PUBLIC HEALTH DATA
STANDARDS CONSORTIUM

**PHDSC**

Promoting Standards Through Partnerships

BUILDING A ROADMAP FOR HEALTH INFORMATION SYSTEMS
INTEROPERABILITY FOR PUBLIC HEALTH

(Public Health Uses of
Electronic Health Record Data)

WHITE PAPER

2007

CONTENTS

## PHDSC - IHE Task Force Participants

| | Name | Affiliation |
|---|---|---|
| 1 | Ali, Mohamad Arif | Allegheny General Hospital |
| 2 | Arzt, Noam | HLN Consulting, LLC |
| 3 | Baker, Dixie | SAIC |
| 4 | Baldwin-Stried, Kimberly | Health Care Compliance Professional |
| 5 | Boone, Keith | GE Healthcare |
| 6 | Carney, Timothy Jay | Indiana University School of Informatics |
| 7 | Chan, Helen | Public Health Laboratories |
| 8 | Correll, Pamela | State of Maine Public Health |
| 9 | Dobbs, David | SAIC |
| 10 | Elkin, Peter | Mayo Clinic |
| 11 | Finitzo, Terese | OZ Systems |
| 12 | Fourquet, Lori | eHealthSign |
| 13 | Franck, Richard | IBM |
| 14 | Goldwater, Jason | SRA International |
| 15 | Green, Jim | LA County Department of Public Health |
| 16 | Greenberg, Marjorie | CDC/ National Center for Health Statistics |
| 17 | Haas, Janet | NYU Hospitals Center |
| 18 | Handler, Eric | Health Care Agency for Orange County |
| 19 | Hanrahan, Lawrence | Wisconsin Dept. of Health and Family Services |
| 20 | Hayes, William | Health Policy Institute of Ohio |
| 21 | Helmus, Lesliann | Virginia Dept. of Health |
| 22 | Hickey, Michael | LA County Health Services Administration |
| 23 | Hill, Michael | San Joaquin County Public Health Services |
| 24 | Honey, Alan | HL7/OMG HSSP |
| 25 | Jenders, Robert | UCLA/Cedars-Sinai Medical Center |
| 26 | Keating, Patrick | Pennsylvania Department of Health |
| 27 | Kern, Linda | Pinellas County Health Dept. |
| 28 | Kirnak, Alean | SW Partners |
| 29 | Klein, Gunnar | Karolinska Institutet, Sweden |
| 30 | Klein, Sally | Fox Systems |
| 31 | Knoop, Sarah | IBM |
| 32 | Kumar, Manoj | BlueCross BlueShield of Florida |
| 33 | Landry, Laura | Long Beach Dept of Health and Human Svcs |
| 34 | Lawton, David | Nebraska Health & Human Services System |
| 35 | Le, Linh | New York State Dept. of Health |
| 36 | Leitner, Johann | Advanced Business Software |
| 37 | Lipkind, Karen | CDC/NCHS |
| 38 | Lober, Bill | University of Washington |
| 39 | Lou, Jennie | Nova Southeastern University |
| 40 | Lozzio, Carmen | University of Tennessee School of Medicine |
| 41 | Maizlish, Neil | Public Health Division, City of Berkley |
| 42 | Martin, Karen | Martin Associates |
| 43 | McCord, Dave | TM Floyd & Company |

| 44 | Monsen, Karen | Washington Colorado Public Health and Environment |
| 45 | Onaka, Alvin | Hawaii Department of Health |
| 46 | Orlova, Anna | PHDSC & Johns Hopkins University |
| 47 | Parykaza, Marcy | Delaware Division of Public Health |
| 48 | Raimondi, Mary Pat | CareFacts |
| 48 | Ram, Roni | IBM |
| 49 | Renly, Sondra | IBM |
| 50 | Ross, Will | Mendocino Informatics |
| 51 | Sailors, R. Matthew | Methodist Hospital, Houston, TX |
| 52 | Salkowitz, Sue | American Immunization Registries Association |
| 53 | Savage, Rob | American Immunization Registries Association |
| 54 | Sniegoski, Carol | JHU Applied Physics Lab |
| 55 | Snow, Laverne | University of Utah |
| 56 | Staes, Catherine | University of Utah |
| 57 | Suarez Walter | PHDSC & Institute for HIPAA and HIT Education |
| 58 | Sumner, Walt | Washington Univ. School of Medicine, St. Louis |
| 59 | Sutliff, Cindy | American Immunization Registries Association |
| 60 | Thames, Sandy | CDC/ NCCDPHP |
| 61 | Tilden, Chris | Kansa Dept of Health and Environment |
| 62 | Tsai, Christopher | Brigham & Woman's Hospital |
| 63 | Wangia, Victoria | University of Kansas |
| 64 | Williamson, Michelle | CDC National Center for Health Statistics |
| 65 | Xu, Wu | Utah Department of Health |
| 66 | Zimmerman, Amy | Rhode Island Department of Health |

## Executive Summary

The development of this White Paper has been facilitated by the Public Health Data Standards Consortium (PHDSC)[1] and the Integrating the Healthcare Enterprise (IHE).[2] The White Paper was developed by the participants of the PHDSC-IHE Task Force. The information in this document represents the views of the individual Task Force participants and may not represent the views of their organizations.

The overall goal of this effort is to facilitate standardization of health information exchanges between clinical care and public health. The objective is to engage the public health community in a dialogue with health information technology (HIT) vendors to assure that the work processes and data needs of public health stakeholders in health information exchanges are 1) well understood and agreed upon by stakeholders themselves, and then (2) communicated clearly to the developers of the interoperable clinical Electronic Health Record (EHR) systems and Public Health information systems (EHR-PH Systems).

The White Paper consists of three sections. The first section describes public health and population health practices of public health agencies that require health information exchanges with clinical care. The second and third sections describe Immunization and Cancer Surveillance domains in the IHE Technical Tasks for Information Exchanges outline. The Appendix section contains the description of examples of other public health domains (research, chronic care, personal health record, surveys, obesity, cancer, etc.).

The PHDSC-IHE Task Force participants believe that this effort will result in the formation of a Public Health Domain at IHE to begin collaboration between public health and HIT vendor communities to guide the development of the *IHE Integration Profiles* for the Electronic Health Record Systems to enable electronic information exchanges between clinical and public health settings. So, this White Paper serves as a framing document for the creation of the Public Health Domain at IHE.

***PHDSC and IHE invite public health experts to review the White Paper.***

During the review period, we would like to invite representatives of public health domains/programs to submit a description of their domains/programs using the IHE Technical Tasks for Information Exchange outline, so the final White Paper can include other examples of public health domains in addition to the immunization and cancer surveillance domains. This will help to identify potential public health domains/programs for the development of the *IHE Integration Profiles* in the upcoming year(s).

***We also would like to invite the reviewers to join our Task Force to participate in the formation of a Public Health Domain at IHE to begin collaboration between public health and HIT vendor communities to guide the development of the IHE Integration Profiles for the Electronic Health Record Systems, to enable electronic information exchange between clinical and public health settings.***

---

[1] Public Health Data Standards Consortium (PHDSC). URL: http://www.phdsc.org
[2] Integrating the Healthcare Enterprise (IHE). URL: http://www.himss.org/ASP/topics_ihe.asp

## What is Public Health

**Mission**
The mission of public health is to protect the public from health threatening diseases, assure disease prevention by providing access to care for individual patients, promote and restore wellness, and "to assure the conditions in which people may be healthy."[3]

*The patient-centric mission of public health* is carried out using publicly-funded healthcare services. Vulnerable or at-risk patients may receive patient care services directly in their homes or at a health clinic funded by a public health agency. There are community health centers funded in the US by the Health Resources and Services Administration (HRSA) that provide a safety net for low income families. Public health funds may also be used to pay for and provide laboratory, pharmacy and other services for eligible populations. In this role, public health care is similar to private health care.

*The population-based mission of public health* is carried out on various levels of government. The public health infrastructure includes agencies that operate on a local, state and/or federal level. In the US, there are 3000 local health departments, 50 state health departments and several federal health agencies, including the Centers for Disease Control and Prevention (CDC), Agency for Healthcare Research and Quality (AHRQ), Indian Health Service (IHS), and many others. In some states, the state health agency plays the key role in delivering services to communities; in other states, local health departments take the leading role. In some jurisdictions, public/private partnerships or other organizational entities may be involved in delivering public health services (*e.g.*, immunization coalitions – community-based groups that include parents).

**Stakeholders**
To fulfill its population-based and patient-centric mission, public health is represented by at least the following stakeholders:

- Population at large
- Public health practitioners (including epidemiologists, environmental health specialists, health educators, public health nurses, administrators)
- Health care providers (including, but not limited to, publicly-delivered healthcare providers, e.g., safety net clinic)
- Laboratories
- Payers
- Healthcare purchasers
- Pharmacies
- Other governmental agencies (e.g., environmental, law enforcement)
- Professional Associations
- Research institutions
- Individual consumers, particularly vulnerable populations.

---

[3] Institute of Medicine. Future of Public Health. Report. 2002. 2nd edition. URL: http://www.iom.edu/?id=15251

## Public Health Organization

During the past 40 years, the population-based services of public health have been delivered using a categorical disease-specialized and services-specific domain approach. For example, public health agencies usually include the following programmatic areas and services: communicable disease control, lead poisoning prevention, vital registration, injury control, mental health services, substance abuse prevention and treatment, chronic disease prevention, newborn screening, immunizations, etc. (Tables 1 and 2).[4] This domain-specific organization of public health is supported by funding allocations that in turn shape the disease/domain-specific organizational structure of public health agencies, public health research activities, and workforce training.[5]

Table 1. Personal Health, Population Level Assurance and Environmental Health Services Provided by Local Health Departments (LHD)[6,7]

| Personal Health Services | LHDs Providing Service, % | Population Level Assurance Services | LHDs Providing Service, % | Environmental Health Services | LHDs Providing Service, % |
|---|---|---|---|---|---|
| Adult immunization | 91% | Communicable Disease surveillance | 89% | Food service regulation | 76% |
| Childhood immunization | 90% | Tuberculosis screening | 85% | Public swimming pool regulation | 67% |
| Tuberculosis treatment | 85% | Environmental Health surveillance | 75% | Septic tank installation | 66% |
| Sexually transmitted disease (STD) treatment | 61% | High blood pressure screening | 72% | Schools/daycare centers | 65% |
| Women, Infant & Children (WIC) | 67% | Tobacco use prevention | 69% | Private drinking water protection | 57% |
| Family Planning Services | 58% | HIV/AIDS screening | 67% | Lead inspections | 53% |
| Outreach and enrollment for medical insurance | 42% | Blood lead screening | 66% | Hotels/motels regulation | 49% |
| EPSDT | 46% | Sexually transmitted disease screening | 64% | Campgrounds/ RVs regulation | 39% |
| Prenatal care | 40% | Obesity prevention | 56% | Smoke-free ordinances | 38% |
| Oral health care | 31% | Vector control | 54% | Groundwater / surface water protection | 40% / 33% |

---

[4] Lasker RD, editor. Medicine and public heath: the power of collaboration. 1997. New York, NY.

[5] Burke TA, Shalauta NM, Tran NL, Stern BS. The environmental Web: a national profile of the state infrastructure for environmental health and protection. J Public Health Manag Pract; 3(2):1-12.

[6] Scutchfield, F.D., & Keck, C.W. Principles of public health practice, 2nd ed. 2003. Thomson/Delmar Learning: Clifton Park, NY.

[7] 2005 National Profile of Local Health Departments, National Association of County & City Health Officials, July 2006. www.naccho.org

| Personal Health Services | LHDs Providing Service, % | Population Level Assurance Services | LHDs Providing Service, % | Environmental Health Services | LHDs Providing Service, % |
|---|---|---|---|---|---|
| Obstetrical care | 32% | Diabetes screening | 51% | Public drinking water protection | 30% |
| Laboratory services | 32% | Unintended pregnancy prevention | 51% | Health-related facilities regulation | 30% |
| Home health care | 28% | Cancer screening | 46% | Food processing | 30% |
| School-based clinics | 25% | School health activities | 41% | Mobile homes / housing inspections | 29% |
| HIV/AIDS treatment | 26% | Chronic disease surveillance | 41% | Indoor air quality activities | 29% |
| Correctional health | 20% | Injury control | 40% | Solid waste disposal regulation | 28% |
| Comprehensive primary care | 14% | Cardiovascular disease screening | 36% | Tobacco retailers | 21% |
| Behavioral/mental health services | 13% | Behavioral risk factors surveillance | 36% | Animal Control | 21% |
| Substance abuse services | 11% | Syndromic surveillance | 33% | Hazardous material response | 19% |
| Emergency medical services | 7% | Substance abuse prevention | 26% | Hazardous waste disposal | 18% |
|  |  | Violence prevention | 25% | Land use planning | 16% |
|  |  | Injury surveillance | 24% | Noise pollution | 14% |
|  |  | Mental illness prevention | 14% | Occupational safety & health activities | 12% |
|  |  |  |  | Radiation control | 10% |

Table 2. Examples of Healthcare and Public health Responsibilities of State Health Departments (SHD)[8]

| Responsibilities | SHDs Providing Service,% | Responsibilities | SHDs Providing Service,% |
|---|---|---|---|
| **Healthcare Responsibilities** | | | |
| Public health laboratory | 79 | Medical examiner | 21 |
| Rural health | 79 | State mental health authority | 19 |
| Children with special healthcare needs | 77 | State public health licensing agency | 17 |
| Minority health | 72 | State mental institution or hospital | 17 |
| Institutional licensing agency | 60 | Partial/split responsibility for Medicaid | 17 |
| State health planning & development agency | 53 | Medicaid state agency | 15 |
| Partial/split leadership of environmental agency | 51 | Lead environmental agency | 15 |
| Public health pharmacy | 34 | State tuberculosis hospital | 15 |
| State nursing home | 28 | Health insurance regulation | 15 |
| **Public Health Responsibilities** | | | |
| State public health authority | 97 | Disaster Preparedness | 77 |
| Newborn Screening | 100 | Perinatal Epidemiology | 77 |
| Immunizations | 87 | Violence Prevention | 68 |
| Bioterrorism | 89 | Emergency Medical Services Regulation and Service Provision | 64 |
| Injury Control Epidemiology | 87 | Quality Improvement or Performance Measurement | 62 |
| Injury Control & Prevention | 87 | Toxicology | 57 |
| Breast and Cervical Cancer Screening | 87 | Breast and Cervical Cancer Treatment | 45 |
| Chronic Disease Epidemiology | 85 | Radon Control | 55 |
| Tobacco Control and Prevention | 83 | Institutional Review Board | 45 |
| Cancer Epidemiology | 83 | State Title XXI Children's health Insurance Initiative | 28 |
| Environmental Epidemiology | 79 | | |

---

[8] Beitsch LM et al. Structure and functions of state public health agencies. APHA. 2006:96(1):167-72

**Public Health Functions**

As a health care provider, public health clinics carry out all functions of a health care delivery system.

