
# BUILDING A ROADMAP FOR HEALTH INFORMATION SYSTEMS INTEROPERABILITY FOR PUBLIC HEALTH

## (Public Health Uses of Electronic Health Record Data)

WHITE PAPER

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# 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 | Association of 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 (NCHS) |
| 17 | Haas, Janet | New York University Hospitals Center |
| 18 | Handler, Eric | Health Care Agency for Orange County |
| 19 | Hanrahan, Lawrence | Wisconsin Department of Health and Family Services |
| 20 | Hathaway, Alecia | GlaxoSmithKline |
| 21 | Hayes, William | Health Policy Institute of Ohio |
| 22 | Helmus, Lesliann | Virginia Department of Health |
| 23 | Hickey, Michael | LA County Health Services Administration |
| 24 | Hill, Michael | San Joaquin County Public Health Services |
| 25 | Honey, Alan | HL7/OMG HSSP |
| 26 | Jenders, Robert | UCLA/Cedars-Sinai Medical Center |
| 27 | Keating, Patrick | Pennsylvania Department of Health |
| 28 | Kern, Linda | Pinellas County Health Dept. |
| 29 | Kirnak, Alean | Software Partners |
| 30 | Klein, Gunnar | Karolinska Institutet, Sweden |
| 31 | Klein, Sally | Fox Systems |
| 32 | Knoop, Sarah | IBM |
| 33 | Kumar, Manoj | BlueCross BlueShield of Florida |
| 34 | Landry, Laura | Long Beach Dept of Health and Human Svcs |
| 35 | Lawton, David | Nebraska Health & Human Services System |
| 36 | Le, Linh | New York State Dept. of Health |
| 37 | Leitner, Johann | Advanced Business Software |
| 38 | Lipkind, Karen | CDC/NCHS |
| 39 | Lober, Bill | University of Washington |
| 40 | Lou, Jennie | Nova Southeastern University |
| 41 | Lozzio, Carmen | University of Tennessee School of Medicine |
| 42 | Maizlish, Neil | Public Health Division, City of Berkley |
| 43 | Martin, Karen | Martin Associates |
| 44 | McCord, Dave | TM Floyd & Company |

| | | |
|---|---|---|
| 45 | Monsen, Karen | Washington County Public Health & Environment Agency |
| 46 | Onaka, Alvin | Hawaii Department of Health |
| 47 | Orlova, Anna | PHDSC & Johns Hopkins University |
| 48 | Parykaza, Marcy | Delaware Division of Public Health |
| 49 | Raimondi, Mary Pat | CareFacts |
| 50 | Ram, Roni | IBM |
| 51 | Renly, Sondra | IBM |
| 52 | Ross, Will | Mendocino Informatics |
| 53 | Sailors, R. Matthew | Methodist Hospital, Houston, TX |
| 54 | Salkowitz, Sue | American Immunization Registries Association |
| 55 | Savage, Rob | American Immunization Registries Association |
| 56 | Scharber, Wendy | Registry Widgets |
| 57 | Smith, Corey | Aberdeen Area Tribal Chairmen's Health Board |
| 58 | Sniegoski, Carol | JHU Applied Physics Lab |
| 59 | Snow, Laverne | University of Utah |
| 60 | Staes, Catherine | University of Utah |
| 61 | Suarez Walter | PHDSC & Institute for HIPAA and HIT Education |
| 62 | Sumner, Walt | Washington Univ. School of Medicine, St. Louis |
| 63 | Sutliff, Cindy | American Immunization Registries Association |
| 64 | Thames, Sandy | CDC/ NCCDPHP |
| 65 | Tilden, Chris | Kansa Dept of Health and Environment |
| 66 | Tsai, Christopher | Brigham & Woman's Hospital |
| 67 | Wangia, Victoria | University of Kansas |
| 68 | Williamson, Michelle | CDC National Center for Health Statistics |
| 69 | Xu, Wu | Utah Department of Health |
| 70 | 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 vision for this Roadmap is data interoperability throughout the complex web of the entire public health and healthcare enterprise for efficient exchange of health data for public health query.

The overall goal of this effort is to facilitate the necessary linkages, standardization and integration of health data between clinical care and public health to create robust overarching health information exchanges. 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 governmental public health agencies that require access to health information exchanges incorporating clinical care data. The second and third sections describe examples of public health domains/programs (Immunization and Cancer) in the outline of the IHE Technical Tasks for Information Exchanges. Brief descriptions of practices and challenges of health information exchanges in other public health domains (research, chronic care, personal health record, surveys, obesity, trauma, pharmaco-vigilance, etc.) is provided in Appendix 1. Standardization of clinical-public health information exchanges in these domains may be included in the future public health activities at IHE.

The White Paper serves as a framing document for planning public health activities at IHE.

***We would like to invite the public health community to join our collaborative efforts at IHE between public health and HIT vendor communities to guide the development of the IHE Integration Profiles for interoperable Electronic Health Record – Public Health Systems for 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.ihe.net

## What is Public Health

**Mission**

The mission of public health is "to assure the conditions in which people may be healthy."[3] Public Health is society's charge to prevent disease and to protect communities from health threats, through promoting health, restoring wellness, applying disease control measures, and assuring access to healthcare for individual patients. Public Health's mission is accomplished through the collective efforts of the overarching public health enterprise, which in its broadest sense includes the entire healthcare delivery system and its protean components, government agencies, social infrastructure and services, academic centers, the business community and the public served.

Public health indices represent aggregation of data points collected on individuals and consolidated singular events. Commensurately, delivery of public health services and practices occur at the community (population-based) level and at the individual (patient-centric) level, regardless of public or private healthcare funding streams. However, for the purposes of this White Paper this section elaborates further on 'traditional government-funded' healthcare services and regulatory functions, as specific public health databases have and are being developed need to become interoperable not only among themselves but with clinical health data (whether publicly or privately funded or generated).

*Government-sponsored patient-centric public health* services are carried out using publicly-funded healthcare services. Vulnerable or at-risk patients may receive specialized or general healthcare services directly in their homes or at health clinics operated under a public health agency. For example in the United States, there are community health centers funded by the Health Resources and Services Administration (HRSA) that provide a safety net for low income persons. Local and state health agencies may provide selective and/or general healthcare services funded through a variety of government programs, including states' general fund, Centers for Disease Controls and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), etc.. Public funds may also be used to provide laboratory, pharmacy and other services for eligible populations. In this role, publicly funded healthcare is similar to private health care.

