and in some cases, local level.

Educational outreach will be particularly critical during this phase of the Consortium’s work. The primary message—an articulation of the value of data standards—will be similar across audiences; however, the message will need to be tailored to match each audience’s perspective. Exhibit E-3 lists the specific strategies and partners for this phase of the Consortium’s work.

Exhibit E-3: Strategies for Building Partnerships/Educating Constituencies

| Strategy | Target Audience(s) | Partners |
|--|--|--|
| 1. Strengthen educational partnerships | ASTHO NACCHO The Academy | NAHDO, NEDSS |
| 2. Coordinate educational activities with NEDSS | NEDSS | NCHS, ASTHO and NACCHO |
| 3. Reach out to other partners | See Table E-1 | NCHS, ASTHO, NACCHO, NAHDO and NEDSS |
| 4. Secure funding | DHHS: CDC and HRSA Other federal agencies (USDA, DOJ) Health related foundations (Robert Wood Johnson, W. K. Kellogg, and California Healthcare Foundations) | CDC, NCHS, ASPE and others |
| 5. Personal appeal to state health officers | State health officers | ASTHO |
| 6. Campaign to increase awareness of data standards issues and motivate participation (presentations, listserv, broadcast e-mails, educational programs) | Decision-makers, collectors, and users | NCHS, ASTHO, The Academy, NEDSS and others |

Phase 2: Participate in the Development of National Standards

Once the public health and research communities are motivated for action, the Consortium needs to organize those willing to participate to effectively represent the voice of public health and health services research in standards development efforts. It will need specific individuals to serve on designated standards setting bodies. It will also need a structure that can bring together the wide diversity of interests within the public health and research communities so that a finite number of designated individuals can effectively represent “public health” at the national level. Providers and insurers worry that public health agencies will have unreasonable demands for what information gets



included in standard data transactions. It is important that the different segments of public health work together to carefully choose what elements are most important.

The educational needs during this phase will be to give specific audiences the information they need to participate in the standards development process. They will need to know:

- What standards are under development at the national level that impact public health;
- Which standards setting organizations have purview over what data systems or data elements;
- How the standards setting process works;
- What the implications of various proposed standards might be for public health;
- How they can provide input to this effort (either directly or through the Consortium).

There will need to be a constant flow of information between the individuals representing public health in standards development efforts and the public health and research communities at large. The public health community will need to know enough about how standards are developing to be able to provide the best input possible. The Consortium will need to play an active role in ensuring this communication occurs.

Exhibit E-4 lists the specific strategies for this phase of the Consortium’s work.

Exhibit E-4: Strategies for Participating in the Development of National Standards

| Strategy | Target Audience(s) | Partners |
|--|--|---|
| 1. Post brief summaries on what public health and researchers need to know about data standards development | Decision-makers, collectors, and users | ASTHO, The Academy, others for dissemination via web linkages |
| 2. Recruit and train a critical mass of public health representatives | Decision-makers, collectors, and users | CDC, ASTHO and The Academy Others to help identify and recruit representatives including APHA, NCVHS, SHARP or other regional organizations, NAPHSIS, state data consortia |
| 3. Engage the public health community around data standards development for a particular data system | Decision-makers, collectors, and users | Depends on data system selected |
| 4. Develop a web-based clearinghouse to track standards development efforts relevant to public health and health services research | Funders, decision-makers, users, collectors, and suppliers | CDC, NAHDO, NAPHSIS, WEDI SNIP, AMIA, ANSI, HISB, SDOs and others |



Phase 3: Support Implementation

As standards are adopted at the national level, the Consortium will need to provide support and guidance to states in the implementation of standards. Organizations will need to know what standards will be important to implement in the near and long term and how to actually make it happen. They will need tips on where to start and how to secure funding, implementation guides for specific standards as they are developed, guidance on how to organize and manage the process, strategies to overcome barriers, and various other types of technical assistance.

Interviews indicated that states would have significant educational needs during the implementation phase. In addition to tools to help states work through the process, states are eager to learn from the experiences of others who have gone through standards adoption and data integration efforts.

Exhibit E-5 lists the specific strategies for this phase of the Consortium’s work.

Exhibit E-5: Strategies for Supporting Implementation

| Strategy | Target Audience(s) | Partners |
|--|------------------------------------|---|
| 1. Create a public health implementation guide for selected national standards as they relate to public health | Collectors, users, and suppliers | Depends on standard—should include organizations involved in standard development, vendors, and suppliers of data |
| 2. Create an Implementation Toolbox | Decision-makers and collectors | ASTHO, NEDSS, NAHDO and state data consortia or regional workgroups |
| 3. Develop a web-based clearinghouse to track data integration and standards implementation efforts | Decision-makers, users, collectors | CDC, NAHDO, NAPHSIS and others |



I. BACKGROUND

The transformations occurring in our society around information and communication technologies offer tremendous potential to support health and health care. Information is the cornerstone of the science behind both care delivery and public health. New technologies exist that are capable of delivering information to consumers, patients, professionals, and policy-makers when and where they need it, so they can make informed decisions related to the health of individuals and the public. While other sectors of the economy such as financial services have completely entered the electronic information age, the transformation of clinical care delivery and public health has been much slower. Better use of information for health and health care depends on the development of a National Health Information Infrastructure (NHII).²

As defined by the National Committee on Vital and Health Statistics (NCVHS):

“The National Health Information Infrastructure is the set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health.”

The NHII is beginning to emerge through a set of public and private initiatives. One of the critical enablers to the development of this infrastructure is a comprehensive set of standards for all health data. Uniform data standards are methods, protocols, or terminologies agreed to by an industry to allow disparate information systems to operate successfully with one another.³

Enacted in 1996, the Administrative Simplification (AS) provisions of The Health Insurance Portability and Accountability Act (HIPAA) require the Secretary of Health and Human Services (the Secretary) to adopt standards to support electronic data interchange for a variety of transactions involving health care data. While the national health care community had been working towards standardization for many years, the federal mandate provided the impetus and the structure for key players to join forces to accelerate the process.

Although focused on insurance transactions and not mandated for most public health related data transactions, these standards will have important implications for public health. The health care encounter is the source of a significant portion of public health data. Lack of adoption of standards will make it more difficult to communicate with the clinical care delivery system especially for those data systems that rely heavily on administrative data (e.g., hospital discharge data sets). HIPAA also requires adoption of

² National Committee on Vital and Health Statistics. Toward a National Health Information Infrastructure. [On-line], Available: <http://www.ncvhs.hhs.gov/NHII2kReport.htm>

³ National Committee on Vital and Health Statistics. (July 6, 2000) Uniform Data Standards for Patient Medical Record Information. Report by the National Committee on Vital and Health Statistics to the Secretary of the U.S. Department of Health and Human Services.

*“We may be naïve
in public health.*

*‘We’re exempt, so
who cares?’*

*But public health
still must commun-
icate with its
business partners—
not only to talk the
talk, but translate
private sector
concepts into public
health terms.”*

National Immunization
Registry Consultant



standards for claims attachments and directs the National Committee on Vital and Health Statistics to study issues and make recommendations on uniform data standards for patient medical record information. The claims attachment represents the bridge between administrative and clinical information. The medical record is a primary source of data for disease registries, reportable disease tracking and immunization registries. The medical record also provides information for birth and death statistics and many other public health databases. The adoption of clinical data standards for both care delivery and public health will facilitate the electronic interchange of data which is now primarily paper-based. Electronic interchange will improve the efficiency, accuracy, and timeliness of reporting.

Other features of HIPAA, like the development of unique identifiers for individuals, employers, providers, and health care plans, will greatly enhance the ability to link data across encounters and sites of care. This will allow individuals to perform research on health care quality and outcomes linked to site of care and insurance status, patterns of morbidity, and risk factors for disease.

HIPAA also stipulates that the Secretary must develop standards to protect the privacy and security of data. These standards, released in December 2000, will also have important implications for how public health data are collected, transmitted, and stored.

Recognizing the importance of HIPAA to public health data, the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention, in collaboration with the Agency for Healthcare Research and Quality (AHRQ) and the National Committee on Vital and Health Statistics (NCVHS), sponsored a workshop in November 1998, to examine the implications of HIPAA for the practice of public health and health services research. This workshop brought together leaders in health statistics, research, and informatics to examine the challenges and opportunities presented by HIPAA.

Workshop participants recognized the need to organize the public health and research communities around data standards needs and issues. In January 1999, the Public Health Data Standards Consortium (the Consortium) was established to serve as a mechanism for ongoing representation of public health and health services research in the implementation of HIPAA-AS and other data standards setting processes. The primary mission of the Consortium is as follows:

“The Consortium will improve the health and health care of the U.S. population through improved health related information by expanding involvement in existing health data standards and content organizations and determining standards needs through consultation with data leaders and data users. The Consortium will facilitate the use of existing national standards and identify priorities for the development of new data standards for public health and health services research. The Consortium will work with its members and other partners



to educate the public health and the health services research communities about health data standards issues.”⁴

The Consortium’s initial focus has been on the HIPAA transaction standards and tangible results in this arena will be important to build the Consortium’s credibility in public health and with relevant standards development organizations. As the Consortium develops critical mass, the intent is for it to broaden its efforts beyond encounter data to support the full array of public health data standards needs.

Data standards are not only necessary to support the interface with the private sector, standards are also critical to support the flow of information across public health programs and levels of government. Developed largely through categorical funding, the systems that support public health are fragmented with different systems across programs and across jurisdictions. Public health is beginning to realize the value of integration and standardization. In some cases, standards development and implementation and data integration efforts are underway including the CDC’s National Electronic Disease Surveillance System (NEDSS) and immunization efforts. In other cases, there is a mature process for national standards development, including The North American Association of Central Cancer Registries (NAACCR).

This education strategy assumes that the Consortium will continue to make HIPAA related standards its first priority, but that resources permitting, it will expand its efforts to support a broader array of standards development and implementation efforts related to public health.

II. ROLE OF THE EDUCATION WORK GROUP AND GOALS OF THE EDUCATION STRATEGY

A primary role of the Consortium is to educate the public health and health services research communities on data standards issues. Recognizing the need for support of this role, the Consortium created the Education Work Group to develop, facilitate, and oversee the implementation of an education strategy. The goals of this group are to:

- Educate local, state and national organizations and their business partners on the importance of standardization of data content and format.
- Motivate the public health and health services research communities to:
 - Reduce public respondent, health care provider and payer burden;
 - Phase out in a step-wise logical manner the collection of unused and obsolete data;
 - Adopt existing standards;

⁴ Public Health Data Standards Consortium. Mission [On-line]. Available: <http://www.cdc.gov/nchs/otheract/phdsc/phdsc.htm>



- Engage in the standards process to improve existing standards;
- Create an understanding of the importance of standard identifiers to facilitate data analysis.⁵

The Education Work Group will focus on priorities related to data standardization including HIPAA implementation. It will complement and coordinate its work with the other Consortium committees and work groups and other related data standardization initiatives. As a first step, the Work Group contracted with The Lewin Group, Inc. (The Lewin Group) in collaboration with the National Association of Health Data Organizations (NAHDO) to develop an education strategy to guide the initial efforts of the Work Group.

The goals of the education strategy are to:

- Articulate why public health data bases should migrate to existing data standards, possibly beginning with HIPAA transaction standards, and why public health needs to engage in standards setting activities for the benefit of public health clients and public health organizations;
- Identify the multiple audiences for educational outreach;
- Identify possible collaborators and experts needed to develop educational content and implement the education plan;
- Identify relevant data bases at the state level and the types of standards that apply;
- Identify and prioritize the types of educational products that are needed, including evaluation tools that provide valuable feedback to the Consortium and its Education Work Group on their success;
- Formulate a plan for developing and delivering educational messages and materials, which may include tutorials, teleconferences, newsletters, exhibits, presentations, listservs, and websites; and
- Serve as a vehicle to attract organizational and financial support to implement the plan.

III. METHODOLOGY

The Lewin Group and NAHDO worked closely with the Education Work Group to develop the education strategy. The Work Group provided input on the project work plan and approach, participated in the interview process, identified relevant materials for inclusion, reviewed the outline for the strategy, and will review this and the final draft of the education strategy.

⁵ Public Health Data Standards Consortium. (July 13, 2000) Proposed Charter Education Work Group (Draft Document) Education Work Group



The Lewin Group drew on a broad range of reference materials for background and content information. These included published papers, white papers as presented on the websites of various organizations, and past research conducted by NAHDO. The team also attended NAHDO's annual meeting in December 2000. Appendix A provides a listing of reference materials and websites used.

With input from the Work Group, The Lewin Group team identified a limited number of experts to interview to support the development of the education strategy. Collectively these experts contributed knowledge about health data standards, public health data needs and uses, the value of data standards, the process of data standards development and implementation, the appropriate audiences for educational outreach, the educational needs of various constituencies, and the most appropriate educational messages and methods for reaching target audiences. Types of people consulted included state health officers and other state health department staff, providers, policy-makers, researchers, Centers for Disease Control and Prevention (CDC) officials, Consortium members, and representatives of standards setting bodies. Appendix B provides a list of the individuals interviewed, Education Work Group Members, and the Lewin and NAHDO team.

NAHDO conducted a series of case studies on key data system types to assess HIPAA readiness and to identify major standardization issues around collection, quality, analysis, use, and dissemination of data. These case studies provide information about standards and formats used by major health data sets and address questions such as:

- What are the primary uses of major health data systems? What information needs do they support?
- How do data flow in and out of each data system?
- To what extent are data systems linked?
- What are the technical strengths and weaknesses of major health data systems?
- Do data systems use national standards for collecting, editing, using and disseminating the data?
- What are the benefits and barriers to adopting or implementing national standards?
- What are some solutions for overcoming barriers and how could the Public Health Data Standards Consortium help?

The information from the case studies fed into all aspects of the education strategy and is summarized separately as Appendix C.

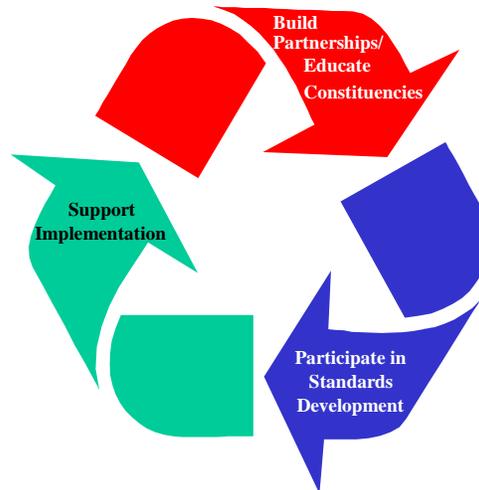
The project team then synthesized the research from each of the efforts described above and distilled the findings into consistent themes. These themes helped the team to determine the overall framework for the education strategy, the audiences for outreach, partners to help develop content and implement the strategies, the specific messages, and approaches as described below.



IV. FRAMEWORK

The work of the Consortium involves an ongoing and repeating process that we have divided into three major stages of effort and depict in Exhibit 1.

Exhibit 1 Framework for Consortium Support of Data Standards in Public Health



While these stages are progressive with regard to each standards related issue that the Consortium takes on, at any given point in time there will likely be efforts occurring across all three stages. For example, the Consortium might be supporting the implementation of HIPAA Administrative Simplification standards as they relate to hospital discharge databases at the same time that they are participating in the development of national standards for the patient medical record. Each stage of work has a different set of education requirements.

The Consortium's role may vary in its implementation of each phase of the education strategy. The Consortium is an organization of member organizations and intends to compliment and support not duplicate, compete with, or reinvent the work of its members. While data standards and data integration are integrally linked, the Consortium's role will primarily relate to data standards development and implementation not to the full array of activities necessary to support data integration in public health. We have identified the following roles that the Consortium may play:

- Advocate: Articulate the rationale for standards; build momentum for change;
- Convener: Bring together the diverse constituencies within public health and research;
- Voice: Represent the voice of public health and research in standards development; and
- Education and support resource: Support implementation of data standards at the state and local levels.



In this section, we describe the stages of work and briefly discuss the role of education in each stage. Sections seven through ten provide detail on the specific educational strategies proposed to support each phase of work.

A. Phase 1: Build Partnerships/Educate Constituencies

In order to meet its mission, the Consortium will need extensive involvement of the public health and health services research communities and support from the various entities that fund the practice of public health and research like legislative bodies, governmental agencies, and foundations.

One role of education during this phase will be to reach out to others in the public health and research communities and motivate them to get actively involved in the Consortium's work. Since its inception, the Consortium has been building a base of members to accomplish its work—determining standards needs, carrying out the education strategy, representing public health on standards setting bodies, providing support to organizations implementing standards, and other activities. Current Consortium members have taken on a substantial workload even with the Consortium's efforts being relatively narrowly focussed on HIPAA Administrative Simplification issues at this time. During this phase, the Consortium should work to strengthen its member base, build awareness of the Consortium's work and develop the necessary partnerships to implement this education strategy.

Partnership goes beyond membership or subscription to the Consortium listserv. Partners will play an active role in the implementation of the education strategy.

A second role of education during the partnership building/constituency education phase of the work will be to reach out to potential funders to make them aware of the critical nature of the Consortium's work and convince them to supply resources. Building a base of active members and carrying out the Consortium's work will require substantial resources. Some of these resources will be in-kind contributions of staff time to various activities. The Consortium will need direct funding above current levels to continue hosting meetings, to expand staff support as the Consortium broadens efforts beyond HIPAA, to fund the dissemination of its messages, to fund travel for Consortium member activities, and to carry out other critical activities. Possible funders include the federal government (other parts of CDC, other agencies within the Department of Health and Human Services [DHHS], other departments, etc.), foundations, and state governments.

Finally, the Consortium will have to motivate the entire public health community to take action at the state, and in some cases, local level. Building support in the top several layers of health and human services agencies has been cited as one of the most critical success factors in state processes to move towards data integration and standardization. Implementation of data standards requires an agency level commitment to make it happen. Senior level decision-makers will need to secure the funding and organize and oversee the implementation process.

Educational outreach will be particularly critical during this phase of the Consortium's work. The primary message—an articulation of the value of data standards—will be



similar across audiences; however, the message will need to be tailored to match each audience's perspective.

B. Phase 2: Participate in the Development of National Standards

Once the public health and research communities are motivated for action, the Consortium needs to organize those willing to participate to effectively represent the voice of public health in standards development efforts. The Consortium will need two layers of involvement. First, it will need specific individuals to serve on designated standards setting bodies to represent the public health and health services research communities. Second, the Consortium will need to develop a structure to funnel input from a diversity of segments of the public health community to those designated to represent "public health" at the national level. The public health and research communities are a highly diverse collection of programs and interests. There are multitudes of different data systems that currently operate autonomously. An individual qualified to represent the interests of encounter data sets might have limited knowledge of the needs of infectious diseases surveillance data sets. However, it will not be feasible for every different segment of the public health and research communities to be individually represented at the national level.

"...Because [public health data] is fragmented and compartmentalized, this information often cannot be aggregated to describe persons, populations, communities, or issues. The development and evolution of these separate information/surveillance systems has resulted in a patchwork of data systems, which has in turn led to duplication of effort, left critical information gaps, strained cooperative relationships, and made it difficult to accomplish the mission of public health."

Integrating Public Health Information and Surveillance Systems
HISSB, Spring 1995.

The educational needs during this phase will be to give specific audiences of the strategy the information they need to participate in the standards development process. They will need to know:

- What standards are under development at the national level that impact public health;
- Which standards setting organizations have purview over what data sets or data elements;
- How the standards setting process works;
- What the implications of various proposed standards might be for public health;
- How they can contribute input to this effort (either directly or through the Consortium).

Also there will need to be a constant flow of information between those representing public health and the research communities at large so that the public health community knows enough about how standards are developing to be able to provide the best input possible.

C. Phase 3: Support Implementation

As standards are adopted at the national level, the Consortium will need to provide support and guidance to states and localities in the implementation of standards. Organizations will need to know what standards will be important to implement in the near and long term and how to actually make it happen. They will need tips on where to start and how to secure funding, implementation guides for specific standards as they are



developed, guidance on how to organize and manage the process, strategies to overcome barriers, and various other types of technical assistance.

Interviews indicated that states would have significant educational needs during the implementation phase. In addition to tools to help states and localities work through the process, states are eager to learn from the experiences of others who have gone through standards adoption and data integration efforts. Tools could also be made available to private sector organizations to strengthen ties to the rest of the delivery system.

V. AUDIENCES DEFINED

Discussions with work group members and interviewees identified five audience types for educational outreach. These include:

- Decision-makers (e.g., state public health officials, senior deputy public health officers, federal decision-makers);
- Funders (e.g., legislatures, federal agencies, foundations);
- Collectors (e.g., state and local public health agency staff, researchers);
- Users (e.g., state and local public health agency staff, researchers, consumers, media); and
- Suppliers (e.g., provider organizations, laboratories, information system vendors, payors).

These audiences are defined by their different roles with respect to public health data and information. Since a particular individual might play multiple roles, the audiences overlap. For example, a researcher might conduct a survey and then use that data combined with data from other sources to inform a research project. That researcher would be both a “collector” and “user” of public health data.

Below we describe each audience by answering five questions:

- Who are they?
- What role should they play in each of the major phases of work?
- What is the “hook” for getting them involved?
- What is their readiness for change and what barriers exist to their embracing change?
- What methods are best to reach this audience?

A. Decision-makers

We define decision-makers as senior level governmental officials in health and human services agencies who make decisions about cross-program initiatives and funding priorities related to public health. At the state level decision makers include directors of public health departments, state health officers, senior deputies, division chiefs, and chief

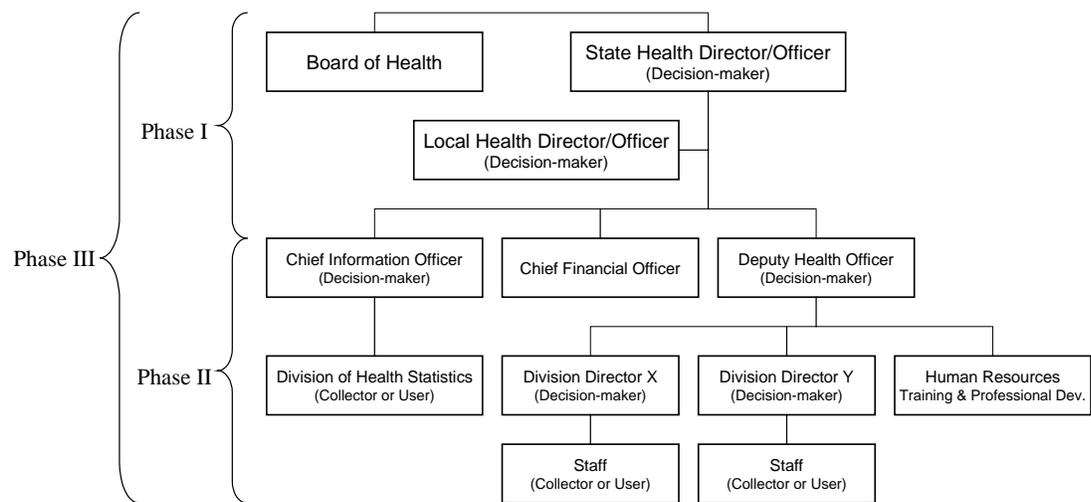


information officers. This group also includes organizations that represent these individuals (e.g., Association for State and Territorial Health Officials). At the federal level, the Consortium will need the support of people who make data decisions relevant to public health across a range of departments and/or agencies. These include CDC, the Health Resources and Services Administration (HRSA), the Health Care Financing Administration (HCFA), the US Department of Agriculture (USDA), Women’s, Infants and Children (WIC) Program, the US Department of Justice (bioterrorism) and others. This initial education strategy will focus on state decision-makers as the Consortium’s first priority. Federal decision-makers will be discussed in their role as funders and partners (see VI. Partners).

