

A PUBLIC-PRIVATE SECTOR COLLABORATION TO IMPROVE PUBLIC HEALTH AND HEALTH CARE QUALITY

FOUNDATION FOR eHEALTH

EXECUTIVE SUMMARY

February 28, 2002

OVERVIEW

Since November 2001, through a public-private partnership, the Centers for Disease Control and Prevention (CDC) and its public health partners at the state and local levels (including APHL, ASTHO, CSTE, NACCHO, NAHDO, and others), the eHealth Initiative (eHI) and its members, and now the Centers for Medicare and Medicaid Services (CMS) have been working on a collaborative effort to bolster the public health infrastructure and connectivity between multiple health care organizations and public health partners across the country, which will not only improve our nation's public health surveillance capability, but will also ultimately improve the delivery of care across the entire health care system. This public-private sector collaboration has focused on filling this public health information gap by *leveraging current health care information systems and other existing electronic health care data sources* to enhance public health surveillance processes (including collection, organization, analysis, and dissemination).

Through the Foundation for eHealth, the private sector through eHI, CDC, and now CMS will work together with health care providers, state and local public health agencies, and local coalitions to identify critical public health and quality-related data needs and develop strategies to rapidly, efficiently, and securely capture and transmit relevant health care information to and among public health partners. Such information will likely include specific laboratory and pharmacy transactions, emergency room visits, hospital admission data, and data from out-patient visits. These data will be integrated and transmitted using CDC's National Electronic Disease Surveillance System (NEDSS), which is a broad initiative designed to use national data and information system standards for the development of efficient, integrated, and interoperable surveillance systems at state and local levels.

The work described above is taking place both at the national level and at the state and local level through demonstration projects. The work at the national level is involving the CDC, CMS, state and local public health partners (including but not limited to APHL, ASTHO, CSTE, NACCHO, NAHDO, NAPHSIS, etc.), eHI and its members (including health care providers, health plans, health care information technology vendors, organizations which house large amounts of clinical and administrative data, national standards organizations such as HL7 and LOINC, and non-profit organizations interested in furthering this agenda—such as AMIA), local health data coalitions, privacy and security experts, and other key stakeholders.

UNIQUENESS AND SIGNIFICANCE OF THIS INITIATIVE

This initiative is significant because members of eHI develop health care information technology systems and services to or obtain data from a *majority* of the point-of-service health care providers in the United States, including hospitals, pharmacies, and office-based providers. For example, members of eHI provide health care information systems for over 80% of the nation's health systems and manage over 25% of the nation's pharmacy information.

This initiative is unique in that it leverages existing private sector information systems and electronic health care data for the benefit of the public health sector. This is critical, because our nation's providers are currently facing a multitude of cost and quality issues. Coordinating efforts among public and private stakeholders will help our nation's providers play their important role in community surveillance and detection by reducing the burden on and improving the effectiveness of an already challenged system. By leveraging existing sources of electronic community health care information, public health surveillance can expand without increasing the data-sharing burden currently placed on all types of health care providers.

This initiative represents a critical next step towards accelerating greater data standardization, enhancing information systems interoperability, and facilitating broad adoption of supporting policies and technologies. The power of combining a national need for interoperable systems with data and architectural standards through CDC's NEDSS with the expertise and leadership of health care industry leaders and national standards organizations, is extraordinary, and will provide the catalyst that is needed to drive greater data standardization, connectivity and compliance with privacy and security policies—all of which serve as critical barriers to a national health information infrastructure which is greatly needed to drive greater quality health care.

ALIGNMENT WITH BROADER HEALTH CARE OBJECTIVES

CDC is committed to improving the public health infrastructure, including systems at the Federal, state and local levels that are essential to assess health risks, detect and prevent disease and monitor environmental conditions.

The mission of both eHI and the Foundation for eHealth is to improve the quality, safety and cost-effectiveness of health care through the use of information technology. As noted in the recent NCVHS report *Information for Health: A Strategy for Building the National Health Information Infrastructure*, we as a nation have a timely opportunity and an urgent need to build a 21st century health support system—a comprehensive, knowledge-based system capable of providing information to all who need it to make sound decisions about health. This report does not call for a national database of patient records or a centralized healthcare system—it instead calls for an *interconnected set* of technologies, practices, relationships, standards, and applications that support the many facets of health and health care.