*Government-sponsored population-based public health services are* delivered throughout all levels of government. Government public health infrastructure includes agencies that operate on a local, state or territory and federal level. In the United States and its territories, there are approximately 3000 local health departments, approximately 2,000 public health laboratories, over 50 state/territorial health departments, and several federal health agencies, including the Department of Health and Human Services (HHS) agencies such as CDC, Agency for Healthcare Research and Quality (AHRQ), Indian Health Service (IHS), Food and Drug Administration (FDA), Environmental Protection Agency (EPA), Department of Agriculture (DoA) and others.

In some states, the state health agency plays the key role in delivering healthcare and public health services to individuals and communities; in other states, local health departments take the leading role. In some jurisdictions, public/private partnerships or other entities may be involved

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

in delivering direct care and public health services (*e.g.*, immunization coalitions – community-based groups that include parents).

**Public Health Enterprise Stakeholders**

The following is intended to provide broad context to the public health enterprise and its complexity with respect to potential data integration. However, in order for public health to fulfill its patient-centric and population-based data responsibilities, this White Paper seeks to focus initially on developed public health and healthcare domains and expand accordingly as time, resources and public resolve permit:

- Public and consumers served:
  - Consumers-patients, special or vulnerable groups, communities, society;
- Traditional government-sponsored public health agencies & practitioners:
  - Public health departments (city/county, state/territory, federal)
  - Epidemiologists/biostatisticians, environmental health specialists, health investigators, health educators, public health nurses & physicians, administrators, veterinarians/zoologists, scientists, technicians, policy analysts, consultants and others employed by government and dedicated to specific public health functions/services;
  - Targeted public health agency services and clinics (i.e., HIV, Sexually Transmitted Diseases (STD), maternal and child health, etc.)
- Clinical care delivery systems (publically and privately funded):
  - Federally qualified health clinics, locally funded indigent care hospitals & clinics, Indian Health Services;
  - Commercial and employer funded healthcare services;
  - Department of Defense (DoD) healthcare services, Department of Veteran Affairs (VA) healthcare services;
  - Retail & wholesale pharmacies and distribution centers;
  - Long-term care, and home healthcare;
  - Disease management vendors and others;
- Health care providers:
  - Physicians, nurses, health extenders, technicians (laboratory, imaging, pulmonary, physical therapy etc.), pharmacists, chiropractors, podiatrists, physiatrists, etc.;
  - Support personnel – e.g., medical records, administration, actuaries, quality programs, health information technology vendors and others either directly or indirectly involved in patient care data points;
- Laboratories:
  - Public health laboratories (local, state and federal)
  - Commercial laboratories
- Payers & purchases:
  - CDC, HHS, CMS, divisions of government (cities, counties, territories and states), DoD, VA;
  - Healthcare management organizations, indemnity insurance (associated vendors – e.g., billing services, pharmacy benefit management (PBM) companies, other vendors & subcontractors);

    - Employers;
    - Patients;
- Manufacturers / industry:
    - Pharmaceuticals, devices, equipment, supplies;
    - Research and development (R&D);
- Animal health and food safety:
    - Veterinarians;
    - Ranchers and farmers;
    - DoA inspectors;
- Other governmental institutions not listed elsewhere:
    - Local, e.g., environmental, emergency management services/fire & law enforcement, schools, etc.;
    - Federal, e.g., in the United States, FDA, EPA, DoA, Department of Interior (DoI), Department of Homeland Security (DHS), etc.;
- Professional associations and specialty societies;
- Academic; research & development institutions:
    - Universities and research institutes (e.g., in the United States, National Institutes of Health (NIH), Armed Forces Institute of Pathology (DoD), Naval Medical Research Institute (DoD), VA, AHRQ, etc.;
    - Commercial, such as biotech and pharmaceutical & foundation supported, etc..

**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 & 2). This domain-specific organization of public health is supported by funding allocations and state laws that dictate which diseases are reportable. If no federal funds are attached, then State Legislatures largely decide the priorities of Local Health Departments. All this in turn shapes the disease/domain-specific organizational structure of public health agencies, public health research activities, and workforce training.[4]

[4] 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. 1997. 3(2):1-12.

Table 1. Personal Health, Population Level Assurance and Environmental Health Services Provided by Local Health Departments (LHD)[5,6]

| 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% |
| 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% |

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

[6] 2005 National Profile of Local Health Departments, National Association of County & City Health Officials, July 2006. URL: www.naccho.org

Table 2. Examples of Healthcare and Public health Responsibilities of State Health Departments (SHD)[7]

| 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 | | |

## 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.[8,9]

### *Assessment*

- Monitor health status <individual, community/population> to identify community health problems;
- Diagnose and investigate health problems and health hazards in the community;

[7] Beitsch LM et al. Structure and functions of state public health agencies. APHA. 2006. 96(1):167-72
[8] Institute of Medicine. Committee for the Study of the Future of Public Health, 1988.
[9] Public Health Foundation. URL: www.health.gov/phfunctions/public.htm

- 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 reported by clinicians comprises a large portion of data used to conduct disease surveillance, case investigation, case management, and care coordination. Aggregated clinical data are used to perform population health 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. It should be noted that the datasets used for surveillance purposes in various jurisdictions are not standardized. There is a need to develop a standardized dataset(s) for disease-specific and population-level health information exchanges.

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.[10]

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.[11]

[10] 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.

[11] 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.

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 organizations | Assessment<br><br>Policy development & implementation<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>✓ Contact Information<br>✓ Race<br>✓ Ethnicity<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 |

## 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 systems 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. In the United States, there is mandatory data reporting on 62 notifiable infectious diseases across all states and territories[12]. In addition, various jurisdictions require clinicians to report data on the conditions that are of interest for a specific jurisdiction (reportable conditions). This data is reported by clinician and/or laboratory to a local health department. The latter reports this data to the state health department that in turn reports this data to CDC. Besides infectious disease reporting, various public health programs receive data from clinicians, e.g., immunization registries, chronic disease registries, etc. Public health reporting is mostly done using paper forms sent by fax or mail.

Condition-specific information is used at the local and state level for case investigations to facilitate effective public health response. Case investigation often includes follow-up phone calls with the reporting clinician to obtain more information on the case and/or interviews with the patient. Public health reporting from state health departments to the federal agencies (e.g., CDC) is done mostly for statistical purposes, e.g., National Notifiable Disease Surveillance System (NNDSS)[13]. The different purposes of reporting at the local/state and federal levels often make these information systems to be stand-alone systems as well.