Senior level state officials will be important players in all three stages of the Consortium’s work. They are a primary audience for partnership building/constituency education. They will need to be active supporters of the work of the Consortium both by carrying the standards message upward to state legislatures and by carrying the message downward through all levels of their own organizations. During the standards development stage, a subset of these individuals (or members of their staff) will be needed to represent public health in the standards setting process. Finally, senior level state public health officials will need to drive the implementation of standards at the state level. In Exhibit 2, we depict a typical organizational chart for a state health department and indicate which levels of staff would be most involved in each phase of the education strategy.

Exhibit 2: Typical Organizational Chart of State Health Departments

Senior level state officials are a primary audience for partnership building/constituency education.



The commitment of these levels of senior management throughout implementation was cited as a critical factor by state interviewees who have already embarked on standardization efforts. Standardization, by its nature, must start as a top down initiative because efforts will cross multiple public health and even social service programs that in the past have been managed in relatively autonomous units with limited sharing of systems and information. Since individual programs may have relatively well-developed



information systems, programs will often have to give up something that works well for their unit in order to reach a common goal of standardization for the entire organization. This type of change will require a sustained commitment from top management.

This commitment must carry through several layers of the state agencies that manage public health programs. Standardization efforts can take many years and will likely span multiple administrations and tenures of state health officers. While the state health officers need to provide the vision for change, drive the initial commitment, and work with the legislature and others to garner funding and get the process started, the senior deputy directors, division chiefs, and chief information officers (where they exist) need to manage the implementation process and ensure that it survives changes in administration. The commitment of career rather than appointed officials is critical to avoiding a staff attitude of “this too shall pass” if staff can hold on to the status quo until someone new comes along. Senior deputies will need to set up the necessary work groups and manage the operational aspects of standardization.

“Fragments of information on persons, communities, or topics are isolated in many different places. For example, a single patient may be treated by multiple providers, each with its own record system. Services provided for individual patients by public agencies may be recorded separately in the data systems of numerous categorical programs. Information needed to characterize the overall health of communities may be included in the records systems of health, environmental, social service, criminal justice, and other agencies.”

Integrating Public Health Information and Surveillance Systems, Spring 1995

Several arguments will likely be effective in getting this audience to participate in standards related efforts. First, this audience must be convinced that a strong rationale exists for moving to data standards. This rationale includes the business case for standardization, arguments around why public health must enter the National Information Infrastructure, how data standards support the larger goal of integration, and why “it’s the right thing to do.” This rationale is presented in detail in Appendix D.

Interviews suggested that more personal or emotional means of motivating health officials can also be effective. Fear of being perceived as “behind” other states can move state health officials to take action. Also, a desire to be perceived as a leader and a change agent can be personally and professionally motivating to individuals.

The readiness for change varies tremendously across states. Most state health officials are at least aware of HIPAA and other standardization efforts (e.g., National Electronic Disease Surveillance System). Many, however, do not have a good sense of what HIPAA and other data standards mean to public health or what they should be doing. A minority of states have already embarked on data integration or standardization projects on their own. This segment of this audience is highly educated on the rationale and process for standardization across programs at the state level but may or may not be sold on the rationale for *national* data standards.

Barriers that this audience will need to overcome include:

- Inertia within the status quo;
- Lack of resources to invest in data standards efforts;
- Existing statutory language and administrative rules governing the data elements collected in a state;
- Resistance to abandoning what may have already been accomplished by the state or even individual programs in order to move to national standards; and



- The desire for a state to go it alone to avoid being slowed down by the national process.

Methods recommended to reach this audience include personal interactions, conferences, and internet communications and will be discussed in detail later in this document.

B. Funders

As discussed earlier, the Consortium's work will require substantial resources at each stage. Potential funders for data standardization efforts include state legislatures, federal agencies, and foundations.

During the partnership building/constituency education phase, the Consortium will need funds to support educational efforts. It will need funding to host and/or attend meetings, expand staff support, and develop and disseminate educational messages. During the standards development phase, funding will be required to organize the public health community so that it can be adequately represented on national standards setting bodies. Funding will be needed to support the time and travel expenses of individuals representing public health interests, to create a venue for public health interaction around standards setting efforts, and to support educational efforts needed at this stage. In the implementation stage, funding will be required for the Consortium to develop tools to assist states in implementation, and funding will be needed to support states' implementation efforts.

In the future... States will be linked together so that rapid comparisons of DNA fingerprints can be done to identify when foodborne illness occurring in different states has a common source.

It is unlikely that states will provide other than in-kind (e.g., staff time) funding for the first two phases of the work since this work is national in nature. Therefore, the Consortium will need to look to federal agencies and foundations for financial support. The Consortium's current funding is through the National Center for Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC) and DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE). Other parts of the federal government should contribute to this effort since other programs are affected. We recommend that the Consortium tightly coordinate its education efforts with the National Electronic Disease Surveillance System (NEDSS) and that NEDSS contribute funding to support the Consortium. Other federal agencies that oversee public health programs also need to contribute. These include the Agency for Health Care Research and Quality (AHRQ), HCFA, USDA (WIC), and HRSA. All of these federal agencies or departments collect health related data from states and would benefit from standardization.

Funders could provide in-kind support as well, such as providing information to their constituents through their regular mechanisms of communication. For example, AHRQ's Healthcare Cost and Utilization Project (HCUP) project meets annually with state government data organizations and state hospital associations. The HCUP project could discuss the activities of the Consortium and issues related to standardization during these meetings.

There are several "hooks" for securing federal funding. First, fear of bioterrorism, foodborne illness, multi-drug resistant bacteria, and emerging infections are fueling



increases in funding for CDC initiatives. A common information infrastructure is critical to controlling biological threats that increasingly cross programmatic and geographic boundaries. Second, measuring national performance relative to Healthy People 2010 goals requires better and more comparable data across states. The basic rationale for standardization and integration provides additional arguments that might be effective with this audience (see Appendix D).

Senior level Consortium members from NCHS and other parts of CDC should take the lead in reaching out to other federal agencies. These appeals should be made directly to officials managing key programs (e.g., WIC, Medicaid, etc.). Patterns of categorical funding and restrictions on the use of funding for cross-program initiatives are barriers that need to be worked through with federal agencies.

Health-related foundations such as the Robert Wood Johnson, the W. K. Kellogg and the California Healthcare Foundations should be approached for grant dollars to support data standardization.⁶ Foundations are interested in identifying disparities in health and health care for different subgroups of the population. Better data supports research on these issues. Large health-focussed foundations are also interested in promoting partnerships among levels of government, communities, and providers. Data standards that support integration are supportive of these partnerships.

“An analogous situation that most office workers could relate to is having to use three different word processors in an average day. Imagine if you have to be trained on and familiar with all the subtleties of Microsoft Word, Corel Word-Perfect and Lotus WordPro!”

Supporting Public Health Surveillance through the National Electronic Disease Surveillance System

<http://www.cdc.gov/od/hissb/docs/NEDSS%20Intro.pdf>

Personal interaction between Consortium members and foundation leadership would be the most effective way of gaining direct financial support for Consortium efforts. The Consortium should also work with foundations to develop grant-making programs that would get money to states to support implementation and provide model grant applications to state agencies wishing to secure foundation funding for their efforts.

While dollars to support standardization can flow through the Consortium for the first two stages of work, the final implementation stages will require both funding for Consortium educational activities and funding for state implementation activities. Consortium funds will still need to come from the federal government and foundations, but actual implementation will require state legislatures to allocate funds to supplement federal and foundation grant dollars. Discussions with states that have undertaken data integration and standardization indicate that their efforts have been funded by a wide array of federal and state programs as well as through grants from foundations.

Among the funders discussed, the state legislatures are likely to be the least knowledgeable about data standards and as such will be difficult entities from which to secure a commitment. This group can be reached through organizations such as the National Conference of State Legislators. We recommend, however, that the

⁶ While the California Healthcare Foundation focuses its grantmaking on California activities, it has a track record for funding efforts that affect both California and the rest of the nation. It recently released a report related to California's readiness for HIPAA, both the transaction and privacy standards.



Consortium provide support to senior level public health officials around how to make the case for funding to their own state legislature rather than using Consortium resources to reach this audience directly. The lack of a highly visible immediate impact of data standardization efforts is a potential barrier to getting the support of state legislatures.

C. Collectors

Data collectors are the individuals that collect, compile, and maintain public health data. Data collectors include a wide array of state and local public health agency staff as well as health services researchers. These individuals might be licensing or certification directors, registrars, epidemiologists, statisticians, or other types of professionals. Nearly every program has a repository of data and most of these data are maintained in separate systems. Some data are collected directly from individuals served by public health departments, some data are reported by health care providers and laboratories, some data are collected by researchers, while other data are collected from funeral directors and others in the community.

The people who collect, compile, and maintain public health data will need to be represented in the national standards development process. The size and diversity of this audience will make it impossible for each program, research discipline, and/or state to have a seat at the standards setting table. Hence there will need to be a structure to get input from data collectors that ensures that the needs of different programs and research areas are addressed in the standards setting process.

“Eight independent laboratories were integrated into a uniform system. Generic summary reports that took weeks to compile now are available to users in one query. Notification letters and responses were automated.”

More importantly, collectors will need to be actively engaged in the implementation of standards. This audience will need to retool their systems to conform to data standards, ensure that data definitions are adhered to, and that coding is accurate. A motivating force for collectors may be the possibility of coming together to influence standards to meet public health and health services research goals.

Readiness for change varies both across states and across programs within a state. Some programs in a state might still be primarily paper-based while others are already automated. States must interface with localities which are even more variable in readiness. Getting this audience motivated for change will require top down support from senior level public health officials.

While arguments for data quality and timeliness still apply, this group is likely to be the most resistant of all of the audiences to change. Many data systems are currently autonomous and standardization and integration is a direct threat to this autonomy. Collectors may fear loss of historical data, that new systems will be sub-optimal with respect to their programs, that they will no longer be needed if data systems are automated, or that demands for their data may increase.

Since this is the primary audience for implementation, this audience will require the most intensive educational support. Methods to reach this audience include convening managers within states or regions at a technical seminar funded by CDC or ASTHO where they could observe demonstrations of best practices; internet accessible

Wadsworth Center of
The New York State
Department of Health



information and tools; and distance learning. One interviewee stated that the best forum for training is a classroom with repeated follow-up but noted that distance learning programs make training programs more accessible to a wider audience of participants, usually at a lower cost.

D. Users

Users are those groups or individuals that use public health data. Many collectors of data are also users. Users include public health agency staff at all levels of government who use this data to perform core functions of public health. Data collected at the state and local level are often transmitted to the CDC or other federal agencies. Many other groups access public health information as well. Data are used by health services researchers in a wide variety of studies. Some data are released to the public where data might be used by private organizations (e.g., a hospital might use discharge data to understand its market position), consumers (e.g., some states collect and release data on mortality rates for procedures by provider), or the media.

Users need to be represented in the standards development process to raise awareness of the value of standardization from a public health perspective, to develop partnerships with the private sector around standards, and to ensure that standard data elements and definitions meet the needs of different public health user groups. For example, collecting the mother's medical record number in the birth registry may not be important to the primary user of birth registry data, but is very important to researchers who want to link birth outcomes to the mother's use of health care services or her medical history.

As with collectors, this group is large and diverse. Not all user groups will be able to sit at the table. Like collectors, user groups will need a way to funnel their input into the standards development process with limited direct involvement with standards setting bodies. Given its mission, the Consortium will need to take action to ensure the involvement of its core constituencies—state public health agencies and health services researchers—in the standards development process. Other users, such as consumers and the media, are less of a priority at this time.

The business case for convincing public health agency staff users of data to support data standards centers on improved data quality, timeliness, and comparability. Data standards and data integration will improve this group's ability to perform public health tasks such as identifying public health threats, assessing health status, evaluating programs and policies, and educating the public about health issues. Public health agency data users will also be better able to work with their colleagues in other states to identify and respond to public health threats that cross jurisdictional lines. These users also face a significant risk around access to data if they do not engage in the data standards setting process.

As users of public health data, researchers stand to gain tremendously from data standardization and integration. Standard identifiers will create the ability to link data across programs and jurisdictions to create a more complete picture of the health of the public and reveal how various factors impact it. If researchers are not represented at the

Today...Many epidemics are identified serendipitously.

Example: doctor calls second doctor to consult an unusual cluster of disease; second doctor notes that he has seen other patients with the same symptoms. Investigation indicates national epidemic linked to L-tryptophan.

In the future... Automated systems will scan data to identify unusual clusters of disease.



table in standards development efforts, however, standards will likely not address their needs, and they run the risk of losing access to certain types of data altogether. Privacy standards in particular pose a significant risk to data access for researchers, if they have not adequately made their case for the value of their research.

The readiness of user groups to engage in data standards varies. Some public health agency users have been involved in state level standardization and integration issues or in efforts to standardize programmatic data across states. Others have had little exposure to the issues. The research community has been less involved in data standardization and integration efforts.

The chief barrier to engaging users is figuring out how to best represent their diverse interests through a finite number of representatives on standards setting bodies.

The chief barrier to engaging users is figuring out how to best represent their diverse interests through a finite number of representatives on standards setting bodies. Providers and insurers worry that public health agencies and researchers will have unreasonable demands for what information gets included in standard data transmissions. To be responsive to this concern, public health and research users of data will have to carefully choose what elements are most important.

Public health agency users of information should be reached through the senior leadership of state health departments. These leaders should determine who on their staff is qualified to engage in the standards development process and will need to allocate time for those people to participate in standards development activities.

Research users of information need to be reached through their professional organizations. We recommend the Academy for Health Services Research and Health Policy, the Agency for Health Care Research and Quality and the American Public Health Association as the three principal organizations with whom to work to reach this audience.

E. Suppliers of Information

Suppliers of information are the organizations that report information to public health entities. These include hospitals, laboratories, physicians, and other providers as well as payors and funeral directors. We also include in this group other organizations that are involved in the supply chain of health care information. These include the data clearinghouses that transmit information among providers and payors, vendors that build and support their information systems and create capacity for electronic data interchange (EDI), and the organizations that set data standards for the information created, stored, and transmitted by these organizations.

These groups are currently working to establish national standards for HIPAA compliance. As an audience for the Consortium's work, particularly in the standards development phase, they need to be made aware of public health needs for information and take this into account in the development of standards and in building their own information systems. One respondent noted that public health is not on the vendor radar screen, for example. This audience needs to see its interaction with public health as a key business function that their information and information systems need to support.



“Approximately 40,000 test results have to be reported ... each month. These reports are sent to 300 different state and local health agencies, each of which has its own reporting requirements. The majority of these reports are sent on paper... Even when states use electronic interfaces ... they do not use them consistently across programs, which can make the electronic process cumbersome and complicated...”

SmithKline Beecham
Clinical Laboratories
Representative

The primary rationale to get this audience involved is the business case on their end for data standards and systems that are supportive of meeting their legal reporting obligations to public health. Large laboratories have already been brought into partnerships with public health on a pilot basis around automated reporting of test results. Public health also has established partnerships with sentinel hospitals for certain types of infectious diseases surveillance. These efforts have worked well for both providers and public health by providing more timely and higher quality information more efficiently.

Barriers that the Consortium will need to overcome with respect to suppliers include:

- The perception that public health and researchers want an unreasonable and inappropriate amount of data or that the data requested are unreliable for public health or research purposes (e.g., hospital representatives report that race/ethnicity data are unreliable);
- The feeling that public health and researchers will not consider all of the parties being affected (in some cases, burdened) by the data standards proposed;
- Provider resistance to accepting standards that require a medical record extract;
- Unwillingness to pay to support the electronic transmission of public health data;
- Feeling that the return on investment in information systems that support public health reporting is minimal for hospitals and physicians. Hospital representatives even perceive that, as covered entities, achieving benefits in four years from HIPAA Administrative Simplification standardization is unrealistic. They report that additional dollars spent on standards implementation leave slimmer margins to invest in patient care.

For HIPAA standards, these audiences can be reached through the standards setting bodies in the course of public health becoming more involved in their activities. For non-HIPAA related standards development and implementation, these organizations need to be involved as partners with public health as in the case of the electronic laboratory reporting initiatives currently being supported by the CDC. A priority area for relationship development should be vendors of health information systems.

VI. PARTNERS

The Consortium will need to expand its current set of partnerships to leverage its resources and develop the critical mass it needs to reach out to various parts of the public health community and make its voice heard. Partnership goes beyond membership or subscription to the Consortium listserv. Partners will play an active role in the implementation of the education strategy. Roles may include:

- Representing the interests of various stakeholder groups in the further development and implementation of this education strategy;
- Providing access to key audiences;
- Collaborating in the development and dissemination of educational materials;



- Representing the interests of public health on standards setting bodies;
- Providing financial support for carrying out the education strategy;
- Taking responsibility for components of the education strategy.

Through the course of interviews and review of literature, we identified examples of several organizations with which the Consortium might partner or strengthen its relationship. We would expect the Consortium to add to this list over time. Exhibit 3 divides the list of partners into three categories. “Extensive” denotes those organizations that should play a central role in the overall implementation of this strategy. These organizations will provide critical linkages to key audiences including state and local health officials and health services researchers. “Targeted” includes organizations that are involved in standards setting activities and offer the potential for coordination on specific activities. “Limited” indicates organizations that might work with the Consortium on a more limited set of discrete strategies. Appendix E provides a description of the organizations recommended in the extensive and targeted partnership categories.

Exhibit 3: Partners

| Extensive | Targeted | Limited |
|---|--|--|
| <ul style="list-style-type: none"> • DHHS, Centers for Disease Control <ul style="list-style-type: none"> – National Center for Health Statistics – National Electronic Disease Surveillance System • Association of State and Territorial Health Officials • Association of Public Health Laboratories • Council of State and Territorial Epidemiologists • National Association of County and City Health Officials • National Association of Health Data Organizations • National Association for Public Health Statistics and Information Systems • Academy for Health Services Research and Health Policy | <ul style="list-style-type: none"> • The National Committee on Vital and Health Statistics • The American Medical Informatics Association • Southern HIPAA Administrative Regional Process • Government Information Value Exchange for States • Workgroup for Electronic Data Interchange • North American Association of Central Cancer Registries • The Massachusetts Health Data Consortium • New York State Department of Health, Statewide Planning and Research Cooperative System • The Minnesota Health Data Institute • Utah Health Information Network | <ul style="list-style-type: none"> • The Health Care Financing Administration • The Agency for Healthcare Research and Quality • Health Resources and Services Administration • Assistant Secretary for Planning and Evaluation • The American Public Health Association • The National Committee for Quality Assurance • Vendors of information systems • American National Standards Institute-Healthcare Informatics Standards Board • Standards Development Organizations |

Many of the organizations across all categories are already represented on the Consortium’s Steering Committee and several already play an active role. Rather than



duplicating efforts, the Consortium can build on experience and efforts of its membership and leverage the experience of other partners in building partnerships/educating constituencies, participating in the national data standards discussion, and supporting implementation of standards at the state level. In addition, partnership will allow for broader dissemination of educational messages to the audiences of interest. Organizations may move across categories of involvement over time.

VII. EDUCATION STRATEGY: OVERVIEW

Below we outline the specific educational tools and methods that we recommend to support the Consortium's work across the three phases. For each phase we present:

- The primary goal of the education strategy for this phase of work;
- Barriers that the Consortium is likely to face in meeting this goal;
- Specific educational strategies for meeting this goal including:
 - Message;
 - Target audience;
 - Method/tools for delivering that message;
 - Partners with whom the Consortium should work to implement the strategy.

Specific educational strategies are summarized at the end of Section X.

VIII. EDUCATION STRATEGY PHASE I: BUILD PARTNERSHIPS/EDUCATE CONSTITUENCIES

A. Primary Goal

As discussed above, to meet its mission, the Consortium will need extensive involvement of the public health and health services research communities and the financial support of the various entities that fund their work. The primary goal of Phase I, Build Partnerships/Educate Constituencies, will be to communicate a compelling rationale (see Appendix D) for moving to data standards in order to get these groups motivated to fund and/or take an active role in developing and/or implementing data standards. During this phase the Consortium will need to build strong partnerships with several key organizations in order to assemble the critical mass necessary to support the next two phases of work. It will also need to make connections with other organizations that can support the Consortium in more limited ways. The priority audiences for outreach during this phase will be decision-makers, funders, and users.

B. Barriers to Meeting Goal

The Consortium will need to overcome a number of key barriers in order to motivate the public health and research communities to engage in the data standards development and implementation process. Embracing data standards will be a costly and time consuming



effort. The Consortium will have to communicate a compelling argument specifically designed to address key barriers including:

Lack of a clear mandate for public health and research; substantial inertia within the status quo. While the delivery system faces a clear HIPAA mandate and associated deadlines for compliance, most public health and research communities do not. As such, these communities potentially believe they have the option to maintain business as usual. The inertia to do this is substantial.

Lack of funding for standards development. Public health agencies face many pressing and competing needs at all levels of government. The traditional categorical mode of funding public health programs provides little money for general infrastructure development, the benefits of which cross different programs. Organizations that have undertaken data standards and data integration efforts have needed to cobble together funding from various sources.

Federal and state politics. Traditionally public health programs have been developed categorically to respond to specific diseases, threats to the health of the public, or needs of particular populations. The political process around securing and protecting money to serve a particular interest has contributed to the fragmented nature of public health programs and the data systems that support them. Categorical funding represents a key barrier to integrated information systems across programs. To ensure that money is not diverted to other purposes, categorical programs often have limits on how resources obtained through these programs can be used. These resources can be staff, hardware, software, etc. For example, the USDA reportedly has limitations on how WIC hardware and software can be used.

In a number of states, the data collection methods are specifically defined in statute or rules and the process required to make changes to the rules is lengthy. Many states would be reluctant to re-open debate on specific data collection.

Differing levels of readiness. States are at vastly different levels of readiness. Some are engaged in the national process, some are developing and implementing their own standards apart from this national process, others understand the need but have not taken action, and still others have only a limited awareness of the issue. This level of readiness can vary even within states across programs. For example, in one state the STD program is using a fully electronic system to gather and transmit STD information from the field to state and local health departments while the TB program uses a “flip file” to track cases.

Lack of awareness in the research community around why and how they should be involved. Interviews with the research community indicated limited awareness of how HIPAA and other data standards will affect their ability to obtain and use data.

Need for states, localities, and/or programs to change what they have already accomplished in order to get involved with broader initiatives. Many states and large urban public health jurisdictions have developed standards to support integration of data



sets across their own agencies and programs. Some programmatic areas have gotten pretty far down the path of developing standards (e.g., vital statistics, immunizations, and various disease registries). These initiatives may have to be reworked to fit into a set of national standards.

Difficulty of convincing states and programs not to go it alone. Some states or programs may lack confidence that a national process will meet the needed timeframe of those who are already primed to move forward.