As a governmental agency, public health is mandated to protect and improve the health of all people within a legal jurisdiction. It regulates healthcare services and coordinates healthcare delivery and resources allocation. The activities of public health agencies are focused on the following three core functions and ten essential services[9,10]:

*Assessment*
- Monitor health status <individual, community/population> to identify community health problems;
- Diagnose and investigate health problems and health hazards in the community;
- Evaluate effectiveness, accessibility, and quality of personal and population-based health services;
- Research for new insights and innovative solutions to health problems

*Policy development and implementation*
- Develop policies and plans that support individual and community health efforts
- Inform, educate, and empower people about health issues
- Mobilize community partnerships to identify and solve health problems

*Assurance*
- Enforce laws and regulations that protect health and ensure safety
- Assure a competent public health and personal health care workforce.
- Link people to needed personal health services and assure the provision of health care when otherwise unavailable

**Public Health Data Sources**

Individual-patient clinical data comprises a large portion of data used to conduct communicable disease surveillance, case investigation, case management, and care coordination. Aggregated clinical data are used to perform surveillance to detect public health threat events and monitor the population's health status. To fulfill the goal of protecting the public's health, health care providers and public health agencies need the capability to exchange pertinent health information about individuals and communities.

In addition to clinical data, other data sources are needed for public health decision making. For example, public health practitioners use environmental data, housing data, socio-economic data, geographic data, as well as information generated from surveys and research activities to meet the goals of public health programs.[11]

---

[9] Institute of Medicine. Committee for the Study of the Future of Public Health, 1988.
[10] Public Health Foundation. URL: www.health.gov/phfunctions/public.htm
[11] Yasnof W, Overhage J, Humphrey B, LaVenture M. A national agenda for public health informatics. J Am Med Inf Ass 2001;8(6):535-45.

Table 3 provides a non-exhaustive list of examples of public health categorical domains, stakeholders, core functions, services and interventions, data sources and data types.[12]

Table 3. Examples of Domains, Stakeholders, Functions, Services & Interventions, Data Sources & Public Health

| Domains | Stakeholders | Core Public Health Functions | Essential Services & Interventions | Data Sources | Data Types |
|---|---|---|---|---|---|
| Infectious diseases<br>Injury/Trauma<br>Sexually transmitted diseases<br>Consumer product safety<br>Environmental health<br>Occupational health<br>Substance abuse<br>Mental health<br>Chronic diseases<br>Bioterrorism<br>Disability | Elected official<br>Policy maker<br>Health Department<br>Researcher<br>Private sector<br>Clinician<br>Educator<br>Citizen<br>Community<br>Population<br>Community-based organiza-tions | Assessment<br><br>Policy development and implementa-tion<br><br>Assurance | Monitoring<br>Surveillance<br>Screening<br>Survey<br>Risk assessment<br>Policy research<br>Policy development and implementation<br>Regulation<br>Outreach<br>Case management<br>Advocacy<br>Social Marketing<br>Education<br>Evaluation | Physician's office patient medical record<br>Registries<br>Patient hospital records<br>Emergency Medical Services records<br>Governmental regulations and guidelines<br>Research databases<br>Peer-reviewed and non-peer-reviewed literature<br>Population-based surveys<br>Client surveys | Demographic Data<br>Healthcare Data:<br>✓ History<br>✓ Physical Exam (PE)<br>✓ Lab (Results, Orders)<br>✓ Procedure Notes<br>✓ Radiology (Results, Orders)<br>✓ Medication Prescriptions<br>✓ Nursing notes<br>✓ Impressions<br>Resource Data<br>✓ Types<br>✓ Costs<br>✓ Personnel Management<br>✓ Resources Management<br>Environmental Data<br>Housing Data<br>Socio-Economic Data<br>Other |

Appendices 1-9 provide brief descriptions of the following examples of public health domains/programs:

Appendix: Examples of Public Health Domains/Programs

| | | | |
|---|---|---|---|
| 1 | Research | 6 | Trauma Registries |
| 2 | Personal Health Record (PHR) | 7 | Chronic Diseases |
| 3 | Cancer Surveillance | 8 | Birth and Death Registries |
| 4 | Patient Safety and Population Health Perspectives | 9 | Obesity |
| 5 | Surveys | | |

---

[12] Orlova AO and Lehmann HR. A UML-based meta-framework for system design in public health informatics. AMIA 2002 Symposium Proceedings, November 9-13, San-Antonio, TX: 582-586.

**Health Information Technology in Public Health**

For many decades, public health agencies and research institutions have been utilizing information technology (IT) to facilitate data management activities (data gathering, analysis, reporting, etc.). Public health information systems are created to support specific needs of disease-specific program areas within health departments, i.e., newborn screening, birth defects, vital registration, immunization, communicable disease surveillance, chronic disease surveillance, school health, injury prevention, preparedness, etc. (Tables 1 & 2). These systems deploy various software products that are often custom-made and are not interoperable. Many of these systems contain redundant data; however, the varying data formats and standards preclude data integration across systems for public health decision support and research. These sytems lack the ability to provide real-time data back to providers for care coordination and disease prevention. The sections below describe the public health data gathering activities of clinical data that represent the major portion of public health data of interest.

Current Practices on Data Reporting from Clinical Settings to Health Department Programs

Most public health information systems are populated with data reported by health care providers. There is mandatory data reporting to CDC on 62 notifiable infectious diseases across all 50 states in the US[13].This data is reported by clinicians to their local health departments. The latter reports this data to the state health department that in turn reports this data to CDC.  In addition, various jurisdictions require clinicians to also report data on the conditions that are of interest for a specific jurisdiction (reportable conditions). Besides infectious disease reporting, various other public health programs receive data from clinician, e.g., immunization registries, chronic disease registries, etc. In some jurisdictions, clinicians are expected to report data to both their local health department programs and their state health department programs.

In many jurisdictions, data is currently reported using paper forms sent by fax or mail. For example in one state, providers (primary and emergency physicians) need to report data on 62 notifiable (mandatory) conditions and 32 reportable (state-specific) conditions using (a) over 50 various disease-specific Adobe Acrobat-generated paper forms required by the state communicable diseases surveillance system. This is in addition to providing data to other numerous programs maintained by the state health department. Lack of integration and interoperability across public health systems leads to the duplication of efforts and frustration among providers and consumers asked to provide the same information on multiple forms of varying formats to various programs. None of these activities are reimbursed by health insurance.

According to the national data, public health data systems currently suffer from limitations such as underreporting (only 49% of cases are getting reported to public health agencies),[14,15] lack of

---

[13] Centers for Disease Control and Prevention (CDC). Nationally Notifiable Infectious Diseases. URL: http://www.cdc.gov/EPO/DPHSI/phs/infdis.htm

[14] Campos-Outcalt D, England R, Porter B. Reporting of communicable diseases by university physicians. Public Health Rep 1991;106:579-583.

[15] Marier R. The reporting of communicable diseases. Am J Epidemiol 1977;105:587-590.

representativeness, lack of timeliness, inconsistency of case definitions across systems, inability to integrate data across the systems, etc.[16,17]

Figures. 1a-d present schematic views of paper-based data reporting by healthcare providers to various public health data systems at the State and local levels. These views may also be applicable to any web-based data reporting to individual public health data systems maintained by the programs.

EHR-based Health Information Exchanges between Clinical Care and Public Health
Because of the automation of clinical data – inpatient and increasingly outpatient – via the Electronic Health Record Systems (EHRS), public health programs stand at the threshold of change in the way in which they gather programmatic data.

Many of the information systems used by local health departments are not capable of exchanging data through RHIOs or with health care service delivery agencies. Many of them are not capable of sending/receiving HL7 messages and cannot or do not comply with other nationally accepted vocabularies and standards. In addition, many of the systems are not configured to serve as an electronic medical record to receive information from physicians; this restricts their ability to contribute to a longitudinal health care record for those clients for whom they serve as a primary care provider Nationally, electronic health record systems are beginning to be certified taking into account these considerations. The issue of compatibility/interoperability of these systems with public health systems to be able to send, receive and exchange relevant data for both public health and clinical practice needs to be addressed.[18]

---

[16] Centers for Disease Control and Prevention (CDC). Lesson Five: Public Health Surveillance. Principles of Epidemiology in Public Health Practice. Third Edition (Print-based). 336-409. Available at: http://www.cdc.gov/training/products/ss1000/ss1000-ol.pdf . Last accessed November 29, 2006.
[17] Konowitz PM, Petrossian GA, Rose DN. The underreporting of disease and physicians' knowledge of reporting requirements. Public Health Rep 1984;99:31-35.
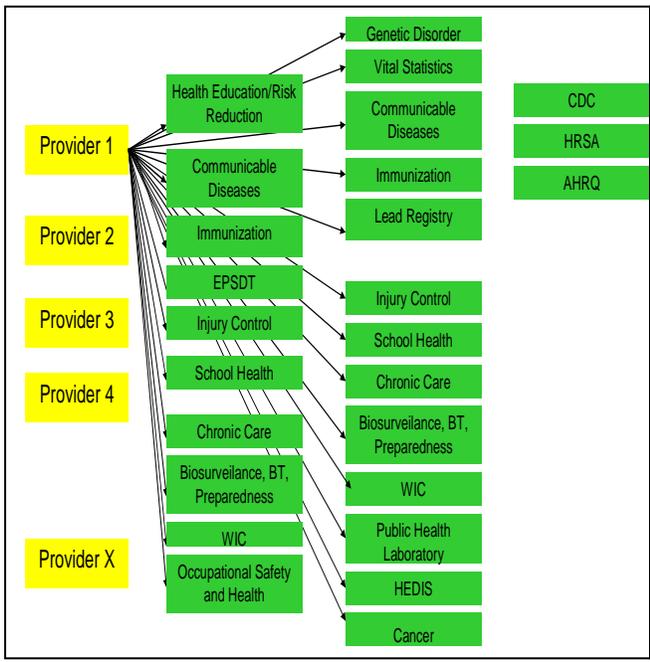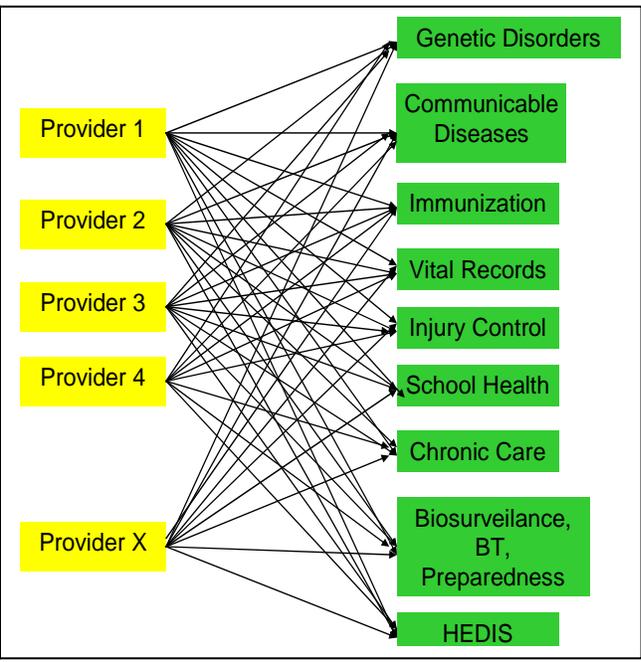[18] Laverne Snow. Personal Communications. June 9, 2007.
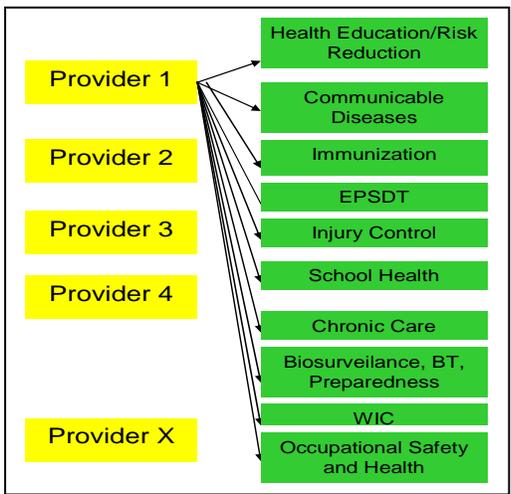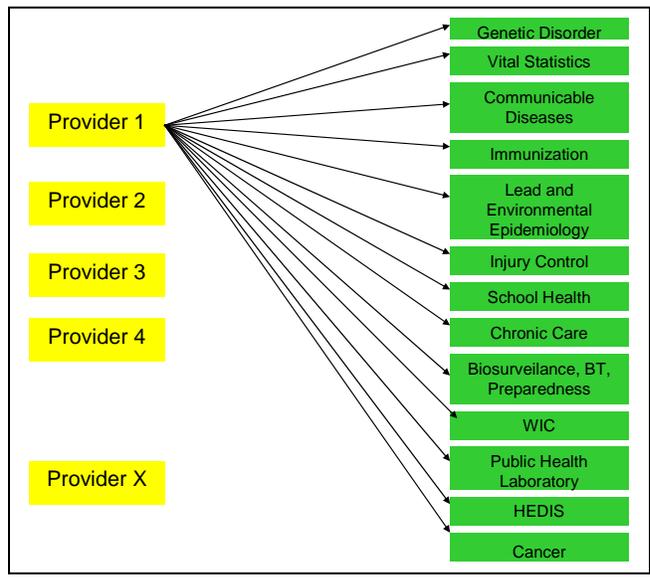
Fig 1. Paper-Based Data Reporting by Health Care Provider to Various Public Health Data Systems:
    a - Provider's Data Reporting to Local Health Department Data Systems;
    b - Provider's Data Reporting to State Health Department Data Systems:
    c - Provider's Data Reporting to Local and State Health Department Data Systems;
    d - Multiple Providers Data Reporting to State Health Department Data Systems.