One of the primary barriers to a national health information infrastructure is the lack of clinical data standardization and connectivity within and across health care systems across our nation. eHI and its Foundation for eHealth have engaged nationally recognized experts to articulate a “path” or a high-level strategy for moving forward on clinical data standardization, with the goal of driving more rapid adoption of and compliance with existing standards and accelerated development of other needed standards.

As noted in a recent Gartner Group research note, “...anyone who has followed the information standards process knows that standards adoption is a complex process; tricky to start, and easily derailed. The adoption of the process is often influenced less by the quality of the standard than by the economics of the adoption process within the affected market or industry.” It is our intent that, by convening public and private sector stakeholders around a small, workable set of data elements which serve a highly important national objective--such as public health surveillance-- and by directing federal and state funding towards an electronic public surveillance system which also serves as the foundation for data sharing and connectivity amongst a broader set of healthcare stakeholders for a broader set of health care goals—together we will jump-start and further data standardization and connectivity efforts across the nation’s health care system, so that significant gains can be made related to the quality, safety, and cost-effectiveness of health care for all Americans.

A PUBLIC-PRIVATE SECTOR COLLABORATION TO IMPROVE PUBLIC HEALTH AND HEALTH CARE QUALITY

FOUNDATION FOR eHEALTH

SUMMARY PAPER

February 28, 2002

OVERVIEW

Since November 2001, through a public-private partnership, the Centers for Disease Control and Prevention (CDC) and its public health partners at the state and local levels (including APHL, ASTHO, CSTE, NACCHO, NAHDO, and others), the eHealth Initiative (eHI) and its members, and now the Centers for Medicare and Medicaid Services (CMS) are working on a collaborative effort to bolster the public health infrastructure and connectivity between multiple health care organizations and public health partners across the country, which will not only improve our nation's public health surveillance capability, but will also ultimately improve the delivery of care across the entire health care system. Improving the public health infrastructure is a critical objective for the nation. The Administration, Congress, the CDC and other expert public health organizations recognize that public health surveillance must be enhanced throughout the nation's public health system, especially at the local and state levels, to rapidly detect unusual, unexpected, or unexplained community health events and react to them with appropriate resources. This public-private sector collaboration has been focused on filling this public health information gap by *leveraging current health care information systems and other existing electronic health care data sources* to enhance public health surveillance processes (including collection, organization, analysis, and dissemination). As noted above, recent discussions with CMS indicate that they will join the collaboration, as they are also interested in the transmission of standardized electronic data from our nation's providers, to support quality of care objectives.

Through the Foundation for eHealth and with the support of our Foundation partner and convener, eHI and its members, CDC, and now CMS will work together with health care providers, state and local public health agencies, and coalitions at the state and local level. Together, we will identify critical public health and quality-related data needs. We will then develop strategies to rapidly, efficiently, and securely capture and transmit relevant health care information to and among public health partners. Relevant information will likely include specific laboratory and pharmacy transactions, emergency room visits, hospital admission data, and data from out-patient visits. These data will be integrated and transmitted using CDC's National Electronic Disease Surveillance System (NEDSS), which is a broad initiative designed to use national data and information system standards for the development of efficient, integrated, and interoperable surveillance systems at state and local levels.

This initiative is significant because members of eHI develop health care information technology systems and services to or obtain data from a *majority* of the point-of-service health care providers in the United States, including hospitals, pharmacies, and office-based providers. For example, members of eHI provide health care information systems for over 80% of the nation's health systems and manage over 25% of the nation's pharmacy information.

This initiative is unique in several ways. First, it leverages existing private sector information systems and electronic health care data for the benefit of the public health sector. This is critical, because our nation's providers are currently facing a multitude of cost and quality issues. Coordinating efforts among public and private stakeholders will help our nation's providers play their important role in community surveillance and detection by reducing the burden on and improving the effectiveness of an already challenged system. By leveraging existing sources of electronic community health care information, public health surveillance can expand without increasing the data-sharing burden currently placed on all types of health care providers. Second, it tests various data and technology migration strategies to ensure achievement of national integration objectives.