Fear of increased workload. Some public health entities express concern that staff will not have the capacity to appropriately manage the increased volume of and demand for public health data. Some fear that better, more comparable data may lead to more people wanting data and increase the burden on “keepers.” Others fear that better data may uncover problems which cannot be solved with existing resources.

Fear of increased accessibility to data. State public health officials may not want their information to be more public. There are times when it is good to keep information out of the public’s eye (e.g., to avoid unwarranted panic). Standardization may make it harder to protect the confidentiality of data.

Upfront costs are high; process is lengthy, and benefits accrue over a long period of time. It may be hard to motivate public health officials (whose tenure may be short) to take on the challenge of data standards given the long-term commitment required in order to obtain a benefit.

C. Specific Educational Strategies

Below we outline a series of strategies to achieve the primary educational goal for this phase. Strategies one through three discuss important partnerships that the Consortium will need to strengthen or build to gain access to key audiences and leverage its limited resources. We highlight four critical partnerships that will broadly support the work of the Consortium. We then list other organizations with which the Consortium could collaborate to carry out specific components of this strategic plan. Strategy four relates to funding and strategies five and six are geared toward building awareness and motivation and educating the public health and research communities at large around data standards issues.

1. Strengthen educational partnerships with ASTHO, NACCHO, and The Academy

ASTHO is the national organization representing state and territorial public health agencies—the primary group that needs to be motivated to take action around data standards. NACCHO represents nearly all local health departments in cities, counties, townships, and districts. ASTHO and NACCHO have already developed some educational materials on specific national data standards policies and initiatives. The interests of ASTHO, NACCHO and the Consortium relative to data standards are concurrent. ASTHO and its affiliates (CSTE and APHL) and NACCHO can both take on



responsibility for various educational activities and provide access to their membership which includes key public health decision-makers at the state and local levels.

The Academy is the major association representing the health services research community and health policy makers. A stronger partnership with the Academy would increase the Consortium's reach into decision-makers, collectors, and users in the health policy and research community.

a) Messages

While ASTHO and NACCHO already understand the importance of data standardization for their members, the Consortium will need to convince the Academy that data standardization is a critical issue for their membership. The Consortium will need to motivate all three partners to become actively involved in data standards development and implementation, secure commitment of time and resources to the efforts of the Consortium, and get increased access to the membership of ASTHO, NACCHO and the Academy.

Messages that will be effective in accomplishing these goals include:

Clear articulation of how their membership will be impacted by HIPAA. The Consortium needs to clearly articulate the intersection between HIPAA standards and public health data. Without clarity about what data standards affect which public health data systems, it is difficult to overcome the inertia to maintain the status quo.

The business case for data standards and data integration. ASTHO, NACCHO and the Academy need to increase the priority level of data standards in its overall member support strategy because data standards make sense for its membership. Data standards promote efficiency, reduce errors, and improve the timeliness, quality, and quantity of information. Better data will improve the ability of public health officials and researchers to do their job (see Appendix D for more details of the business case). The delivery of this message should include specific examples of benefits (e.g., how electronic laboratory reporting has increased timeliness, number, and completeness of reportable disease data).

The risks NACCHO and ASTHO members face in NOT moving to data standards. A second reason for ASTHO and NACCHO to concentrate more effort on data standards is the risk for its membership of NOT moving to data standards when many of public health's data trading partners are. Public health depends on the delivery system for much of its data. The government has mandated that the delivery system adopts national data standards, including use of the Health Level Seven (HL-7) and Accredited Standards Committee-X12. For another part of the government to place information demands on the delivery system that are not consistent with these strategies will stress the important partnership between public health and the delivery system and may even threaten access to data.

Potential to lose by the Academy NOT being involved. If user groups such as the Academy's members are not involved in the development of data standards, they run the



risk of standard data elements and definitions being developed that do not meet their needs. For example, a recent topic of “conversation” on the Consortium’s listserv has been standards for the de-identification of data for privacy reasons. A standard that removes patient zip code could greatly impact researcher ability to link health care status to demographic factors.

Specific proposals for collaboration. The Consortium should approach ASTHO, NACCHO and the Academy with specific proposals for how they can be partners in the Consortium’s work. What tasks can they and/or their affiliates perform; what resources can they commit; what access can they provide for the Consortium to their memberships. Later in this strategic plan, we suggest specific activities that ASTHO and/or its affiliate organizations might be involved in. The Consortium may want the Academy to encourage its members to participate in Consortium activities by identifying important data needs, documenting the benefits of having certain data, and contributing to the business cases for specific elements or sets of elements. It may be beneficial for a health services researcher to be on the “team” that presents a business case to a Standards Development Organization (SDO) as an expert on the value of the data proposed. The Academy can also provide a forum for discussion among researchers around data standards issues (listserv), provide access to researchers at its annual meeting (currently in progress), and potentially even sponsor seminars for researchers on data standards issues.

Potential to gain from the Academy’s involvement in data standards development. Data standards have the potential to improve the usability of data for research purposes, if researchers make their needs known in the standards development process. Data will be more comparable across programs and different geographic areas. Standard identifiers will facilitate the linkage of data across settings of care and over time.

b) Audiences

The specific audiences for these messages are the senior leadership and boards of ASTHO, NACCHO and the Academy.

c) Tools and Methods

We recommend that designated members of the Consortium be assigned to developing partnerships with ASTHO, NACCHO and the Academy. These individuals would meet with senior leadership or board members of ASTHO, NACCHO and the Academy with specific ideas for collaboration.

d) Partners

NAHDO could help foster the partnership with the Academy as NAHDO is an affiliate member. The CDC (NEDSS) has already been working with ASTHO and NACCHO and might be helpful in establishing that partnership.



2. Coordinate educational activities with National Electronic Disease Surveillance System (NEDSS)

As mentioned earlier, NEDSS is a CDC effort to create interoperability among the myriad of data sets that support the surveillance of infectious diseases. While the Consortium has been focusing on HIPAA standards related to administrative transactions, NEDSS has been focusing on standards around the clinical data that feeds surveillance systems. While NEDSS is currently represented on the Consortium, efforts of the two entities have been relatively distinct. As the focus of HIPAA standards development evolves to include the patient medical record, the information of focus for the Consortium and NEDSS will intersect. Coordination of the messages of NEDSS and the Consortium will enhance the effectiveness of the CDC voice in promoting standards that meet the full array of public health needs. Lack of coordination could create confusion in the public health community.

a) Messages

The Consortium needs to explore with senior leadership of the CDC how partnering with NEDSS will allow the CDC to reach its long-term vision for data integration more quickly. Key messages include:

The relationship between HIPAA standards and the broad range of standards needed to support public health. As HIPAA efforts begin to move into the claims attachment and explore the patient medical record, HIPAA will begin to impact the clinical data that is the primary source for much of the data that feeds public health systems including surveillance systems. At this point NEDSS and Consortium messages to public health will need to be consistent.

The desire for states to integrate data systems across the spectrum of health and human services programs not just pieces of it. Some states are already developing standards and systems to integrate data across the full range of their programs. These states would like a vision for integration that goes beyond surveillance.

The benefits to NEDSS of coordinating efforts. Coordinating with the Consortium could increase the speed at which the CDC attains its larger vision of data integration. One Consortium member suggested that the Consortium collaborate with the CDC to begin expanding the Public Health Conceptual Data Model to include public health data sets beyond surveillance.

Risks of not coordinating. Failure to develop unified “CDC” message around data standards could lead to confusion and frustration at the state level.

b) Audiences

The primary audience for these messages is the senior leadership of the CDC and the NEDSS initiative.



c) *Tools and Methods*

The Consortium should approach NEDSS and top CDC leadership with a proposal to develop a joint Education Work Group around data standards.

d) *Partners*

The Consortium should use the leadership of ASTHO and its affiliates, CSTE, APHL, and NACCHO, to help make the case for coordination. ASTHO can represent the needs of the states for a unified vision for public health data that goes beyond infectious diseases surveillance. Also, NCHS members of the Consortium should play a lead role in developing this relationship.

3. *Reach out to other partners*

The four organizations/initiatives above represent a core or base set of partnerships that the Consortium will need to actively develop to implement this education strategy. As mentioned in Section VI, Partners, several organizations are already involved in the work of the Consortium in either an extensive or targeted manner. These relationships should continue. The Consortium membership is also broadly representative of organizations that work with the public health and research communities. The role of these and other organizations will need to be expanded to help reach specific audiences or develop specific educational materials.

a) *Messages*

Clear articulation of how developing or expanding the relationship with the Consortium would be mutually beneficial. The Consortium will need to approach each target organization with a rationale as to why it would be in their benefit to collaborate with the Consortium.

Specific proposals for collaboration. The Consortium should approach each group with a specific proposal for collaboration. This would include: what tasks they would perform; what resources would be required; and what the Consortium would offer them in return. In each of the specific strategies discussed throughout the remainder of this report, we identify potential partners who could contribute to strategy implementation.

b) *Audiences*

Organizations that should continue to play an extensive or targeted role in Consortium activities include:

- The National Center for Health Statistics (NCHS), CDC (currently providing staff and financial support);



- The National Association of Health Data Organizations (NAHDO) (currently actively involved as a member and contractor);
- The National Committee on Vital and Health Statistics (NCVHS);
- The American Medical Informatics Association (AMIA);
- Southern HIPAA Administrative Regional Process (SHARP) or other regional organizations;
- National Association for Public Health Statistics and Information Systems (NAPHSIS); and
- State data consortia (e.g., The Massachusetts Health Data Consortium, The New York State Department of Health Statewide Planning and Research Cooperative System, The Minnesota Health Data Institute, The Utah Health Information Network).

Organizations who can support the implementation of the education strategy in a limited capacity include:

- The Health Care Financing Administration (HCFA);
- The Agency for Healthcare Research and Quality (AHRQ);
- The Health Resources and Services Administration (HRSA);
- The American Public Health Association (APHA);
- Assistant Secretary for Planning and Evaluation (ASPE);
- The National Committee for Quality Assurance (NCQA); and
- Vendors of information systems.

c) Tools and Methods

We recommend that designated members of the Consortium be assigned to developing a partnership with each target organization at the time that the Consortium is ready to implement a strategy where the organization could be of help. These individuals would meet with senior leadership or board members of the organization with specific ideas for collaboration.

d) Partners

The Consortium should work with ASTHO, NACCHO, NAHDO, NCHS and NEDSS to approach these organizations.

4. Secure funding

In order to be able to carry out its mission, the Consortium needs funding. As noted above, potential funding sources for the Consortium include federal agencies and



foundations. We recommend that the Consortium undertake a concentrated effort to secure grant funding for its activities.

a) Messages

The business case for data standards development and implementation (See Appendix D: Rationale for Moving to Data Standards). Funders need to be convinced that data standards development and implementation are a good investment.

The potential benefits of data standards for research. Foundations will be particularly interested in how data standards will support research to improve health and health care (See Appendix D).

The role of a common infrastructure in controlling biological threats that cross programmatic and geographic barriers. Integrated data systems increase the ability of the nation's public health system to identify and control threats like bioterrorism, multi-drug resistant bacteria, and emerging infections.

The need for comparable data to assess performance relative to Healthy People 2010 goals. Data standards will improve the ability of state and federal public health officials to assess progress relative to the goals of Healthy People 2010 and to better evaluate programs geared toward improving health status.

The benefits of comparable data to measure health system performance. The lack of data standards currently makes it difficult to assess health system performance.

Activities required to move forward. Funders need to be made aware of the massive effort required to achieve data standards across the myriad of public health and research programs at all levels of government.

b) Audiences

Funders that should be approached include federal agencies within DHHS including the Office of the Assistant Secretary for Planning and Evaluation, CDC, and HRSA, other federal departments like USDA (around WIC program), DOJ (around bioterrorism), and health related foundations such as the Robert Wood Johnson Foundation, the W.K. Kellogg Foundation and the California Healthcare Foundation.

c) Tools and Methods

We recommend that Consortium members directly approach the leadership of potential funding organizations. We recommend that the Consortium develop a summary of this education plan to give funders a sense of the effort required to support data standards development and implementation. We also recommend that summary versions of the Rationale for Moving to Data Standards (See Appendix D), tailored to address the interests of each funding organization, be disseminated to these funding organizations.



d) *Partners*

Possible partners include CDC, NCHS, ASPE and others.

5. *Personal appeal to State Health Officers to get involved*

One of the most important audiences for the Consortium to involve in data standards efforts are state health officers. State health officers will need to be committed to the concept of data standards and be the primary flag-bearers at the state level--both upward to state legislatures to get funding to move forward and downward in state agencies to make it happen.

a) *Messages*

The rationale for moving to data standards (See Appendix D). State health officers will respond to a strong business case for data standards. In an environment of constrained funding, state health officers will need to be convinced that data standards will both improve performance and lower costs.

States that don't adopt data standards will be left behind. The fear of a state being perceived as “backward” or “behind” other states can be a motivating factor for the senior leadership of state agencies.

Having led a state through the data standards implementation process is professionally rewarding to state health officers. State health officers that lead their agencies through data standards implementation processes will be sought after by other states. They will be perceived as leaders and change agents.

b) *Audiences*

The primary audience for these messages is state health officers.

c) *Tools and Methods*

Given the relatively small number of state health officers, we recommend a personal approach to reaching out to them by other state health officers or senior level state public health officials who are already involved in the Consortium's work. We recommend a three tier approach:

Telephone contact. The Consortium should begin by hosting conference calls where small groups of state health officers are brought together to discuss data standardization and integration. These groups should be constructed so that state health officers that are already leading efforts are grouped with those who are not. This approach should create peer pressure to embrace change and foster a productive exchange of ideas.



Written materials. The Consortium should develop brief high level materials describing the benefits of data standardization and integration for state health officers. These materials should be distributed in conjunction with other forms of contact.

Personal contact. Consortium members should bring together small groups of state health officers at events that they are likely to attend (e.g., ASTHO and NAHDO annual meetings).

d) *Partners*

The Consortium should work closely with ASTHO to implement this strategy.

6. Campaign to increase awareness of data standards issues and motivate participation in the public health and research communities.

The Consortium should undertake a multi-faceted awareness campaign to promote data standards to key audiences across the public health and research communities.

a) *Messages and Audiences*

The core message of this campaign is the rationale for moving to data standards (Appendix D). This message should be tailored to appeal to different audiences in the public health and research communities.

Decision-makers and Funders: Focus on the business case for data standards. Data standards will promote efficiency, reduce errors and improve the timeliness, quality and quantity of information.

Collectors: Focus on how data standards will improve the flow of data. Data standards support automated information flow. Automation increases the speed of data reporting and supports a more rapid response to public health threats. This message must specifically address collectors' fears around how their jobs will change. Emphasis should be placed on how data standards and automation free up the time of public health workers to perform more important tasks like investigation, analysis, and response.

Users: Focus on the possibilities for enhanced research using standard data sets. For researchers data standards will increase comparability of data over time and across jurisdictions. Data standards will also allow the linkage of data across programs and settings of care. For public health department users data standards will improve the ability to perform public health tasks such as identification of public health issues, assessment of health status, and policy and program evaluation. Materials should provide specific examples of what can be done with better data.



b) Tools and Methods

We suggest four primary methods to reach these audiences:

Presentations at Key Meetings. The Consortium should present the rationale for moving to data standards at as many meetings as is practical. Presentation materials should be crafted to present the most appropriate message for each audience and for different levels of readiness. Exhibit 4 presents a suggested list of meetings for consideration. An effort should be made to get a major public health and/or research association (APHA, ASTHO, and the Academy) to make data standards and integration a highlighted topic of an annual meeting within the next two years.

Audience Specific Listservs. The Consortium should promote its existing listserv to increase participation from the public health community. The listserv should be publicized as part of presentations, on the website, on partner's websites, etc. The larger the listserv, however, the lower the likelihood of two-way communication. Therefore, the Consortium should also create several listservs targeted to particular audiences, e.g., the research community, to promote communication on specific topics.

Monthly Broadcast E-mails. The Consortium should do monthly broadcast e-mails about data standards issues. These e-mails should be brief and high level with linkages to more detailed information on each topic. An important and timely topic would be the implications of privacy standards for public health and research. These e-mails can be used to update the public health and research communities on standards development and implementation.

Educational programs. The Consortium should develop programs to educate the audiences discussed above on the rationale for moving to data standards. These programs could be delivered via teleconferences, video conferences, or "train-the-trainer" programs.

c) Partners

The Consortium should work with each of its major partners (ASTHO, NACCHO, The Academy, NCHS, and NEDSS) to create and disseminate messages appropriate for each audience. The Consortium will also need to work with sponsors of the meetings identified to get data standards on the agenda. The Consortium should approach other organizations (e.g., APHA) on the list of potential partners to help promote these activities to key audiences.



Exhibit 4: List of Meetings for the Consortium to Attend

| Name of Meeting | Date | Place | Sponsorship |
|---|-------------------------|--------------------------|--|
| Healthcare and the Internet: Risks and Opportunities | February 2, 2001 | Boston, MA | Massachusetts Health Data Consortium |
| Annual Healthcare Information and Management Systems Society (HIMSS) Conference and Exhibition | February 4-8, 2001 | New Orleans, LA | HIMSS |
| National Association of County and City Health Officials (NACCHO) Leadership Conference | March 1-2, 2001 | Washington, DC | NACCHO |
| Public Health Data Standards Steering Committee Meeting | March 21-22, 2001 | Arlington, VA | National Center for Health Statistics (NCHS) |
| Developing a National Agenda for Public Health Informatics | May 15-17, 2001 | Atlanta, GA | American Medical Informatics Association |
| National Association for Public Health Statistics and Information Systems (NAPHSIS) Joint Meeting with NCHS | May 20-24, 2001 | Albuquerque, NM | NAPHSIS |
| Academy Annual Meeting - Research to Action: Shaping our Health Care Future | June 10-12, 2001 | Atlanta, GA | Academy for Health Services Research and Health Policy (Academy) |
| Association of Public Health Laboratories (APHL) / Council of State and Territorial Epidemiologists (CSTE) Annual Meeting | June 10-13, 2001 | Portland, OR | CSTE/APHL |
| National Association of County and City Health Officials (NACCHO) 2001 Annual Conference | June 27-30, 2001 | Raleigh, NC | NACCHO |
| The National Conference on Health Statistics | July 23-25, 2001 | Washington, DC | NCHS |
| Association of State and Territorial Health Officials (ASTHO) Annual Meeting | September 18-21, 2001 | Orlando, FL | ASTHO |
| American Health Information Management Association (AHIMA): 73rd Annual Conference | October 13-18, 2001 | Miami Beach, FL | AHIMA |
| American Public Health Association (APHA) Annual Conference | October 21-25, 2001 | Atlanta, GA | APHA |
| Expected: National Association of Health Data Organizations (NAHDO) Conference | Expected: December 2001 | Expected: Washington, DC | NAHDO |



IX. EDUCATION STRATEGY PHASE II: PARTICIPATE IN THE DEVELOPMENT OF NATIONAL STANDARDS TO SUPPORT PUBLIC HEALTH

A. Primary Goal

The primary goal of Phase II of the education strategy is to encourage and increase public health involvement in the national standards development process. The voices of the public health and health services research communities have not been well-represented on national standards setting bodies. Besides public health providers who seek reimbursement, public health and research communities do not face a mandate for compliance with national standards. Health care industry representatives who sit on standards setting bodies often do not have a clear understanding of the functions of public health or health services research, who or what represents these communities, and the ways that collaboration with public health is beneficial to their business goals.

The focus of this phase is to identify and educate representatives of the public health and research communities about what they need to know to participate in national standards development to support public health and get them involved. Key audiences include collectors and users of data who are identified by decision-makers at the federal and state levels and supported by funders. Both the Consortium and its partner, the CDC, have engaged in the national standards setting dialogue. The Consortium presented proposals to X12 to revise the claim standard to address public health needs, e.g., the collection of race/ethnicity, mother's medical record number and other diagnosis indicator. The CDC has been actively participating in HL-7 and, to a lesser extent, X12 meetings. This phase is dedicated to increasing participation and unifying the diverse voice of the public health and health services research communities.

B. Barriers to Meeting Goal

The Consortium faces barriers to getting the public health and researcher communities involved in the national data standards development process. The education strategies must overcome barriers including:

Lack of unified national leadership in standards development process for public health. Key audiences, such as state public health officials and their staff, are unsure of whom to go to for information on national data standards setting, i.e., the CDC, HCFA, etc. It is difficult to find individuals or organizations that represent the diversity of public health and health services researcher information needs and those with the technical know how to participate in the national discussion. Materials about national standards, Standards Development Organizations (SDO), and HIPAA compliance exist, but they are scattered and vary in content depending on the health delivery system perspective for which they were written. The Consortium has begun to overcome this barrier, serving as a mechanism for ongoing representation of public health and health services research in the implementation of HIPAA Administrative Simplification and other data standards setting processes.

In the case of cancer registries, when national standards are used, multi-level reporting without redundant or conflicting information needs benefits all players (e.g., American College of Surgeons, state registries, regional registries, CDC, and NCI). Duplicate records are readily identified and merging of regional files with other data such as driver's license and vital records is possible.



Lack of funding for standards development efforts. Limited funds exist for data standards development for public health at the national level and for implementation at the state and local levels. State health officers rarely support their staff to participate in out of state activities. Much of the current state participation in national standards development efforts is voluntary. Many individuals take time away from their core job responsibilities to participate. Some standards setting organizations require fees to be members, e.g., X12, HL-7.

Efforts to develop data standards are resource intensive. The standards setting process is consensus based and requires a major investment by participants. Consensus on the content of data standards is usually reached through a lengthy comment and revision process before the SDO publishes the final standard. Standards produced through this process are usually of high quality because the process relies on input from a broad group of participants. But the process is expensive and time consuming. It would be difficult for some states to justify the expense of sending the same state representatives to regular meetings of national standards setting bodies. Representatives from the states of Utah and New York are some exceptions. Utah Medicaid participates on WEDI. New York State SPARCS participates in ASC X12 and on the National Uniform Billing Committee as the Consortium representative.

Public health leaders may be waiting for the private sector to work out the bugs of standards development and implementation before investing in the process. A complex standard typically takes five to seven years to evolve from a concept to publication. In addition, a standard is not considered complete until it is validated through use, but such acceptance may take even longer than the actual development process.⁷ Public health may not want to invest the time in standards development and implementation, forfeiting its opportunity to have input into the process.

An urgent need has not been identified. Public health and health services researchers may not see that the value of uniform data outweighs the perceived costs of participating in the process.

C. Specific Educational Strategies

We recommend four strategies to achieve the goal of representing the voice of public health and health services researchers in standards development efforts. The first strategy involves the Consortium enhancing its website by posting educational materials on the national standards development efforts. Strategies two and three relate to identifying and training or supporting representatives to participate in the process on behalf of public health. The fourth strategy involves the Consortium partnering with another organization

⁷ Brandt, Mary D. (April 2000). Health Informatics Standards: A User's Guide Journal of AHIMA. [Online] Available: <http://www.ahima.org/journal/features/feature.0004.1.html>



to create a resource for key audiences to go to for up-to-date information on national data integration and standards completed or in process.

1. Post brief summaries for public health staff, health services researchers and the public on what they need to know about national standards development efforts.