Lack of integration and interoperability across public health program information systems leads to the duplication of efforts, unnecessary costs and frustration among providers and consumers asked to provide the same information on multiple forms of varying formats to various programs. The extra costs associated with the silos of efforts are not reimbursed by health insurance. According to the national data, public health data systems currently suffer from limitations such as underreporting, lack of representativeness, lack of timeliness, inconsistency of case definitions across systems, inability to integrate data across the systems, etc.[14]

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[12] Centers for Disease Control and Prevention (CDC). Nationally Notifiable Diseases Surveillance System. URL: http://www.cdc.gov/ncphi/disss/nndss/nndsshis.htm

[13] Same.

[14] 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.

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.

In the United States, the Public Health Information Network (PHIN) initiative[15] has been aimed to address the lack of integration of public health information systems. PHIN efforts are dedicated to identifying and implementing standards-based information exchanges across public health information systems.

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 public health agencies were developed before standards for information exchange existed. Most are not capable of exchanging data electronically within the agency programs, across the agencies and/or with healthcare organizations. Many of them are not capable of sending/receiving standardized messages and cannot or do not comply with nationally accepted vocabularies and health information technology (HIT) standards. In the United States, electronic health record systems (EHR-S) are beginning to be certified to be compliant with the nationally adopted HIT standards. There is a need to assure that public health information systems needs are taken into account in the EHR-S certification, so the interoperable EHR-based clinical and public health information systems will be able to send, receive and exchange relevant data for both public health and clinical practices.

"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".[16]

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.[17] Provision of real-time aggregated community-level information back to providers - bi-directional EHRS-based data exchanges between public health practitioners and

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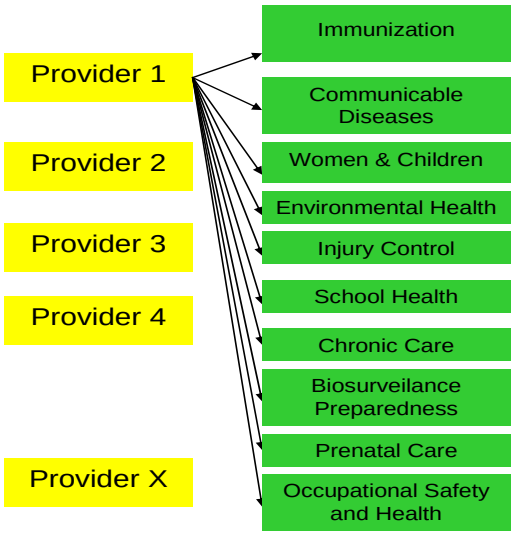
[15] Centers for Disease Control and Prevention (CDC). Public health Information network (PHIN). URL: http://www.cdc.gov/PHIN/

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

[17] 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

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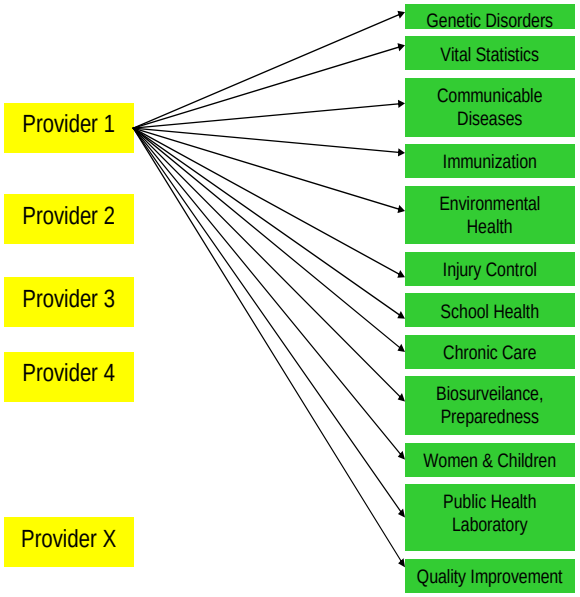


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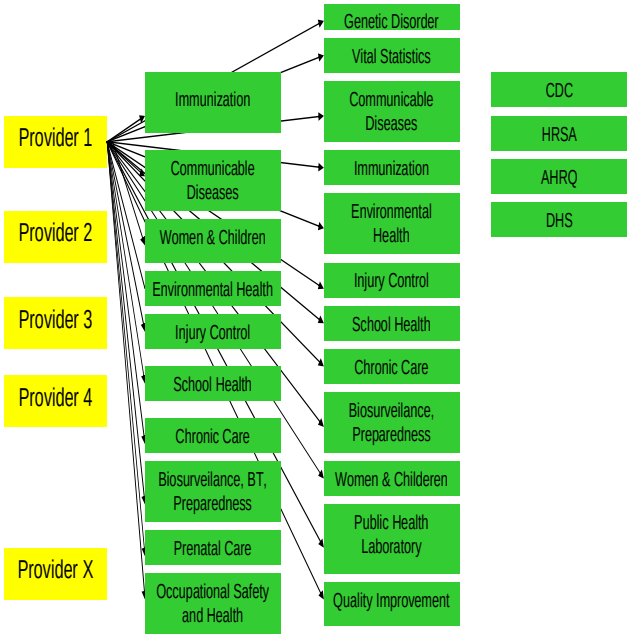
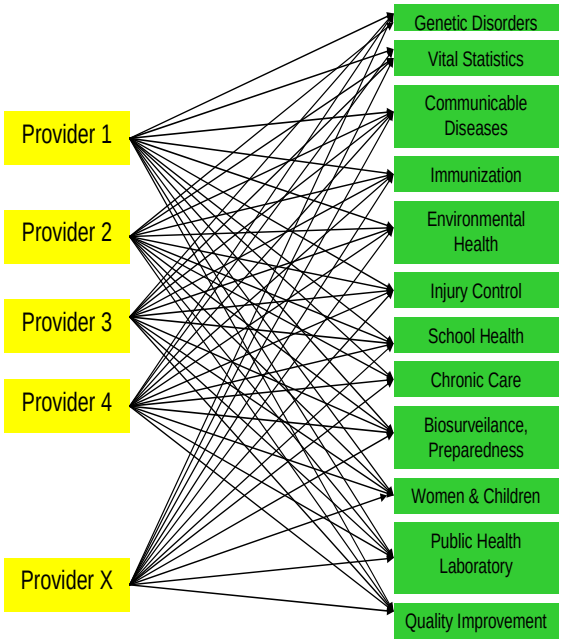



c




d

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.

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.

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. In the United States, the Health Information Technology Standards Panel (HITSP)[18] 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 System, 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 & confidentiality of personal information; however, they do not cover all potential actors in health data exchanges[19]
6. Functional standards, i.e., workflow/dataflow standards[20]
7. Other, i.e., information technology infrastructure standards, interoperability standards.