 "Many public health agencies are examining their existing information systems and seeking to improve their ability to support programmatic needs to detect, assess, and respond to a range of threats to the public, including infectious diseases, pandemics, such as avian flu, bioterrorism, and chronic diseases such as obesity, diabetes and asthma. The challenges of transitioning from a paper environment to an electronic environment involve rethinking the workflow, staff skills, resources, habits, and culture of an organization".[19]

Electronic transmission of data from the clinical care settings to public health agencies via EHRS is essential to (1) support key public health functions and services and (2) supply public health data repositories, *e.g.*, registries, research databases, etc., for aggregated analysis of the health status of populations.[20] Provision of real-time aggregated community-level information back to providers - bi-directional EHRS-based data exchanges between public health practitioners and clinicians - will inform clinical decision support, improve care coordination and response capabilities to a public's health threat event. The integrated Electronic Health Record-Public Health (EHR-PH) systems will become the backbone of a NHIN and regional HIEs.

Fig.2 represents a schematic view of the difference between the current public health data reporting mechanism (Fig.2a) and the future standardized EHR-PH health information exchange (Fig. 2b). When the EHR-PH connectivity is completed, various public health data systems will be able to electronically receive data from clinical EHRS, so *when an authorized provider enters patient data into his/her EHRS, various public health programs - as authorized users - can receive/retrieve/view/access their data of interest.* [21]

To facilitate the development of interoperable EHR-PH systems there is a need for standardization of health information exchanges across the clinical and public health enterprise. The US Health Information Technology Standards Panel (HITSP)[22] identified the following categories of standards for system interoperability:
1. Data content standards, i.e., vocabularies and terminology standards (CDA2, SNOMED, ICD, X12, NCPDP, Omaha, etc.)
2. Information content standards (Reference Information Models (RIMs) standards)
3. Information exchange standards, e.g., messaging standards (HL7)
4. Identifier standards, e.g., National Provider Identifier (NPI) standard
5. Privacy and security standards - the US Health Insurance Portability and Accountability Act (HIPAA) privacy regulations provide a framework to protect privacy &

---

[19] Common Grounds: Transforming Public Health Information Systems. Robert Wood Johnson Foundation. 2006 Call for Proposals. URL: http://www.rwjf.org

[20] Public Health Data Standards Consortium. Electronic health record-public health perspectives. White Paper. PHDSC Ad Hoc Task Force on the Electronic Health Record-Public Health. March 9, 2004.: 27p. plus 9 Attachments. URL: http://www.phdsc.org/knowresources/papers/docsandpdfs/PHDSC_EHRPH_WhitePaper2004.pdf

[21] Orlova AO, Dunnagan M, Finitzo T, Higgins M, Watkins T, Tien A, Beales S. An electroninc health record-public health (EHR-PH) system prototype for interoperability in 21st century health care systems. Am Med Inform Assoc. (AMIA), Annual Symposium, Proc., 2005.

[22] Health Information Technology Standards Panel (HITSP). American National Standards Institute (ANSI). URL: http://www.amsi/org/hitsp

confidentiality of personal information; however, they do not cover all potential actors in health data exchanges.[23]

6. Functional standards, i.e., workflow/dataflow standards[24]
7. Other, i.e., information technology infrastructure standards, interoperability standards (IHE).
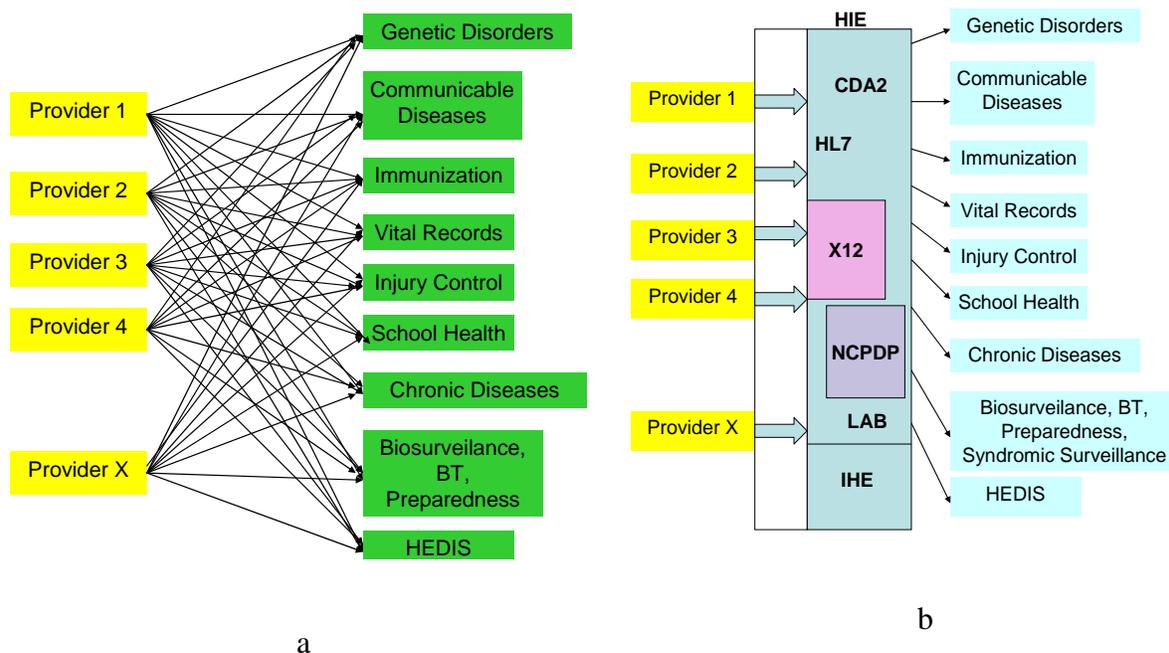


a

b

Fig.2. Health information exchanges between clinical care and public health agency:
a – current paper form – based information exchange;
b – standardized EHR-PH –based information exchange.

Fig. 2b presents examples of standards (CDA2, HL7, X12, NCPDP, IHE) that the EHR-PH HIEs will have to support.

To help facilitate the development of the standardized EHR-PH health information exchanges, it is critical to start a dialogue between the public health community and EHRS developers to assure that the work processes and data needs of public health stakeholders are well understood and agreed upon by stakeholders themselves and then communicated clearly to the developers of the interoperable EHR-PH systems. The section that follows presents two examples of the beginning of this dialogue by describing one of the public health domains in the IHE suggested framework for the technical tasks for information exchanges.

[23] See http://www.ncvhs.hhs.gov/060622lt.htm
[24] Developing a Vision for Functional Requirements Specification for Electronic Data Exchange between Clinical and Public Health Settings: Examples of School Health and Syndromic Surveillance in New York City. Public health Data Standards Consortium. 2006, 40p plus attachments.

## Technical Tasks for Information Exchanges: Examples of Public Health Domains

IHE provided a list of Technical Tasks for the description of the information exchanges related to a domain as follows:

1. What is <Domain Name>?
2. Who are <Domain Name> Stakeholders?

Technical Tasks for Information Exchanges

3. Expressing the criteria
4. Selecting a site
5. Identifying a patient meeting certain criteria
6. Retrieving additional data elements (queries)
7. Reporting data elements (notifications)
8. Data review/feedback (filters)
9. Analysis/evaluation
10. Mapping
11. Aggregation/Reporting
12. Communication

We used Immunization and Cancer Surveillance as examples of public health domains (Tables 1 & 2) and have attempted to describe them in terms of the IHE proposed technical tasks for information exchanges between clinical and public health EHR-PH systems. The section below includes the descriptions of the existing use cases and standards identified by the immunization domain and cancer surveillance experts to date as well as the existing IHE profiles applicable to these domains. It also includes the list of existing and emerging standards and possible future IHE profiles needed to meet the EHR-PH health information exchange tasks of these domains, so these future profiles might be built.

## Example of Immunization Domain

### 1)      What is the Immunization Domain?

Immunization is critical to control many infectious diseases including polio, measles, diphtheria, pertussis (whooping cough), rubella (German measles), mumps, tetanus, and *Haemophilus influenzae* type b (Hib). In the US, CDC is continuing the investment to assist states in developing immunization information systems (IIS, Immunization Registries) - confidential, computerized population-based information systems that collect vaccination data within a geographic area to ensure that all people are appropriately protected against vaccine-preventable diseases.[25] IISs are typically structured as data repositories of patient demographic and immunization history information, and ancillary patient information.  The IIS strives to maintain a complete immunization history for each patient because a single patient may receive immunizations from a series of different providers who may not share the patient's records with each other.

---

[25] American Immunization Registry Association (AIRA). URL: http://www.immregistries.org).

By consolidating vaccination records from multiple health-care providers, generating reminder and recall notifications, and assessing clinic and vaccination coverage, registries serve as key tools to increase and sustain high vaccination coverage. The Healthy People 2010 objective is to increase to 95% the proportion of children aged <6 years who participate (*i.e*., have two or more vaccinations recorded) in fully operational, population-based immunization registries.[26]

IISs usually include a decision support module called a "vaccine forecast module", or VFM, which evaluates the completeness of a person's immunizations based upon standard clinical practices. This evaluation is used as a tool in assessing a provider's immunization coverage rate, and improving it through such techniques as reminder/recall and case management. The VFM can also suggest what immunizations should be given in any particular clinical visit.

The IIS receives data either through direct data entry or through electronic data exchange with providers who give immunizations. US IISs may also facilitate electronically sharing immunization data among providers who have patients in common. In this sense, IISs embody an early healthcare interoperability effort.

## 2)    Who are the Immunization Registry Stakeholders?
The following are the IIS stakeholders:

- Clinicians
- Consumers
- Public Health Agencies (local, state and federal)
- Professional Organizations, i.e., AIRA
- Schools

The US effort on the development of the Immunization Registries and their information systems is sponsored by CDC[27], state and local governments, and by private foundations throughout the country. The American Immunization Registry Association (AIRA) is the US professional non-profit organization that promotes IISs and standards for electronic data exchange among IISs, including HL7 Implementation Guides.[28] Because the goal of IISs is to maintain immunization records for an entire population, IIS programs seek to gain the participation of all public as well as private providers serving their population base. Decision support rules embodied in the VFM are derived from the Advisory Committee on Immunization practice (ACIP) recommendations.[29] Often, state-specific local interpretations of the ACIP recommendations result in variations of decision support rules being implemented in different IISs.

Table 3 represents IIS Use Cases evolved from information supplied by the Canadian Infoway project that have been adopted by AIRA. (The Canadian Infoway group contributed heavily to

---

[26] Department of Health and Human Services. Healthy People 2010, 2nd ed. Understanding and improving health and objectives for improving health (2 vols.). Washington, DC: U.S. Department of Health and Human Services, 2000.

[27] Centers for Disease Control and Prevention (CDC). Vaccines and Immunizations. URl: http://www.cdc.gov/vaccines/ Last accessed July 11, 2007.

[28] American Immunization Registry Association (AIRA). URL: http://www.immregistries.org).

[29] Centers for Disease Control and Prevention (CDC). Advisory Committee on Immunization Practice (ACIP). URl: http://www.cdc.gov/vaccines/pubs/ACIP-list.htm Last accessed July 11, 2007.

the development of HL7 Version 3 Immunization Domain message standards.) These Use Cases have been mapped to the IHE Tasks for Information Exchanges.

IIS may focus upon childhood immunizations, and include only pediatric patients. Recently IISs are tendin to include adolescent and adult immunizations as well, and can be used as tools for disaster preparedness, e.g., pandemic influenza prevention planning and/or in the eventuality that smallpox or other immunizations need to be given in mass to a population in response to a bioterrorism incident or risk of one.

IISs are supported by well-developed bodies of national, and especially, state law. Thus, patients may be excluded from an IIS based upon refusal to sign a required consent (opt in) form, or because they have taken advantage of a provision to opt out of inclusion.

### 3)    Expressing the criteria
The inclusion of a patient in a US IIS is governed by:

1. Clinical immunization guidelines, e.g., American Academy of Pediatrics (AAP) guidelines[30]
2. State regulations (the legal mandate or absence of a mandate) to provide data to the IIS and the practical enforcement of such mandates
3. The willingness of providers to contribute data if not legally mandated to do so.
4. The target population
5. The disclosure/consent policy of the jurisdiction.

### 4)    Selecting a Site
IISs are operated by public health agencies or non-profit organizations established for that purpose. These are typically housed within state or local governments or they may be independent non-profit organizations. State law and memoranda of understanding enable public clinics, safety-net providers, private providers, and schools as well as Women, Infant and Children (WIC)[31] and other social services providers to participate in IISs. Thus, IISs include a central data repository hosted by the IIS program organization, but are also accessed and touched by all types of care-giving sites in a geographic region.