The Consortium will establish itself as an educational resource to public health, health services research communities, and the public in the implementation of HIPAA Administrative Simplification and other data standards setting processes. We recommend that it enhance its website to provide easy to read materials on the national process from a public health and research perspective. The questions in the section on messages below are suggested topics for educational products.

a) Messages

What are data standards? As defined by NCVHS, “Uniform data standards are methods, protocols, or terminologies agreed to by an industry to allow disparate information systems to operate successfully with one another.”⁸ Data standards are technically complex and difficult for a non-technical audience to interpret and follow. For example, typical users of public health data do not have the technical skills to interpret the implementation guides which translate the codes for diseases, procedures, etc. into content.⁹ This educational product will define data standards, their types (e.g., vocabulary, structure and content, messaging, security/privacy), and provide examples of those most relevant to public health and health services research communities, e.g., HIPAA Administrative Simplification standards.

What are standards setting organizations? Standard setting organizations include SDOs and Data Content Committees (DCC). SDOs are organizations that develop and maintain the models, data dictionaries, structure, syntax, and implementation materials for electronic transaction standards. All designated SDOs maintain policies that meet the requirements of the American National Standards Institute (ANSI) for open participation and assurance of due process. This educational product will identify the SDO’s relevant to public health and health services researchers. Readers will know which SDO to approach when contemplating a particular standard type. DCCs are committees that provide a national forum for discussion, review, and action regarding change requests to the data sets associated with health care financial and administrative transactions. The US Department of Health and Human Services designated six SDOs and DCCs to play an

⁸ National Committee on Vital and Health Statistics. (July 6, 2000) [Uniform Data Standards for Patient Medical Record Information](#). Report by the National Committee on Vital and Health Statistics to the Secretary of the U.S. Department of Health and Human Services.

⁹ The Lewin Group. (October 16, 1998) [Engaging Public Health and Health Services Research in the Health Data Standards Development Process](#). (Draft Document) Salinsky, Eileen.



active role in the HIPAA Administrative Simplification transactions maintenance process: Accredited Standards Committee X12 (X12); Dental Content Committee; Health Level Seven (HL-7); National Council for Prescription Drug Programs; National Uniform Billing Committee (NUBC); and National Uniform Claim Committee (NUCC).¹⁰ These organizations will be described in the educational product. It will also describe how SDOs interact with DCCs and other players involved in the process of standards setting.

What is the process for setting standards? Public health and health services researchers do not understand the standards setting process and the jurisdiction of SDO's over particular issues.¹¹ This educational product will summarize the process of national standards setting. Simplified steps include: 1) presenting the need for a standard to the American National Standards Institute (ANSI); 2) designating an SDO to develop the standard; 3) developing the concept, drafting the proposed standard, commenting, and reaching consensus among industry representatives, professional associations, consumer groups, government agencies, vendors; 4) publishing the standard; 5) revising the standard based on comments about implementation.

What standards are relevant to public health and health services research? This product will interpret issues being raised at standards setting organizations from a public health perspective for public health audiences. For example, why is the provider identifier an important standard for public health analysis? To develop and update this product, the Consortium will need to closely monitor standards setting discussions. In addition, the Consortium representatives need to bring to these discussions a clear and consistent definition of public health and its information needs across the broad range of functions it performs. Public health can be defined differently depending on the emphasis of a particular state or locality and what entities are under the health related department. For example, it is hard to separate public health functions from direct service delivery by public health clinics. Many public health agencies are in the same department as Medicaid and other medical and non-medical assistance programs. The Consortium has adopted a broad definition of public health. "The public health vision, as exemplified in the objectives of the Healthy People 2010 initiative, is healthy people in healthy communities and the mission is to promote physical and mental health and prevent disease, injury and disability."¹²

¹⁰ Department of Health and Human Services. (March 2000) Memorandum of Understanding among Organizations Designated to Manage the Maintenance of the Electronic Data Interchange Standards Adopted under the Health Insurance Portability and Accountability Act of 1996 [On-line], Available: <http://www.aha.org/hipaa/resources/mou.asp>

¹¹ The Lewin Group. (October 16, 1998) Engaging Public Health and Health Services Research in the Health Data Standards Development Process. (Draft Document) Salinsky, Eileen.

¹² Public Health Data Standards Consortium. (November 27, 2000) The Operating Principles of the Public Health Data Standards Consortium [On-line] Available: <http://www.cdc.gov/nchs/data/phdsc/copfinal.pdf>



How are the public health and health services research communities currently involved in these efforts? What more can they be doing? In this product, the Consortium can describe its current efforts in standards setting (e.g., diagnosis indicator, race/ethnicity definitions included in claim standard, mother's medical record number on claim standard) and what more can be done (e.g., expanded collection of e-codes, payer type definitions, county code, source of admission code, functional status definitions, readmission indicator, national provider identifier, unique individual identifier).

How can you get involved? The Consortium will outline the steps different audiences can take to get involved in the national standards setting process. As audiences may be more likely to get involved when standardization is the law, the Consortium will provide a timeline for passage of the laws relevant to public health and health services research communities. One respondent cautions, however, that the timeframe allotted by law for the development of standards may not be sufficient to fully test the implementation of the standards.

Involvement includes meeting attendance, participation on sub-committees or work groups, or board representation. Steps will be slightly different for decision-makers than collectors and users. Decision-makers, such as public health senior leadership, will also be provided with steps to develop state and local initiatives that are in line with national initiatives.

b) Audiences

The audiences for these educational products will be anyone who accesses the Consortium website. It will be written for decision-makers, and collectors and users of health information.

c) Tools and Methods

We recommend that members of the Consortium be tasked with developing draft one-pagers on the messages outlined above. These documents will be circulated for comment, revised and posted on the website. The website design should allow for easy access to these documents. The Consortium needs to establish a process for updating these products and monitoring their use.

d) Partners

ASTHO has already drafted one-pagers on some overlapping topics, such as SDOs. Each one-pager answers four questions: What is the effort? What's been accomplished? What are the next steps? What does it mean to states? The Consortium might also leverage its partnership with the Academy to help with the interpretation of standards from the health services research perspective. The Consortium can look to its other partners as possible venues for web dissemination either directly or through linkages to the Consortium's website.



2. Recruit and train a critical mass of public health representatives

A key goal of this phase of the Consortium's work is to get broader representation of the public health community on the major standards setting organizations. The Consortium needs to prioritize which organizations in which it would like to have a voice (e.g., X12, HL-7, NUBC, NUCC), identify the types of people or organizations which could best represent public health, and then support these individuals or organizations to participate in the work of the SDOs. Representatives' expertise should span different data systems. Their roles will include serving on standards setting bodies and funneling input to and from these bodies that represent the diversity of segments of the public health and health services research communities.

a) Messages

Some of the Consortium representatives participating in the national standards setting process will be senior health department staff identified by state health officers. Many of the same messages used to get state health officers involved in the building partnerships/educating constituencies phase of the education strategy apply to the recruitment of these representatives:

- *The rationale for moving to data standards, e.g., increased data quality, timeliness, and comparability.*
- *States that don't adopt data standards will be left behind.*
- *Having participated in the national standards development process will be professionally rewarding.*

Other representatives will be from national partners and potential funders, including ASTHO, The Academy, and the CDC who will respond to messages mentioned above, such as:

- *Clear articulation of how their constituencies will be impacted by HIPAA.*
- *The potential to gain from involvement in data standards.*
- *The potential to lose by NOT being involved.*
- *The role of a common infrastructure in controlling biological threats that cross programmatic and geographic barriers.*

Once representatives are recruited, they need to be trained to serve on standards setting bodies from a public health and health services research perspective. The primary training message is:

How to participate in the standards setting discussion. Representatives will learn to:

- *Develop an understanding of the data standards and integration issues facing the organizations they represent;*



- Bring these issues to a meeting of all representatives for consensus on pressing issues for the Consortium to address;
- Prepare for their participation in the standards setting discussion by reviewing the minutes from prior meetings, by identifying who sits on the board of the SDO or DCC, etc.;
- Represent the public health and health services researcher voice in standards setting discussions;
- Funnel input from the standards setting discussion back to the Consortium and the organizations they represent.

b) Audiences

State and federal decision-makers comprise one audience as senior officials will most likely suggest members of their staff qualified to engage in the process.

Collectors and users of health information are candidates for participation in national standards setting discussions. They have the technical knowledge as well as an understanding of the information needs in segments of the public health and researcher communities necessary to be representatives in the national standards development process. The size and diversity of collectors and users in public health and research communities means that all programs, researcher disciplines and states cannot have a seat on these bodies. There needs to be a structure to get input that ensures that different needs are addressed.

c) Tools and Methods

The Consortium will work with its partners to help identify and recruit representatives to sit on standards setting bodies. We recommend that the Consortium make a personal appeal to state health officers to recommend key staff to participate. The Consortium should consult the growing number of regional efforts. The Consortium may also draft a cooperative agreement with federal agencies to participate in standards setting discussions. Representatives' suggested term is three years.

Training for representatives should include reviewing the one-pagers on the Consortium's web-site. The Consortium should leverage the work of other organizations around training, e.g., SDOs.

The critical mass of representatives should convene quarterly (via conference calls) to discuss pressing issues in the public health and research communities which could be taken to the national standards discussion. Representatives should come to these meetings having reached consensus at their home institutions about information needs that standards can or cannot address.



The Consortium should post a schedule for who is attending which standards discussions throughout the year. Representatives should summarize the discussion for distribution to the Consortium.

d) Partners

As mentioned above, the major partners for recruitment and training of the Consortium representatives on standards setting bodies include the CDC, ASTHO, and its affiliates, and the Academy. Other possible organizations that could help in identifying and recruiting representatives include APHA, NCVHS, SHARP or other regional organizations, NAPHSIS, and state data consortia.

3. Engage the public health community around data standards development for a particular type of data system.

The Consortium may want to begin its more strategic involvement in national standards development efforts by choosing to develop appropriate standards for specific data element in a particular data system that resonates with a large number of states. Each standard setting effort sets a precedent for future efforts and provides an opportunity for learning. If benefits are realized on the implementation side (e.g., new budget line item to support standardized data for X public health function or data system), then the Consortium develops a track record for its next activity. As this strategy is not an educational effort, per se, it does not fit into the framework of identifying messages, audiences and tools and methods. We discuss this strategy in terms of the steps the Consortium needs to take to implement it.

a) Steps for Strategy Implementation

Choose a data system for standardization that will generate interest and support from state and federal representatives as well as private health care industry representatives. Candidate suggestions made by interview respondents include various disease registries, hospital discharge data sets, vital statistics, etc.

Leverage existing research on standards for this data system. The Consortium should determine whether HHS, as part of its requirement under HIPAA or other organizations, have selected or developed a standard setting process for the data system or specific data element(s) or transaction(s) associated with the system. The Consortium should research whether standards setting activities have begun at national or local levels.

Form a work group with expertise in the data system of interest. The Consortium should develop a work group for the standards development of the data system of interest. This work group would be charged with developing the business case for standardization of specified components of the data system and identifying which SDO would be most likely to develop the standard.



Develop a business case for the standardization of specific data elements within the data system. The discussion of the business case for standards should demonstrate that a problem is being solved through standards development. Representatives from the hospital industry who have been involved in the standards setting process stress the importance of evaluating the information needs that proposed standards address and the implications of proposed standards on parties responsible for adopting them.

Prepare for the presentation to SDOs. SDOs fear that public health agencies and researchers will have unreasonable demands for what information gets included in standard data transmissions. The Consortium should be prepared to answer the following questions:

- What information need does the standard address? Why?
- What are the benefits of collecting the data?
- What are the costs of collecting the data? Does it require a medical record extract which places a burden on providers?
- How good or poor is the data quality? How reliable are the data?
- Is the standard feasible to adopt?
- Is the standard ethical to adopt? Will the data be misused?

b) Partners

Once the Consortium has identified the portion of the data system of most importance to standardize, it should partner with a national or state organization that is furthest along in its research of this data system. For example, if the Consortium chooses to start with cancer registries, it should partner with the North American Association of Central Cancer Registries. In addition, it should develop a relationship with the SDO most likely to develop the standard and possibly a vendor to provide input on implementation issues.

4. *Develop a web-based clearinghouse to track standards development efforts relevant to public health and health services research.*

The area of data integration and standards development is moving rapidly. Innovation is occurring across the country as organizations work to solve common data problems that face public health. A critical need identified by state health officials is for better information and improved access to information on the various activities underway across the country. These activities would include standards development efforts by various national standards setting organizations and standards implementation efforts at state and local levels. State health officials would like their organizations to be able to benefit from the experience and activity of others. Current information networks are informal and largely word of mouth and information is scattered.



a) Messages, Tools and Methods

We recommend that the Consortium and its partners play an active role in tracking and disseminating information on an ongoing basis about efforts related to standards development efforts. In this Phase, Phase II of the education strategy, we outline the messages, tools and methods necessary to support an inventory of the existing standards development efforts that are relevant to public health and health services research. In the next Phase, Phase III of the education strategy, we discuss tracking standards implementation efforts.

We envision that the Consortium will develop a user-friendly web-based tool that provides a listing of standards development efforts with brief descriptions, contact information, and links to additional information available on the internet. Users should be able to type in a key word for a data element or data set into a search engine and receive the following information:

- whether standards are under development;
- which organization is involved in developing the standard;
- which standards setting organization has purview over this standard type;
- the status of standard development (e.g., adoption, implementation, or sunset);
- the implications of the standard for public health;
- contact information for persons involved in the standards development;
- links to experts via industry organizations (e.g., WEDI SNIP) and other information available on the internet;
- when the information was last updated.

The research necessary to develop this tool involves identifying what standards currently exist and which are relevant to public health as well as what public health data types exist and whether standards setting or data integration efforts are underway. NAHDO's listing of public health data types is a start to this effort. (See Appendix F.) It will be important to clearly identify the data elements included in the standard and the coding structure for those data elements.

Additional Consortium staff or dedication of staff by Consortium partners will be required to implement this strategy.

b) Audiences

The clearinghouse will be targeted for use by decision-makers, users, collectors, and suppliers of information as well as the general public.



c) *Partners*

NAHDO, with its technical capabilities and its understanding of public health, is a possible partner to help the Consortium develop the web-based clearinghouse. Since this type of resource would be useful to all types of organizations that deal with health data, the Consortium might want to partner with CDC, NCHS, HCFA, WEDI SNIP, SHARP or other regional organizations, AMIA, ANSI-HISB, SDOs and/or NAPHSIS to develop this clearinghouse.

The Consortium should leverage existing metadata, or “data about data,” systems. For example, it is currently seeking linkages to the United States Health Information Knowledge Base (USHIK) metadata registry. USHIK is being developed by the Department of Defense and the Health Care Financing Administration to build, populate, demonstrate and make available a data registry to assist in cataloging and harmonizing data elements across organizations. Its current focus is on HIPAA data elements.

X. EDUCATION STRATEGY PHASE III: SUPPORT IMPLEMENTATION

A. Primary Goal

The primary goal of educational activities during Phase III is to provide support and guidance to states in all aspects of data standards implementation. Organizations will need help to organize the process, secure funding, decide which standards to implement, and work through the steps necessary to implement various data standards.

B. Barriers to Meeting Goal

Difficulty in knowing where and how to start. States face multiple and potentially competing needs for data standards and integration. Data standardization can occur within a level of government across programs, across levels of government for a particular program, or across states for a particular program. For example, a state could choose to join a national effort to develop standards for its cancer registry or it could develop standards across all registries for the state.

Lack of connectivity is a barrier to standards implementation. Data standards presuppose electronic transactions. Many current transactions in public health are paper based, and some partners in data exchange may not have the technology or skills required.

Lack of funding for standards implementation efforts. Translation or conversion to national standards from legacy systems is expensive and may be difficult. As mentioned earlier funding for infrastructure improvement activities is currently limited by the historical pattern of categorical funding.

Lack of uniformity in how public health is structured at the state level. Each state has a unique structure. Public health activities may be in autonomous units or in units linked to Medicaid, insurer and provider regulation, and/or social services. Sometimes all public



health activities are controlled at the state level and sometime localities have significant authority. Different structures make it difficult to develop solutions that can be easily replicated.

Lack of coordination across the multiple data standardization and integration efforts occurring in public health. Many efforts are currently underway within states or across states for particular data sets (e.g. infectious diseases surveillance systems, immunization registries, cancer registries, vital records systems, etc.) There is currently no formal mechanism to coordinate these efforts or even facilitate the sharing of information across initiatives.

Staff or organization resistance. Staff may resist data standardization and integration processes because of fears of loss of historical data, loss of autonomy, increase workload, or loss of job security. Organizational ownership of existing systems may cause resistance to change these systems, as well.

Separation of program and information technology staff. Standards implementation requires commitment from both the content and technical experts. However, there is often a gap between program and information technology operations. Program staff may not have the knowledge or skills to appreciate emerging technologies and the implications for public health practice. State experience difficulties recruiting and retaining qualified public health information technology professionals. Technical experts may not have the substantive expertise necessary to determine whether the implementation is useful.

C. Specific Educational Strategies

1. Create a public health implementation guide for selected national standards as they relate to public health.

The Consortium should develop a practical guide to help public health entities respond to national data standards. The Consortium may want to choose an administrative simplification standard or claims attachment most relevant to public health to begin or choose a data standard not directly related to HIPAA. Implementation guides for standards ensure consistency in implementation. An implementation guide should provide standardized data requirements and content for all users of a particular standard.

a) Messages

This implementation guide should include a detailed explanation of the data standard by defining:

- What business use or transaction the standard deals with and how it relates to public health;
- A mapping of the information flows as they relate to public health;



- Utility and requirement of each data field;
- Systems for coding and tables of recommended codes;
- Specification of applicable values;
- Examples of complete messages.

b) Audiences

This guide should be structured to provide information to collectors—the people who collect and maintain data sets and handle transactions involving public health data—as well as users and suppliers.

c) Tools and Methods

The guide should be disseminated via the web. People should have the option to download the document from the web directly or purchase a bound version for a nominal fee. Efforts are underway by the Consortium to develop a readable data dictionary for the X12N 837 standard.

d) Partners

The Consortium should work closely with other groups who have developed implementation guides. The typical process for developing an implementation guide includes organizations involved in developing the standard in question, users and collectors of data, vendors of information systems, and suppliers of data. For example, the CDC has developed an implementation guide for HL-7 as it relates to electronic laboratory reporting of public health information. They worked with people involved in developing the HL-7 standards, collectors and users of data at CDC, and Shared Medical Systems, a vendor of information systems.¹³

2. Create an implementation toolbox

Health Officers interviewed perceive there to be a high level of awareness about the need for standards setting to support integrated data systems but not much information on how to actually make it happen. Interviewees suggested that the Consortium construct a “toolbox” that outlines the key steps of the process in concrete terms and provides supporting materials around each step. This toolbox would be primarily web-based but could incorporate distance-based educational seminars and programs at conferences.

¹³ Centers for Disease Control and Prevention. (October 1997) Health Level Seven Specifications for Electronic Laboratory-Based Reporting of Public Health Information.

“We need a better public health data model to better represent the complexity of many public health transactions.”

Wadsworth Center of
New York State
Department of Health



a) Messages

The content of these educational materials and programs would cover the educational needs described by state representatives during our interview process. Educational modules would include:

Assessing Readiness: Readiness relates to the degree of integration, linkage and sharing of data sets at the state level or among states and their information trading partners. For example, states with an Intranet are better positioned than states without an Intranet for communicating information about standards. The American Hospital Association conducted a survey of its members to assess their current overall readiness to meet the HIPAA requirements and to determine the services and resources they need to meet privacy, security and administrative simplification regulations.¹⁴ This tool provides a potential model to replicate for public health agencies.

Making the case for funding at the state level: This module would be designed to help state health officers and other senior level public health officials make the case to those within their state who influence funding decisions including the governor, senior deputies to the governor, and the state legislature. This would provide a sample business case for standards development including information on how standards support a more effective public health response to current threats like bioterrorism, emerging infections, foodborne illness, and drug resistant bacteria. This module could include canned presentations that state public health officials could modify for use with their constituencies. These materials could be disseminated via the web.

Estimating resource requirements: States will need guidance as to how to develop a budget for various levels of effort. Budgets will vary based on the scope of the effort. States who are in the midst of efforts can help develop budget templates.

Identifying alternative funding sources: This module would help senior level public health officials and public health program management identify other sources of funding. This tool would be a web-based listing of federal and foundation grant-making programs that support data standards implementation. It would also provide case studies describing how various states secured funding for their efforts and emphasize the need for creativity. For example, the States of Illinois and Wisconsin have committed and opportunistic Health Officers who use portions of categorical or discretionary funds to pay for integrated information systems. The State of Illinois used Health Alert Network funding to connect all of its local health departments to each other. The state of Wisconsin paid for its web-based immunization registry with 12 different funding sources.

¹⁴ American Hospital Association. (March 2000) HIPAA Privacy, Security, and Administrative Simplification Regulations. Member Readiness and Needs Assessment. [On-line], Available: <http://www.aha.org/hipaa/resources/HIPAASurveyReport.pdf>



Writing applications for funding: This module would include “grant templates” to help senior level public health officials and public health program management actually secure funding. States who have been successful in securing funding would be asked to share de-identified grant applications to serve as models for others. Possible existing grant programs at the CDC include NEDSS, Emerging Infections Program, Health Alert Network, and Electronic Lab Capacity. One of the goals of the Robert Wood Johnson Turning Point initiative is integrated information systems and data standards are required to make this happen. Research would need to be conducted to identify other grant programs. States would be encouraged to work in partnership with others to secure funding (e.g., private providers, universities, other states).

Building a team to make it happen: This module would be geared towards state health officers to give them information on how other states have organized their efforts. This would include what kinds of people have been involved (including vendors/contractors), what partners were included (e.g., public health departments have worked closely with laboratories on standards for the electronic transmission of reportable disease data), what advisory bodies were convened, what structure was used to organize the work, and what strategies did states use to bring people on board. Special emphasis would be placed on the need for a very high level individual to champion the effort and the need to develop structures that help to bridge the gap between program and information technology staff at the state level.

For example, to get started Wisconsin put together a data steering committee of 20 individuals representing local health departments, the state, community-based organizations, and others. This body identified information needs at the grass roots level and put together the blue prints for a Wisconsin public health information initiative. The Health Officer’s job was to secure funding from the state legislature.

Mapping data flow: Mapping data and data flow is a useful tool to help identify trading partners for data exchange and applicable standards for data sets. The Consortium could provide sample data maps (e.g., Wisconsin has developed a preliminary map of data though it is not currently for public dissemination).

Determining where to start: The Consortium should develop recommendations for how to prioritize standardization efforts based on the status of national standards development efforts and the track record of states in implementing particular standards sets.

Models for integration. The Consortium should provide alternative models for data integration used by different states. This model would provide information of which data sets have been integrated across which programs (public health and beyond). The web-based clearinghouse on integration and implementation could provide content for this tool (see Phase III, Strategy 3).

Expanded Public Health Conceptual Data Model (PHCDM). The Consortium should work with NEDSS to expand the PHCDM to include the full range of public health data. The purpose of the current model is to document the information needs of public health and facilitate the development of standards to support infectious diseases surveillance.



Steps necessary to implement national data standards. The Consortium would use case studies to illustrate the steps that states went through with respect to different standards/integration efforts. The case studies that NAHDO completed as part of this project could be used as content in this set of materials. For example, case study research on immunization registries revealed that annual immunization registry surveys are a model to monitor and inform states about standards priorities. The case study materials along with additional research could be used to develop manuals for implementation of different standards sets.