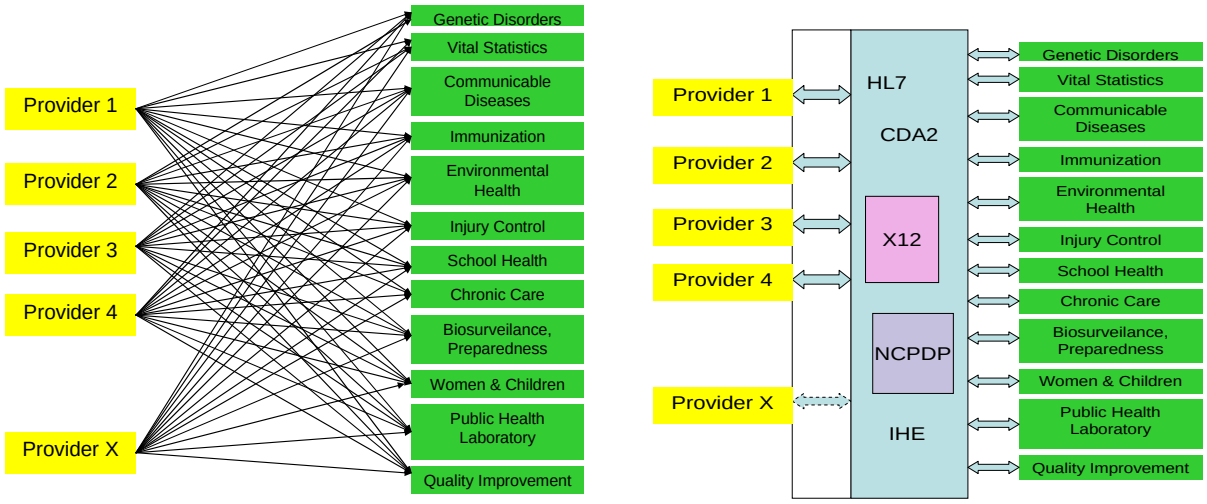
Fig.2 represents a schematic view of the difference between the current public health data reporting mechanism (Fig.2a) and the future standardized EHR-PH health information exchange (Fig. 2b). When the EHR-PH connectivity is completed, various public health data systems will be able to electronically receive/exchange data from/with standardized 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 as well as communicate individual- and/or population-level information back to providers.*** [21]

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

[19] National Committee on Vital and Health Statistics. Privacy and Confidentiality in the Nationwide Health Information Network. URL: http://www.ncvhs.hhs.gov/060622lt.htm

[20] 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. URL: http://www.phdsc.org/about/committees/pdfs/nhin/NYC_School_Health_SSS_Spec_Final_103006.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.




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.

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 two of the public health domains (Immunization and Cancer Surveillance) in the IHE suggested framework for the technical tasks for information exchanges.

To continue this dialogue we included in the Appendix 1 brief descriptions of the other examples of public health domains/programs that rely on clinical-public health information exchanges as follows:

1 Research
2 Cancer Surveillance – Indian Health Services Perspectives
3 Patient Safety and Population Health Perspectives
4 Surveys
5 Trauma Registries
6 Chronic Diseases
7 Birth and Death Registries
8 Obesity
9 Personal Health Record
10 Pharmacovigilance

Standardization of clinical-public health information exchanges for these domains may be included in the future public health activities at IHE.

## 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.[22] 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.

[22] 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.[23] Data sharing regarding compliance with vaccination between Board (Departments) of Education and Local Health Departments may facilitate this goal.

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
- Health Plans and Payers
- Consumers
- Public Health Agencies (local, state/territorial and federal)
- Professional Organizations, i.e., AIRA
- Schools and Childcare

The US effort on the development of the Immunization Registries and their information systems is sponsored by CDC[24], 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.[25] 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.[26] Often, state-specific local interpretations of the ACIP recommendations result in variations of decision support rules being implemented in different IISs.

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

[24] Centers for Disease Control and Prevention (CDC). Vaccines and Immunizations. URL: http://www.cdc.gov/vaccines/

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

[26] Centers for Disease Control and Prevention (CDC). Advisory Committee on Immunization Practice (ACIP). URL: http://www.cdc.gov/vaccines/pubs/ACIP-list.htm.

Table 3 represents examples of the IIS Use Cases evolved from information supplied by the Canadian Infoway project. The Canadian Infoway group contributed heavily to 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 tending 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. In the United States, the FDA and DoD would also be stakeholders in such an endeavor.

IISs are supported by well-developed federal, 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[27]
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)[28] 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.,

[27] American Academy of Pediatrics. Immunization. URL: http://www.aap.org/healthtopics/immunizations.cfm
[28] U.S. Department of Agriculture. Women, Infant and Childen (WIC). URL: http://www.fns.usda.gov/wic/

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.

Table 4: 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 |

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[29] 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

[29] Maryland Department of Health and Mental Hygiene.Vaccine for Children Program. URL: http://www.edcp.org/html/vfchmpg.html

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.[30]

## 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

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

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 on-line transaction processing (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."[31] 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.

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

Table 5. 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 | To be determined | HL7 V3.0 (POIZ), HSSP RLUS |
| Report Adverse Event | Future Notification Version of OED | HL7 V3.0 (PORR), HSSP RLUS |
| Inventory Management | To be determined | X12 |
| Emerging Profiles/Standards | | |
| Vaccine Forecast Module (VFM):<br>- validation<br>- recommendation | Decision Support Profile proposed for the 2008 IHE Development Cycle | 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 |

## 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, region, city and community levels to better understand and tackle the cancer burden while advancing clinical, epidemiologic, and health services research". [32]

Regional, state and national cancer registries are data systems that collect, manage, and analyze data about cancer cases and cancer deaths in a defined population, 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. [33]

The US requires reporting of cancer to the national cancer programs. The National Cancer Institute (NCI) Surveillance, Epidemiology and End Results (SEER) program[34], was established by the National Cancer Act in 1971. Public Law 102-515, enacted in 1992, established the National Program of Cancer Registries (NPCR) under the direction of the Centers for Disease Control and Prevention.

The proportion of the United States population covered by a cancer surveillance program has increased over time. In 2004, it was estimated that there was 100% geographic coverage of cancer mortality in the United States population, with quality data on cancer incidence for approximately 98% of the population, when all registry data are combined. State cancer registries began collecting data at different times. For example, Connecticut (the oldest cancer registry) began in the 1930s, and other states have added registries more recently. The Healthy People 2010 objective 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 has been met.

The US effort to develop Central Cancer Registries and their information systems also includes state governments, and professional medical associations. In the US, these organizations continue 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.