### 5)    Identifying a Patient
In the context of IISs, this topic is interpreted as **Patient Identity Resolution**. The patient's identity must be resolved when an immunization record is initially stored, retrieved or updated. IISs universally include some sort of record matching software, at least in the U.S., where the collected records are consolidated from disparate provider information systems, each having its own scheme of assigning identifiers. No universal patient identifier is on the horizon in the U.S., and no existing identifier scheme (i.e. Social Security Number) has been determined to be viable for determining patient identity without the use of record matching software.

---

[30] American Academy of Pediatrics. Immunization. URL: http://www.aap.org/healthtopics/immunizations.cfm

[31] US Department of Agriculture. Women, Infant and Childen (WIC). URL: http://www.fns.usda.gov/wic/ Last accessed July 11, 2007

Table 3:  Immunization Information Systems: Existing and Emerging Use Cases

| Use Case Name | Use Case Description | IHE Tasks for HIEs |
|---|---|---|
| **Existing Use Cases** | | |
| Find Patient Query | Search for client in the patient registry based on demographic characteristics when a unique identifier is not available. | Identifying a patient (Patient Identity Resolution) |
| Find Associated Identifiers Query | Query to retrieve all known identifiers for specifically identified patient. | |
| Get Patient Demographics Query | Query to retrieve details of a specific patient based on a specific identifier. | |
| Update Demographics | Submit patient demographic information, including identifiers, for adding, updating or deleting. | |
| Immunization History Query | Retrieve a patient's immunization history from an IIS. | Retrieving additional data elements (Queries) |
| Immunization Detail Query | Patient-specific query on immunization plans, events, consents and adverse reactions. | |
| Inventory Management | Many use cases (not elaborated). | |
| Update Immunizations | Request that the IIS record that one or more immunizations of a patient has occurred - includes add, change, updates and maintenance of an immunization record. | Reporting data elements (Notifications) |
| Report Adverse Event | Request that an immunization related adverse event be recorded. | |
| Immunization Candidate Query | Query that can be made of all individuals in the Immunization Registry who meet specific clinical criteria, for example receipt of a previous immunization or to identify an age cohort eligible for immunization. | Aggregation/ Reporting |
| **Emerging Use Cases** | | |
| Vaccine Forecast Module (VFM) - validation portion | A decision support module which takes as input a validated patient immunization history, and other information such as patient age, contraindications, immunity, etc., and, using clinical practices rules, outputs a validated immunization history for the patient. | Data review/feedback (Filters) |
| Vaccine Forecast Module (VFM) - recommendation portion | A decision support module which takes as input a validated patient immunization history, and other information such as patient age, contraindications, immunity, etc., and, using clinical practices rules, outputs a recommendation of next immunizations for that patient | Analysis/evaluation |
| Document Transfer | A request for a particular document in human-readable form.  The most common example is official immunization record for a patient. | Communication |
| Report | A request for a particular report.  Input includes the report to be run and its parameters.  Output may be a document in human-readable form. | Aggregation/Reporting |
| Codesets | | Mapping |

In one situation, the identity resolution occurs during a query for a patient record. This may be during an encounter with the patient him/herself, and may be done through a user interface connected to the IIS, or though an electronic interface such as HL7, for example, in a case where the user is connected to an EHR system and the EHR system performs the query.

The query may be based upon available patient demographic data, such as name, date of birth, gender, etc.; a local identifier in a provider EHR system such as a medical record ID; community health services identifier such as WIC ID; or upon a system or user assigned unique identifier which the IIS can use as an index. In the patient demographic query, identity resolution involves returning candidate matches, from which the user makes a selection (or simply selects, in the case of a single returned match). In the other queries, the use of an identifier results in a single match (or none at all).

In another situation, a demographic record is sent electronically to the IIS. In this case, a determination must be made as to whether or not the record belongs to a patient already known to the IIS. Again, matching software may be used to make a match based upon demographic data, or, if an identifier known to the IIS is supplied with the data, it can be used as an index into existing data. Depending upon the outcome, the record is added, updated, or deleted in the IIS.

### 6)      Retrieving Additional Data Elements (Queries)

Clinical information stored by IISs includes not only immunization data, but other continuity of care data required to make a good assessment of immunizations due. Such data includes disease history, contraindications, allergies, adverse reactions and refusals to immunize. IISs also may maintain vaccine inventory information to support direct data entry screens that allow for the recording of immunizations with their vaccine manufacturer and lot number as they are given and may also decrement the inventory and provide accountability to Vaccine for Children[32] doses administered. This is needed in recording lot numbers, manufacturers, etc. Finally, vaccine shortages may be taken into consideration by the VFM in generating recommendations of vaccines due.

IISs are queried for any or all of patient's immunization information by point of care users who consider the IIS data in care delivery. This may be done after a query resolving the patient's identity using demographic information, or in the same step with it. The query may originate from a user logged into a client-server or n-tier application that accesses the IIS database directly (the more common case) or from a remote system using the HL7 messaging or other means.

To date, models where IISs query other sites on demand in order to assemble a complete record of patient immunization data (federated models) are rare or non-existent. IISs almost universally follow a central repository model. However, it is a goal of IISs, upon accepting a query, to be able to in turn query other IISs, especially in the case where the requested patient is not found. For example, a regional IIS would seek data from the state IIS, or a state IIS from an IIS in another state. In the US, some special healthcare authorities, such as the Indian Health Service, Department of Defense, and Veterans Health Administration are also sources for immunization information. Systems interoperability efforts are underway, but in practice, few are yet

---

[32] Vaccine for Children Pprogram. URL: http://www.edcp.org/html/vfchmpg.html Last accessed July 11, 2007

implemented. Such interoperability is a large part of the mission of IIS standards organizations such as AIRA.

## 7)    Reporting Data Elements (Notifications)

Immunization records are data entered manually by participating providers, usually after retrieving an existing immunization history from the IIS and then giving an immunization. Most commonly, this is done by users logged in to a client-server or n-tier web-based application which directly accesses the IIS database.

Immunization records are also transmitted electronically to the IIS from EHR and other systems, e.g. practice management systems. These may be notification-based, that is, single records sent in real-time as they are created via HL7 connections; or they may occur as batch uploads, either in HL7 or other (proprietary) format. IISs also receive data from demographic sources such as Vital Records (Registration) Programs for birth records and death records, or demographic data from health plan or practice panels only for purposes of creating common indexes and avoiding double data entry.

Double data entry on behalf of providers (in the EHR and in the IIS) is a substantial challenge to provider adoption of IISs. Interoperable electronic interface between a provider's EHR or practice management system and IIS, and consequent reduction of double data entry, is an important goal of IISs.

## 8)    Data Review/Feedback (Filters)

Examples of data review and feedback services, referred to here as *filters*, include:
- Data quality measures present in user interfaces or HL7 interfaces
- Audit and/or activity log data
- Edit filters
- Validation of immunization histories

The first item is self-evident, and includes field-level constraints in user screens, as well as validation of the syntax of update messages received electronically.

IISs are required to maintain audit logs recording accesses to data. Reports are available to share the data in these logs with auditors or system administrators, and under HIPAA with patients or their guardians if requested. Activity logs are user-level records of actions taken on a patient's record, for example, that a reminder was generated.

Because IISs store data originating at different providers' sources, some IISs restrict editing or updating of data from a particular provider source to users or electronic connections associated with the source provider.

Validation of immunization histories, and prediction of immunizations due, discussed below, are often performed together in the VFM, but they are really two separate functions. Both make use of a set of decision support rules based on the ACIP recommendations describing the standard clinical practice pertaining to immunizations. In the validation step, the rules are used to determine which immunizations in a patient's history are in fact medically valid. Two vaccines

given too close together, for instance, may not both be valid, and waiting too long between shots may invalidate a series.

Likewise, some data entry or data quality errors are filtered out in the validation process, by the VFM or in some implementations as data is added to the system. Duplicates – records of the same immunization from two different provider data sources – are detected. Duplicates are common in U.S. IISs because a patient shifting to a new provider may bring a paper record or even verbal accounting of his past immunizations, called a *historical record,* which is data-entered into the new provider's EMR system. Both the original and second copy may then be transmitted to the IIS, creating the duplicates. The process of manually entering historical data is error-prone, causing the data validation process to be somewhat heuristic. In 2006, the AIRA Modeling of Registry Operations Workgroup (MIROW) developed a best practice guideline *Vaccine Level De-duplication Information Systems* to provide a uniform process for IIS to resolve duplicate immunizations.

## 9) Analysis/Evaluation

Two typical IIS functions are described in this section:

- Prediction of immunizations due
- Evaluation of coverage rates based upon the above

Having validated an immunization history, the VFM can predict next immunizations due based upon the same ACIP and clinical practice rules that were used in the validation process. This prediction is known as a *recommendation.* Its format is similar, but not identical, to a set of immunization records. An immunization history carries vaccine administration such as lot number, manufacturer, body site and vaccinator; a recommendation carries an interval of dates in which the recommended vaccine should be given, and other information.

The validated history and the recommendation are made available to users at the point of care. They also are used in provider-based or population-based tools aimed at increasing coverage rates. Such tools include reminder/recall and case management.

## 10) Mapping

IISs use standard code tables to enable semantic interoperability. For example, the CVX and MVX codesets established by the CDC create common codes for vaccines and vaccine manufacturers. There are, however, other datasets within IISs that do not have established standards, for example, provider identifiers (IDs) but these may later be resolved when the use of the National Provider Identifier (NPI) required by HIPAA becomes mandatory.

In the U.S., the American Immunization Registry Association (AIRA) maintains the HL7 Implementation Guide for IIS, and associated code set standards.[33]

---

[33] Health Level Seven (HL7) Implementation Guide for IIS. URL: http://www.immregistries.org/pubs/index.phtml)

## 11)    Aggregation/Reporting

IISs have the ability to produce certain reports, as required by government agencies or for the internal operation of IIS program itself.   Such reports analyze the success of the IIS in capturing its population's data, provider or regional immunization coverage rates, vaccine usage, and so forth.  In this sense, they operate as analysis databases as well as OLTP systems.  Interference of analysis activities with user response times is a concern, and more mature IISs make a secondary copy of data for analysis purposes.

HL7 Version 3 immunization message standards (proposed) include a "candidate query", which queries for an aggregation of data.  Parameters are specified which determined the result set, that is, set of data returned.   While the use of HL7 2.5 messaging standard is expected to be continued for the large number of ILSs currently in production, the trend in the interoperable use of IISs is extending to remote access to the aggregation and reporting aspects of IISs in the future.

## 12)    Communication

A common feature of IISs is the ability to produce an official immunization record specific to the state or local jurisdiction (some jurisdictions have no official format for this information).  The record contains an immunization history for a patient in a certain format, and is signed by an authorized provider.  It is required for school entry in the US as well as for child group care in many jurisdictions and is also recommended for international travel.  Its format differs from state to state, but many states now permit a paper record generated by an IIS with required letterhead or other elements to be an *official* record for these uses as well as a personal record for the patient or parent.

**Suggested Future Applicable Standards**

Existing US standards for IIS data exchange are presented in the "Implementation Guide for Immunization Data Transactions Using V.2.3.1 of the Health Level Seven (HL7) Standard Protocol."[34] This implementation guide is maintained by the CDC in cooperation with AIRA.

Table 4 presents a list of examples of possible existing and emerging IHE profiles and other standards that may be applicable to IIS.

The description of the immunization domain as an example of public health domains in this White Paper helps both public health practitioners and HIT vendors by describing the domain in terms that both communities would understand as well as by identifying existing and emerging standardization efforts and needs to be addressed in the future collaboration between public health community and IHE.

---

[34] Health Level Seven (HL7) Implementation Guide for Immunization Data Transactions .V.2.3.1. URL: http://www.immregistrries.org/pubs/index.phtml

Table 4.  Future Possible IIS Applicable Standards

| IIS Use Case Name | Candidate IHE Profiles | Other Applicable Standards |
|---|---|---|
| | Existing Profiles/Standards | |
| Find Patient Query | PIX/PDQ | HL7 V2.5 (QPB), HL7 V3.0 (PRPA), HSSP Entity Identification Services (EIS) |
| Find Associated Identifiers Query | | |
| Get Patient Demographics Query | | |
| Update Demographics | | |
| Immunization History Query | QED | HL7 V2.5 (QBP, VXQ), HL7 V3.0 (POIZ), HL7 CCD, HSSP Retrieve, Locate, Update Service (RLUS) |
| Immunization Detail Query | | |
| Update Immunizations | Future Notification Version of QED | HL7 V2.5 (VXU), HL7 V3.0 (POIZ), HL7 CCD, HSSP RLUS |
| Immunization Candidate Query | ? | HL7 V3.0 (POIZ), HSSP RLUS |
| Report Adverse Event | Future Notification Version of OED | HL7 V3.0 (PORR), HSSP RLUS |
| Inventory Management | ? | X12 |
| | Emerging Profiles/Standards | |
| Vaccine Forecast Module (VFM) - validation portion | Proposed Decision Support Profile | HSSP Decision Support Service (DSS) with various HL7 V3 messages passed as payload |
| Vaccine Forecast Module (VFM) - recommendation portion | Proposed Decision Support Profile | HSSP Decision Support Service (DSS) with various HL7 V3 messages passed as payload |
| Document Transfer | XDS/XDR | HSSP RLUS, HL7 CDA |
| Report | XDS/XDR | HSSP RLUS, HL7 CDA |
| **Codesets** | | |

## Example of Cancer Surveillance Domain

### 1)      **What is the Cancer Surveillance Domain?**

Cancer surveillance serves as the "foundation for a national comprehensive strategy to reduce illness and death from cancer. Such surveillance is the indispensable tool that enables public health professionals at the national, State, and community levels to better understand and tackle the cancer burden while advancing clinical, epidemiologic, and health services research". [35]
State-based cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths, and are designed to:
- Monitor cancer trends over time;
- Determine cancer patterns in various populations;
- Guide planning and evaluation of cancer control programs (e.g., determine whether prevention, screening, and treatment efforts are making a difference);
- Help set priorities for allocating health resources;
- Advance clinical, epidemiologic, and health services research;
- Provide information for a national database of cancer incidence. [36]

In the US, CDC is continuing the investment to assist states in developing cancer surveillance information systems—computerized population-based information systems that collect data on the diagnosis and treatment of cancer within a geographic area.
Cancer Surveillance registries are typically structured as data repositories that include:
- patient demographics:  sex, date of birth, address at diagnosis;
- cancer diagnostic information: date of diagnosis, primary location of the cancer, histologic type, stage of disease progression;
- treatment; and
- follow-up and survival data.