Third, this initiative represents a critical next step towards accelerating greater data standardization, enhancing information systems interoperability, and facilitating broad adoption of supporting policies and technologies. The power of combining a national need for interoperable systems with data and architectural standards through CDC's NEDSS, with the expertise and leadership of health care industry leaders and national standards organizations is extraordinary, and will provide the catalyst that is needed to drive greater data standardization, connectivity and compliance with privacy and security policies—all of which serve as critical barriers to a national health information infrastructure which is greatly needed to drive greater quality health care.

HIGH-LEVEL OBJECTIVES FOR THE PUBLIC-PRIVATE SECTOR COLLABORATION

As noted in the Memorandum of Understanding between the CDC and eHI, the objectives of the Collaboration are as follows:

- Convene public and private stakeholders with interests in the collection and analysis of data from sources of electronic health care data for public health (and now health care quality-related) purposes.
- Identify data that will be potentially useful to public health surveillance.
- Conduct exploratory analyses to evaluate utility of such data in electronic formats (e.g. geographic coverage, timeliness, baseline variability).
- Evaluate the feasibility of and methods for rapidly capturing and transmitting such data.

- Develop and test strategies to assist in the rapid capture and transmission of data specified from various sources using NEDSS, which is designed to electronically facilitate the collection, management, transmission, analysis and dissemination of surveillance data.
- Work closely with key stakeholders to address other critical issues associated with implementation, such as those related to “data ownership,” local partnership development, data standards, and privacy and security--by helping to frame the issues and defining the necessary steps to address these concerns.

The work described above is taking place both at the national level and at the state and local level through demonstration projects. The work at the national level is involving the CDC, CMS, state and local public health partners (including but not limited to APHL, ASTHO, CSTE, NACCHO, NAHDO, NAPHSIS, etc.), eHI and its members (including health care providers, health plans, health care information technology vendors, organizations which house large amounts of clinical and administrative data, national standards organizations such as HL7 and LOINC, and non-profit organizations interested in furthering this agenda—such as AMIA), coalitions (such as those working in Massachusetts, Minnesota, Utah, Washington, and North Carolina, in conjunction with the HealthKey Collaborative), privacy and security experts, and other key stakeholders. The work of the Collaboration at the national level will be led by a Steering Group, or a consortium of key stakeholders, including the above-identified parties, as well as our foundation convener/partner.

The Collaboration will then test the developed strategies and approach through a set of demonstration/pilot projects at the state and local level, which will be driven by local stakeholders and supported by many of the entities as outlined above.

THE PUBLIC-PRIVATE SECTOR COLLABORATION TO IMPROVE PUBLIC HEALTH —AT THE NATIONAL LEVEL

In order to achieve the objectives described above, since November 2001, participants in the Public-Private Sector Collaboration to Improve Public Health have been and will continue to focus on the following:

- Convening public and private stakeholders with interests in the collection and analysis of data from various electronic health care information sources for public health and health care quality-related purposes.
- Developing public health and health care quality data requirements.
- Evaluating the high-level feasibility of obtaining such data in electronic formats from existing health care information system applications and other data sets within the current health care delivery system, by applying a set of developed criteria.
- Developing strategies to transmit such data from existing information sources within the health care delivery system.

- Developing a set of objectives and evaluation criteria for demonstration/pilot projects to test such strategies.
- Working with a set of demonstration sites to test strategies developed.
- Evaluating strategies developed, through the work and results of the demonstration/pilot projects.
- Incorporating knowledge gained from both the designated demonstration sites, as well as other demonstration projects across the country, to refine and improve strategies.
- Disseminating knowledge gained from the process to all key stakeholders to catalyze and improve data standardization and connectivity-related projects across the U.S. health care system.

It is anticipated that this work will be funded through a combination of foundation, government, and other private sector grants and contributions.

To assist in this Collaboration, eHI is exploring strategic alliances with other organizations with similar goals, such as the HealthKey Collaborative, who in the past, have worked with a number of states to facilitate the sharing of health care data and information for public health and health care quality-related purposes.

