

THE NATIONAL HEALTH INFORMATION INFRASTRUCTURE AND POPULATION HEALTH

NHII

The National Health Information Infrastructure (NHII) is

- a) an initiative set forth to improve the effectiveness, efficiency and overall quality of health and health care in the United States,
- b) a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that would improve decision-making by making health information available when and where it is needed, and
- c) the set of technologies, standards, applications, systems, values, and laws that support all facets of individual health, health care, and public health.

The NHII dimensions are represented by three overlapping circles, each representing a particular focus with overlap into the adjacent areas. Additionally, the scope would include healthcare research. The three dimensions are:

- *Personal Health*-includes a personal health record that is created and controlled by the individual or family, plus non-clinical information such as self-care trackers and directories of health care providers. The confidentiality of personal health records and consumers' control over their own records are basic tenets of this vision, consistent with the HHS privacy regulations.
- *Health care delivery* -includes information such as provider notes, clinical orders, decision-support programs, digital prescribing programs, and practice guidelines. Healthcare providers will retain responsibility for their own patients' medical records.
- *Public health*-enable sharing of information to improve the clinical management of populations of patients such as vital statistics, population health risks and disease registries.

POPULATION HEALTH

Population health, which is used somewhat interchangeably with the term public health in NHII documentation, refers to activities that focus on the health of defined groups of individuals. This concept originated in the early work of public health and is now the foundation of the public health agency core functions of assessment, policy development and assurance activities. It is also the foundation of clinical research and clinical quality improvement activities.

Population health could be greatly enhanced by aggregating some elements of clinical data encompassed by the NHII initiative, but also requires other data to be complete. These other data add information about demographics, environmental risks, regulatory inspections, health systems performance, and animal health. NHII will not satisfy all requirements of population health assessment but can contribute very valuable human

health information to population health surveillance, epidemiology, clinical quality improvement, and clinical research activities.

The Research and Population Health topic group created at the 2003 NHII Conference has been separated into two distinct groups for the 2004 Conference. The following NHII goals and recommendations for Population Health were developed as a result of the 2003 NHII Conference. The 2003 Goals and Recommendations have been modified slightly to conform to the more specific focus of the new Population Health topic group.

NHII POPULATION HEALTH GOAL STATE 2003

1. Multiple purpose data use
2. Population health data standardization
3. Reliable means of linking people in various data sets
4. Support for secure access and information exchange
5. Support for various ownership models of data

PROPOSED NHII POPULATION HEALTH GOAL STATE 2004

Goals 1 & 2 have been expanded from the 2003 format in an attempt to provide more specific information.

1. Multiple purpose data use
 - A) Individual patient clinical data can be easily aggregated for appropriate population level uses
 - B) Clinical data can be easily integrated with non-clinical data related to demographics, disease risks, and health services
2. Population health data standardization
 - A) Personal health clinical data standards support population level uses
 - B) Standards are developed that are specific to population level data uses
3. Reliable means of linking people in various data sets
4. Support for secure access and information exchange among population level data users
5. Support for various ownership models of data that allow for appropriate population level uses of the data

CONSENSUS NHII POPULATION HEALTH RECOMMENDATIONS FROM 2003 AND PROGRESS MADE IN THE LAST YEAR

SHORT TERM RECOMMENDATION 1

- Adopt a complex adaptive system approach to support data exchange and interoperability in population health. Define the key elements to allow for this kind of approach.

Lead organization identified at the 2003 Conference:

- HL-7

Progress made in the last year:

- IOM

Guidance / Definition of EHR Systems with specific key capabilities:

While this is NOT a direct result of strategies or action items identified during the 2003 NHII Conference, it is still very much related. In May 2003, the Department of Health and Human Services (DHHS) asked the Institute of Medicine (IOM) to provide guidance on the key care delivery-related capabilities of an electronic health record (EHR) system.