Overcoming barriers. States will need pointers on how to overcome key barriers such as staff resistance, difficulties in getting staff to work together, lack of technical know how among staff, fears about loss of autonomy, different levels of readiness across departments, technical difficulties, etc.

User friendly data dictionaries and implementation guides for different standards sets. As new standards are developed the Consortium should add new implementations guides. The first priority should be HIPAA related standards, but it could also work with NEDSS around standards for surveillance. The web-based clearinghouse to track standards development efforts could provide content for this tool (see Phase II, Strategy 4).

b) Audiences

The audience for the implementation toolbox will primarily be decision-makers (state health officers) and collectors (state health department staff). At this point we do not recommend implementation support for the research community (as collectors) because of resource constraints.

c) Tools and Methods

These tools would be disseminated via the website through written materials and manuals, and web-based tutorials. Several distance-based learning seminars could be offered to provide more intensive instruction on selected topics for specific levels of staff. We also recommend that CDC or ASTHO fund a seminar where state health officers and/or senior level deputies could be trained on the basics of managing data standards, integration and implementation. This seminar could be held in conjunction with another relevant meeting (e.g., ASTHO annual meeting). We recommend that the Consortium leverage the regional work efforts of groups like the Southern HIPAA Administrative Regional Process (SHARP).



d) *Partners*

We recommend that the Consortium work collaboratively with ASTHO, NEDSS and NAHDO to develop and disseminate these materials. States who have gone through integration and standardization efforts should be consulted in the development of materials. Other possible organizations for consultation include the Government Information Value Exchange for States (GIVES),¹⁵ SHARP, the Massachusetts Health Data Consortium, the Minnesota Health Data Institute and the Utah Health Information Network.

3. *Develop a web-based clearinghouse to track data integration and standards implementation efforts in public health.*

Phase II, Strategy 4 described a web-based clearinghouse of standards *development* activities. We recommend that this clearinghouse also track information about *implementation* efforts related to data standards and integration across states or programs. Innovation is occurring all over the country. States face many of the same problems and could learn a huge amount from the experience of others. As mentioned earlier, current information networks are informal and largely word of mouth and information that could be helpful is scattered.

a) *Messages, Tools and Methods*

We recommend that the Consortium and its partners play an active role in tracking and disseminating information on an ongoing basis about efforts related to standards implementation and data integration efforts. In this Phase, Phase III of the education strategy, we outline the messages, tools and methods necessary to support creating a partial inventory of standards implementation efforts that are being undertaken by public health agencies and health services researchers. We do not envision that this will cover every activity in every state. The intent would be to have a representative sample of activities and case studies around key programs or data sets.

We envision that the Consortium will enhance the user-friendly web-based tool described in Phase II Strategy 4 to provide a listing of what various states, regions, or programs are doing around standards implementation and data integration. This listing would include brief descriptions of the activity, information on the entities involved in the activity, contact information, and links to additional information available on the internet. Users should be able to type a state, a program, or a type of data into a search engine and receive the following information:

¹⁵ GIVES is a collaborative government and health care industry group focusing on the sharing of information through a clearinghouse highway and providing a forum for discussing and resolving issues in meeting HIPAA standards. For more information contact Joyce Young at (919) 661-5881.



- what standards implementation or integration activities are currently going on;
- what organizations are involved in the effort;
- which program or data set is the focus of the effort;
- the status of implementation;
- any case study information in existence (e.g., NAHDO's case studies of state efforts would be a good resource to include on this website);
- contact information for persons involved in the effort;
- links to experts via industry organizations (e.g., WEDI SNIP) or other information available on the internet;
- when the information was last updated.

Research would be required to develop a critical mass of efforts to include on this website. The clearinghouse needs to promote cross-fertilization and the sharing of knowledge among the public health and health services research communities. Additional Consortium staff or dedication of staff by Consortium partners will be required to implement this strategy and support the clearinghouse users.

b) Audiences

Funders comprise one audience as resources and staff are needed to research, develop and maintain the web-based clearinghouse.

The clearinghouse will be targeted for use by decision-makers, users, and collectors.

c) Partners

ASTHO, with its linkages to public health agencies, is a possible partner to help the Consortium develop the web-based clearinghouse. NAHDO, with its expertise in state encounter data, is another possible partner. The CDC may be helpful because some of its grant programs focus on data integration, electronic data exchange, or data standards. For example, the organizations working under Electronic Laboratory Capacity grants to develop electronic laboratory reporting capabilities have from time to time shared case studies about progress and issues with other grantees. Linkages to this type of information would be helpful to other states considering such efforts.

The Consortium should leverage existing metadata, or “data about data,” systems. For example, it is currently seeking linkages to the United States Health Information Knowledge Base (USHIK) metadata registry. USHIK is being developed by the Department of Defense and the Health Care Financing Administration to build, populate, demonstrate and make available a data registry to assist in cataloging and harmonizing data elements across organizations. Its current focus is on HIPAA data elements.



D. Phases I, II and III Summary

Exhibit 5 summarizes the strategies for each phase of the framework.

Exhibit 5: Summary of Educational Strategies

| Strategy |
|--|
| PHASE I |
| 1. Strengthen educational partnerships |
| 2. Coordinate educational activities with National Electronic Disease Surveillance System (NEDSS) |
| 3. Reach out to other partners |
| 4. Secure funding |
| 5. Personal appeal to State Health Officers to get involved |
| 6. Campaign to increase awareness of data standards issues and motivate participation in the public health and research communities |
| PHASE II |
| 1. Post brief summaries for public health staff, health services researchers and the public on what they need to know about national standards development efforts |
| 2. Recruit and train a critical mass of public health representatives |
| 3. Engage the public health community around data standards development for a particular type of data system |
| 4. Develop a web-based clearinghouse to track standards development efforts relevant to public health and health services research |
| PHASE III |
| 1. Create a public health implementation guide for selected national standards as they relate to public health |
| 2. Create an implementation toolbox |
| 3. Develop a web-based clearinghouse to track data integration and standards implementation efforts in public health |



XI. EVALUATING THE STRATEGY IMPLEMENTATION

[This section will be written for the next draft.]

A. Goals of the Evaluation

B. Sample Indicators of Change Expected as a Result of Strategy Implementation

1. *Indicators for Phase I*

a) *Evidence Necessary to Measure the Expected Change*

2. *Indicators for Phase II*

a) *Evidence Necessary to Measure the Expected Change*

3. *Indicators for Phase III*

a) *Evidence Necessary to Measure the Expected Change*



APPENDICES



APPENDIX A: REFERENCES AND WEBSITES USED

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Health Alert Network, <<http://www.phppo.cdc.gov/han>>

Health Care Financing Association, <<http://www.hcfa.gov>>



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National Association of Health Data Organization, <<http://www.nahdo.org>>

National Center for Health Statistics, <<http://www.cdc.gov/nchs>>

National Committee for Quality Assurance, <<http://www.ncqa.org>>

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Washington Publishing Company, <<http://www.wpc-edi.com/models/Primer2.html>>



APPENDIX B: INTERVIEW RESPONDENTS AND PROJECT TEAM

Interview Respondents

| Interviewee | Title | Organization Name |
|--------------------------|--|---|
| Mr. George Arges | Director, Health Data Management Group | American Hospital Association |
| Ms. Suzie Burke-Bebee | Health Informatics Specialist | National Center for Health Statistics, Centers for Disease Control and Prevention |
| Dr. Claire Broome | Senior Advisor to the CDC, Director, Integrated Health Information Systems | Centers for Disease Control and Prevention |
| Dr. John Chapin | Administrator | Department of Health and Family Services, State of Wisconsin |
| Mr. Robert Davis | SPARCS Coordinator | New York State Department of Health |
| Mr. Tom Doremus | Information and Communications Specialist | Public Health Foundation |
| Ms. Marjorie Greenberg | Chief, Data Policy and Standards Staff | National Center for Health Statistics, Centers for Disease Control and Prevention |
| Dr. David Kindig | Director | University of Wisconsin |
| Dr. Alana Knudson-Buresh | Senior Director, Public Health Information and Infrastructure | Association of State and Territorial Health Officials |
| Mr. Garland Land | Director | Missouri Department of Health |
| Mr. Jon Lawniczak | Director, Government Relations | Coalition for Health Services Research |
| Dr. Steven Lazarus | President | Boundary Information Group |
| Ms. Denise Love | Executive Director | National Association of Health Data Organizations |
| Dr. John Lumpkin | Director | Illinois Department of Public Health |
| Mr. Ron Mar | Training Unit and Resource Center Manager | Illinois Department of Public Health |
| Dr. A. Richard Melton | Deputy Director | Utah Department of Health |
| Ms. Kathy Reep | Vice President, Financial Services | Florida Hospital Association |
| Dr. Helen Regnery | Chief of the Executive Secretariat, HISSB | Centers for Disease Control and Prevention |
| Dr. Jan Root | Standards Manager | Utah Health Information Network |
| Dr. Barbara Starfield | Professor of Health Policy and Pediatrics | The Johns Hopkins University |
| Mr. Elliot Stone | Executive Director & CEO | Massachusetts Health Data Consortium |
| Mr. Andrew Webber | Vice President | National Committee for Quality Assurance |
| Dr. Kepa Zubeldia | President | Claredi |



Consortium Education Work Group

| Name | Title | Organization Name |
|--------------------------------|---|---|
| Robert Davis (Co-Chair) | SPARCS Coordinator | New York State Department of Health |
| Dr. Walter Suarez (Co-Chair) | Executive Director | Minnesota Health Data Institute |
| Suzie Burke-Beebe (Vice-Chair) | Health Informatics Specialist | National Center for Health Statistics, Centers for Disease Control and Prevention |
| Hetty Khan (Secretary) | Health Informatics Specialist | National Center for Health Statistics, Centers for Disease Control and Prevention |
| Roxanne Andrews, PhD | Research Scientist | Agency for Healthcare Research and Quality |
| Tom Doremus | Information and Communications Specialist | Public Health Foundation |
| Doug Drabkowski | Director, Program Development | Association of Public Health Laboratories |
| Anne Elixhauser, PhD | | Agency for Healthcare Research and Quality |
| Marjorie Greenberg | Chief, Data Policy and Standards Staff | National Center for Health Statistics, Centers for Disease Control and Prevention |
| Neva Kaye | Director, Medicaid Managed Care Resource Center | National Academy for State Health Policy |
| Dr. Alana Knudson-Buresh | Senior Director, Public Health Information and Infrastructure | Association of State and Territorial Health Officials |
| Jon Lawniczak | Director, Government Relations | Coalition for Health Services Research |
| Denise Love | Executive Director | National Association of Health Data Organizations |
| Ron Mandersheid, PhD | Center for Mental Health Services | Substance Abuse and Mental Health Services Administration |
| Helen Regnery | Chief of the Executive Secretariat, HISSB | Centers for Disease Control and Prevention |
| Barbara Rudolph, PhD | Director | Bureau of Health Information, Wisconsin |
| Murray Sagsveen | | |
| Elliot Stone | Executive Director & CEO | Massachusetts Health Data Consortium |
| Ralph Timperi | Assistant Commissioner | Association of Public Health Laboratories |
| Michelle Williamson | Health Informatics Specialist | National Center for Health Statistics, Centers for Disease Control and Prevention |



The Lewin Group and National Association of Health Data Organizations Team

| Name | Title | Organization Name |
|--------------------|--------------------|---|
| Christina Andrews | Senior Manager | The Lewin Group |
| Carrie Chen | Project Manager | National Association of Health Data Organizations |
| Alexee Deep | Research Analyst | The Lewin Group |
| Denise Love | Executive Director | National Association of Health Data Organizations |
| Luis Paita, PhD | Deputy Director | National Association of Health Data Organizations |
| Caroline Steinberg | Vice President | The Lewin Group |
| Anne Yang | Research Analyst | The Lewin Group |



APPENDIX C: NAHDO CASE STUDIES

Case Studies for
Public Health Data Standards Education Strategy

Conducted by NAHDO for
The Lewin Group, Inc. and the National Center for Health Statistics,
Centers for Disease Control and Prevention

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BACKGROUND

The Public Health Data Standards Consortium's (the Consortium) current mission is to improve the health and health care of the population through improved information by expanding involvement in existing health data standards and content organizations and determining standards need through consultation with data leaders and data users.

The Consortium has identified educating the public health and the health services research communities about HIPAA and other health data standards issues as a primary goal. In this regard, the Consortium formed a standing Education Work Group to develop and implement an education strategy for the Consortium to communicate the need for public health databases to migrate to existing standards.

The Centers for Disease Control and Prevention provided funding for The Lewin Group to develop the "Public Health Data Standards Consortium Millennium Education Strategy" in collaboration with the Consortium's Education Work Group. This project includes two major streams of work: developing the education strategy; and identifying the relevant databases and data systems that support public health at the State level and the type of data standards that apply.

The Lewin Group subcontracted with The National Association of Health Data Organizations (NAHDO) to conduct case studies in support of this project. This report summarizes the findings from the case studies.

OBJECTIVES OF THE CASE STUDIES

The National Association of Health Data Organizations (NAHDO) was tasked to collaborate with The Lewin Group and the Consortium's Education Workgroup to evaluate the standards opportunities and challenges for a select number of key health data systems that are maintained by states. Information was collected through literature reviews and interviews and summarized for presentation to the Consortium.

STUDY DESIGN

NAHDO with the help of the project team performed the following tasks:

- Compiled a list of 59 public health data bases collected at the state level (See Appendix F);
- Developed selection criteria used to identify target data bases for further study;
- Identified six data systems and state and federal agency contacts representing these data systems;
- Made initial contact with persons knowledgeable about the data system;
- Described the project and the information needs;
- Scheduled interviews with the contact persons or arranged for response by email;
- Conducted phone interviews lasting up to two hours for each call;



- Reviewed relevant publication or agency's website as either supplemental or alternative sources of information;
- Transcribed and synthesized discussions with the contact persons and integrated information gathered from other sources.

Data systems were stratified according to the primary data base function (e.g., Vital Records, Encounter, Workforce, Registries, Surveillance/Infectious Disease, etc.) and criteria for selecting systems for further study were applied. These criteria included:

- Universality across states (high to low);
- National significance (e.g., Healthy People 2010, national surveys or data systems, etc.);
- Estimated number of data suppliers and data users.

The data systems identified for the case studies included:

- Vital Records;
- Immunization Registries;
- Cancer Registries;
- State Laboratory Reporting;
- Electronic Inpatient Discharge Reporting;
- Medicaid Encounter.

The interviews were structured to gather information needed to address the objectives of the project. The following questions were asked:

- What are the primary uses of [the data system]? What information needs does it support?
- How does data flow into [the data system] (i.e., describe the data collection process)?
- To what extent does [the data system] link with other data systems?
- How does data flow out of [the data system] (e.g., data dissemination)? What are the levels of reporting required (e.g., voluntary or mandatory)?
- What are the strengths of [the data system]?
- What would you like to see improved?
- Does [the data system] use or plan to use national standards for collecting, editing, using and disseminating the data?
- What are the benefits of adopting national standards?
- What are or were the barriers to adoption national standards (e.g., political, technical, other)? Who might oppose standards adoption?
- What solutions for overcoming these barriers do you see and how could the Public Health Data Standards Consortium help?



The rest of this report summarizes the findings for the data systems reviewed. The findings are based on information collected from individuals and published or online literature. The data systems reviewed and informants interviewed are listed below:

- Immunization Registries:
 - Dave Ross, All Kids Count;
 - Wu Xu, Ph.D., Director, Office of Health Care Statistics, and Administrator, Utah Statewide Immunization Information System (USIIS), Utah Department of Health;
 - Sue Salkowitz, National Immunization Registry Consultant.
- Cancer Registries:
 - Warren Williams, Health Scientist, National Program of Cancer Registries, CDC;
 - Mary Hutton, CDC;
 - Barry Gordon, Ph.D., Cnet Solutions, Berkley, CA;
 - Raymond K. Powell, Pennsylvania Department of Health.
- Vital Records System:
 - Pamela Akison, National Association of Public Health Statistics and Information Systems (NAPHSIS);
 - Barry Nangle, Director, Office of Vital Records and Health Statistics, Utah Department of Health;
 - Mary Anne Freedman, National Center for Health Statistics, CDC.
- Inpatient Electronic Submission:
 - Robert Davis, Director, NY SPARCS, New York State Department of Health.
- Laboratory Reporting:
 - Alok Mehta, Research Scientist, Wadsworth Center, New York State Department of Health.

SUMMARY OF FINDINGS

The national standards experiences of existing public health data systems demonstrate that there are clear benefits to public health when national standards are adopted. These benefits include:

- Administrative simplification in performing key public health functions;
- Improved and more timely information to inform decisions;
- Enhanced provider and patient satisfaction and health;



- National standards that meet the needs of all developers and achieve community-wide compatibility;
- Reduced information systems development cycles, saving time and money otherwise spent to solve data exchange issues in isolation;
- Capacity to share and exchange data to all legitimate stakeholders across programs and geographic locations;
- Improved quantity and quality of data reported to public health;
- Interoperability with private sector and other public health data systems;
- Strengthened business partnerships within and outside of public health;
- Commercial and market interest by the vendor community.

See Appendix D for a detailed discussion of the rationale for moving to data standards.

A few public health data systems can serve as models for national standards development and implementation. The North American Association of Central Cancer Registries (NAACCR), the Committee for Immunization Registry Standards and Electronic Transactions (CIRSET Workgroup), and the national Birth Certificate standards are examples of national consensus processes that bring together high-level subject matter experts to define common information standards and structures. National standards are an essential first step, but as these initiatives have discovered, not the only steps. Local implementation of these national standards is challenged due to economic, political and cultural barriers.

Challenges to Standards Adoption in Public Health

Economic

Most of today's public health information systems have developed independently. They were designed to meet local needs under differing regulatory structures and varying access policies. Translation or conversion to national standards from legacy systems is expensive and may be difficult.

Other barriers include:

- Limited commercial market for public health information applications;
- Inadequate or under-funded health information infrastructure development and maintenance;
- Difficulties in retention and recruitment of qualified public health information technology professionals.



Political and cultural

- Organizational ownership of existing systems may cause resistance to change these systems;
- Privacy and data ownership issues;
- Public health is underrepresented in the standards development organizations' process;
- Perception that public health is exempt from HIPAA.

Broad Solutions to Overcoming Challenges

Standards development and implementation makes sense, but in order to overcome resistance and complacency, the Consortium can facilitate and support a multi-pronged approach. The payoff to establishing integrated information systems is not immediate or trouble-free. Solutions to overcoming the challenges, which inform the Education Strategy, include:

Funding and technical assistance

- Federally-funded pilot data exchange projects to identify the best practices in implementation;
- Funding of cost-benefit studies to document the costs of systems implementation and administrative simplification savings;
- Establish a mechanism to facilitate technology transfer between states;
- Establish incentives for adopting national standards at the state and local level;
- Funding and technical assistance to support start-up development and sustain systems at the local level.

Forging new types of partnerships

- Recruitment and retention of private provider clinics and offices;
- More cross fertilization or communication between the clinical world with the financial/billing world;
- Federal-state-private sector collaboration in systems implementation;
- Nurture a market for private public health information solutions.

Education and outreach

- Education of all stakeholders in the public and private sectors about the value of implementing national standards;
- Representation of public health to broad audiences;
- Public health leadership and training;



- Recruit and retain private sector providers.

Breakthrough Opportunities

The Consortium is implementing solutions to overcome challenges at an opportune time. Three major forces transforming the health care industry and public health include: The Administrative Provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the National Electronic Disease Surveillance System (NEDSS) and the widespread adoption of Internet technology by all sectors of the industry.

HIPAA

HIPAA imposes the technical infrastructure essential for standardization and national data systems development and defines a national process for the transaction of health care data. While much of public health might be exempt from the insurance transaction components of HIPAA, private data systems which supply the data to public health are not. Further, the process for promulgating national standards and HIPAA's focus on enabling technologies around privacy and security benefit public health data systems directly.

National Electronic Disease Surveillance System (NEDSS)

Since 1995, the CDC has been working to develop, implement, and evaluate the NEDSS, electronic information systems that will include data standards, an Internet-based communications infrastructure, and policy-level agreements on data access and sharing. NEDSS will eventually automatically gather data from a variety of sources on a real-time bases. In 1999, CDC funded the Health Alert Network (HAN) and in 2000 increased funding for HAN and NEDSS. HAN will use the Internet as a backbone for communicating surveillance and other information related to a bioterrorist event. NEDSS implementation and funding could serve as a catalyst to forge new partnerships and improve the technical capacity and assistance across public health data systems.

Internet

The Internet is lowering the barriers to access of public health information by private physicians. The single greatest barrier to private sector participation in public health data systems is the recruitment and retention of physicians. Physicians are reluctant to adopt new computing platforms and absorb the cost of implementing new systems. The World Wide Web will provide the breakthrough to engaging the individual practitioner in his office. Over 90 percent of individual physicians now have access to the Internet. Web-based interfaces are cheaper than network solutions and enable doctors to access essential public health information on line.

The Consortium should incorporate HIPAA, NEDSS and the Internet into all of its activities and partnerships.



Potential Directions for the Public Health Data Standards Consortium

The Consortium is in a position to address these challenges and opportunities. The Consortium transcends agencies and data systems and includes federal and state representatives, is not constrained by political or funding policies, and can allow its mission and goals to be flexible and evolve with the industry. Drawing from these strengths, the Consortium can and should create a vision for public health information systems and bring diverse groups together to shape this vision and address common issues.

In shaping this vision, the Consortium would be advised to:

- Recognize that public health systems are unique and vary in readiness for Consortium intervention and support;
- Clearly define its mission and role in light of the evolving environment;
- Identify its target audience(s) and the related clinical content areas;
- Support the development of a national standards process.

The Consortium is in a unique position to advance standards implementation at the local and state levels. Based on the results of the case studies, NAHDO recommends the following Consortium actions:

- Secure funding and ongoing staff support for Consortium efforts;
- Serve as a clearinghouse of national standards initiatives;
- Continue to convene experts and leaders, serving as a bridge across sectors and programs;
- Initiate reconciliation or coordination of clinical standards and billing transaction standards efforts and issues;
- Establish mechanisms for reaching out to the private sector to garner support.

Each of these actions can be mapped to specific educational strategies.

As data systems evolve, sharing and exchanging data between all trading partners with other states becomes essential. Achieving common compatibility across states that meets the needs of all developers is a daunting task, but well worth the effort. States that have blueprints in the form of minimal functional and core standards save time and money in the development cycle—money that otherwise would be spent to solve data exchange issues in isolation.