THE DEMONSTRATION PROJECTS—AT THE LOCAL LEVEL

As noted above, the Collaboration at the national level will develop national requirements and strategies to leverage sources of electronic health care information to provide data to support public health surveillance and health care quality-related processes. These strategies will be tested through a set of demonstration projects, which will be driven from the state and local levels. These demonstration projects will likely involve state and local public health agencies, CDC, eHI, local providers, health care information technology suppliers, national organizations which house large amounts of clinical and administrative data, standards organizations, coalitions such as the Health Key Collaborative, privacy experts, and other critical stakeholders. Recent discussions with CMS indicate that they may participate in such demonstration projects. Again, this work will take place at the state and local level and will be led by state and local consortia and/or state and local public health partners.

It is anticipated that funding for these demonstration projects will come from a combination of governmental sources at the federal and state level (including FY 2002 emergency supplemental and FY 2003 funding provided to the states by various federal agencies), foundations, private sector contributors, and local project participants.

The following summarizes the proposed work and objectives related to such demonstration projects.

Objectives. At least three demonstration site locations will be identified to rapidly develop the capacity to use existing data sources to provide data to and among local and state public health agencies. The initial implementation sites will seek to achieve the following objectives:

- Test strategies developed at the national level using a previously established core set of data types.
- Demonstrate that a standardized approach can be implemented across a range of systems, vendors, and health care delivery organizations.
- Produce tools and methods that can be easily replicated in a broad range of geographic and health care settings.
- Develop a detailed understanding of the requirements to make priority data types available for public health surveillance.
- Create a range of options for meeting the data aggregation and reporting requirements of local and state public health organizations.

Data. Through the work of the public-private sector collaboration, CDC and eHI developed a priority set of data types that are perceived to be valuable for public health surveillance and which can be rapidly implemented at a reasonable cost. The following summarizes those data types.

Data Type	Rationale
Lab Results	Lab results are generally rapidly available and can provide public health officials with data that may assist them in identifying potential outbreaks
Orders	Tracking the orders for specific types of tests might enable public health officials to identify potential outbreaks earlier.
Microbiology Results	Microbiology test results are indicators of a number of diseases that are a high priority for public health surveillance.
Complaints	This data has high potential value for public health surveillance. There will be limitations in the areas of coding and data quality. It may be necessary to work with both coded and free text data. It will also be important to differentiate complaints based on their source, e.g., provider, patient, etc. If the demonstration projects can develop broadly applicable strategies for addressing these limitations this will be a major step forward in making this data available for public health surveillance.
Patient Demographics	Will need to be linked to all other data types in order to provide meaningful information. Patient demographics alone would not be useful for public health surveillance
Pharmacy	The existence of large sets of these data and the importance of such make this a viable option.
Diagnoses (Admitting	These data are highly standardized and the ease of export is deemed to be high.

Data Type	Rationale
(Admitting and/or Discharge)	

It is anticipated that the above-identified data types will be the focus of initial implementation efforts. During subsequent phases additional data types will be added to the core set.

Data Sources. Each initial implementation site will seek to leverage the sources of electronic health care data available within its health care delivery environment. At a minimum, each of the initial three sites under the Collaboration will capture data streams from hospitals. In some locations it is also desired that we capture data streams from commercial laboratories, public health laboratories, non-hospital health care settings and other large administrative and clinical data sources. It is expected that multiple vendor systems will be represented among the health care organizations participating in each demonstration location. This will enable each location to develop tools and methods that are vendor-independent.

Data Normalization Tools and Methods. Demonstration sites will need to develop strategies for making data with variances in transaction structure and coding useful for public health surveillance. In the long term, improvements in the standardization of transaction structure and coding will eliminate the current variability. Each jurisdiction may need to develop strategies that are tailored to the capacity of the information sources from which data are extracted and the public health departments that will use the data. Issues of security and confidentiality will also be an important consideration in selecting a local approach.

Data Recipients. Each initial implementation site will determine the public health organizations that will receive the surveillance data. The projects will maintain the flexibility to adapt to the current state and local practices for acquiring and analyzing public health surveillance data.