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[32] Healthy People 2010, Chapter 3: Cancer. URL: http://www.healthypeople.gov/document/html/volume1/03cancer.htm#_Toc490540737

[33] Centers for Disease Control and Prevention (CDC). National Program for Cancer Registries (NPCR). URL: http://www.cdc.gov/cancer/npcr/about.htm

[34] National Cancer Institute. Surveillance, Epidemiology and End Results. URL: http://www.seer.cancer.gov

Cancer registries serve as the foundation for cancer related research and public health assessment. It is envisioned that, in the future, electronic reporting standards will be established and implemented throughout the US to support reporting obligations from health care practitioners to state central cancer registries.

**2) Who are the Cancer Surveillance Stakeholders?**

The following are the Cancer Surveillance stakeholders:

- Clinicians and health care providers
- Consumers/patients/public
- Non-governmental Organizations (American Cancer Society, state, regional and local cancer prevention and control coalitions, advocacy groups)
- Public health agencies (local, state and federal)
- National standards-setters (North-American Association of Central Cancer Registries (NAACCR), American College of Surgeons' Commission on Cancer (ACoS-CoC), College of American Pathologists (CAP), CDC, NCI)
- Those who maintain standards (e.g., SNOMED, HL7, LOINC)
- Professional organizations, e.g., (National Cancer Registrars Association (NCRA), CAP
- Software developers
- Researchers

The North American Association of Central Cancer Registries (NAACCR) is an umbrella organization with a membership comprised of 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, and electronic reporting of cancer diagnoses, including data item definitions and standard codes.

**3) Expressing the Criteria**

Cancer surveillance programs are mandated and supported by federal and state laws and regulations. All health care providers in a state or territory are required to transmit, or allow the registry to access, information pertaining to the diagnosis and/or treatment of reportable cases of cancer. While all medical practitioners involved with the diagnosis or treatment of cancer patients are required to report to their respective state cancer registry, cancer registries may choose to implement active physician reporting only for selected specialties, such as dermatology. In turn, after the state registry consolidates the information across health care providers, the data is sent to the NCI-SEER Program and/or CDC-NPCR. Reporting from the state to the national level is done annually and all state registries adhere to a core case definition, with some state and national registries requiring additional collection of cases, and transmit common data items in a standard format.

The inclusion of a patient in a cancer registry is governed by:

1. Federal and state laws and regulations mandating the collection of cancer surveillance data. Case definitions are generally influenced by international partners, such as World Health Organization (WHO) and International Association on Research for

Cancer (IARC). The International Classification of Disease–Oncology (ICD-O) manuals are maintained by WHO.

2. Compliance with state and federal data privacy and confidentiality regulations, with no provision for opt-out of inclusion.
3. Reportability criteria established and maintained by the cancer surveillance domain.

| 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

Central Cancer Registries are operated by public health agencies or their designated bona fide agents (e.g. schools of public health, etc.). These are typically housed within state governments or within a university school of public health or medical school. Federal and state law require hospitals, clinicians, and freestanding diagnostic and treatment centers, to report to central cancer registries. Thus, cancer registries provide a central data repository at both the state and federal 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 | Table 2 In 2004, 100% geographic cancer mortality coverage was attained. High quality incidence data exists for 98% of the population (all registries combined).<br>Source:[url]http://www.cdc.gov/cancer/npcr/npcrpdfs/US_Cancer_Statistics_2004_Incidence_and_Mortality.pdf[/url] | Central Cancer Registries are established in state government or within a university's public health or medical school.<br>Federal cancer registries are maintained at the CDC and the NCI. |

## 5) Identifying a Patient

In the context of Cancer Surveillance Information Systems, this topic is interpreted as **Case-finding and Case Ascertainment**. Central cancer registries receive multiple reports on a single patient from multiple health care providers. Common data sources[35] for detecting cancer cases in the cancer registry's defined population include but are not limited to:

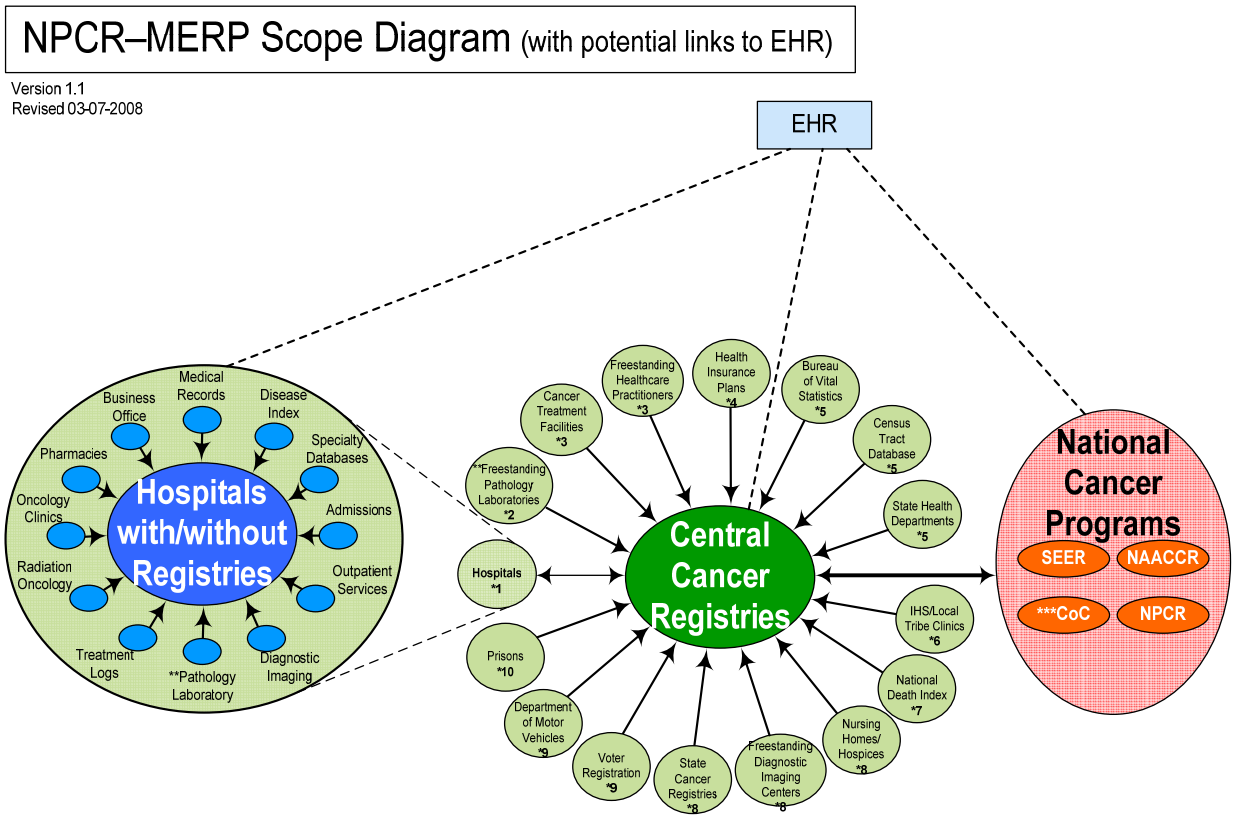
1) Health Care Facilities:
    a. Hospitals