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Exhibit C-1: Summary Matrix Of Findings From Case Studies Of Data Systems

Draft

| IMMUNIZATION REGISTRIES (IR) | CANCER REGISTRIES (CR) | VITAL RECORDS SYSTEMS (VR) | LABORATORY REPORTING SYSTEMS (LAB) | MEDICAID ENCOUNTER DATA | INPATIENT DISCHARGE ELECTRONIC REPORTING |
|---|--|--|--|--|---|
| <p>1. What are the primary uses of [the data system]? What information needs do they support?</p> | | | | | |
| <p>Primary Goals of IR's are:</p> <ul style="list-style-type: none"> • Improve immunization rates; • Tracking immunizations administered to children. <p>IR's typically provide information support for the following administrative tasks:</p> <ul style="list-style-type: none"> • Reminder and recall; • Forecasting need for immunizations; • Vaccine management; • Immunization status assessment; • Generation of reports; • Inventory tracking. <p>Other information needs that can be met by data from IR are as follows:</p> <ul style="list-style-type: none"> • Calculation of immunization rates for performance reporting (e.g., HEDIS); • Public health research. | <p>Statewide cancer registries are patient and disease-oriented databases of information about cases of cancer.</p> <ul style="list-style-type: none"> • Health statistics; • Epidemiologic and surveillance information about the incidence and treatment of cancer; • Staging of cancer to influence treatment choice by clinicians; • Time trends and risk factor indexing to evaluate treatment effectiveness. | <p>There are two primary purposes or uses of Vital Records data (Birth Certificate and Death Certificates): 1) legal purposes and 2) health statistics.</p> <p>Certificates support the public's source of information to document births and deaths for various legal requirements.</p> <p>Health statistics encompasses the following uses:</p> <ul style="list-style-type: none"> • Planning and evaluation of public health programs; • Health education, community assessment and public statistics; • Health research. <p>A birth or death event may trigger other public health program applications, such as the immunization registry process.</p> | <p>Laboratory data for local, state, and federal health agencies support:</p> <ul style="list-style-type: none"> • Identification of cases for investigation and follow-up; • Estimation of the magnitude of a health problem, including trends in incidence and distribution; • Detection of outbreaks or epidemics; • Evaluation of control and prevention intervention; • Monitoring of changes in infectious agents; • Epidemiologic and laboratory research; • Detection of changes in health practice; • Facilitation of planning. | <p>Medicaid encounter data (fee for service [FFS] or managed care [MC] encounter data) primarily support the operations of a state Medicaid program, including:</p> <ul style="list-style-type: none"> • Administration of benefits; • Rate setting and provider contracting; • Quality assurance monitoring; • Fraud and abuse. <p>Because Medicaid enrollees are also recipients of other state services, Medicaid data support other program and public health information needs. Linking of MMIS data provides enhanced information to:</p> <ul style="list-style-type: none"> • Immunization registries; • Outreach/case management for prenatal care. <p>Beginning Jan. 1999, under the Balanced Budget Amendment (BBA), Medicaid agencies must report encounter data to HCFA.</p> | <p>Approximately 44 states collect inpatient hospital discharge data and a growing number of states are expanding data collection to include non-inpatient health services data.</p> <p>Hospital discharge data supports:</p> <ul style="list-style-type: none"> • Research – internal and external information requests; • In New York State, the hospital discharge database, SPARCS, has been used to calculate the hospital reimbursement rates; • Hospital market analysis; • Data source for many commercial query engines. |



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|---|---|---|--|--|---|
| 2. How does data flow into [the data system] (i.e., describe the data collection process)? | | | | | |
| <p>The CDC has defined the core data elements for an immunization registry and these were reviewed and approved by the National Vaccine Advisory Committee (NVAC). The minimum data elements are incorporated into the HL7 immunization transaction standard.</p> <p>Variations in the process are driven by a number of factors:</p> <ul style="list-style-type: none"> • Which transactions and functions described above are embedded in the system; • Technical capabilities of the host of the registry; • The sources of data. Data sources may vary and include one or a combination of the following: <ul style="list-style-type: none"> – Private offices and clinics – Health plans – Public health clinics – Birth certificates – WIC program – Foster care program. • Existence of a pass-through agency; • The frequency in which the data sources transmit the records; • Format and mode of submission: | <ul style="list-style-type: none"> • A first report of a cancer is usually identified from a pathology or operative report; • A tumor registrar identifies the cases, manually abstracts information into an electronic abstract and transmits the records to the state Central Cancer registry or regional registries; • State or regional registries handle duplicates and create files that are reported to the state registry; • The Central Cancer registry in turn transmits the information to national data aggregators (National Cancer Institute (NCI), American Cancer Society (ACS), and North American Association of Central Cancer Registries (NAACCR)); • The record is continuously updated with additional clinical information. | <p>Birth Certificates:</p> <p>The source of information is the medical record, submitted mostly by hospital providers. Across the country, there may be some variation, but most vital record data are transmitted to health departments in batch and flat file format.</p> <p>Death Certificates:</p> <p>Death Certificates are submitted mostly by funeral directors. States vary in the Death Certificate process and the data flow. In Utah, these death certificates are not reported to the state health department directly but are reported to the local health departments. Local health departments then report the death data to the state.</p> <p>The Death Record master file is used primarily for statistical purposes. The Death Certificate has 80 fields.</p> | <ul style="list-style-type: none"> • Billing, admission, pharmacy, and patient demographic information are stored in separate hospital systems; • Local codes must be translated to standard codes. Hospitals may have a separate interface engine to map the code from a local to a national code. These translators, though expensive to build, can be used to send an outbound message to public health as well as integrate the hospital's own various data systems; • Laboratories and clinicians are required to report various diseases to multiple jurisdictions in a variety of formats. | <p>Medicaid-participating providers submit claims for services or managed care contractors are required to report encounters to the Medicaid agency.</p> | <ul style="list-style-type: none"> • Data comes into the NY State system from providers or their agents in every way except on paper. That includes tape, cartridge, diskette, and of course electronically through our secured internet process; • The results of each submission are communicated back to the submitter using the same mode of transmission; • Electronic submissions are returned electronically. Tape, cartridge, and diskette submissions are returned in hard copy; • Most providers submit on a monthly basis. The NY State system does not limit the frequency of submissions from providers. |



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|---|------------------------|----------------------------|------------------------------------|-------------------------|--|
| <ul style="list-style-type: none"> – Periodic batch file submission on storage media – Batch mode online (most common) – On-line point-of-service (real time) transmission through an electronic data interchange. | | | | | |



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|---|---|---|--|---|--|
| 3. To what extent does [the data system] link to other data systems? | | | | | |
| <p>Information sources described ongoing or intended linkage with the following data systems:</p> <ul style="list-style-type: none"> • Birth and death records; • Women, Infant and Children (WIC) records; • HMO eligibility and Medicaid eligibility files for contract issues and HEDIS or other performance measurement reporting; • VacMan (Vaccine ordering system); • Adverse events reporting (VARs) for immunization reaction tracking. <p>Linkage with reporting systems relevant to children:</p> <ul style="list-style-type: none"> • Lead screening • Perinatal screening • Asthma reporting | <p>State registries merge the regional files and link with other state databases (driver's license, vital records) to update and validate the information, which is sent back to the regional registries.</p> <p>State health department-based registries consolidate data from multiple sources to assemble an overall record of diagnosis, treatment, and outcome for each case.</p> <p>Linkages with reporting systems relevant to children often include:</p> <ul style="list-style-type: none"> • Lead screening • Perinatal screening • Asthma reporting | <p>Birth Certificate:</p> <p>Birth records are linked with data systems of other programs mainly for special projects. E.g., the WIC program, Medicaid eligibility files, hospital discharge data, and immunization registry.</p> <p>In Utah, systematic linkage occurs with the Immunization Registry. Linkage also occurs for special projects (such as WIC and Medicaid studies) but not on a routine basis.</p> <p>Death Records:</p> <p>The Social Security Administration (SSA) is supporting the development of the Electronic Death Record as a way to identify deaths and link these to benefits administration.</p> | <p>Linkages with other agencies and organizations within and across public health, federal agencies, professional organizations, state legislatures, and epidemiology programs are encouraged.</p> | <p>Though policies and practices vary by state, Medicaid data often are linked to major public health data sets and private data systems:</p> <ul style="list-style-type: none"> • Immunization Registries; • Vital Records; • MCH programs; • HMO enrollment files (for plan-level HEDIS rates). | <p>The NY SPARCS system links with several data systems, e.g., Department of Health (DOH) cancer, surveillance, emergency medical services, maternal and child health, and vital statistics systems.</p> <p>There is also linkage with external purchasers of the SPARCS data. The NY State Data Protection Review Board tightly controls external linkages. For example, the composite Unique Personal Identifier is never released in its reported form. It is encrypted, which limits purchasers' ability to link with other data sources from outside DOH.</p> |



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|--|---|---|---|--|---|
| <p>4. How does data flow out of [the data system] (data dissemination)? What are the levels of reporting required?</p> | | | | | |
| <p>Data collection processes for registries are driven by several factors:</p> <ul style="list-style-type: none"> • Which transactions and functions are embedded in the system; • Sources of data (e.g. clinic, WIC, vital records, etc). • Frequency of data transmissions <p>Data submissions and outflows can occur in hard copy/faxed reports, but periodic batch submissions via modem or media are likely the most common at present.</p> <p>Submissions also occur through electronic transfer using HL7 flat file interfaces. Usually, a system will use a custom or flat-file format.</p> <p>Typical outflows from IR’s include the following:</p> <ul style="list-style-type: none"> • Vaccine administration and inventory reports; • Vaccine for Children reports; • Assessment of Coverage (CASA) protocol and/or community-based protocol reports; • Reminders and recalls; • HEDIS data reporting; • Administrative reports which | <p>Data are forwarded from state and/or regional registries to national systems:</p> <ul style="list-style-type: none"> • CDC surveillance data • National Cancer Institute’s SEER data system • North American Association of Central Cancer Registries (NAACCR). <p>Hospital-level department data sources report across systems and in one major teaching hospital, over 30 different systems can report cancer-related data to registries.</p> | <p>Birth Certificates: Medicaid eligibility workers and other public health programs with legitimate need can access the Birth Certificate data manually to document dates of birth for welfare clients and other authorized uses.</p> <p>Death Certificates: While dissemination and access differ dramatically by State, in Utah, agencies authorized to access death files (e.g., courts) receive an electronic batch update monthly and use these data to flag deaths of clients in their systems.</p> <p>Aggregate statistical dissemination of both data types occur through annual and special publications and in some states through web query systems or on-line access of aggregate statistics.</p> <p>Utah reports a standard file of both data sets to the National Center for Health Statistics (NCHS), as do most states using the standard format required by NCHS.</p> | <p>There is a great deal of variability among submitting laboratories and receiving public health agencies. The data flow process varies depending on the state where the reporting occurs.</p> <p>In twelve states that responded to a survey about their data flow process, paper-based reporting systems have a mechanism requiring laboratories to report data to a local or state public health agency depending on the disease.</p> | <p>State Medicaid agencies vary in their data dissemination and data sharing policies.</p> <p>HCFA requires Medicaid agencies to submit standard reports, for example:</p> <ul style="list-style-type: none"> • SURS (States Utilization and Review Subsystems) • Encounter data (FFS/MC). | <p>Most discharge data systems publish aggregated data in the form of annual reports.</p> <p>Many discharge data systems are making the data available through internet query systems.</p> <p>In New York, data release is under tight control of the Data Protection Review Board.</p> |



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| <p>vary by state.</p> <p>Other outflows:</p> <ul style="list-style-type: none">• Response to telephone inquiries or batch inquiries in hard copy by physicians;• Online access (through the web or client-server setup) by authorized individuals (own patients' records only). | | | | | |
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|--|--|---|---|---|---|
| 5. What are the strengths of [the data system]? | | | | | |
| <p>The population-based nature of the registries, which link with other health data bases to provide important health status information about target populations.</p> <p>Informants identified the following as important features of IR’s in general or their particular system:</p> <ul style="list-style-type: none"> • The interface and integration with the private sector; • The regional aspect of registries; • The de-duplication process; • Web application; • Calculation of HEDIS immunization rates for statewide and sub-populations. | <p>The clinical detail and complexity make this an interesting data system.</p> <ul style="list-style-type: none"> • State registries provide important clinical data on episodes and outcomes of care in a uniform manner; • Its link with the clinical and cancer world is strong—clinicians use the data to evaluate clinical effectiveness and the data support staging and indexing of cancer diagnoses across the country; • Data quality using systems of edits and quality control procedures have evolved over time and new procedures are routinely incorporated to further improve data. | <p>The data are population-based and provide essential information for public health management.</p> <p>In Utah, the in-house vital records system is flexible and it is not dependent on a vendor system. It can be modified to meet changing information needs quickly and cheaply.</p> | <p>The Electronic Lab Report will receive all results; it is not limited to positive results.</p> | <p>Medicaid encounter data are used to administer the Medicaid program, but also offer a rich source of information for other public health programs:</p> <ul style="list-style-type: none"> • EPSDT (periodic child health screening exams); • Identification of case management clients; • Linkages with other major public health data sets; • Database of participating providers/physicians. | <p>Discharge data systems provide a source of health utilization data for every hospitalization:</p> <ul style="list-style-type: none"> • Statewide • All patient, all payer encounters, including self and uninsured patients. <p>Many states adopt a Uniform Billing 92 or administrative billing format that reduces the amount of clinical detail but reduces provider burden and cost.</p> |



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|---|---|---|---|--|--|
| 6. What would you like to see improved? | | | | | |
| <ul style="list-style-type: none"> • Provider Participation: Informants identified the need to make it easier for providers to report the data. Making the operational aspects of provider reporting smoother and helping providers see the value in reporting are essential to success. • Improve linkages: Address problems with linkage, including record identification/duplication issues arising from differences between birth names and real names. Some state confidentiality laws block portions of the birth record from Irs, which limits matching and reduces the accuracy of the population base. | <ul style="list-style-type: none"> • To be able to collect clinically-detailed data in a more timely and complete fashion; • Structured reporting standards and secure pipelines to transmit data and information; • Improved outcomes and clinical evaluation applications. | <ul style="list-style-type: none"> • Integrated more fully with other related public health data systems; • Web access for on-line reporting and movement away from a client-server environment; • Common intake standards across public programs; • A hospital or enterprise-level early identifier (pre-medical record issue) much like a Master Patient Index across programs and providers; • Improved training and editing standards and protocols. | <ul style="list-style-type: none"> • Protection of patient privacy and confidentiality; • Improved linkage with the state epidemiological programs; • Linkages and interfaces of lab data beyond infectious diseases; • Improved data modeling training and resources at the state level to build systems to address unique and complex functions (e.g., microbiology applications); • Dynamic and flexible systems to adjust to changing reporting requirements; • System transparency to both the producers and consumers of information • Recruitment and retention of qualified staff—ability to compete more effectively with the private sector; • Processes in place to apply national standards to the local-state level. National standards are a start, but not precise. There is interpretation and coding/translating standards which is difficult; • Training and outreach to convince lab directors, technical people, and users at the program level to get their buy in and convey benefits. | <p>Data sharing with public health is facilitated by a model Data Sharing Agreement developed by HCFA/CDC/HRSA.</p> <p>A unique patient identifier would reduce the cost and complexity of linking Medicaid data with other public health systems (e.g., immunization registries). While public health programs may use the patient’s Social Security number, Medicaid does not.</p> <p>The Medicaid agency and culture are more oriented to health care finance and beneficiary services than to data sharing. Conversely, health departments are in the health information business, more clinically oriented and accustomed to data sharing.</p> <p>Since Medicaid is a big budgetary player in states, it is important to promote a culture that actively supports the provision of information for public health and research purposes.</p> | <p>The goal of the New York State DOH SPARCS electronic data is that it is used by one hundred percent of all hospitals submitting data to the system. (Current usage is about 70 percent of submitting hospitals.)</p> <p>National standardization of unique state fields and the development of standard definitions and formats for these fields will be accomplished through a national data standards implementation guide.</p> |



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|--|--|--|---|--|--|
| 7. Does [the data system] use or plan to use national standards for collecting, editing, using, and disseminating the data? | | | | | |
| <p>The CDC has defined the core data elements for an immunization registry and these were reviewed and approved by the National Vaccine Advisory Committee (NVAC). The minimum data elements are incorporated into the HL7 immunization transaction standard.</p> <p>The core data elements, identified as “desirable by registries” are specified using HL7 standards in an implementation guide, developed by consensus of registries that were ready to implement HL7 messaging.</p> <p>Minimum functional standards of immunization registries have been approved by a consensus of over 75 percent of immunization program managers and an evaluation process is under development to allow greater accountability in the degree to which registries implement the national standards as recommended by NVAC.</p> | <p>Adherence to NAACCR standards by states is voluntary, but many hospitals participate in the accreditation program for cancer hospitals maintained by the American College of Surgeons (AcoS). SEER and NPCR require the collection of standard data items and codes that are consistent with NAACCR standards.</p> <p>Registries are required to export or import using a standard record layout defined by NAACCR and NAACCR also defines edit protocols.</p> <p>NAACCR has a process for developing and annually updating consensus standards and is working with HL-7 and CDC to help registries tap into the clinical information streams already occurring in health systems.</p> <p>A data dictionary, implementation guide, application of LOINC codes, and evaluation of SNOMED vocabulary is underway to facilitate implementation of HL-7 standards by Cancer Registries.</p> <p>Edit rules are portable and are used by most vendors directly. The AcoS uses the same edit</p> | <p>The US Standard Certificate developed by NAPHSIS and NCHS defines a core national data set with standards for coding structures, collection, and editing protocols.</p> | <p>Since 1995, the CDC has been developing and implementing the National Electronic Disease Surveillance System (NEDSS)—electronic information systems that automatically gather health data from a variety of sources on a real-time basis.</p> <p>The Public Health Conceptual Data Model is the foundation of NEDSS and there is intent to integrate this with other clinical data models, such as HL-7.</p> | <p>X12N, UB-92 are the major national standards that will apply to Medicaid systems. The core claims/encounter data set will drive the structure of provider to Medicaid transactions.</p> <p>Local codes, which proliferated as state legislatures expanded the scope of services for Medicaid recipients, will disappear under HIPAA. Local codes permitted non-physician providers to bill for unique treatments and services delivered to Medicaid clients (e.g., transportation, medical equipment, case management).</p> <p>The national standardization of local Medicaid payer codes is a major undertaking.</p> | <p>Most discharge data system adopt UB-92 standards and will likely progress to X12N 837 institutional standards as provider capacity to report electronically increases.</p> <p>State unique fields related to policy and public health importance are not standardized. States vary in how and what they collect outside of the UB92. A national effort to develop implementation standards for public health and research data needs is underway.</p> |



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| | <p>rules.</p> <p>The national cancer standards process coordinates efforts between the AcoS, NCI, and NAACCR registries which all work together. The data applications between the players differ, but collaboration occurs.</p> <p>Data entry serves all state and national data flows.</p> <p>Standards for disease staging are defined by AcoS, NAACCR and registries set the standards for risk factor indexing, and all work to define other national standards.</p> <p>Respondent reports that having 3 major data systems/flows is a good thing, leaving room for innovation and helping to parse the complexity out to various players.</p> | | | | |
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|---|--|--|---|---|---|
| 8. What are the benefits to adopting national standards? | | | | | |
| <ul style="list-style-type: none"> Vendors are more likely to invest in development of tools to collect and use the information; Reduces reporting and processing burden; Improves the quality of the data; Improved funding opportunities for all players because of the interoperability with other industry systems. Besides two-way messaging and updates, moving to an HL-7 environment will accommodate the immunization information needed to administer the programs. E.g., the current claims transaction is sufficient for many current transactions in the billing environment, but it cannot handle the immunization history. | <ul style="list-style-type: none"> Increased interoperability among providers throughout the health care system; Greater flexibility and efficiency in capturing data; Real-time queries of detailed information; Standard vocabularies and clinical messaging standards will provide a future for robust information retrieval and high data quality control; Consistency of data among states to compare rates and identify regional and national cancer trends; Incorporation of programs written to edit and improve data quality; When national standards are used, multi-level reporting without redundant or conflicting information needs benefits all players (e.g., American College of Surgeons, state registries, regional registries, CDC, and NCI); Duplicates are readily identified, merging of regional files with other data such as driver's license and vital records. | <ul style="list-style-type: none"> States receive financial incentives from NCHS to adopt existing standards; Comparability in data aggregation. | <ul style="list-style-type: none"> Funding from CDC's NEDSS efforts; Integration of multiple health labs which were previously independent permits identification of patient movement across the system and has reduced report preparation time from weeks to instant query; Specimen tracking and reporting is streamlined and automated. Data are more timely and the exchange of data with epidemiology is much more efficient. | <p>Administrative Simplification and compliance with HIPAA regulations.</p> | <ul style="list-style-type: none"> Support from the provider community—the data suppliers; Relations with key players in the industry continue to improve; The quantity and the quality of the data continue to improve. |



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|---|---|---|---|--|---|
| <p>9. What are/were the barriers to adopting national standards (political, technical, and other)? Who might oppose?</p> | | | | | |
| <ul style="list-style-type: none"> • The informatics world is more closely aligned to the claims/billing world than to the clinical or public health world; • Deployment - the user and receiver must negotiate the use of national standards between them; • <u>Economic barriers</u>: The private sector pays for what their clients want. In public health, there has not been a strong commercial constituency or driver for systems development; • <u>Public Health Attitudes</u>: Public health may believe that their systems are exempt from the HIPAA privacy and confidentiality rules. Public health will eventually realize that they are the business partners for providers and their clearinghouses and vendors. Public health will need to articulate their positions with the private sector in mutually-understandable terms. • Other barriers: • “Non-compliant” legacy systems; • Providers’ clinical and billing systems may not interface; | <p>Though a national standards-setting process is in place through NACCR, the conversion to HL-7 standards transactions will pose challenges.</p> <p>Cancer registries are complex and the national standards process under HIPAA will not address the complexity and clinical detail necessary for cancer registry applications.</p> <p>The HIPAA process is designed for administrative simplification. Applying the national standards process to define national clinical standards and associated vocabularies and codes for these standards will yield more robust information. The challenge is overcoming barriers and challenges to adoption of such standards, including:</p> <ul style="list-style-type: none"> • Providers readiness: providers have been slow to transition to HL-7 and few have the capacity to implement national registry standards; • Implementation of national HL-7 standards is expensive and potentially | <ul style="list-style-type: none"> • Changing to HL-7 may be challenging for birth certificate systems; • Complacency—most Registrars are content with their current systems; • Few death certificates are electronic. | <ul style="list-style-type: none"> • State laboratory directors have invested in existing systems and technical staff who understand the existing system. Independence and autonomous systems staff feel a certain “freedom” to their autonomy; • Unrealistic expectations as to what standards offer may lead to frustration and even resistance; • Parallel systems may continue until the new way is “proven” to work. This causes duplication of effort and leads to frustration by staff; • Culture change issues: understaffed agencies and variable capacity of local and state health department to absorb and use more data; • Concerns about data quality during the transition from existing to electronic laboratory reporting; • Regulatory obstacles and concerns about security; • Small operations may be dependent on vendors for incorporating standards which is expensive. | <p>Medicaid agencies are relying on managed care organizations to provide comprehensive or special (carved-out services) to enrolled populations. Under managed care contracts, the individual encounters may disappear.</p> <p>Local codes will need to migrate to national standards and this will be an expensive undertaking for the MMIS systems.</p> | <p>State Medicaid programs that might not be capable of accepting national standards formats from industry, though with HIPAA this may be a moot issue.</p> |