The public health cancer surveillance domain maintains a comprehensive record for each patient because a single patient may receive diagnostic and/or treatment services from a series of different providers who may not share the patient's records with each other. By consolidating cancer records from multiple health-care providers, public health cancer registries serve as the foundation for cancer related research and public health assessment.   The Healthy People 2010 objective is to increase the number of States that have a statewide population-based cancer registry that captures case information on at least 95 percent of the expected number of reportable cancers.[37]

The Cancer Surveillance registry receives data either through electronic data reporting from hospital cancer registries or by a combination of electronic or paper reporting from health care facilities without a cancer registry.  All medical practitioners involved with the diagnosis or treatment of cancer patients are required to report to their respective state cancer registry.  Many

---

[35] Health People 2010, Chapter 3:  Cancer.
http://www.healthypeople.gov/document/html/volume1/03cancer.htm#_Toc490540737
[36] CDC-NPCR Website:  http://www.cdc.gov/cancer/npcr/about.htm
[37] Health People 2010, Chapter 3:  Cancer.
http://www.healthypeople.gov/document/html/volume1/03cancer.htm#_Toc490540737

health care practitioners throughout the US are now using established electronic reporting standards to meet their reporting obligations.



NPCR–MERP Scope Diagram (with potential links to IHE)

Version 1.0
Revised 08-01-2007
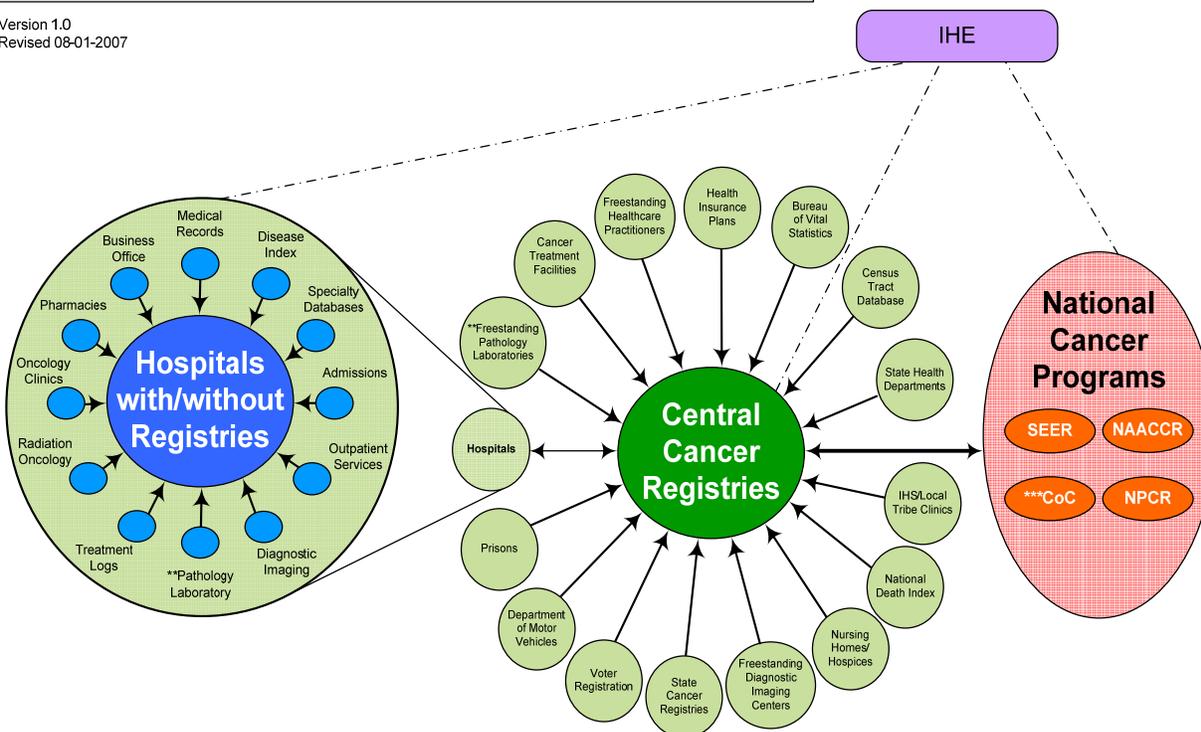
NPCR–MERP includes cancer data sources and the lines drawn to the Central Cancer Registries and the National Cancer Programs
**Pathology Laboratories–Freestanding and Hospital–send data to both the Hospital Registries and the Central Cancer Registries
***CoC receives data directly from hospitals.

The diagram above displays the scope of the National Program of Cancer Registries Modeling Electronic Reporting Project (NPCR-MERP) with a possible link between the Hospitals, Central Cancer Registries and National Cancer Programs to the IHE.  The NPCR-MERP has been developing UML diagrams and associated use cases to demonstrate best practices using automation and electronic reporting methods to complete cancer surveillance functions and processes.  The work has focused on three different levels: the hospital level, the state/regional level, and the national level.  Through this work, the NPCR-MERP has been thinking futuristically about how the cancer surveillance business will be impacted by the electronic health record (EHR) and IHE implementation.  As the EHR and IHE become more defined, the Cancer Surveillance community would like to evaluate how the business of cancer surveillance registries will function in this new infrastructure.

## 2)      Who are the Cancer Surveillance Stakeholders?
The following are the Cancer Surveillance stakeholders:
- Clinicians and health care providers
- Consumers/patients

- Public health agencies (local, state and federal)
- National standards-setters (NAACCR, CoC, CAP, CDC, NCI)
- Those who maintain standards (e.g., SNOMED, HL7, LOINC)
- Professional organizations, e.g., NCRA, CAP
- Software developers
- Researchers

The US effort to develop Cancer Surveillance Registries and their information systems is sponsored by CDC[38], the National Cancer Institute[39], state governments, and professional medical associations. The North American Association of Central Cancer Registries is an umbrella organization with a membership comprised of all of the standard setting organizations for cancer surveillance, all population-based cancer registries in the United States and Canada, and stakeholders actively involved in cancer surveillance. With the support of the National Cancer Institute's Surveillance, Epidemiology and End Results program (NCI-SEER), the Center for Disease Control's National Program of Cancer Registries (CDC-NPCR) and the American College of Surgeons' Commission on Cancer (ACoS-CoC), NAACCR coordinates the development and implementation of standards for data collection, electronic reporting of cancer diagnoses. The current cancer surveillance programs cover 100% of cancers occurring in the U.S population, providing comprehensive information for research and public health assessment activities.

## 3)      Expressing the Criteria

Cancer Surveillance registries are supported by federal and state laws and regulations. Every state requires reporting of all cancer diagnoses. In turn, each state is required to report cases to either the NCI-SEER Program or the CDC-NPCR. All state registries adhere to the same case definition and reportability criteria, and collect a standard, comprehensive set of data items. The inclusion of a patient in a US cancer surveillance registry is governed by:

1. National case definition and reportability criteria established by the cancer surveillance domain and maintained by the NCI-SEER Program[40].
2. Federal and state laws and regulations to collect cancer surveillance information with no provision of opt-out of inclusion.
3. Specific language exempting cancer surveillance activities from HIPAA privacy regulations related to reporting cases to state and federal programs.
4. Compliance with state and federal data privacy and confidentiality regulations.

---

[38] Centers for Disease Control and Prevention (CDC). National Program of Cancer Registries. http://www.cdc.gov/cancer/npcr
[39] National Cancer Institute, Surveillance, Epidemiology and End Results.  http://www.seer.cancer.gov
[40] NAACCR Standards for Cancer Registries:  Volume II:  Data Standards and Data Dictionary. http://www.naaccr.org

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 3 | Expressing the criteria | Hospital CR:<br>• Casefinding<br>• Prepare Event Report<br>Central CR:<br>• Prepare Event | Criteria are expressed as Business Rules within the Use Case(s).<br>• Case Definition and Reportability Criteria<br>• Federal and state mandates requiring reporting<br>• Required Data Items |
| Hospital CR:  http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR:   http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 4)    Selecting a Site

Public Health Cancer Surveillance registries are operated by public health agencies. These are typically housed within state governments or within a university school of public health or medical school. Federal and state law enable hospitals, clinicians, and freestanding diagnostic and treatment centers, to report to public health cancer surveillance systems. Thus, cancer surveillance registries provide a central data repository at both the federal and state level. The federal registries are maintained by the CDC-NPCR and the NCI-SEER.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 4 | Selecting a site | No Use Cases required.<br>100% coverage of the cancer population within the U.S in established state and federal cancer surveillance registries | Public Health Cancer Surveillance Registries are established in state government or within a university's public health or medical school. Federal cancer surveillance registries are maintained at the NCI and the CDC. |

## 5)    Identifying a Patient

In the context of Cancer Surveillance Information Systems, this topic is interpreted as **Case-finding and Case Ascertainment**. Public health cancer surveillance registries receive multiple reports on a single patient from multiple health care providers. Common data sources[41] for detecting the inclusive cancer registry population include but are not limited to:

1) Health Care Facilities:
    a. Hospitals
    b. Freestanding diagnostic and treatment centers (pathology laboratories and radiation oncology centers)
    c. Clinics/Physician Offices
    d. Nursing Homes
2) Non-Health Care Facilities
    a.  Health Insurance Plans
    b. Vital Records (Death Certificates and National Death Index)
    c. Census Tract Database

---

[41] NPCR-MERP Central Cancer Registry Domain Diagram.
http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/registry.htm

3) After a diagnosis of cancer has been identified according to national case definition, selected reports and data items are electronically or manually reported to the cancer surveillance registry.

Because no universal patient identifier is on the horizon in the U.S., and no existing identifier scheme (i.e. Social Security Number) has been determined to be viable for determining patient identity without the use of record matching software, probabilistic record matching software is employed to group the collected records into one demographic record for the patient. The query is based upon available patient demographic data, such as name, date of birth, gender, and social security number. Patient matching software determines either a match with an existing record, no match with any existing record, or potential match with one or more records. Additional data items, such as patient address, and name of attending physician are sometimes used to resolve potential matches.

Once all records are grouped under a unique identifier for the patient, a determination must be made as to the number of primary cancers a patient has. Following national standards for determining number of primary tumors, cancer surveillance registries review and consolidate reports into a single cancer record[42]. Efforts are underway in the registry community to create a decision support system for determining number of primary tumors for a patient.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 5 | Identifying a patient meeting certain criteria | Hospital CR:<br>• Case-finding<br>• Prepare Event Report<br>Central CR:<br>• Prepare Event Report<br>• Perform Rapid Case Ascertainment | All medical practitioners making a diagnosis of or treating cancer are required to report. Active case finding is performed in medical facilities diagnosing or treating cancer patients |
| Hospital CR: http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR: http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 6)    Retrieving Additional Data Elements (Queries)

Clinical information stored by public health cancer surveillance systems includes demographic data, medical information relating to date of diagnosis, primary location of the cancer, stage of disease progression, treatment, follow-up and vital status. Detailed address census tracting is performed so cancer surveillance data can be linked to socio-economic factors provided in the 2000 census. Inclusion of additional data such as genetic markers and co-morbidity in cancer surveillance registry may be possible with electronic reporting from the EHR.

Linkages with other health systems enhance the completeness and quality of the cancer surveillance registry. Linkage with the Indian Health Service improves the quality of race data, allowing more detailed analysis to be performed for the Native American population. Linkages with state Vital Records and the National Death Index provide an efficient means of determining patient survival without intruding on the patient and/or health care provider. Additionally,

---

[42] 2007 Multiple Primary and Histology Coding Rules. URL: http://www.seer.cancer.gov January 1, 2007.

linking with health care claims data allows the cancer surveillance registry to capture treatment that is now occurring outside acute care facilities.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 6 | Retrieving additional data elements (queries) | Hospital CR: <br>• Perform Abstracting <br>• Perform Passive Follow-up <br>• Perform Active Follow-up <br>Central CR: <br>• Perform External Linkage to Improve Data <br>• Conduct Death Clearance <br>• Conduct Follow-up <br>• Perform Interstate Data Exchange | Linkage with data sets to obtain more information: <br>• Indian Health Service <br>• State and National Death Certificate files <br>• Census tract address files Health Insurance Plan Voter Registration and Department of Motor Vehicles (obtain Vital Status) |
| Hospital CR: http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm <br>Central CR: http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 7)        Reporting Data Elements (Notifications)

Cancer records are routinely transmitted electronically to the Public Health Cancer Surveillance Registry from the hospital-based cancer registry. They usually occur as a batch upload using the cancer standard record layout format maintained by NAACCR.[43]  NAACCR is currently revising its record layout format to follow the HL7 messaging standard.  Additionally, healthcare providers can report cancer cases manually through a web-based application that directly accesses the appropriate state cancer surveillance registry.  Electronic reporting of pathology laboratory data has been implemented in several state cancer surveillance registries using HL7 messaging standards.