[35] Centers for Disease Control and Prevention (CDC). National Program for Cancer Registries (NPCR). Modeling Electronic Reporting Project (MERP) URL:.
http://www.cdc.gov/cancer/npcr/informatics/merp/workgroups/registry.htm

b. Freestanding diagnostic and treatment centers (pathology laboratories, freestanding surgical treatment centers, radiation oncology centers)
c. Clinics/Physician Offices
d. Nursing Homes

2) Non-Health Care Facilities
   a. Health Insurance Plans (includes federal, public and private plans)
   b. Vital Records (Death Certificates and National Death Index)

The diagram below displays the scope of the cancer surveillance domain as described by the National Program of Cancer Registries' Modeling Electronic Reporting Project (NPCR-MERP). The domain has three levels of data reporting: the hospital level, the state/regional level, and the national level.




NPCR–MERP includes cancer data sources and the lines drawn to the Central Cancer Registries and the National Cancer Programs
*Numbers rank the data sources on the quality of useful data available on a scale of 1 being the most useful and 10 being the least useful.
**Pathology Laboratories–Freestanding and Hospital–send data to both the Hospital Registries and the Central Cancer Registries
***CoC receives data directly from hospitals.

The cancer surveillance community is actively evaluating how the cancer surveillance business will be impacted by the electronic health record (EHR) and IHE implementation. As the EHR becomes more defined, the Cancer Surveillance community will evaluate how the business of cancer registries will function in this new infrastructure.

Linkages between cancer data from health care providers and data from external sources set the Cancer Surveillance Domain apart from many public health surveillance systems. Experiences

gained from these activities can inform efforts to develop information system interoperability, providing insight into both opportunities and challenges in the use of electronic health record data.

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 in central cancer registries 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 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.

All records are grouped under a unique identifier for the patient. While central cancer registries organize data reported from multiple health care facilities by individual patients, they routinely analyze the data by cancer diagnoses. It is important to note that a patient may be diagnosed with more than one primary cancer. While many public health diseases report the number of patients who contract the disease, public health cancer surveillance reports the number of cancers that have occurred. The number of primary cancers a patient has is determined by following national standards[36]. This collaborative effort to develop a set of rules for classifying multiple primary tumors effort received input from most cancer surveillance stakeholders including CoC, NCRA, CDC-NPCR, NCI-SEER, and numerous Registrars. A consolidated record containing the best information from all of the submitted reports is created for each primary cancer. Efforts are underway in the registry community to develop a system that will automatically apply standard multiple primary rules to determine the number of primary tumors that exist for an individual 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.<br>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)

Cancer Registries are typically structured as data repositories that include:

- patient demographics: sex, race, date of birth, address at diagnosis;
- cancer diagnostic information: date of diagnosis, primary site (anatomic location) of the cancer, histologic type, stage of disease progression;
- cancer treatment; and

[36] 2007 Multiple Primary and Histology Coding Rules. URL: http://www.seer.cancer.gov January 1, 2007.

- follow-up and survival data.

Additional cancer data are collected in response to requirements established by state legislatures.

In order to provide certain information, cancer registry personnel must review narrative information in the patient's record and apply complex rules to obtain the final information. These data do not exist in the EHR as discrete data or even within a single medical report. For example, knowing how far that cancer has spread throughout the body, called cancer stage, is critical for determining prognosis and for selecting the appropriate treatment. Cancer registrars must review the surgical report, pathology report, and other tests results and apply rules from the American Joint Commission on Cancer to determine the appropriate stage at diagnosis.

Inclusion of additional data such as occupational, exposure, geographic information and co-morbidity/complications information in cancer surveillance registry may be possible with electronic reporting from the EHR. Several SEER registries have piloted the development of a Residual Tissue Repository. With appropriate safeguards to protect patient identity, this type of effort may provide new insight with respect to cancer etiology, prevention, and prognosis. Such specialized activities are generally performed by a subset of registries until cost-effectiveness and utility are demonstrated. For example, follow-up for survival is performed primarily in SEER registries because of the resources needed to link to records such as the National Death Index.

Detailed address census tracting is performed so cancer surveillance data can be linked to socio-economic factors provided in the 2000 census. Access to these data provide opportunities to explore relationships between cancer and other variables of interest, to expand the interoperability of public health information systems.

Linkages with other health systems enhance the completeness and quality of the cancer surveillance data. 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, 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 Central Cancer Registries from the hospital-based cancer registry. They usually occur as a batch upload using the cancer standard record layout format maintained by NAACCR.[37] Additionally, healthcare providers can report cancer cases manually through a web-based application that directly accesses the appropriate state central cancer registry. Some health care facilities continue to report cases via paper submission. NAACCR has established an HL7 standard for electronic reporting of pathology reports[38]. Use of this standard has been implemented in several state surveillance registries and provides an excellent example of a real, rather than theoretical, transfer of clinical data to a public health domain.

Duplicate entry of data, once for traditional paper medical record and then entered again in the hospital cancer registry database has been a substantial challenge. An increase in the accuracy and 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 the need to enter data multiple times. The cancer surveillance community is currently evaluating standards that have been identified by national healthcare initiatives with a focus on developing a standard electronic health record. This evaluation will provide information for NAACCR to make an informed decision on modifying their current business practices.

[37] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries, Volume I: Data Exchange Standards and Record Description. URL: http://www.naaccr.org

[38] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries, Volume V: Pathology Laboratory Electronic Reporting Version 2.0. URL: http://www.naaccr.org

| 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 for pathology reports;<br>Use of standardized fixed format record layout 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 | | | |

**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 community has developed a standard data editing software[39] for cancer registry records that:

- Provides data quality and completeness edits for all required data items;
- Provides intra- and inter-record checks to verify accuracy and identify conflicts;
- Allows creation of registry-specific edits; and
- Includes a reporting mechanism for correcting and monitoring data errors and discrepancies.

This editing function has been included in all hospital and central cancer 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 Central Cancer Registry editing software could serve as a foundation for developing data quality checks for EHR, thereby minimizing the efforts in "re-creating the wheel."