Exhibit C-1: Summary Matrix Of Findings From Case Studies Of Data Systems

Draft

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| <ul style="list-style-type: none"> • Implementation of reporting systems at the provider level pose technical and financial challenges • Training needs: Translating local and state codes to national standards will require that personnel have the necessary skills to understand their own systems as well as national standards. | <p>disruptive to current processes;</p> <ul style="list-style-type: none"> • Registry Directors are familiar and comfortable with flat file structures; • Many registry software developers lack the interfaces and experience to implement electronic data interchange; • Uncertainty about who will pay for and provide the adequate support, training, education, and capacity building to make this happen; • Messaging environments are new to public health; • Some registry personnel are concerned that automation might displace their roles; • Mainframe/legacy systems still rule in some registries; • Laboratories that use small vendors will keep their own systems (cost issue); • Privacy and data ownership issues must be negotiated; • State regulations and statutes vary and may require revision when national standards are adopted; • Manuals and other documentation and software code must be revised. To ensure that revisions are correct, an audit of data is also necessary. | | | | |
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Exhibit C-1: Summary Matrix Of Findings From Case Studies Of Data Systems

Draft

| IMMUNIZATION REGISTRIES (IR) | CANCER REGISTRIES (CR) | VITAL RECORDS SYSTEMS (VR) | LABORATORY REPORTING SYSTEMS (LAB) | MEDICAID ENCOUNTER DATA | INPATIENT DISCHARGE ELECTRONIC REPORTING |
|--|---|--|---|---|--|
| 10. What solutions for overcoming these barriers do you see and how could the Public Health Data Standards Consortium help? | | | | | |
| <p>Solutions include:</p> <ul style="list-style-type: none"> • Federal funding has supported the development of immunization registries; • Training and changing the public health culture and the private health care culture are long-term strategies. Instilling public health perspectives to the private health care system will be essential. • Public health, in order to make the business case, must have an understanding of business, their information systems, and be able to market the message in their language; • PHDSC can help public health shift its focus from developing software solutions to better articulating public health business and information needs to the marketplace and then let them develop tools that in turn serve public health; • Opportunities around HIPAA may include the privacy/security provisions that promote the development of enabling technologies to make the reporting and access of data via the Internet safer; • States will have to work | <p>Strategies NAACCR has identified for converting to national HL-7 standards for registries:</p> <ul style="list-style-type: none"> • Application of LOINC codes; • Implementation Guide (underway); • Evaluation of SNOMED vocabulary; • Testing of specifications in implementation guide; • Work with vendors to develop/adapt software. <p>The danger of oversimplification in national standards setting is a major concern. When addressing national standards for complex systems like Cancer Registries identifying information needs and dissecting them finely at the front end of the standards process for aggregating up at the user end is preferred.</p> <p>Needed education of users and collectors:</p> <ul style="list-style-type: none"> • About advantages and disadvantages of standardized messaging; • How current jobs may be affected and enhanced through automation • Case studies based on the success of the X12/HL-7 Claims Attachment Workgroup and other clinical reporting projects (NEDSS, DEEDS, NIP, ELR); | <ul style="list-style-type: none"> • The 2003 Birth Certificate will expand provider reporting. The provider community may take this opportunity to implement the electronic reporting of Birth Certificate data; • NEDSS could push BC integration with other public health systems and promote data sharing and electronic messaging— putting it all together. | <ul style="list-style-type: none"> • Funding helps justify certain changes and activities, reducing resistance. Helps get the “buy-in” needed to make changes; • Health Alert Network and NEDSS funding will be helpful in shaping information systems; • Concerted efforts to enhance IT infrastructure development at all levels must be ongoing; • Technical capacity to map incoming lab data to various databases and appropriate linkages; • Commitment at the top may be important, but sustaining change over the long-haul, middle management/merit employees make it happen; • Training of public health IT staff will facilitate local implementation; • Interface solutions and interaction with industry and other business partners; • Targeting of early, small successes will bring people on board to make the harder, larger changes. • National definition of | <ul style="list-style-type: none"> • The X12N Medicaid caucus has been a useful forum for promoting the national standardization of local codes and assisting Medicaid agencies with HIPAA implementation; • Medicaid and public health can work in tandem to assure the unique needs of Medicaid and public health programs are represented in the national standards processes defined under HIPAA. | <ul style="list-style-type: none"> • Funding and support for a national effort to identify priority non-billing, state fields important to policy development, research, and public health assessment; • Development of standards for state-unique fields and the national coordination of education efforts across states to adopt these standards. |



Exhibit C-1: Summary Matrix Of Findings From Case Studies Of Data Systems

Draft

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| <p>together to build regional system networks/linkage and share data. The link with the private sector will force connections with hospitals, clinics, and physician offices as well as managed care organizations.</p> | <ul style="list-style-type: none"> • Mapping between the current NAACCR Data Dictionary and standard vocabularies as used in HL-7 transactions. <p>Needed capacity building efforts:</p> <ul style="list-style-type: none"> • Establishing HL-7 interfaces are expensive; • Conducting pilot implementation projects and document lessons learned, sharing these with other registries; • Building onto existing messages so vendors can turn additional ones on at low costs; • Incentives for public health and providers to invest the time and resources to make a consistent public health reporting system happen; • Partnering with the private sector, communicate standards to vendors, and use regulatory tools to encourage movement to standards. • Adopting certain clinical national standards, and the vocabularies and code sets used within those standards, may support the harvesting of a much greater degree of clinical detail that is currently obtained with the registry datasets alone. <p>Possible Consortium activities:</p> <ul style="list-style-type: none"> • Identify target audiences and the clinical content of interest to guide priorities and strategies. | | <p>unified electronic reporting approaches, using standard HL-7 messages;</p> <ul style="list-style-type: none"> • Generic HL-7 readers to accommodate state to state variation; • LOINC and SNOMED coding conventions for lab environments. | | |
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APPENDIX D: RATIONALE FOR MOVING TO DATA STANDARDS

WHY SHOULD PUBLIC HEALTH ADOPT HIPAA AND OTHER DATA STANDARDS?

Recent national attention to data standards, stimulated by the federal Administrative Simplification standards mandate of The Health Insurance Portability and Accountability Act (HIPAA), will have important implications for the practice of public health and health services research. Although these standards are focused on insurance transactions and not mandated for most public health related data transactions, the health care encounter triggers the reporting of a majority of public health data. Failure to adopt these standards will make it more difficult to communicate with the clinical care delivery system especially for those databases that rely heavily on administrative data (e.g., hospital discharge data sets).

HIPAA also requires adoption of standards for claims attachments and investigation of standards for the electronic medical record. The claims attachment represents the bridge between administrative/financial information and clinical information. The medical record is a primary source of data for disease registries (e.g., tumor, reportable disease databases), trauma registries, vital statistics, immunization registries, and other public health databases. The adoption of clinical data standards for both care delivery and public health will create the ability for electronic interchange of data which is now primarily paper-based. Other features of HIPAA, such as the development of unique identifiers as well as standards to protect the privacy and security of data, will also have an impact on how public health data are collected, transmitted, stored, and used.

Unless serving as providers or insurers, public health organizations face no clear federal mandate to adopt HIPAA standards, and the rationale for such action has not been widely communicated. With some exceptions, the public health and health services research communities have not actively participated in national standards discussions or implemented national standards at the state or local level. The purpose of this document is to provide a compelling rationale for decision makers and funders at the federal and state level and in the private sector to support standards related efforts for public health and health services research. Key messages presented here include:

- The business case supports data standards in public health.
- An electronic environment is emerging in the health sector; public health risks being left out.
- Data standards support integration.
- Not adopting standards places public health data and relationships at risk.



THE BUSINESS CASE SUPPORTS DATA STANDARDS IN PUBLIC HEALTH

The private sector's primary motivation to create standards for electronic data interchange (EDI) in the early 1990's was to lower administrative costs and improve operations. Data standards decrease the time and money associated with administrative transactions and improves the quality, quantity, and accessibility of information. Public health can expect to achieve similar benefits.

Standardization increases efficiency on both sides of the data transaction.

For the public health and health services research communities standardization will allow faster processing of and response to data received, reduction of errors, and consistent reporting. For providers, standards across reporting jurisdictions will decrease the burden associated with reporting data to public health.

In the state of Illinois, electronic transmission of laboratory data from local providers to the state according to HL-7 standards has eliminated unnecessary steps in the reporting process and decreased reporting time.

Consolidation in the health care industry means that many laboratory and hospital systems serve multiple states. Different state reporting requirements and systems make it difficult for these entities to create their own systems to support the reporting of public health information. Standards across jurisdictions would decrease the burden on public health's information trading partners.

“Approximately 40,000 test results have to be reported...each month. These reports are sent to 300 different state and local health agencies, each of which has its own reporting requirements. The majority of these reports are sent on paper....Even when states use electronic interfaces...they do not use them consistently across programs, which can make the electronic process cumbersome and complicated...”

Rich Aranowski, SmithKline Beecham Clinical Laboratories from Electronic Reporting of Laboratory Information for Public Health, January 7-8 1999, Summary of Meeting Proceedings

Standardization reduces costs.

The benefits of standards for EDI are expected to outweigh the hardware, software and training costs necessary for implementation. Electronic submission of claims for reimbursable public health (including Medicaid) services will reduce costs for public health agencies. Electronic interchange of other data will produce efficiencies as well.



- In its 1993 report, the Workgroup for Electronic Data Interchange (WEDI) projected a savings to the health care industry of \$8.3 billion annually if full EDI is implemented.¹⁶
- The Utah Health Information Network (UHIN) estimates the transition from paper to EDI claims submission has yielded annual savings of \$75 to \$250 million just for hospital care alone.¹⁷
- Standardization experiences of New York State Department of Public Health's hospital discharge system has reduced provider and industry reporting burden, thus improved the quantity and quality of data reported to public health.

The Massachusetts Health Data Consortium highlights some of the benefits of EDI:

- *Standard interfaces lower costs for software development and maintenance;*
- *Standards minimize data translation costs;*
- *Administrative overhead costs are reduced;*
- *Standard electronic transactions help prevent fraud and abuse*

Data standards support the electronic flow of information.

The transition from paper-based to electronic transmission of public health data requires national data standards. Electronic data transmission in public health will increase the speed of data reporting and support a more rapid response to public health threats. Automation improves compliance with reporting requirements and completeness and timeliness of reports.

¹⁶ Massachusetts Health Data Consortium (2000). The Benefits of Administrative Simplification [On-line] Available: <http://www.mahealthdata.org>

¹⁷ Utah Health Information Network, <<http://www.uhin.com>>



Automation frees up the time of public health workers to do more important tasks like investigation, analysis, and response. Public health departments will spend less time waiting for data, reentering data, searching for data, and cleaning data.

Electronic laboratory reporting of notifiable diseases in Hawaii yielded the following benefits:

- *2.3-fold increase in the number of reports;*
- *Electronic reports were received four days earlier than paper reports;*
- *76 percent of data fields were completed in electronic reports versus 60 percent in paper reports;*
- *Electronic reports were more likely to provide patient and physician phone numbers (necessary for case investigations and follow-up)*

*Centers for Disease Control and Prevention. (January 7-8, 1999)
Electronic Reporting of Laboratory Information for Public Health
(Summary of Meeting Proceedings).*

In the future...

Automated surveillance systems will be built to routinely collect and analyze anonymous patient data from health care providers on a real time basis to identify unusual clusters of disease. Such a system will speed the identification and response to public health threats.

Automated analysis of emergency room data could have minimized the impact of the cryptosporidium outbreak in Milwaukee in 1993 where emergency rooms were clogged before reports of an unusual level of disease filtered up to public health officials.

Standardization improves data quality and utility.

Data standardization improves the ability to link data from different sources or programs and increases its comparability. Data standards facilitate the identification of critical linkages (e.g., across disease types, between environmental factors and disease). For example, linkage of data sets across diseases can identify critical relationships such as that of MDR-TB to HIV.

Data standards make comparing data across states and localities possible. Public health data from seemingly unrelated events across the country can be analyzed to identify patterns and trends and suggest public health actions to safeguard populations. For example, CDC's PulseNet network of public health laboratories uses gel electrophoresis to finger-print DNA and then disseminate the information electronically to participating states. This type of



information exchange allows for rapid identification of foodborne pathogens within what is now a national food supply. Several recent outbreaks involving contaminated meat were rapidly identified and halted due to this type of information exchange.¹⁸

Better and more comparable data support performance measurement and improvement.

Comparable data allows public health officials and researchers to better evaluate programs and strategically allocate resources. Measuring and comparing performance relative to national benchmarks, such as Healthy People 2010 objectives, provides an incentive for improved performance. One state found that holding organizations to public and standard reporting motivates them to improve their business processes.

“States that have implemented Immunization Registries often discover benefits that extend beyond the direct registry function. States now have a reliable, centralized source of statewide clinician data and find that HMOs are eager to forge partnerships with public health to improve and support their HEDIS reporting.”

*Sue Salkowitz
National Immunization Registry
Consultant*

Standards further public health’s ability to perform core functions.

Access to better data through standardization will improve the ability of public health officials and researchers to do their jobs. Specific tasks supported by better information include:

- Identifying public health threats;
- Assessing the health status of the population;
- Focusing programs and policies where they are needed most and are proven to be effective;
- Informing and educating people about health issues;
- Evaluating policy and program effectiveness;
- Conducting research to improve health and health care.

“The #1 product public health provides to customers is information.”

*John Lumpkin
Director, University of Illinois
Department of Public Health*

¹⁸ Centers for Disease Control and Prevention Press Release: National Computer Network in Place to Combat Foodborne Illness, <http://www.cdc.gov/ncidod/dbmd/pulsenet/pulsenet.htm>.



AN ELECTRONIC ENVIRONMENT IS EMERGING IN THE HEALTH SECTOR; PUBLIC HEALTH RISKS BEING LEFT OUT

Better use of information for health and health care depends on the development of a National Health Information Infrastructure (NHII).¹⁹ The public health and health services research communities must become a part of this emerging electronic environment.

A critical enabler to the development of the NHII is a comprehensive set of standards for all health data. The care delivery system is rapidly moving to an electronic environment both for administrative transactions and for clinical data management and exchange; public health workers and health services researchers should not be left behind.

“The National Health Information Infrastructure is the set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health.”

The National Committee on Vital and Health Statistics

There is a critical distinction between entities creating their own electronic environment vs. entering the emerging e-environment in the health care sector. Some public health organizations may have achieved technical sophistication specific to their organization or specific programs. However, a move to an electronic environment based on proprietary technologies, applications, and systems misses the larger goal of interoperability across all programs and jurisdictions and with data trading partners.

DATA STANDARDS SUPPORT THE LARGER GOAL OF INTEGRATION

Data standards are necessary to support the larger goal of integration of public health information and surveillance systems. Public health is accomplished through partnerships among federal agencies, state and local health departments, providers, laboratories, educational institutions, associations, foundations, communities, and individuals. The variability in data collection and software systems hampers the efficient flow of information—especially given the limited infrastructure and technical know-how for data management in the public health sector. Public health must ensure that decision-makers have access to high quality data on which to base rational and effective public health policy. Current methods of data collection place a substantial burden on partners across levels of government and between the public and private sector.²⁰

¹⁹ National Committee on Vital and Health Statistics. [Toward a National Health Information Infrastructure](http://www.ncvhs.hhs.gov/NHII2kReport.htm). [On-line], Available: <http://www.ncvhs.hhs.gov/NHII2kReport.htm>

²⁰ Centers for Disease Control and Prevention, Health Information and Surveillance Systems Board. (Spring 1995). [Integrating Public Health Information and Surveillance Systems](http://www.cdc.gov/od/hissb/) [On-line] Available: <http://www.cdc.gov/od/hissb/>



For example, The State of Missouri reported that an impetus for moving to standards and integration was complaints from local health departments about the need to respond to competing system requirements for federal versus state government programs.

Integration can occur at many levels: across programs; across organizations; across jurisdictions; across levels of government; across settings of care; across public and private sectors; or across different types of data.

States report the desire to integrate data systems across the spectrum of health and human services programs as well as across states and jurisdictions. Some states are already developing standards and systems to integrate data across the full range of their programs, e.g., Missouri, Utah, Illinois. States can achieve economies of scale in information system development if they work together. Also, integrated data systems increase the ability of our public health system to identify and control threats such as bioterrorism, multi-drug resistant bacteria, and emerging infections that cross programmatic and geographic barriers.

Data standards and integration are necessary to support linkage of different data types (e.g., administrative, clinical and survey data) at the individual level to support research, while protecting confidentiality and privacy in a secure environment. Standard identifiers will create the ability to link different data types to create a more complete picture of the health of the public and how various factors impact it.

NOT ADOPTING STANDARDS PLACES PUBLIC HEALTH DATA AND RELATIONSHIPS AT RISK.

“It’s the right thing to do.”

Public health depends on the private delivery system for much of its data. The private sector has a mandate to move to data standards for health data transactions. The public health community needs to follow this mandate as well to preserve and strengthen its ties to the care delivery system. The government has mandated that the delivery system adopt HIPAA standards. For another part of the government to place information demands on the delivery system that are not consistent with these strategies will stress the important partnership between public health and the delivery system.

Illinois’ Cornerstone System

Built using HL-7 standards for electronic data interchange, the State of Illinois’ Cornerstone system integrates data related to maternal and child health into one modular database system. The system is eight years old and is built off of 22 standards. This system allows users to efficiently and effectively coordinate patient services across traditional categorical public health programs, such as Women, Infants and Children, well child services, and immunization services. The Cornerstone system is linked to the State’s Immunization Registry which integrates immunization information across settings of care, i.e., public health, Medicaid, WIC and private providers.



Not engaging in standards development processes threatens access to and usefulness of data.

If public health officials or researchers choose not to participate in the standards development discussion, they run the risk of data standardization policies being developed that may not support needed access to data by public health. For example, a recent topic of “conversation” on the Consortium’s listserv has been standards for the de-identification of data for privacy reasons. A standard that removes patient zip code could greatly impact researcher ability to link health status data to demographic factors. Absence from the standards setting table may also lead to the development of standards that do not meet public health and researcher needs, e.g., missing data elements or poorly defined data elements.

Lack of standardized and integrated data systems is a threat to the health of the public.

A common information infrastructure is critical to controlling biological threats that increasingly cross programmatic and geographic boundaries. Data standards will help address real and current fears about bioterrorism, foodborne illness, multi-drug resistant bacteria, and emerging infections.



APPENDIX E: DESCRIPTION OF EXTENSIVE AND TARGETED PARTNERS

A. Extensive Partners

The Department of Health and Human Services (DHHS) is the home of the Centers for Disease Control and Prevention (CDC) and other national agencies that are desired partners to the Consortium in its implementation of its education strategy. Existing DHHS partnerships include:

- *The Centers for Disease Control and Prevention (CDC):* The CDC is viewed by many in both the public and private sectors as the national voice of public health. Relative to state and local health departments, the CDC is well-funded and potentially has the resources and the knowledge to play the leadership role in standards development and implementation efforts. There are currently a myriad of standards related efforts occurring within CDC, the Consortium among them.²¹ The CDC represents several audiences for the education strategy: decision-makers, funders, users, and collectors of data. The effectiveness of the CDC voice in promoting standards will depend on its ability to coordinate its own standards related efforts and present a long-term vision that meets the broad array of public health data needs across all programs and levels of government. If funded to do so, the Consortium could expand its current partnership with the CDC to help make this happen.
- *The National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC):* The Consortium has gotten financial and staff support from NCHS, the federal government's principal vital and health statistics agency. NCHS provides statistical information to guide actions and policies to improve the health of the nation. The partnership between the Consortium and NCHS has been instrumental in developing a critical mass of activity to build the credibility of the Consortium as a voice of public health in standards development efforts around HIPAA.
- *CDC's National Electronic Disease Surveillance System (NEDSS):* The CDC is also funding NEDSS. NEDSS is an effort to develop a collection of complementary computerized information systems that support automation of health data gathering, facilitate the monitoring of the health of communities, assist in the analysis of trends and detection of emerging public health problems, and provide information for setting health policy. As part of this effort, the CDC has developed the Public Health Conceptual Data Model, a framework for documenting the information needs of public health. This framework focuses on infectious diseases surveillance, but the vision is to expand the model to include other types of public health data.

²¹ In 1995, CDC/ATSDR established the Health Information and Surveillance System Board (HISSB) to formulate and enact policy concerning the planning, development, maintenance, and use of integrated public health information and surveillance systems. Several projects have emerged out of HISSB. The HISSB is being replaced by another coordinating and governance structure for CDC information systems.



NEDSS is currently supportive of the Consortium, but the efforts of the two groups have been relatively distinct with the Consortium doing more work around administrative data impacted by HIPAA and NEDSS focusing on clinical data related to infectious diseases surveillance. As the focus of HIPAA shifts to privacy, security, and patient medical record data, there will be increasing overlap between the two efforts. Going forward it will be critical that NEDSS and Consortium messages be coordinated, especially as the Consortium expands its efforts to encompass the full array of public health data. NEDSS has been communicating its surveillance specific standards messages to various audiences including state health officers, county health officers, the Association of Public Health Laboratories (APHL), the Council of State and Territorial Epidemiologists (CSTE), the National Association for Public Health Statistics and Information Systems (NAPHSIS), and others. NEDSS has provided resources to the Association of State and Territorial Health Officials (ASTHO) to be at the table in standards setting efforts. Another critical next step is for the Consortium and NEDSS to work together with various stakeholder groups across public health (e.g., ASTHO, CSTE, or the NAHDO) to expand the Public Health Data Conceptual Model to include a broader array of public health data.

The Consortium's partnership efforts should also be directed to national associations that represent key audiences for the education strategy:

- *Association of State and Territorial Health Officials (ASTHO)*: ASTHO is the national non-profit organization representing the state and territorial public health agencies of the United States, the U.S. Territories, and the District of Columbia. These agencies are the primary audience for the strategy. ASTHO has significant experience in bringing together public health policy-making organizations for several of their past and on-going projects. ASTHO, in cooperation with the National Association of County and City Health Officials (NACCHO), formed The Public Health Information and Infrastructure Policy Committee (PHIIP). PHIIP assesses policy and programmatic issues related to health data, health data systems, and the capacity of the state and local public health information infrastructure to appropriately measure population health status.²² Among other activities, PHIIP is in the process of drafting one-page information sheets on specific national data standards policies and initiatives. Its products could be developed in partnership with the Consortium to educate states on what national data standards mean to them. ASTHO also has a cooperative agreement with NEDSS.
- ASTHO affiliates, such as the *Association of Public Health Laboratories (APHL)* and the *Council of State and Territorial Epidemiologists (CSTE)*, are additional partners. APHL is a non-profit association dedicated to working with its members to actively promote the interest of public health laboratories. Members include state public health laboratory directors and county, city, environmental health, environmental quality, and international laboratory directors. Its mission is to promote the role of public health laboratories in support of national and global objectives, and to promote policies and programs which

²² Association of State and Territorial Health Officials, <<http://www.astho.org>>



assure continuous improvement in the quality of laboratory practices. The CDC plans to support national partner organizations of state and local health departments, including APHL, to assist with coordination and communication of NEDSS efforts.²³

- CSTE is a professional association comprised of epidemiologists in states and territories whose mission is to work jointly to detect, prevent, and control conditions that affect public health. One important component of the CSTE's strategic plan is to facilitate data integration. Such data integration is vital to allowing the CSTE to fulfill other components of its long-term plan such as implementing a National Public Health Surveillance System and implementing electronic laboratory surveillance and electronic data systems. For example, CSTE is partnering with NEDSS by promoting state adoption of NEDSS, educating policymakers at the state and federal level about the importance of data integration, and soliciting feedback about problems that arise when states are transitioning to data standards. The CSTE is also working to develop a set of common chronic disease indicators which will include a minimal set of diseases, conditions and risk factors that are standardized across all states in order to allow for consistent comparisons across populations.
- *National Association of County and City Health Officials (NACCHO)*: NACCHO was formed in July 1994 when the National Association of County Health Officials and the U.S. Conference of Local Health Officers combined to form a unified organization representing local public health. It is a nonprofit membership organization serving all of the nearly 3,000 local health departments in cities, counties, townships, and districts across the country. NACCHO provides education, information, research, and technical assistance to local health departments and facilitates partnerships among local, state, and federal agencies in order to promote and strengthen public health. It promotes national policy, develops resources and programs, and supports effective local public health practice and systems that protect and improve the health of people and communities.