The Letter Report (<http://books.nap.edu/html/ehr/NI000427.pdf>) issued on July 31, 2003 in response to the DHHS request identified a population-related capability (#2) among the four key capabilities of an EHR system: (1) longitudinal collection of electronic health information for and about persons, where health information is defined as information pertaining to the health of an individual or health care provided to an individual; (2) immediate electronic access to person- and population-level information by authorized, and only authorized, users; (3) provision of knowledge and decision-support that enhance the quality, safety, and efficiency of patient care; and (4) support of efficient processes for health care delivery. It also provides numerous connections between the adoption of EHRs (seen as part of a healthcare IT infrastructure) and the ability to conduct the functions of public health, such as early detection and rapid response, organizing and executing large scale inoculation campaigns, etc.

-HL7 -

Development of an EHR functional model

In addition, the IOM work (see above) is the first step of a two-step process. While the IOM is being asked to identify core care delivery-related functionalities of an EHR system, Health Level Seven (HL7), a leading standards-setting organization working on the development of an EHR functional model, is working to incorporate these core functionalities into the model, and further specify each functionality along three dimensions: (1) develop a functional statement or definition (what), (2) establish a rationale for the functionality (why included), and (3) establish a compliance metric or test.

- PHDSC

The **Public Health Data Standards Consortium** (PHDSC) is a voluntary confederation of federal, state and local health agencies, national and local professional associations and public and private sector organizations. The PHDSC recognized the need to bring a common voice from the public health community to the national efforts of standardization of health and health care information for HIT implementation via HER and, on December 2, 2003, it launched a voluntary Ad Hoc Task Force on Electronic Health Record-Public Health (EHR-PH) in an attempt to provide a public health perspective in the evaluation of the HL7 EHR functional model.

Sixty four volunteers participated in the EHR-PH Task Force. The Task Force activities showed a need for a better understanding of informatics perspectives of public health by the various stakeholders. As the result, participants developed a White Paper entitled “Electronic Health Record: Public Health Perspectives” ([http://ehr.medigent.com/assets/collaborate/2004/03/29/PHDSC%20EHR-PH%20white%20paper%20\(04-03-09\).doc](http://ehr.medigent.com/assets/collaborate/2004/03/29/PHDSC%20EHR-PH%20white%20paper%20(04-03-09).doc)). The White Paper represents views of the Task Force participants. **The purposes of the White Paper are (1) to communicate to the public health community a need for broader involvement in the national effort to standardize clinical and public health data and systems and (2) to describe public health perspectives on the EHR.**

The White Paper includes an attempt to cross-map the HL7 EHR functions to the core public health functions. The cross-mapping demonstrates that at this high level of abstraction, the core public health functions (assessment, policy and assurance) are well represented in the HL7 EHR functional model. However, a more granular level of cross-mapping is needed to assure the ability of the model to support public health work and data flows. The White Paper also includes a list of use cases proposed for more granular cross-mapping of the HL7 EHR functions and three examples of those cross maps, *i.e.*, immunization, hypertension and diabetes. This can further lead to use case(s) demonstration projects of the EHR application in public health.

- CHI (Consolidated Health Informatics)

CHI is a key project in the Bush Administrations’ egov “Government to Business” portfolio. It is emerging as the primary e-health standards vehicle in the federal health care sector. It “adopts a portfolio of existing health information interoperability standards (health vocabulary and messaging) enabling all agencies in the federal health enterprise to “speak the same language” based on common enterprise-wide business and information technology architectures” (from the egov Government to Business portfolio).

CHI’s influence in the rest of the healthcare industry is huge. Adoption of standards at the federal level will establish a primary driver and provide the lead industry has been anticipating for a long time.

CHI includes 24 categories (or domains) of messaging and standard health information identified by an OMB led intergovernmental workgroup. It evaluates existing standards appropriate for each domain through interagency teams; develops consensus within the Council membership around these standards based on domain team recommendations; recommends specific standards for each domain to the NCVHS; commits agencies to adopt the NCVHS approved standard within their Information Technology Architecture.

CHI Council is composed of 23 Federal Agencies that are major health data producers and consumers. CMS leads the Council and the Secretary of HHS issues the standards after NCVHS recommends their adoption. NCVHS is permanent advisory board to the Secretary of HHS on a wide range of health data and communication issues; its membership includes government, academia, private foundations, and business organizations.