Confidentiality and Security. Ensuring the confidentiality and security of all data will be critical to the success of this initiative. All demonstrations will comply with the requirements of HIPAA. Each initial implementation site will have final authority over the security and confidentiality methods, policies, and procedures that they will adopt.

Local Project Management. Each location will have an organization that is responsible for project management. Project management will include:

- Establishing and maintaining working relationships among the public and private organizations participating in the demonstration.
- Ensuring that confidentiality and security methods, policies, and practices are developed and maintained.

- Overseeing the development of strategies and tools for data normalization.
- Defining and overseeing the implementation of the methods and tools required to support data sharing with public health agencies.
- Sharing results with the public-private collaboration at the national level as well as other demonstration sites involved in the process, to facilitate learning and improvement.

Leveraging The Work of Existing Projects. In order to be effective and drive sustainable change, this Collaboration will seek to work closely with other demonstration projects that are already in process, such as those performed by various local health data consortia.

Reporting and Incorporating Knowledge Gained From Other Demonstration Projects. Each demonstration project will be responsible for reporting results and knowledge gained both to the other demonstration sites and to the public-private sector collaboration at the national level, which will synthesize, evaluate and share the information with all key stakeholders, and modify national strategies and requirements as appropriate.

It is also anticipated that the results and knowledge gained from other demonstration projects across the nation (beyond the initial pilot sites identified as part of this project) will be fed into the public-private collaboration at the national level, to facilitate improvement of national strategies for standardization and connectivity across the entire health care system (for both public health and non-public health purposes).

Evolution. Each project will undertake an initial implementation phase that will at a minimum accomplish the following:

- Establish a baseline capacity to extract priority public health data from existing sources of electronic health care data including data from multiple vendor hospital systems and other data sources (e.g., office-based providers and pharmacies) across multiple health care organizations
- Apply tools and methods that will address inconsistencies in transaction formats and data coding
- Develop the mechanisms for providing public health organizations with the data that will enhance their capacity to conduct public health surveillance

After the initial implementation is completed, it is expected that locations will expand their capabilities by increasing the number and types of participating health care

organizations and other sources of electronic health care information by incorporating new data types into the extraction and reporting processes.

ALIGNMENT WITH BROADER HEALTH CARE OBJECTIVES

CDC is committed to improving the public health infrastructure, including systems at the Federal, state and local levels that are essential to assess health risks, detect and prevent disease and monitor environmental conditions.

The mission of both eHI and the Foundation for eHealth is to improve the quality, safety and cost-effectiveness of health care through the use of information technology. As noted in the recent NCVHS report *Information for Health: A Strategy for Building the National Health Information Infrastructure*, we as a nation have a timely opportunity and an urgent need to build a 21st century health support system—a comprehensive, knowledge-based system capable of providing information to all who need it to make sound decisions about health. This report does not call for a national database of patient records or a centralized healthcare system--it instead calls for an *interconnected set* of technologies, practices, relationships, standards, and applications that support the many facets of health and health care.

One of the primary barriers to a national health information infrastructure is the lack of clinical data standardization and connectivity within and across health care systems across our nation. eHI and its Foundation for eHealth have engaged nationally recognized experts to articulate a “path” or a high-level strategy for moving forward on clinical data standardization, with the goal of driving more rapid adoption of and compliance with existing standards and accelerated development of other needed standards.

As noted in a recent Gartner Group research note, “...anyone who has followed the information standards process knows that standards adoption is a complex process; tricky to start, and easily derailed. The adoption of the process is often influenced less by the quality of the standard than by the economics of the adoption process within the affected market or industry.” It is our intent that, by convening public and private sector stakeholders around a small, workable set of data elements which serve a highly important national objective--such as public health surveillance-- and by directing federal and state funding towards an electronic public surveillance system which also serves as the foundation for data sharing and connectivity amongst a broader set of healthcare stakeholders for a broader set of health care goals—together we will jump-start and further data standardization and connectivity efforts across the nation’s health care system, so that significant gains can be made related to the quality, safety, and cost-effectiveness of health care for all Americans.