Double data entry in the EHR and in hospital cancer registries is a substantial challenge.  An increase in the accuracy of timeliness of cancer data will be achieved by providing an interoperable electronic interface between a provider's EHR and the hospital cancer registry to eliminate double data entry.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 7 | Reporting data elements (notifications) | Hospital CR: <br>• Receive Batch File <br>• Perform Reporting <br>Central CR: <br>• Receive Batch File <br>• Perform Interstate Data Exchange <br>• Respond to Calls for Data | Use of HL7 messaging or standardized record layout format for reporting hospital cancer registry cases. |
| Hospital CR: http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm <br>Central CR: http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

---

[43] NAACCR Standards for Cancer Registries:  Volume I:  Record Layout.  http://www.naaccr.org

**8)      Data Review/Feedback (Filters)**

Examples of data review and feedback services, referred to here as *editing*, include:
- Data quality measures present in user interfaces or HL7 interfaces
- Data edits
- Audits

The first item includes field-level constraints in user screens, as well as validation of the syntax of messages received electronically.

The Cancer Surveillance Infrastructure system has developed a standard data editing system for hospital cancer registry records that:
- Provides data quality and completeness edits for all required data items;
- Allows creation of registry-specific edits; and
- Includes a reporting mechanism for correcting and monitoring data errors and discrepancies.

The goal of the cancer surveillance infrastructure system is to include an editing function in all hospital and central cancer surveillance registry software to increase the consistency and quality of the data.

Currently there are no standard data edits for the electronic health record (EHR). The Cancer Surveillance Infrastructure System's editing software could serve as a foundation for developing data quality checks for EHR, thereby minimizing the efforts in "re-creating the wheel."

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 8 | Data review/feedback (filters) | Hospital CR: <br> • Perform Editing <br> • Perform Quality Assurance Quality Control <br> Central CR: <br> • Validate Event Report <br> • Match Patient Reports <br> • Match Tumor (cancer) Reports <br> • Perform Consolidation Perform Audits/QA/QC | Use of standard edit sets, standard software |
| Hospital CR:  http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm <br> Central CR:   http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

**9)      Analysis/Evaluation**

The Cancer Surveillance Domain has comprehensive standards for evaluating the completeness, accuracy, and management of data. In addition to those mentioned within this white paper, NAACCR Volume III:  Standards for Completeness, Quality, Analysis, and Management of Data[44] includes:

- Legislation and Regulations

---

[44] NAACCR Volume III:  Standards for Completeness, Quality, Analysis, and Management of Data; www.naaccr.org

- Confidentiality Policies and Procedures
- Staffing Guidelines
- Standards for Data Codes, Data Text and Data Edits
- Monitoring Completeness of Reporting and Ensuring Compliance
- Patient Follow-Up and Follow-Up Success Rates
- Timeliness of Central Registry Reporting

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 9 | Analysis/evaluation | Hospital CR<br>• Perform Analysis<br>Central CR<br>• Perform Analysis<br>• Conduct Linkage for Research | |
| Hospital CR:  http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR:  http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 10)  Mapping

The Cancer Surveillance Information System uses standard code tables to enable semantic interoperability.  All cancer registries use the same data dictionary maintained by the North American Association of Central Cancer Registries (NAACCR).[45]  Additionally, NAACCR maintains the HL7 Implementation Guide for Electronic Reporting of Pathology Reports, and The Electronic Pathology Reporting Guidelines[46].  NAACCR is currently engaged in harmonizing its data dictionary with standards published by HITSP and other Federal E-Health initiatives.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 10 | Mapping | Hospital CR:<br>• Prepare and Transmit Report<br>• Perform Abstracting<br>Central CR:<br>• Prepare and Transmit Report<br>• Validate Event Report<br>• Perform External Linage to Improve Data<br>• Conduct Death Clearance<br>• Provide Data for Use by Others | Mappings from local data item coding systems to standard coding systems are expressed as Business Rules within the Use Case(s). |
| Hospital CR:  http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR:  http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 11)  Aggregation/Reporting

The Cancer Surveillance domain routinely produces comprehensive population-based summaries of incidence, mortality and survival.  These reports tabulate cancers by primary site, sex, race, age group, and sub-regions of the area.  Standards for producing consistent, statistically valid

---

[45] NAACCR Standards for Cancer Registries, Volume II.  Data Dictionary.  http://www.naaccr.org
[46] NAACCR Standards for Cancer Registries, Volume V. Pathology Laboratory Electronic Reporting. http://www.naaccr.org

data have been established and are documented in the NAACCR Volume III: Standards for Completeness, Quality, Analysis and Management of Data[47]. These standards are adhered to by all state and national cancer surveillance programs.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 11 | Aggregation/Reporting | Hospital CR:<br>• Perform analysis<br>• Perform reporting<br>Central CR:<br>• Perform analysis<br>Perform reporting | |
| Hospital CR: http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR: http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

## 12)    Communication

The Cancer Surveillance community has a long history of communicating results to clinicians, researchers and the public. The CDC-NCPR and the NCI-SEER program collaborate to produce the annual Cancer Statistics in the United States, which describes the cancer burden in the nation. In addition to an electronic version of the report, a comprehensive website is maintained for public use[48].

Many population-based cancer surveillance programs are reporting cancer incidence, mortality and survival on their website, both as a traditional report and as a user-queryable database.

| | Technical Tasks | Cancer Surveillance Use Cases | Definitions |
|---|---|---|---|
| 12 | Communication | Hospital CR:<br>• Publish data<br>• Publish Reports<br>Central CR:<br>• Provide Data for Use by Others<br>• Publish data<br>• Publish Reports | |
| Hospital CR: http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/hospital.htm<br>Central CR: http://www.cdc.gov/cancer/ncpr/informatics/merp/workgroups/central.htm | | | |

The description of the cancer surveillance domain as an example of an intelligence gathering public health activity demonstrates the objectives, existing efforts and results of moving an established paper-based system to one that takes advantage of the increased standardization and harmonization between the health care and public health community. It also highlights the need to use electronic methods to connect clinical care with public health activities. Future collaboration between public health community and IHE will help achieve effective, seamless integration between both activities.

---

[47] www.naaccr.org
[48] http://apps.nccd.cdc.gov/uscs/

## Conclusion

We described the field of Public Health – a complex endeavor of multiple domains and programs aimed to protect the public from threatening diseases and to promote wellness – and its needs and experience with HIT adoption. In addition, we also described, in detail, immunization and cancer surveillance as examples of public health domains using the IHE Technical Tasks for Information Exchange outline.

We believe that this effort will help both public health and HIT vendor communities to begin a dialogue in addressing standardization needs for interoperable clinical and public health EHR-PH systems.

Appendix 1. Examples of Public Health Domains - Research

**Research Perspectives**
**[Tim Carney]**

Public Health as a domain is a massive complex mixture of professionals and organizations that work together to achieve the mission of ensuring the nation's health. This complex system extends even further when the measures of international public health practices are taken into account. In defining an Integrated Health Enterprise (IHE) and the corresponding research agenda that should complement it, it becomes essential to define contextual boundaries of this complex system. Such boundaries can serve to facilitate systematic measurement and analysis, thereby formally evaluating the impact of the IHE on public health practice.

At the core of any research agenda of how the IHE can impact public health practice will be a formalized Public Health Informatics (PHI) analytical framework. Such a PHI framework will provide the methods and approaches that can be used to monitor and track the progress of IHE in public health practice. In this context the marriage of Informatics Theory & Practice to Public Health Practice serves as the foundation of analysis in describing the IHE as an enabler of enhanced research capabilities as seen in Figure 1 [1].

Informatics Theory & Practice includes the development and review of organizational and domain specific metrics to measure the progression of information as a strategic resource. This encompasses the categories of data, information, and knowledge formation, structures, standards, utilization, and corresponding infrastructures and environments. Additionally, domain specific informatics activity examines how this categorization leads to meaningful progress in the goals of the domain in question. Public Health Practice can be summarized into three categories of practice.
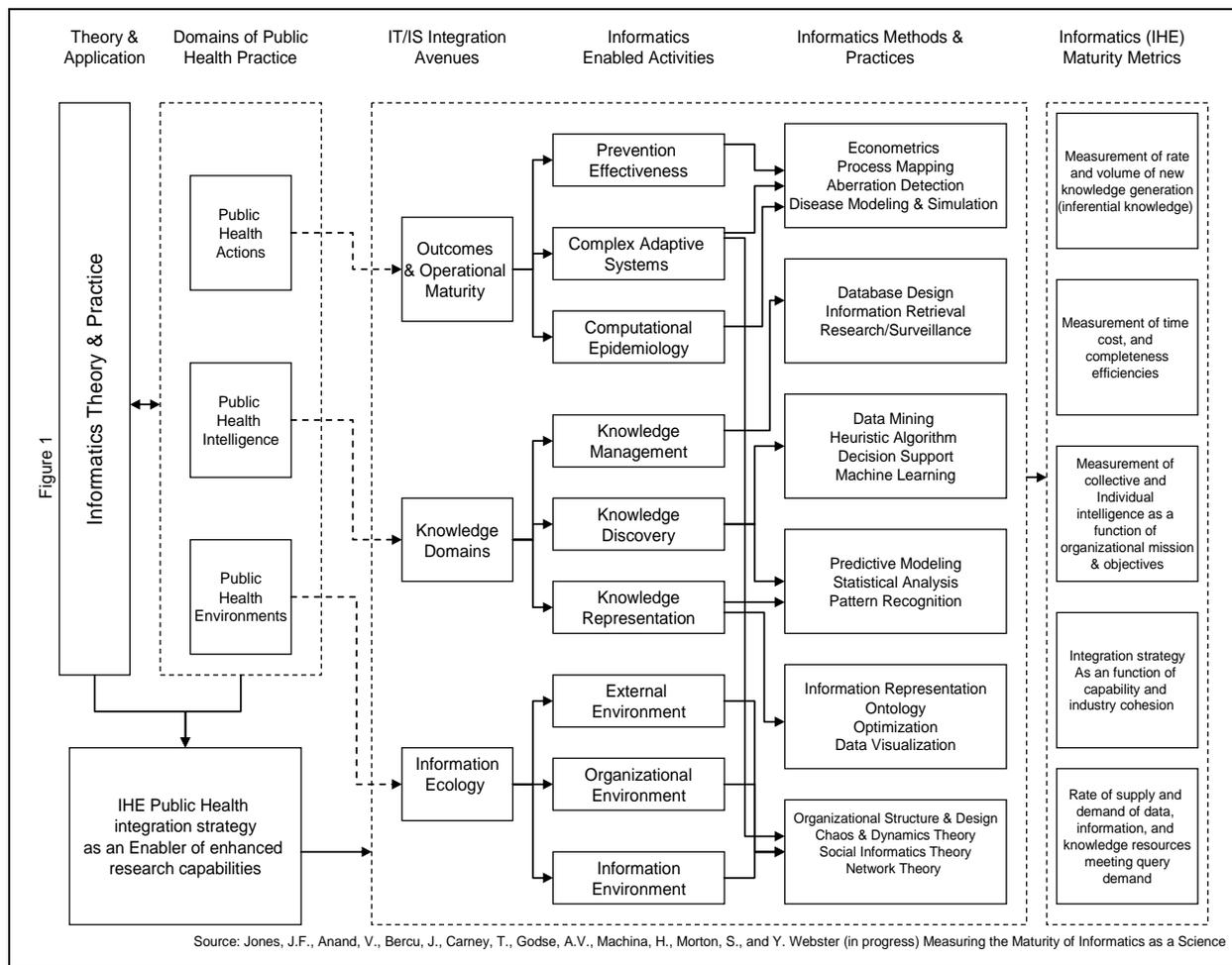
- Public Health Actions
- Public Health Intelligence
- Public Health Environments

Figure 1 continues in outlining how each of these categories of public health practice can be enhanced by the IHE to improve public health research and evaluation on Outcomes & Operational Maturity (e.g., Prevention Effectiveness, Complex Systems Analysis, and Computational Epidemiology), Knowledge Domains (e.g., Knowledge Management, Knowledge Discovery, and Knowledge Representation), and Information Ecology (e.g., External Environment – national/international policy & standards, Organizational Environment – decision & position matrix, Information Environment – point of care)[49,50]

---

[49] Measuring the Maturity of Informatics as a Science. Jones, J.F., Anand, V., Bercu, J., Carney, T., Godse, A.V., Machina, H., Morton, S., and Y. Webster (in progress). Indiana University School of Informatics (IUPUI), Indianapolis, IN (2007)

[50] T. H. Davenport, "Information Ecology: Mastering the Information and Knowledge Environment," Oxford University Press, New York, Oxford (1997).

The true measure of maturity in the impact of the IHE on Public Health Practice can be seen in the application of Informatics Methods & Practices within the Public Health. There should be a direct correlation between varying levels of successful integration of the public health enterprise and the utilization and sophistication in informatics methods and practices. Ideally, such progress can be supported by a formal research agenda that continually examines such topics as; (1) Measuring the rate of new knowledge development (inferential knowledge), (2) Conducting time, cost, and data completeness studies, (3) Analyzing the corresponding increase in both individual and organizational intelligence, (4) Defining integration strategies as a function of industry practices, and (5) Measuring the extent to which public health enterprises are able to meet internal and external demands for data, information, and knowledge as a function of integration.



Figure 1

Source: Jones, J.F., Anand, V., Bercu, J., Carney, T., Godse, A.V., Machina, H., Morton, S., and Y. Webster (in progress) Measuring the Maturity of Informatics as a Science

Appendix 2. Examples of Public Health Domains – Personal Health Record (PHR)

**Individual Patient – PHR Perspectives [Dave McCord]**

Patient Health Records are a new paradigm to the still relatively new and emerging industry of electronic health records. The emergence of the patient centric healthcare model is a demonstration of health and care from the consumers' perspective.