NACCHO's strategic directions and three-year objectives support data integration as its plans include: promoting and supporting local public health agencies to assure the development of local public health systems that have the capacity to provide the "Essential Services;" enhancing the effectiveness of local public health agencies' contributions to improvements in health status and quality of life; and assuring that NACCHO and its members make effective use of information technology. In addition to these plans, NACCHO recently received support from the Centers for Disease Control and Prevention (CDC) to involve local public health agencies in the development and implementation of the National Electronic Disease Surveillance System (NEDSS). NACCHO's role in the NEDSS initiative is primarily to act as a liaison between local public health agencies and the CDC. NACCHO has also worked in collaboration with the Multnomah County Health Department, Oregon, and the Centers for Disease Control and Prevention, on a data alliance project over the last three years. The overall goal of this

²³ Association of Public Health Laboratories. (September 2000) *The APHL Minute* [On-line] Available: <http://www.aphl.org/Minute/9-25-00.pdf>



project was to attempt to build a model for a data sharing alliance between the public and private sector organizations in a local community, which would improve the information available for local public health planning and policy development.

- *National Association of Health Data Organizations (NAHDO)*: NAHDO is a nonprofit national membership organization dedicated to improving health care through the collection, analysis and dissemination of health data. Its objectives are to establish itself as a leader in health and information standards and policy development and in performance measurement initiatives, expand its technical capacity, foster public and private sector collaboration, and enhance member participation.²⁴ NAHDO is currently supporting the Consortium in a research capacity, is contributing to this education strategy and has conducted a study, “Prioritization of Data Needs for State Encounter Data Sets for Public Health and Research Applications.” Its annual meetings are an excellent forum for delivering educational messages to state health personnel. With additional resources, NAHDO could expand its partnership role.
- *National Association for Public Health Statistics and Information Systems (NAPHSIS)*: NAPHSIS aims to provide national leadership in advocating, creating, and maintaining public health information systems that integrate vital records registries, public health statistics, and other health information. In collaboration with other organizations, NAPHSIS develops standards and principles to effectively administer public health statistics and information systems. NAPHSIS commissioned a work group in 1996 to address the concept of virtual State Centers for Health Statistics. The State Centers’ priority functions would be to provide leadership in determining the quality of existing data, establishing standards for measuring data quality, and working proactively to ensure the collection of high quality data.²⁵ It is currently working in collaboration with the Social Security Administration on an Electronic Death Registration System project, the goal of which is to develop a set of standards that can be adopted by all states for electronic death registration.
- *Academy for Health Services Research and Health Policy (the Academy)*: In June 2000, the Association for Health Services Research and the Alpha Center merged to form the Academy. The merger strengthens the bridge between research and policy worlds to enhance translating research into decisions to improve the health care field. The Academy has a large membership base consisting of health services researchers and public and private policymakers in the U. S. The Academy reaches out to its members with its annual meetings, seminars and numerous publications.²⁶ The Academy already is a member of the Consortium. A stronger partnership with the Academy would increase the Consortium’s reach into decision-makers, collectors and users of health data and information. The Education Work Group is discussing ways to foster the partnership including representing the Consortium at the Academy’s upcoming annual meeting.

²⁴ National Association of Health Data Organizations. (December 2000) NAHDO News 15th Anniversary Meeting Edition.

²⁵ National Association for Public Health Statistics and Information Systems, <<http://www.naphsis.org>>

²⁶ Association for Health Services Research, <<http://www.ahsr.org>>



B. Targeted Partners

- *The National Committee on Vital and Health Statistics (NCVHS):* NCVHS serves as the statutory public advisory body to the Secretary of Health and Human Services. It fulfills important review and advisory functions relative to health data and statistical problems of national or international interest, stimulates or conducts studies of such problems, and makes proposals for improvement of the nation's health statistics and information systems. HIPAA gave expanded responsibilities to the NCVHS including advising the secretary on health information privacy and on the adoption and implementation of health data standards. It has become increasingly active over the past several years, addressing issues relating to uniform health data sets, medical classification systems, the need for improved mental health statistics, data needs for minority health and the medically indigent, state and community health data needs, and issues related to the implementation of uniform data standards for HIPAA. NCVHS supported the 1998 HIPAA workshop and has followed the development of the Consortium. NCVHS represents a decision-maker in the implementation of the education strategy. Further developing the relationship between NCVHS and Consortium will be useful as the Consortium makes the business case for additional national data standards for public health.
- *The American Medical Informatics Association (AMIA):* AMIA is a nonprofit 501(c)(3) membership organization of individuals, institutions, and corporations (including physicians, nurses, computer and information scientists, biomedical engineers, medical librarians, and academic researchers and educators) dedicated to developing and using information technologies to improve health care. AMIA was formed in 1990 by the merger of three organizations - the American Association for Medical Systems and Informatics (AAMSI), the American College of Medical Informatics (ACMI), and the Symposium on Computer Applications in Medical Care (SCAMC). Some of the primary activities of the association include organizing an annual symposium conference, publishing a journal, maintaining working groups and special interest groups, involving itself in relevant policy issues and maintaining a resource center. AMIA has been particularly involved in the complex issues surrounding the privacy and confidentiality of electronic medical records. In May 2001, AMIA is holding a Spring Congress on Public Health Informatics where the Consortium will be represented.
- *The Southern HIPAA Administrative Regional Process (SHARP):* SHARP was recently established to meet the immediate need of assessing regional HIPAA Administrative Simplification implementation readiness to bring about regional coordination for successful HIPAA compliance by all stakeholders (specifically the provider community) in the southern regional healthcare industry. Specifically, SHARP's mission is to: create a forum that encourages the necessary dialog among the regional health care implementers of the HIPAA Standards and procedures; identify cross-industry coordination and best practices; coordinate efforts to identify and resolve ambiguities related to HIPAA implementation; adopt an outreach approach to current industry initiatives by conducting information gap analyses and developing recommendations on



- initiatives to address the coordination that must exist within the region for all health care stakeholders.²⁷ There are numerous other regional organizations supporting HIPAA implementation efforts. A list of these organizations can be found on the WEDI website at <http://www.wedi.org/SNIP/Resources/regional.htm>.
- *Government Information Value Exchange for States (GIVES)*: GIVES is a collaborative government health care industry group focusing on the sharing of information through a clearinghouse highway and providing a forum for discussing and resolving issues in meeting the Health Insurance Portability and Accountability Act (HIPAA) legislation. It has been established to meet the immediate need to exchange information, identify common government challenges and share solutions to attain HIPAA compliance. It hopes to minimize the duplication of efforts by individual states.²⁸
 - *Workgroup for Electronic Data Interchange (WEDI)*: WEDI was established in 1991 following a forum convened by the Secretary of the Department of Health and Human Services to address administrative costs in the nation's health care system. While it is not a standards setting organization, WEDI provides a forum for the definition of standards, the resolution of implementation issues, the development and delivery of education and training programs, and the development of strategies and tactics for the continued expansion of electronic commerce in healthcare.²⁹ We classify WEDI into two audience groups for the education strategy: a supplier of information, as it is made up of primarily payors, providers, and vendors, and a decision-maker. WEDI does not yet include a voice for public health on its board. The WEDI Task Group called the Strategic National Implementation Process (SNIP) is a collaborative healthcare industry-wide process resulting in the implementation of standards and furthering the development and implementation of future standards. Specifically, the WEDI HIPAA SNIP Task Group has been established to meet the immediate need to assess industry-wide HIPAA Administrative Simplification implementation readiness and to bring about the national coordination necessary for successful compliance. SNIP formed an Education Work Group to develop messages, target audiences and create a dissemination strategy.³⁰ WEDI SNIP and the Consortium could partner to incorporate the public health perspective in its education of suppliers about HIPAA and other standards implementation.
 - *North American Association of Central Cancer Registries (NAACCR)*: NAACCR is an umbrella organization for central cancer registries. NAACCR provides a means for achieving national consensus about registry standards and representatives. Partnerships

²⁷ The Southern HIPAA Administrative Regional Process (SHARP), Mission statement. [On-line], Available: <http://www.sharpworkgroup.com/mission.html>

²⁸ Government Information Value Exchange for States. *GIVES Vision* Internal Draft Document.

²⁹ Workgroup for Electronic Data Interchange. *SNIP Education Workgroup, Purpose, Scope, and Process* [On-line], Available: http://www.wedi.org/snip/education/purpose_scope.pdf

³⁰ Workgroup for Electronic Data Interchange. *WEDI Vision, Mission, and Guiding Principles* [On-line], Available: <http://www.wedi.org/public/articles/details.cfm?id=309>



with associations such as NAACCR bring the Consortium to the forefront of standards development for specific data base types.

State-specific entities that are further along in the standards setting process are strong partners for the Consortium as they can share their experiences to bring other states on board.

- *The Massachusetts Health Data Consortium (MHDC)*: MHDC was founded in 1978 by the state's major public and private health care organizations. They recognized the need for a neutral agency, an "honest broker," independent of special interests, to collect, analyze and disseminate health care information. In 1994, MHDC organized the Affiliated Health Information Networks of New England Project to improve the state's health care infrastructure among payor and provider organizations. Utilizing a structure of Work Groups, Sub-Groups, the CIO Forum and the Webmaster Group, the Project is facilitating the development of a region-wide comprehensive health data system in which everyone who pays for, delivers or uses health services can make decisions based on readily accessible information. The MHDC hopes to achieve this ideal through the creation of a health information infrastructure that is standards-based, protective of personal privacy and supported by trading partners.
- *New York State Department of Health, Statewide Planning and Research Cooperative System (SPARCS)*: The Statewide Planning and Research Cooperative System (SPARCS) is a comprehensive patient data system established in 1979 as a result of cooperation between the health care industry and government. The enabling regulations for SPARCS require that inpatient data be submitted by all facilities certified for inpatient and that outpatient data be submitted by all hospital-based ambulatory surgery services and all other facilities providing ambulatory surgery services. Data are to be submitted according to a designated format and schedule. In 1992, the Department of Health formed an ad hoc task force to develop data set specifications that would blend the UB-92 nationwide inpatient and outpatient billing requirements with the unique billing and discharge data reporting requirements of New York State. In April 1993, the ad hoc task force released a new Universal Data Set (UDS) Specification which includes reporting codes for use with the UB-92 paper form and a new electronic format. The resulting system streamlines multiple data submission formats into a single format, removing redundant reporting requirements for hospitals and other health care facilities.³¹
- *The Minnesota Health Data Institute (MHDI)*: MHDI is a public-private partnership created by the Minnesota State Legislature to foster a competitive health care system. It has two programs whose purposes support data integration. The Quality Measurement Program's aim to "promote the use of standard performance measures" supports the adoption of data standards in order to facilitate the use of standard performance measures.³² The Minnesota Center for Healthcare Electronic Commerce, a committee of

³¹ New York State Department of Health, Statewide Planning and Research Cooperative System (SPARCS). SPARCS-Who we are. [On-line], Available: <http://www.health.state.ny.us/nysdoh/sparcs/operations/who.htm>

³² Minnesota Health Data Institute, <<http://www.mhdi.org>>



the MHDI, is committed to helping the health care industry adopt standard electronic systems in order to enhance efficiency in health care. The group aims to do this through standards development and training. The committee conducted a statewide survey to assess the types of electronic commerce and electronic data interchange that employers expect to use in the upcoming year. Through the survey, the committee hopes to learn about the barriers and education needs of providers seeking to enhance the use of electronic data reporting.

- *The Utah Health Information Network (UHIN):* UHIN is a broad-based coalition of health care insurers, providers, and other interested parties, including State government. UHIN participants have come together for the common goal of reducing health care administrative costs through standardization of administrative health data and electronic commerce transaction processing. UHIN and its partners developed EDI software on a proprietary free access basis which is designed to efficiently and accurately route standardized health care data and appropriate remittance advice. UHIN overcame the cost barrier of developing a central EDI by sharing the costs among its partners. Data types, claims, remittances enrollment, and error reporting are all standardized using X12. Any health care entity may participate in the UHIN system if they are willing to adhere to the UHIN standards and protocols and agree to the fee assessment.³³

³³ Utah Health Information Network, <<http://www.uhin.com>>



APPENDIX F: NAHDO'S LISTING OF PUBLIC HEALTH DATA SYSTEM TYPES

| DATABASE FUNCTION Primary Type | Major Public Health Data Systems/Bases | SELECTION CRITERIA IN ORDER OF RELATIVE IMPORTANCE | | | | SORT OR STRATA FIELDS | | |
|---|--|--|--|---|--|------------------------------|----------------------|--|
| | | NATIONAL SIGNIFICANCE RANK=1 | UNIVERSALITY Common Data Set RANK=2 | NUMBER OF SUPPLIERS TO USERS/USES RANK=3 | FORMAT National vs. state unique RANK=4 | LIKELY DSMO STRATA VAR | SECTOR STRATA VAR | |
| Health Economics | State-defined financial report Medicare Cost Report | HCFA-required | high high | many-many many-many | state unique national | X12 X12 | Private Private | |
| Health Occupation | Health Professional Surveys/licensure | HRSA tracks | high | many-many | state unique | X12 | Private | |
| Encounter | DIRECT PUBLIC HLTH-PROVIDED CLINICAL SERVICES | | | | | | | |
| <i>Defined: The billing/visit record for direct service provision: -special populations/public health-provided services -health systems encounter or services reported by providers to public health</i> | Cancer Control Screening Encounters | HP 2010 | medium | few-few | state unique | X12 | Public | |
| | Neonatal Follow-up Program | MCH | high | few-few | state unique | X12 | Public | |
| | Early Intervention Visit | MCH | high | few-few | state unique | HL7 | Public | |
| | Hearing and Speech Services | MCH | high | few-few | state unique | HL7 | Public | |
| | HIV/AIDS Treatment and Care | HP Obs | high | few-many | CDC defined | HL7 | Private | |
| | Pregnancy Riskline Phone Encounter | MCH | medium | few-few | state unique | HL7 | Public | |
| | Blood Pressure Control/Screening | CHR | low | few-few | state unique | X12+HL7 | Public | |
| | WIC visit | MCH | high | many-many | national | X12 | Public | |
| | Case Contact Follow-up visits | HP 2010 | high | few-few | CDC defined | HL7 | Public | |
| | Poison Control Telephone Encounter | INJ | medium | few-few | state unique | HL7 | Public | |
| | HEALTH SYSTEMS ENCOUNTER/SERVICES | | | | | | | |
| | Mental Health Encounters | SAMSHA | high | many-few | HCFA1500 | X12 | Public/Private | |
| | Emergency Dept Encounter | HCUP/INJ/CODES | high | many-many | UB92/837 | X12 | Private | |
| | Ambulatory Surgery Reporting | HCUP | high | many-many | UB92/837 | X12 | Private | |
| | Home Health Care Visit | HCFA/M-CARE | high | many-many | HCFA1500 | X12 | Private | |
| | Emergency Room Log Reports | CODES | high | few-few | state unique | HL7 | Private | |
| | Pre-Hospital Incident Report | CODES | med | few-few | state unique | X12 | Private | |
| | Dental Health Visits/Encounters | | high | few-few | ADA | ADA | Private | |
| Hospital Discharge Data | HCUP/CODES | high | many-many | UB92/837 | X12 | Private | | |
| Environmental Health Services Hazardous Waste Solid/Ground Water Tracking | | | | | | | | |
| Disease Surveillance/Infectious Disease | | | | | | | | |
| <i>Consistent with CDC's Surveillance Program</i> | Communicable Disease Control | HP 2010 | | many-many | CDC/NEDSS | HL7 | Private | |
| | HIV Surveillance | HP 2010 | | many-many | CDC/NEDSS | HL7 | Private | |
| | TB Surveillance | HP 2010 | | few-many | CDC/NEDSS | HL7 | Private | |
| | Sexually Transmitted Disease Control | HP 2010 | | many-many | CDC/NEDSS | HL7 | Private | |
| | Notifiable Disease Tracking System | CDC | | many-many | CDC/NEDSS | HL7 | Private | |
| Facility Certification/Licensing | | | | | | | | |
| | Health Facility Licensure | | | many-many | | X12 | Private | |
| | Medicare/Medicaid Certification | HCFA-Mcare | | many-many | | X12 | Private | |
| | Pre-Admission Screening and Annual Resident Review | HCFA-Mcare | | many-few | | MDC--X12 | Private | |



| DATABASE FUNCTION Primary Type | Major Public Health Data Systems/Bases | SELECTION CRITERIA IN ORDER OF RELATIVE IMPORTANCE | | | | SORT OR STRATA FIELDS | |
|--|--|--|---|--|---|--|---|
| | | NATIONAL SIGNIFICANCE RANK=1 | UNIVERSALITY Common Data Set RANK=2 | NUMBER OF SUPPLIERS TO USERS/USES RANK=3 | FORMAT National vs. state unique RANK=4 | LIKELY DSMO STRATA VAR | SECTOR STRATA VAR |
| Public Payers | | | | | | | |
| <i>State-sponsored insurance programs and HCFA required data systems</i> | Medicaid claims/encounter/eligibility Child Health Program encounter/eligibility Public Employee plans claims/eligibility Workers Compensation claims | HCFA-Mcaid HHS | | many-many many-many many-many | | X12 X12 X12 X12 | Private Private Private |
| Population Health Survey | | | | | | | |
| <i>Surveys of state population and sub-populations</i> | Behavioral Risk Factor Surveillance System Diabetes Population-Based Survey Health Status Survey Women's Self-Administered Questionnaire Pregnancy Risk Assessment Monitoring (PRAMS) Mental Health Surveys | CDC, HP 2010 HP 2010, CPS MCH, HP 2010 SAMSHA | | few-many few-few few-many few-few few-few few-few | | CDC QUES STATE UNIQUE STATE UNIQUE STATE UNIQUE SAMSHA/STATE | Public Public Public Public Public |
| Registries | | | | | | | |
| <i>Encounters of defined population subgroups (Newborn, Immunizations)</i> | Child Injury Prevention Program HIV/AIDS Registry Immunization Program Pulmonary/Refugee Program (Tuberculosis) Spinal Cord Injuries Statewide Surveillance for Traumatic Brain Injuries Birth Defects Registry Cancer Registry | CDC, HP 2010 HP 2010, CDC HP 2010 HP 2010 HP 2010, SEERS | | many-many many-many many-many few-few many-few many-few few-few many-many | | CDC CDC HL7 AND X12 CDC X12 AND HL7 X12 AND HL7 X12 AND HL7 X12 AND HL7 | Private Private Priv-public Public Private Private Private Private |
| Screening | | | | | | | |
| <i>Registry/encounters with lab component--</i> | Blood Lead Registry for Adults Blood Pressure/Cholesterol Screening Diabetes Complications Screening Program Data HIV Screening Seroprevalence Medical Examiner System Archives Newborn Screening Program | HP 2010 HP 2010 HP 2010 HP 2010 | | few-mod few-few few-few few-mod few-mod few-many | | HL7 HL7 HL7 HL7 HL7 X12 | Public Public Public Public Public |
| Vital Records | | | | | | | |
| <i>Vital events used by broad audiences for multiple purposes across public hlth</i> | Abortions Birth Certificate Data Death Certificate Data Divorce Certificate Data Marriage Certificate Data | HP 2010 HP 2010 | | many-many many-many many-many many-many many-many | | X12 HL7 HL7 AND X12 X12 X12 | Private Private Private Public Public |

KEY =

| | |
|------|----------------------------|
| HSP | Health Systems Performance |
| SVY | Survey |
| SURV | Surveillance |
| MCH | Maternal Child Health |
| INJ | Injury |
| CD | Communicable Disease |
| LAB | Laboratory |
| MH | Mental Health |
| CHR | Chronic Disease |



APPENDIX G: DICTIONARY OF ACRONYMS AND ABBREVIATIONS

| Acronym | Organization/Term |
|----------------|--|
| Academy | Academy for Health Services Research and Health Policy |
| AHIMA | American Health Information Management Association |
| AHRQ | Agency for Health Care Research and Quality |
| AHSR | Association for Health Services Research |
| AMIA | American Medical Informatics Association |
| ANSI | American National Standards Institute |
| APHA | American Public Health Association |
| APHL | Association of Public Health Laboratories |
| AS | Administrative Simplification |
| ASC-X12 | Accredited Standards Committee-X12 |
| ASPE | Assistant Secretary for Planning and Evaluation |
| ASTHO | Association of State and Territorial Health Officials |
| CDC | Centers for Disease Control and Prevention |
| Consortium | Public Health Data Standards Consortium |
| CPRI-HOST | Computer-based Patient Record Institute-Healthcare Open Systems and Trials |
| CSTE | Council of State and Territorial Epidemiologists |
| DCC | Data Content Committee |
| DHHS | Department of Health and Human Services |
| DOJ | Department of Justice |
| EDI | Electronic data interchange |
| GIVES | Government Information Value Exchange for States |
| HAN | Health Alert Network |
| HCFA | Health Care Financing Administration |
| HCUP | Healthcare Cost and Utilization Project |
| HIMSS | Healthcare Information and Management Systems Society |
| HIPAA | Health Insurance Portability and Accountability Act |
| HISB | Healthcare Informatics Standards Board |
| HL-7 | Health Level Seven |
| HRSA | Health Resources and Services Administration |
| MHDC | Massachusetts Health Data Consortium, Inc. |
| MHDI | Minnesota Health Data Institute |
| NAACCR | North American Association of Central Cancer Registries |
| NACCHO | National Association of County and City Health Officials |
| NAHDO | National Association of Health Data Organizations |
| NAPHSIS | National Association for Public Health Statistics and Information Systems |
| NCHS | National Center for Health Statistics |
| NCPDP | National Council for Prescription Drug Programs |
| NCQA | National Committee for Quality Assurance |
| NCVHS | National Committee on Vital and Health Statistics |



| Acronym | Organization/Term |
|----------------|--|
| NEDSS | National Electronic Disease Surveillance System |
| NHII | National Health Information Infrastructure |
| NIH | National Institutes of Health |
| NUBC | National Uniform Billing Committee |
| NUCC | National Uniform Claim Committee |
| PHDSC | Public Health Data Standards Consortium |
| PHF | Public Health Foundation |
| SDO | Standards Development Organizations |
| Secretary | Secretary of the Department of Health and Human Services |
| SHARP | Southern HIPAA Administrative Regional Process |
| SNIP | Strategic National Implementation Process |
| SNOMED | Systematized Nomenclature of Human and Veterinary Medicine |
| SPARCS | Statewide Planning and Research Cooperative Systems |
| UHIN | Utah Health Information Network |
| USDA | United States Department of Agriculture |
| USHIK | United States Health Information Knowledge base |
| WEDI | Workgroup for Electronic Data Interchange |
| WIC | Women's, Infants, and Children Program at the US Department of Agriculture |
| Work Group | Public Health Data Standards Consortium Education Work Group |