Information about the CHI project can be found at:

http://www.whitehouse.gov/omb/egov/gtob/health_informatics.htm

Detailed Descriptions of each Domain and the basis for the CHI Council\NCVHS Recommendations can be found at: <http://www.ncvhs.hhs.gov/> **Standards CHI Announced on March 21, 2003**

On March 21, 2003, the Departments of Health and Human Services, Defense, and Veterans Affairs announced the first set of uniform standards for the electronic exchange of clinical health information to be adopted across the federal government.

The standards all federal agencies will adopt are:

- **Health Level 7® (HL7®)** messaging standards to ensure that each federal agency can share information that will improve coordinated care for patients such as **entries of orders, scheduling appointments and tests and better coordination of the admittance, discharge and transfer of patients.**
- **National Council on Prescription Drug Programs (NCDPC)** standards for ordering drugs from retail pharmacies to standardize information between health care providers and the pharmacies. These standards already have been adopted under the Health Insurance Portability and Accountability Act (HIPAA) of 1996, and ensures that parts of the three federal departments that aren't covered by HIPAA will also use the same standards.
- The **Institute of Electrical and Electronics Engineers 1073 (IEEE1073)** series of standards that allow for health care providers to plug medical devices into information and computer systems that allow health care providers to monitor information from an ICU or through telehealth services on Indian reservations, and in other circumstances.

- **Digital Imaging Communications in Medicine® (DICOM®)** standards that enable images and associated diagnostic information to be retrieved and transferred from various manufacturers' devices as well as medical staff workstations.
- Laboratory **Logical Observation Identifier name Codes® (LOINC®)** to standardize the electronic exchange of clinical laboratory results.

Additional Standards Announced on May 6, 2004:

On May 6, 2004, the Departments of Health and Human Services, Defense, and Veterans Affairs announced the adoption of **15 additional standards** agreed to by the CHI initiative to allow for electronic exchange of clinical information across the federal government. **The 15 new standards build on the existing set of five standards adopted by HHS in March 2003 and complete the first phase of the CHI initiative.** The new standards agreed to by federal agencies will be used as agencies develop and implement new information technology systems.

The specific new standards are:

- **Health Level 7® (HL7®) vocabulary standards for demographic information, units of measure, immunizations, and clinical encounters, and HL7®'s Clinical Document Architecture standard** for text based reports. (Five standards)
- The College of American Pathologists **Systematized Nomenclature of Medicine Clinical Terms® (SNOMED CT®)** for laboratory result contents, non-laboratory interventions and procedures, anatomy, diagnosis and problems, and nursing. HHS is making SNOMED-CT® available for use in the U.S. at no charge to users. (Five standards)
- **Laboratory Logical Observation Identifier Name Codes® (LOINC®)** to standardize the electronic exchange of laboratory test orders and drug label section headers. (One standard.)
- The **Health Insurance Portability and Accountability Act (HIPAA)** transactions and code sets for electronic exchange of health related information to perform billing or administrative functions. These are the same standards now required under HIPAA for health plans, health care clearinghouses and those health care providers who engage in certain electronic transactions. (One standard.)
- A set of federal terminologies related to medications, including the Food and Drug Administration's names and codes for ingredients, manufactured dosage forms, drug products and medication packages, the National Library of Medicine's RxNORM for describing clinical drugs, and the Veterans Administration's **National Drug File Reference Terminology (NDF-RT)** for specific drug classifications. (One standard.)
- The **Human Gene Nomenclature (HUGN)** for exchanging information regarding the role of genes in biomedical research in the federal health sector. (One standard.)

- The **Environmental Protection Agency's Substance Registry System** for non- medicinal chemicals of importance to health care. (One standard.)

- CFH (Connecting for Health) Collaborative

Connecting for Health was established by the Markle Foundation and receives additional funding and support from the Robert Wood Johnson Foundation. Connecting for Health is a public-private collaborative designed to **address the barriers to development of an interconnected health information infrastructure**. Connecting for Health is currently working to develop an incremental Roadmap intended to lay out near-term actions necessary to achieving electronic connectivity.