However, consumers are not the only focal point in the healthcare model. The trend over the past several months has been for the healthcare industry, such as provider groups, payer groups and various software vendor entities to sponsor solutions that promote the use of patient healthcare information repositories, both standalone and federated. More recently due to the continued high cost of insurance coverage and to control operating expenses many large scale employer groups are taking the lead on providing PHR's to their employees. Recently, Verizon has enabled an initial 40,000 employees the voluntary use of electronic personal health records and is completely portable, even if the employee retires or leaves the company. (http://sev.prnewswire.com/telecommunications/20070509/NYW10309052007-1.html).

So, let us look at what a PHR is and how does it fit into the overall healthcare model. In the simplest of scenarios, consider a hospital or medical facility as a hub of access to consumers in need of medical care, now connect those physicians' private practices to the hospitals or medical facility to provide an exchange of patient data and we begin to establish a healthcare community. Next, let's connect two or more communities together that exchange patient information and we begin to see a RHIO evolve. Now we can take multiple RHIOs, provide connectivity and the exchange of patient data and we begin to have a NHIN form. All of this evolving around the original premise of a consumer having a medical need. The consumer with access to a computer via the Internet and/or the use of convenient devices such as USB drives now empowers the consumer to supplement and provide for a personalized and centralized repository of patient health records that is transportable and interoperable to the healthcare communities.

Secondly, PHR access is typically maintained by the consumer. This empowers the consumer to control who has access to the data content and how the data are maintained. This is important in that the consumer has the ability to be much more aware of the status of the content and, by use of the Internet and the numerous medical/clinical resource sources, can contribute to the consumer's own well being and health.

In terms of population health crisis situations, those consumers utilizing a Web based PHR solution would more than likely continue to have access to their medical records unlike many of the population impacted by the hurricane Katrina.

Additionally, many of the same Web based solutions, be they initiated by an employer or privately by a Web based vendor, would also be available to receive critical population warnings if recall of particular medications were to occur. This provides a significant value to those individuals with PHR's in that they are now able to be personally directly aware of population impacting situations prior to consulting a physician.

The healthcare industry as a whole is only now beginning to consider or address how PHR's privacy and security should be regulated or legislated, if at all.  Yet, the continuing increase in technology, more awareness and use of computers in family settings, and the potentially ever increasing cost of healthcare make the evolution of PHR's a practical resource for consumers to have the opportunity to take responsibility for the management of their healthcare needs.

Appendix 3. Examples of Public Health Domains – Cancer Surveillance

**IHE Cancer Surveillance Perspective**
**[Tim Carney, Sandy Thames, Lori Havener]**

*Background and Statement of Need*
Many examples serve to demonstrate the value of the IHE in Public Health Practice. The public health practice of disease management and its twin activity of disease surveillance each represent the primary areas of interest in defining this potential value. At the core of public health practice is the need for fast, reliable, and well organized intelligence. The intelligence machinery of public health practice is comprised of a complex network of community organizations, local and state health departments, national interest groups, and federal agencies. Each of these components has its own unique sphere of activity, scope, and objectives that all contribute to the overarching mission of ensuring the public's health. Each component of the public health system is required to engage in formal intelligence gathering to accurately determine disease burdens, trends and patterns of care, and resource mobilization priorities and strategies.

The formal intelligence network is essentially comprised of sentinel data gathering points to collect data specific to a disease category, life style/behavior, and/or other criteria of importance to public health practitioners. These networks can have a local/community, statewide, nationwide, or global focus. However, the multiplicity of surveillance systems around the globe with varying data architectures, platforms, coding schemes, etc., has resulted in what the US House Government Reform Committee called "a gaudy patchwork" in need of unification and integration. The committee described US surveillance systems in particular as "wildly variant" and "technologically backward." The Public Health IHE model should ideally provide a means toward standardizing surveillance system activity and harmonizing the practices to create a formal disease surveillance infrastructure capable of enhanced reporting capabilities.

*Cancer Surveillance Domain*
In response to this national disease surveillance push toward harmonization and standardization, the national cancer surveillance infrastructure has been undergoing a renaissance in practice, methods, and architecture for the past several years. The US Cancer Surveillance Infrastructure is comprised of the National Cancer Institute's Surveillance, Epidemiology, and End Results Program (NCI/SEER), and the Centers for Disease Control National Program of Cancer Registries (CDC/NPCR). These two programs alone cover the entire US and US territories to record the over 1.2 million US cancer cases annually.[51]. Despite 100% coverage of cancer incidence and survival, national and international movements are underway to redesign cancer surveillance in response to the electronic health record, regional health information exchanges, and national health IT initiatives. The goal is to define the ideal electronic infrastructure to enhance the existing surveillance infrastructure in monitoring and tracking the spectrum of

---

[51]Centers for Disease Control and Prevention (CDC). National Program of Cancer Registries. URL: http://www.cdc.gov/cancer/npcr/npcrpdfs/0607_npcr_fs.pdf  Last accessed July12 2007.

cancer care, including diagnostic procedures, treatment and palliation, follow-up, and outcomes.[52]

Several efforts are underway to define best practices, define standards, and harmonize with national and international IT efforts. These include but are not limited to the CDC National Program of Cancer Registries – Modeling Electronic Reporting Project (NPCR-MERP), NCI/SEER DMS (Data Management System), North American Association of Central Cancer Registries, Inc. (NAACCR) Interoperability Ad Hoc Committee, American College of Surgeon's Commission on Cancer (CoC), C-Change, and others that meet and employ resources to reform cancer surveillance in response to the demand for change. The IHE in Public Health Practice can result in an integrated disease infrastructure to facilitate electronic surveillance, seamless disease reporting & abstraction, and more real-time data collection & updating, which in turn can produce more timely, complete, and high-quality data on the national and international cancer burden. [53,54,55]

---

[52] Cancer surveillance in the U.S. Can we have a national system? Judith Swan, M.H.S., Phyllis Wingo, Ph.D., Rosemarie Clive, L.P.N., Dee West, Ph.D., Daniel Miller, M.D., Carol Hutchison, C.T.R., Edward J. Sondik, Ph.D., Brenda K. Edwards, Ph.D. Volume 83, Issue 7 , Pages 1282 - 1291

[53] A Vision for Cancer Incidence Surveillance in the United States. Holly L. Howe; Brenda K. Edwards; John L. Young; Tiefu Shen; Dee W. West; Mary Hutton; Catherine N. Correa Cancer Causes & Control, Vol. 14, No. 7. (Sep., 2003), pp. 663-672.

[54] Danielle G. T. Arts, Nicolette F. de Keizer, and Gert-Jan Scheffer.Defining and Improving Data Quality in Medical Registries: A Literature Review, Case Study, and Generic Framework
J. Am. Med. Inform. Assoc. 9: 600-611.

[55] Public health surveillance for chronic conditions: a scientific basis for decisions. Thacker SB, Stroup DF, Rothenberg RB. Stat Med. 1995 Mar 15-Apr 15;14(5-7):695-6.

Appendix 4. Examples of Public Health Domains – Patient Safety & Population Health
Perspectives

**IHE Patient Safety & Population Protection Perspective**
**[Wu XU and Tim Carney]**

One of the most immediate and measurable impact areas of the IHE on Public Health Practice
can be seen in the related areas of Patient Safety and Population Protection.  These two topic
areas make up one of the most robust areas of health related research, quality improvement
movements, and resource mobilization in the United States.  Confidence in both the healthcare
delivery process and in the public health system is an essential ingredient in an efficient health
machinery.[56]

The intersection between direct patient care and population/public health probably occurs more
directly in the areas of safety and protection than in any other specific topic area.  The factors
that help shape the scope and definition of this intersection and corresponding activity are:

- Delivery Mechanism – Individual Provider Organization vs. Health System/Public Health
  Department

- Focus of Actions – Direct Patient Care vs. Population/Community Performance

- Categorization of Defect – Unintentional/Mishap vs. Intentional/Threat.

- Causation – Individual (Knowledge/Capability Deficit) Unpreventable vs. Systematic
  (Process/Operational Deficiencies) Preventable

- Tool – Handwriting and paper communication vs. electronic medical record and electronic
  reporting

The core values that the Public Health IHE can provide to both Patient Safety & Population
Protection are enhanced defect detectably and public health patient safety surveillance capacity.
Formal studies in Patient Safety have described the mixture of person (patient, provider),
organization, and environment, and the corresponding emergence of defects, as a Complex
Adaptive System.  Additionally, such studies demonstrate high diversity in system components,
nonlinear progression (e.g., small change leading to large impact), self-organizing behavior;
display patterns in structure & process, and, demonstrate relationships of importance.[57] This
demonstrates that as the complexity in individual needs and/or organizational activity grows the
ability to successfully detect and respond in a timely manner to defects in patient care and threats
to population may be difficult to achieve.

---

[56] Indiana Patient Safety Center Overview, Betsy Lee, RN, MSPH, March 2007
[57] Egdeware: Lessons from Complexity Science for Health Care Leaders, by Brenda Zimmerman, Curt Lindberg,
and Paul Plsek, 1998, Dallas, TX: VHA Inc.

Public health surveillance in Patient Safety requires to link clinical information to morbidity or mortality data. In the United States, Patient Safety measurement standards are set up by national consensus-building organizations such as the National Quality Forum, or the federal agencies. The states also passed various legislations or regulations to define reportable patient safety sentinel events and/or hospital acquired infections. Unlike the cancer or immunization registries, no national standard requirements for public health surveillance system for patient safety exist. Ideally, a Public Health IHE should provide quantifiable measures of progress in monitoring the complex network, detecting defects, developing interoperable clinical message exchange between providers and public health, and directing resources to address issues in a way that minimizes adverse effects in the health of the patient and population.

Appendix 5. Examples of Public Health Domains – Surveys

## Population-based Surveys

### [Karen Lipkind, Michelle Williamson and Bob Davis[58]]

The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS) is responsible for monitoring the health of the Nation, including monitoring health care delivery. To that end, NCHS runs a series of provider-based surveys that collect information about patient encounters with the health care system. One such survey is the National Hospital Ambulatory Medical Care Survey (NHAMCS)[59], which collects encounter data from sampled visits to a nationally representative sample of about 400 hospital emergency departments (EDs) each year.

Currently, data are abstracted from patients' medical records that are obtained by hospital or contract staff. They are entered into a one-page abstraction form. The data consist of patient and visit characteristics including patient demographics, diagnoses, procedures, specific medications administered or prescribed, encounter dates and times, providers seen, and disposition, including discharge information should the patient be admitted. The data obtained are then processed and assigned codes such as the International Classification of Diseases (ICD-9-CM) codes. For about 44% of EDs, the encounter information is now maintained by the hospitals in electronic medical records (EMRs). NCHS contractors abstract the information directly from a computer screen or printout of the medical record. It would, perhaps, save the burden of abstracting the data manually if the data could be transmitted electronically, directly from the EMR to NCHS.

As the Nation strives towards universal electronic health records, more and more hospitals will be converting to EMR. But do the existing standards for transmitting health data electronically, meet the statistical needs of NCHS? A current study examines the feasibility of transferring EMR data directly into the survey data base without intermediary manual processes by comparing the transmission standards with the survey data set.

The purpose of this study is to compare the NHAMCS-ED data elements with the messaging standards to determine: (1) Which elements are covered? (2) Which are not covered? (3)
What other elements may be standard that could be added to the survey because they are easily obtainable? The study will also serve to guide and suggest future coordination activities that may close the gap for the elements not covered by standards.

The analysis began with the ASC x12 837 Health Care Services Data Reporting Guide. The data elements in the guide were compared to the data collected in the NHAMCS ED. The results of the gap analysis from the 2006 ED Patient Record form show that of the 145 data elements on the NHAMCS, 49 have identical elements, 16 have similar elements, but 80 have no corresponding elements. There are 55 additional elements in the standards that could be added to the NHAMCS to enhance the analytic capabilities of the survey.

---

[58] Paving the Way for the Electronic Medical Record. Karen Lipkind, Michelle Williamson and Bob Davis. TEPR 2007 Dallas, TX, May 22, 2007

[59] National Hospital Ambulatory Medical Care Survey (NHAMCS). URL:
http://www.cdc.gov/nchs/about/major/ahcd/nhamcsds.htm

Some examples of identical elements are patient demographics, medications, and hospital admission and discharge dates. Similar items include expected source of payment and procedures. It was noted that most of the gaps fit into the category of clinical content. The clinical content represents much of what is happening with the AHIC use cases, which NCHS monitors closely. Several elements were identified as possible future enhancements to the NCHS surveys. These include patient's state of residence, county code and marital status. NCHS also might consider obtaining payer and provider information which is not currently available on the ED Patient Record Form. The clinical data may be available in the HL7 Emergency Department Attachment (EDA). A gap analysis of the EDA is currently underway.

Future plans include a similar gap analysis using data from other NCHS surveys.
For example, the National Hospital Discharge Survey (NHDS) reports on inpatient discharges and complements the ambulatory care surveys. Other NCHS survey personnel have expressed interest in working on this project. .

## Electronic Health Records and the National Health and Nutrition Examination Survey
### [Yechiam Ostchega and Lewis Berman]

The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS) is responsible for monitoring the health of the Nation. In this regard NCHS fields a health and nutrition examination survey that collects data on risk behaviors, physical measures, and laboratory and environmental assessments. This survey, the National Health and Nutrition Examination Survey (NHANES), is a nationally representative study and has been in continuous operation since 1999.

The primary objective of NHANES is to collect high quality health and nutrition data and disseminate it in a timely manner. In accordance with this objective, NHANES has the following goals:

- To estimate the number and percent of persons in the U.S. population and in designated subgroups with selected health conditions and risk factors;
- To monitor trends in the prevalence, awareness, treatment, and control of selected diseases;
- To monitor trends in risk behaviors and environmental exposures;
- To analyze risk factors for selected diseases;
- To study the relationship between diet, nutrition, and health;
- To explore emerging public health issues and new technologies;
- To establish a national probability sample of genetic material for future genetic research; and
- To establish and maintain a national probability sample of baseline information on health and nutritional status.