The Central Cancer 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 (e.g. laboratories, treatment facilities, etc.) without a cancer registry. For each cancer patient, a public health cancer registry may receive diagnostic and treatment information from multiple providers who may not share patient's records with each other. A core function of a Central Cancer Registry is to link records together by patient and by the cancer they represent. By creating a consolidated cancer record across all providers, a comprehensive record of a patient's cancer experience with the health care system is available.

[39] Centers for Disease Control and Prevention (CDC). National Program for Cancer Registries (NPCR). Tools for Writing Portable Edits. URL: http://www.cdc.gov/cancer/npcr/tools/edits/

| 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<br>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 Standards for Cancer Registries, Volume III: Standards for Completeness, Quality, Analysis, and Management of Data[40] includes:

- Legislation and Regulations
- 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 community 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).[41] Additionally, NAACCR maintains the HL7 Implementation Guide for Electronic Reporting of Pathology Reports, and The Electronic

[40] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries, Volume III: Standards for Completeness, Quality, Analysis, and Management of Data. URL: www.naaccr.org

[41] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries, Volume II. Data Standards and Data Dictionary. URL: http://www.naaccr.org

Pathology Reporting Guidelines[42]. NAACCR is currently engaged in comparing its data dictionary with other national health standards.

| 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

Standards for producing consistent, statistically valid data have been established and are documented in the NAACCR Volume III: Standards for Completeness, Quality, Analysis and Management of Data[43]. These standards are adhered to by all state and national cancer surveillance programs. 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. Extensive collaboration between many people across state, federal, and non-governmental organizations are necessary to develop these timely summaries.

| 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, public health agencies, non-governmental organizations, and the public. The CDC-NCPR, the NCI-SEER program, and NAACCR collaborate to produce the annual Cancer

[42] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries, Volume V. Pathology Laboratory Electronic Reporting. URL: http://www.naaccr.org

[43] North-American Association of Cancer Registries (NAACCR). Standards for Cancer Registries. Volume III: Standards for Completeness, Quality, Analysis and Management of Data. URL: http://www.naaccr.org

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[44].

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 healthcare and public health communities and IHE will help achieve effective, seamless integration between both activities.

[44] Centers for Disease Control and Preventions (CDC). National Program of Cancer Registries (NPCR). URL: 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.

This effort will help promote communication and collaboration opportunities between the public and private sector on addressing health information technology standardization needs for interoperable clinical and public health EHR-PH systems.

## Appendix 1.1: 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.

One of the hopes of public health information exchanges is that data will become available for research purposes. Research using public health data (e.g. birth data, mortality data, registry data) generally requires multiple data points over many years' time. Service delivery data offer a mechanism to bridge this gap by documenting intermediate outcomes of public health services. Service delivery data become available when client assessments and services are documented using standardized terminologies. Some public health departments have begun to compare outcomes using standardized classification data. There is a potential for standardized language to serve as a meta-language to describe public health problems, interventions, and outcomes. There is potential to link public health service delivery data with population health outcomes, while controlling for population characteristics, in order to evaluate the effectiveness of public health programs in addressing major public health problems.[45]

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:

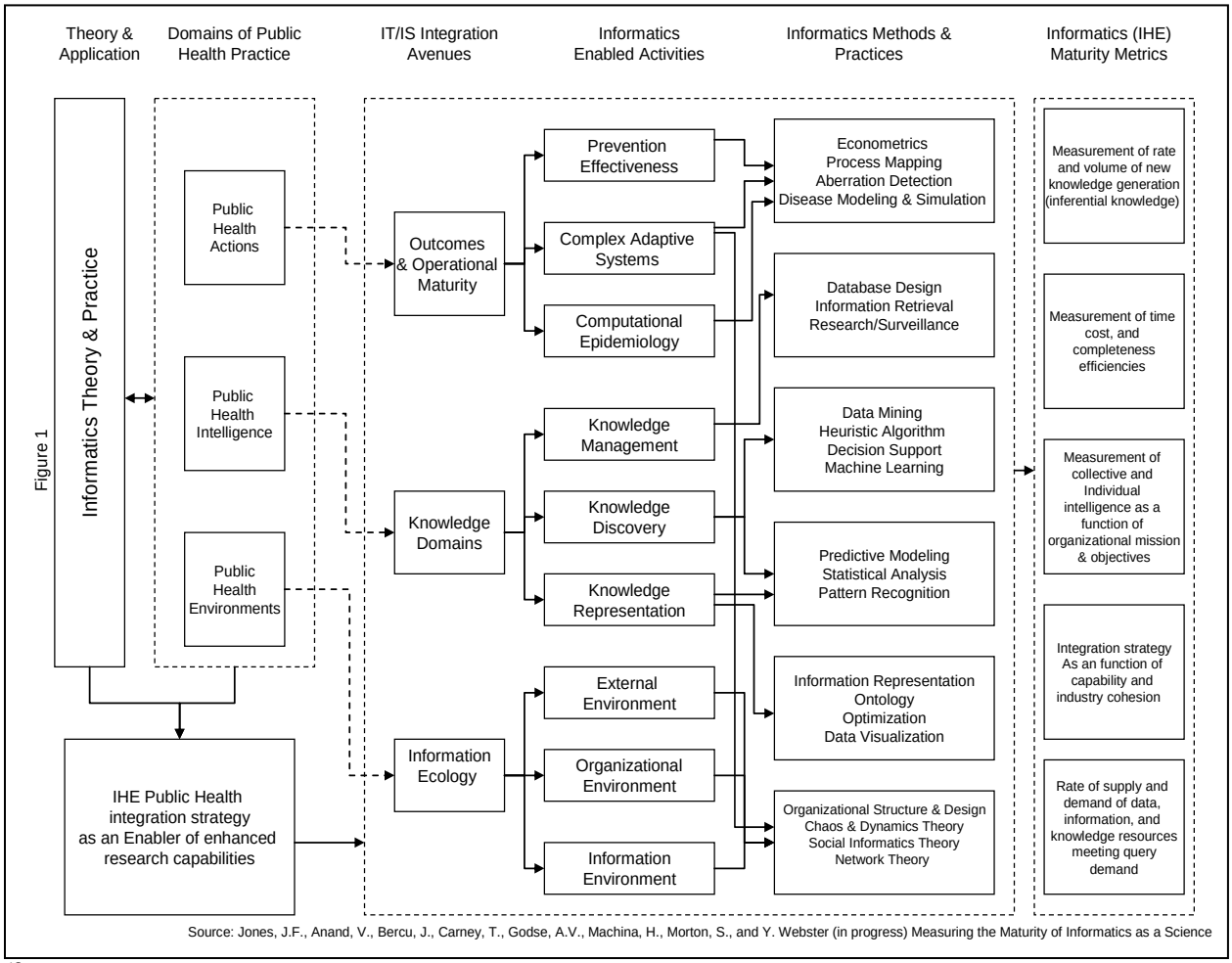
- Public Health Actions
- Public Health Intelligence
- Public Health Environments

Figure 1 outlines how each of these categories can be enhanced by the IHE to improve public health research and evaluation on Outcomes & Operational Maturity, e.g., Prevention

[45] Monsen K. Personal Communications. January 2008.