CFH Phase I (June 2002 - January 2004)

The first phase of the Collaborative's work drove consensus on the adoption of an initial set of data standards, developed case studies on privacy and security, and helped define the electronic personal health record (PHR). To carry out its work, Connecting for Health has organized several working groups focusing on understanding the business and organizational issues of community-based information exchange, the issues relevant to sharing electronic information with patients, and several aspects of technical interoperability. In September 2002, Connecting for Health's Steering Group agreed for the first time on the voluntary adoption of an initial set of data standards and communications protocols for the sharing of healthcare information. The U.S. government announced its adoption of these same standards in March 2003.

Connecting for Health announced unprecedented progress in several key areas including:

- Developing a set of overarching principals to guide ongoing work.
[*The Steering Group Key Themes and Guiding Principle*](#)
- Achieving consensus on an initial set of healthcare data standards and commitment for their adoption from a wide variety of national healthcare leaders, including a number of federal government agencies.
[*The Data Standards Working Group Report and Recommendations*](#)
- Identifying and studying a number of noteworthy privacy and security practices in order to describe and disseminate feasible solutions currently in use.
[*The Privacy and Security Working Group Report and Findings*](#)
- Defining the key characteristics and benefits of consumer-controlled Personal Health Records (PHRs), addressing consumer concerns to allow people to have better access to their health information.
[*The Personal Health Working Group Final Report*](#)

The Healthcare Collaborative Network (HCN) experiment

Discussed on pps 61-66 of the report [*The Data Standards Working Group Report and Recommendations*](#) . The report also includes **a long list of recommendations/action items by stakeholder group.**

The North Carolina Emergency Department Database (NCEDD)

Discussed on pps 21-24 of the report [The Privacy and Security Working Group Report and Findings](#). *The needs of public health have been taken into consideration.*

This report recognizes the **connection between personal, clinical and public health dimensions as critical** and advocates that close facilitation between them is imperative (pg. 42 of the report [The Personal Health Working Group Final Report](#)).

CFH Phase II – (January 21, 2004 -)

CFH announced it will launch a continuation of its effort to promote electronic connectivity in the healthcare field in order to improve patient care and lower costs while protecting patient privacy. The Steering Group committed to create an incremental Roadmap to achieving electronic connectivity. The Roadmap is necessary for prioritizing actions, fostering innovation and leveraging efforts across the public and private sector. Connecting for Health, which was established by the Markle Foundation, also announced that the Robert Wood Johnson Foundation would be joining Markle as a funding partner in the next phase of its work.

Connecting for Health brings with it a continued commitment from many of the nation's foremost leaders in the public and private sector. The Connecting for Health Steering Group is led by Daniel Garrett, vice president and managing director of Computer Sciences Corporation's Global Health Solutions Practice; Herb Pardes, M.D., President and CEO, New York-Presbyterian Hospital; John Lumpkin, M.D., MPH, Senior Vice President for Health Care, Robert Wood Johnson Foundation; and Carol Diamond, M.D., MPH, Managing Director, Markle Foundation's Information Technology for Better Health Program. Janet Marchibroda, Executive Director of the Foundation for the eHealth Initiative serves as the Executive Director.

Connecting for Health will now build on the ground-breaking achievements of its earlier work by identifying, tackling and testing solutions to the technical and policy barriers. Under a plan developed by the Steering Group, Connecting for Health will accomplish its work through four new working groups and a demonstration project. Specific goals of Phase II include:

1. A Roadmap detailing an action agenda of achievable objectives over the next twelve months that will leverage activities between public and private healthcare sectors toward a health information infrastructure that fosters innovation, encourages information sharing, and provides exchange of necessary health information in a private and secure manner.
2. Challenging barriers that impede patient-centered information sharing within a series of Working Groups. Specific areas of focus will be on understanding

the business and organizational issues of community-based information exchange, the issues relevant to sharing electronic information with patients, and certain aspects of technical interoperability. (For more detail on the working groups, see www.connectingforhealth.org.) The working groups and their leaders are:

- *Working Group on Electronic Health and Personal Health Record* chaired by: David Lansky PhD, president of the Foundation for Accountability -FACCT.
 - *Working Group on Accurately Linking Health Information for Safety and Quality* chaired by Clay Shirky, Adjunct Professor New York University Interactive Telecommunications Program
 - *Expert Panel on Organizational Models and Financial Sustainability of Community-Based Health Information Exchange* chaired by David Brailer, MD, PhD, Senior Fellow for Information Technology and Quality of Care at the Health Technology Center
 - *Expert Panel on Data Exchange Standards* chaired by Wes Rishel, Vice President and Research Area Director, Gartner and Past Chair HL-7
3. A Demonstration Project is planned to test and evaluate the working groups' products in real-world settings.

SHORT TERM RECOMMENDATION 2

-Establish standard set of patient characteristic linker variables and accompanying logical methods for matching patients for population health studies. Match can tolerate <100% accuracy.

Lead organizations identified by 2003 Conference:

-AHRQ, NIST, CDC

Progress made in the last year:

- Indianapolis Research

Out of Indianapolis comes the only published research we identified about linking patients in the context of a Local Health Information Infrastructure.

Grannis SJ, Overhage JM, Hui S, McDonald CJ. Analysis of a Probabilistic Record Linkage Technique without Human Review. Proc AMIA Symp. 2003;;259-63.

Abstract: We previously developed a deterministic record linkage algorithm demonstrating sensitivities approaching 90% while maintaining 100% specificity. Substantially better performance has been reported using probabilistic linkage techniques; however, such methods often incorporate human review into the

process. To avoid human review, we employed an estimator function using the Expectation Maximization (EM) algorithm to establish a single true-link threshold. We compared the unsupervised probabilistic results against the manually reviewed gold-standard for two hospital registries, as well against our previous deterministic results. At an estimated specificity of 99.95%, actual specificities were 99.43% and 99.42% for registries A and B, respectively. At an estimated sensitivity of 99.95%, actual sensitivities were 99.19% and 98.99% for registries A and B, respectively. The EM algorithm estimated linkage parameters with acceptable accuracy, and was an improvement over the deterministic algorithm. Such a methodology may be used where record linkage is required, but human intervention is not possible or practical.

Since this approach can be used without human review, it would be appropriate for record linking in the context of population health and is summarized below.

With respect to this recommendation, this and other papers on probabilistic record linkage (the most accurate way to do it) indicate that the set of variables to use and how to match them to achieve the highest level of accuracy is highly dependent on the data being linked. A standard that recommends a single set of variables and a single set of rules for linking data is thus unlikely to work, but a standard could recommend techniques and methods to identify sets of variables/rules for a given dataset. In addition, data sets come with their own list of regulations which often limit what variables can be used and how and many times certain “expected” variables are not even available.

- CDC Efforts

There have been efforts within various CDC programs to encourage and support (through programmatic grant funding) development of best practices in the area of record linking and probabilistic matching algorithms. They have yet to be taken to the national scale.

SHORT TERM RECOMMENDATION 3

-Establish national registry of data definitions, data sets, and metadata for population health.

Lead organizations identified by 2003 Conference:

-HL7, LOINC, NLM (UMLS), NIH

Progress made in the last year:

- HL7 and LOINC

These are de-facto registration authorities for the data content included in their domain of standards. They are expected to be the registration authorities for their areas in the U.S. HIK registry (see below).

- NLM and Unified Medical Language System (UMLS)

Was unable to find evidence of any activity or progress that leverages the standard nomenclatures in NLM's Unified Medical Language System or the UMLS Metathesaurus. If someone did, they did not identify the activity as such.

- U.S. HIK(United States Health Information Knowledgebase):

<http://www.usihk.org/registry/USHIKmain.html>

The United States Health Information Knowledgebase (USHIK) is the metadata registry administered and operated by the Health Informatics Standards Board (HISB), to assist in cataloging and harmonizing data elements across health care Standards Development Organizations (SDO) and other interested health care organizations.