Each year NHANES interviews and examines roughly 5,000 people in 15 different primary sampling units (PSU) throughout the United States. Data are collected through in-person interviews in the home and detailed physical examinations in mobile examination centers (MEC). An important feature of NHANES is the standardization and quality control of the interview, examination, and specimen collection and processing protocols. This standardization

reduces bias by utilizing objective measures, repeatable procedures, and validated and reliable instruments. Inherently the goal is to achieve the highest possible data quality and measurement precision on relevant health data. Thus to link electronic health records (EHR) into NHANES there must be compliance with study standardization and quality.

EHR affords new opportunities to expand NHANES data collection. These prospects fall within numerous areas concomitant with the myriad needs of public health. Specifically, clinically relevant events and outcomes which are captured in an EHR could extend cross-sectional data collection and allow for longitudinal studies. For example, EHR medication data could be used to validate medications that are reported during the home interview. Furthermore, these data could be used to study compliance of controlling chronic diseases, such as diabetes and high blood pressure, with national guidelines. Additionally, EHR can be used for longitudinal data analysis by using NHANES data as a baseline measure. This provides opportunities to assess morbidity.

Finally, considering the cost, complexity, and time constraints of NHANES, EHR could provide an additional mechanism to supplement NHANES. This is contingent upon EHR data adhering to NHANES quality assurance and control procedures, standards, and an ability to map between NHANES data and standard nomenclatures, vocabularies, and coding systems. Thus, EHR may provide considerable potential to complement national health surveys.

Appendix 6. Examples of Public Health Domains – Trauma Registries

## Trauma Registries [Chris Tilden]

Many states maintain a trauma registry to assist health care providers and policymakers in establishing a coordinated approach to trauma care. Trauma registries are systems that aid in the collection of data used to evaluate the care provided to injured patients who meet specific inclusion criteria. A comprehensive trauma registry will allow integration of patient care data (and other data such as patient information) from multiple settings, including pre-hospital, hospital, and rehabilitation providers. Some states maintain registries including information on patients only treated within designated trauma centers, while other states mandate and/or allow patient data to be entered for trauma patients treated at any medical facility. Trauma system data are used to:

- Evaluate and improve the timeliness, appropriateness and quality of patient care;
- Provide a mechanism for comparing patient outcomes across service areas, provider groups, etc.;
- Identify excessively hazardous environments (e.g., specific auto intersections);
- Prioritize and evaluate public health interventions relating to injury prevention;
- Identify injury trends by geographic location, hospital length of stay, etc.;
- Provide data for clinical benchmarking, process improvement, and patient safety; and
- Provide the capability to monitor trauma system trends (HRSA Trauma-EMS System; http://www.hrsa.gov/trauma/registries.htm)

Many states also have pre-hospital data collection systems. Ideally, these emergency medical services (EMS) systems integrate with the state trauma registry. These systems generally provide a secure method of collecting pre-hospital data, and provide systems to analyze, export and share data with other agencies. However, there is not uniformity among all state systems, and from one state system to the next there may be different data fields that exist for the same issue or event. Recognizing the value of standardization, the National Association of State EMS Directors, National Highway Traffic Safety Administration (NHTSA) and the Trauma/EMS Systems program of the Health Resources and Services Administration's (HRSA) Maternal Child Health Bureau developed a national EMS database in 2001. Known as NEMSIS, the *National EMS Information System*, this project was developed to help states collect more standardized elements and submit the data to a national EMS database. Efforts are now underway for states to submit data to this database, which is maintained by the NEMSIS technical assistance center.

Appendix 7. Examples of Public Health Domains – Chronic Diseases

**Kansas Diabetes Prevention and Control Program**
**Diabetes Quality of Care Project – Data Collection and Analysis [Chris Tilden]**

**Overview**

In January 2005, the Kansas Diabetes Prevention and Control Program (DPCP) implemented a multi-year Diabetes Quality of Care Project (DQCP) with healthcare organizations located in 90 sites across the state. Each organization is provided with the Chronic Disease Electronic Management System (CDEMS) for tracking key diabetes quality of care indicators to assist the care team members in proactively managing patients. CDEMS is a public domain software program based on Microsoft Access. CDEMS users can choose which conditions to track (in this case they are tracking diabetes) and what variables are of interest for each condition. The user can also create and edit drop-down lists for faster data entry. For the DQCP, the Kansas DPCP provides CDEMS training and on-going technical assistance. Organizations are also provided a list of the data elements that are required to be reported to the Kansas DPCP quarterly.

**Data Collection and Analysis Process**

The data collection and analysis process for the first year consisted of each organization sending the Kansas DPCP a hard copy of the CDEMS summary report. Kansas DPCP staff would then do a rudimentary analysis of the data that included re-keying some of the data into a Microsoft Excel spreadsheet. Because this method of data collection and analysis was very inefficient, each of the participating health care organizations was asked to export the CDEMS summary data into a Microsoft Excel spreadsheet and then submit the file electronically by email to the Kansas DPCP. The data was then merged into a master spreadsheet for analysis.

While the process had improved, there were still significant barriers. Technical assistance was required for some organizations that did not have staff with sufficient computer skills for exporting data from CDEMS to Excel. Data was often reported incorrectly and required follow-up communications. Developing multifaceted queries in Excel was challenging. And, the 300-350 health care providers participating in the DQCP were becoming increasingly frustrated with the process.

**Central Repository Pilot Project**

To address these issues, a Pilot Project was implemented in five of the DQCP organizations to test a system for collecting CDEMS aggregate data through an Internet-based program. The Kansas DPCP contracted with a private software development company for the following scope of work:

- Develop CDEMS adapter to extract data
- Remove all patient identification data
- Transfer data to a centralized repository through a secure internet connection
- Create customized query capability to run aggregate reports on data stored in the repository

Data from each of the five health care organizations and their eight satellite clinics was successfully transferred via a secure Internet connection on a bi-monthly basis to a centralized

repository allowing the Kansas DPCP to run standard and complex queries and generate aggregate reports. This process substantially decreased the time previously spent on data entry and increased the consistency and accuracy of data collection and analysis.

**Conclusion**
The pilot demonstrated a more cost effective and accurate process for collecting and analyzing diabetes quality of care data on a statewide basis. Because the selection criterion for the Pilot was established to test the portability to all organizations in the DQCP, the success of the Pilot is currently being spread to the other participating health care organizations. This capability will ultimately lead to a diabetes registry system in Kansas.

Appendix 8: Examples of Public Health Domains – Birth and Death Registries

**Vital Statistics (Birth and Death Registration)**
**[David Atkinson and Michelle Williamson]**

The Centers for Disease Control and Prevention's National Center for Health Statistics (NCHS), the National Association of Public Health Statistics and Information Systems (NAPHSIS) and the Social Security Administration (SSA) have developed a partnership to improve the timeliness, quality, and sustainability of state vital registration and statistics systems by adopting national, consensus-based standards and guidelines.[60]

The new birth registration systems will use the revised 2003 U.S. Standard Certificate of Birth and incorporate standardized data-collection instruments, improved methods for capturing data, immediate query of suspect data, query and edit guidelines, and detailed item definitions[61]. They will also integrate with other health information systems and be configurable to accommodate changing data requirements to avoid the difficulties that most states experienced in modifying their systems to accommodate and implement the 2003 revisions to the U.S. standard birth certificate.[62]

The goals of this collaborative effort extend beyond standardizing birth certificate data; however standards are recognized as a central focus of the reengineering process. The partners have already collaborated to identify and develop functional requirements for reengineered, electronic birth and death registration systems. These requirements have served as the initial foundation for the design, development, and implementation of web-based vital records and statistics systems for states. Hospital information systems would be the primary source for birth certificate data, and the certificate would be a byproduct of the patient's medical record[63], especially when electronic health records are adopted by hospitals.[64] Because a fully reengineering effort must extend beyond the technological problems, funding must be available at the State and local level to support both: 1) the development, implementation and adoption of standardized electronic systems, and 2) the reevaluation of the policies and procedures for all birth data collection, production and distribution.

As States and Federal agencies grapple with the challenges of current death registration methods practiced in the United States, electronic death registration (EDR) systems are envisioned as a key facilitator for improvement of the death registration process. Death certificate completion is primarily under the provenance of the funeral directors, while cause and manner of death

---

[60] Rothwell, C., Sondik, E., & Guyer, B. (2004, January). A delay in publication of the "Annual Summary of Vital Statistics" and the need for new vital registration and statistics for the United States. *Pediatrics, 114(6)*, 1671-1672.
[61] Martin, J., Kochanek, K., Strobino, D., Guyer, B., & MacDorman, M. (2005, March). Annual summary of vital statistics - 2003. *Pediatrics, 115,* 619-634.
[62] Rothwell, C., Sondik, E., & Guyer, B. (2004, January). A delay in publication of the "Annual Summary of Vital Statistics" and the need for new vital registration and statistics for the United States. *Pediatrics, 114(6)*, 1671-1672.
[63] Starr, P., & Starr, S. (1995). The impact of changes in information technology, welfare policy, and health care. *Public Health Report, 110,* 534-544.
[64] U. S. Department of Health & Human Services, Public Health Service, Centers for Disease Control & Prevention, National Center for Health Statistics, Division of Vital Statistics. (1998, January). *Report of the working group to improve the quality of birth data*, 1-3

information are supplied by physicians, medical examiners or coroners. The death certificate is the primary source of death information, however current registration processes are labor intensive, employ disparate and limited automated procedures, and require several professionals at different locations to complete each of the more than 2.3 million death certificates registered each year. The problems that are inherent with the current death registration system include inappropriately filed certificates, incorrect or inconsistent entries, or extensive delays in finalizing the certificates after the death occurred.[65] These difficulties adversely impact state and Federal mortality statistics data.

An Electronic Death Registration Partnership Committee was formed consisting of representatives from NCHS, NAPHSIS, SSA, the American Hospital Association (AHA), the American Medical Association (AMA), the National Association of Medical Examiners, and the National Funeral Directors Association to establish guidelines for the development of an electronic death registration system (EDRS). The Electronic Death Registration Partnership Committee collaborated from 1999 – 2004 and reached consensus on a list of basic characteristics of a registration system for death to meet the needs of the various participants in the process. The basic characteristics identified include: (1) content and general design, (2) functionality, (3) support for data quality (4) security and controls, (5) considerations for cause of death reporting, (6) support for business needs of participants, (7) medical examiner and coroner issues, and (8) data uses.[66]

Using funding support primarily from SSA, several states have developed and implemented EDR systems using the EDRS Guidelines. They have incorporated NCHS-prepared specifications on format, structure, and content of the cause-of-death section into these systems.[67] Their experiences have served, and will continue to serve, as the basis for developing and/or enhancing standardized EDR attributes, methods and processes for national standards, implementation and interoperability.

---

[65] National Association for Public Health Statistics and Information Systems. (2007). *Background on electronic death registration.* Retrieved 25 May 2007, from http://www.naphsis.org/projects/index.asp?bid=391.

[66] National Association for Public Health Statistics and Information Systems. (2007). *Characteristics of an electronic death registration system.* Retrieved 25 May 2007, from http://www.naphsis.org/projects/index.asp?bid=390.

[67] National Association for Public Health Statistics and Information Systems. (2007). *NCHS Recommendation for entry of cause of death data.* Retrieved 25 May 2007, from http://www.naphsis.org/projects/index.asp?bid=409.

Appendix 8: Examples of Public Health Domains – Obesity [Kathleen McCormick]

## Obesity
## [Kathleen McCormick]

The Government, industries, media, public health communities, schools and families are working on today's problems of the growing epidemic of obesity in children, youth and adults in this country. Because it is epidemic it ranks as a critical public health threat.  Since the 1970s, the prevalence of obesity has more than doubled for children aged 2-5 years and adolescents aged 12-19. It has more than tripled for children aged 6-11 years. The IOM reported that there were over nine million children over six years old obese in the US.  The IOM has been mandated by Congress to look at obesity prevention initiatives and make recommendations for prevention, monitoring policies and programs, monitoring the progress, and disseminating promising practices. The Robert Wood Johnson Foundation has also requested action in this area.
Findings from studies indicated that obesity is related to local variation, environmental behavioral and social causes, secondary to medical conditions, e.g. diabetes, dietary intake habits, and genetic factors. There are many promising interventions for prevention and behavioral and social indications.

A costly outcome related to obesity is type 2 diabetes. In 2000 according to the IOM 30% of males and 40% of females had been diagnosed with type 2 diabetes. Other costs are the psychological and social costs associated with the stigma of obesity.  State reporting of obesity is related to hospital costs which have tripled over the past decades.  It is estimated that national expenditures for obesity and overweight populations in adults range from $98 billion to $129 billion annually.

Determining what the evidence is to reduce this problem and prevent its occurrence will take integrated information management systems, controlled vocabularies and standards across states to determine what factors contribute to weight. Routinely tracking body mass index (BMI) in children, youth and adults needs to be integrated in routine pediatric and primary health care evaluations.

Multiple stakeholders from diverse settings have key data that can contribute to the identification of causes, positive preventive strategies, successful treatments, and consequences. Communities will require mapping strategies to identify links between obesity and health disparities. The influence of geographic variation in nutrition and physical activity will be essential. Links to special populations with combined genetic predispositions and obesity will be necessary. The influence of gaming technologies on children's behaviors will need to be evaluated.

The utilization of blog and wikis to create new knowledge exchange networks with vulnerable populations needs to be evaluated. Patterns of influence will need to be modeled and mapped for effective treatment programs.  Once standards and guidelines are developed, decision logic needs to be evaluated in personal health records, and electronic health records.