Initiated by HCFA in, or about 2000-2001 in relation with HIPAA. It models a very successful effort in Australia. They will soon be loading HL7 V2.5 and will synchronize with V3.0 when it becomes available. (Currently the USHIK is working off HL7 V1.1). They are looking to load the ADA Clinical Model soon.

The National Alliance for Health Information Technology (NAHIT)

announced on June 7, 2004 (see

<http://www.nahit.org/nahit/content/hitsdirrelease.doc>) that it was making freely available to the public access to its directory of healthcare IT standards. To access the directory, go to <http://www.hitsdir.org/>. The directory contains information about 850 voluntary and mandatory standards and links to over 200 standards development organizations.

SHORT TERM RECOMMENDATION 4

-Develop incentives for data providers to conform to NHII standards and make data available for population health (e.g. Make participation required to receive funding, distribute direct financial incentives, allow equal access to data if they contribute).

Lead organizations identified by 2003 Conference:

-NIH

Progress made in the last year:

- CMS Incentives for EHR-S adoption and use by Healthcare Providers

HHS is the provisions in the recently enacted Medicare Modernization Act to encourage electronic prescribing by physicians participating in Medicare through the use of standards and incentives. Additional provisions of the Medicare Modernization Act support demonstrations providing incentives for physician practices to improve the quality and safety of care for Medicare beneficiaries through effective implementation of selected HIT systems, in up to four States. HHS is preparing a report on options to create incentives in Medicare or other HHS programs to encourage the adoption of interoperable electronic health records and e-prescribing.

- AHRQ Funding for Clinical Data Exchange (Regional and State) Projects

This year, the Agency for Healthcare Research and Quality (AHRQ) will spend \$50 million on health information technology research and demonstration projects aimed at improving the safety, quality, efficiency and effectiveness of care.

- HRSA and CDC Bioterrorism preparedness funding to states

Provides funding for public health agencies and hospitals to enhance their infrastructure to support BT readiness.

SHORT TERM RECOMMENDATION 5

-Develop communications and marketing plans to facilitate alliances in the population health communities

Lead organizations identified by 2003 Conference:

-AHRQ, CDC, ASPE/NHII

Progress made in the last year:

-This recommendation was too non-specific to allow for a focused progress report.

MEDIUM TERM RECOMMENDATION 1

-Develop procedures, processes, and guidelines to ensure that the research community will communicate knowledge back to the public to improve personal health decisions.

Lead organizations identified by 2003 Conference:

-AHRQ, CDC, NIH

Progress made in the last year:

- The Population Health topic group should consider whether this recommendation should be retained since communicating information to the public is already core function of the public health system.

MEDIUM TERM RECOMMENDATION 2

-Funding and leadership for population health in NHII should come from state and local governments and private sector, as well as federal agencies.

Lead organizations identified by 2003 Conference:

- None

Progress made in the last year:

- AHRQ Funding for Clinical Data Exchange (Regional and State) Projects

see description under Short Term Recommendation #4

- HRSA and CDC Bioterrorism preparedness funding to states

see description under Short Term Recommendation #4

- 2004 NHII Conference Population Health Topic Group and Public Health Stakeholder Group

NHII actively solicited participation from state and local governments and the private sector for the 2004 conference.

NEW RECOMMENDATIONS TO BE CONSIDERED FOR 2004

- HHS should clarify the role of NHII/LHII in the development of a national public health information system.

-HHS should solicit explicit support for NHII/LHII development from all federal health agencies, state and local public health departments and their national organizations, schools of public health, and leading clinical quality improvement organizations.

- The architecture of the NHII should support real-time communication to public health of various health events of interest, such as de-identified syndromic data and reportable diseases.

| - The architecture of the NHII should support, and promote the development of standards for, the communication of data and information (in a machine-readable format) about relevant public-health events from public health information systems to electronic health records to support clinical decision making in the context of a public health event.

| - HHS should increase funding for research into record linkage techniques that can serve population health purposes in the context of NHII.

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