Effectiveness, Complex Systems Analysis, and Computational Epidemiology; Knowledge Domains, e.g., Knowledge Management, Discovery, & Representation; Information Ecology, e.g., External Environment–national/international policy & standards; Organizational Environment – decision & position matrix; and Information Environment – point of care.[46,47]

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. 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.




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

[47] Davenport TH. Information Ecology: Mastering the Information and Knowledge Environment. 1997. Oxford University Press, New York, Oxford.

## Appendix 1.2: Examples of Public Health Domains – Cancer Surveillance - Northern Plains Tribal Perspectives on Reducing Cancer Disparities

### The Northern Plains Tribal Cancer Data Improvement Initiative (NPTCDI) [Corey B. Smith, Adeola Jaiyeola, Shinobu Watanabe-Galloway]

**Statement of Need.** Cancer is the second leading cause of death among American Indians and Alaska Natives (AI/AN). The Northern Plains American Indians (NPAI) experience the highest mortality and overall incidence rates for cancer than Whites and other native populations. Compared to other races, the NPAI also report higher prevalence of cancer risk behaviors. In addition, NPAI are more likely to be diagnosed with cancers in later stages than non-natives. Among those affected, economic deprivation, geographic isolation, and lack of advocacy serve to magnify the impact of these health disparities.

Cancer care for NPAI tends to be very fragmented. Most NPAI cancer patients are usually seen first at a non-tribal urban Indian health center or local Indian Health Service (IHS) clinic; but, typically patients are referred to non-IHS facilities for diagnostic and treatment services. This referral system, called Contract Health Services (CHS), is underfunded and often results in care delays. The smaller tribally-operated clinics typically have no electronic referral tracking system. Receiving physicians and facilities do not routinely return diagnostic test results or treatment information to the referring clinics. When information is returned, it is not always timely or complete. Movement in and out of different systems of care, that are frequently hundreds of miles apart, further complicates the presentation of an integrated view of the patient because delivery systems either rely on different implementations of the same clinical information software (for example, the Resource Patient Management System in IHS facilities) or use incompatible software products for recording patient information.

American Indian cancer data are often collected through state surveillance programs and federally-sponsored surveys (for example, BRFSS). However, these data are plagued with limitations, such as small population size, racial misclassification and geographic differences. The usefulness of these data is limited. Specifically, there is an overall lack of data specific to NPAI tribes. Moreover, the quality of available data has been questioned in an environment where cancer services are fragmented and there are communication gaps among service providers. There are also significant barriers to access by tribes who must make difficult decisions regarding the allocation of scarce resources to care for its members across the cancer care continuum. There are currently no reporting mechanisms that allow tribal health directors and their staffs to investigate trends and relationships in patterns of cancer risk. In the absence of timely, usable data, the Northern Plains tribes have difficulty tracking disease status and cancer risk factors in an effort to improve the health status of their people. Furthermore, there are also no reliable estimates of the demand for oncology services by NPAI in a way that would prove useful for identifying gaps in care and reducing cancer disparities.

**Purpose of Northern Plains Tribal Cancer Data Improvement Initiative.** The Northern Plains Tribal Epidemiology Center in collaboration with the University of Nebraska Medical Center has recently embarked on a 5-year project aimed at addressing cancer disparities among NPAI by improving the quality, accessibility, and usability of cancer data. The purpose of the

project, the Northern Plains Tribal Cancer Data Improvement Initiative (NPTCDI), is to improve public health infrastructure in Northern Plains tribal communities by facilitating coordination and communication of cancer data among public health entities and tribes, and, by providing training and technical assistance to tribes, tribal health programs, and AI-serving health organizations in utilizing cancer data.

**Approach to the Problem.** A major goal of the project is to increase the effectiveness of cancer data collection, management, and use. This goal implicitly recognizes the need for developing a model of health information exchange that leads to improvements in both population-level cancer surveillance and tracking of patient-level cancer data. As an initial step toward meeting this goal, project activities are geared toward working with stakeholders at a tribal site to perform an in-depth gap analysis of clinical and administrative information systems with an emphasis on mapping the exchange of data which support early detection and screening for a selected neoplasm in a subset of patients. It is anticipated that it will be possible to extend the same mapping methodology used for understanding data gaps in a narrowly defined set of clinical workflows to population-level cancer surveillance at the tribal level as well as State cancer surveillance programs and registries. What is learned from this evaluation will inform the development of use cases that address the need for improvements to the existing system. Findings may also be used to define a set of design specifications for a prototype patient tracking and surveillance system.

**Potential Benefits.** This NPTCDI represents a small step toward the vision of a more integrated healthcare system. An immediate benefit of the project is that the partnership cultivated through ongoing consultation and participation with tribal stakeholders will result in more effective use of existing information systems for clinical decision-making. It is expected that improvements to the collection, exchange, and use of cancer data will increase the likelihood that NPAI patients receive more coordinated, timely and higher quality cancer care. Finally, a potential benefit of this project is that it will bring attention to the importance of building capacity within the US public health infrastructure for generating, managing and using data more effectively to address health disparities in the most vulnerable populations.

## Appendix 1.3: Examples of Public Health Domains – Patient Safety & Population Health Perspectives

### 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.[48]

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.[49] 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.

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,

[48] Lee B. Indiana Patient Safety Center Overview, March 2007
[49] Zimmerman B, Lindberg C, and Plsek P. Egdeware: Lessons from Complexity Science for Health Care Leaders, 1998, Dallas, TX: VHA Inc.

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 1.4: Examples of Public Health Domains – Surveys

### Population-based Surveys
### [Karen Lipkind, Michelle Williamson and Bob Davis[50]]

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)[51], 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.

The data captured in the NHAMCS and other NCHS surveys could potentially be enhanced and benefit from standardized data content and certified EHR systems. This will potentially increase the accessibility of data for HIEs on a regional and national basis and enhance data exchange for statistical analysis. 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

[50] Lipkind K, Williamson M and Davis R. Paving the Way for the Electronic Medical Record. TEPR 2007, Dallas, TX, May 22, 2007

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

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.

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 1.5: 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 1.6: Examples of Public Health Domains – Chronic Diseases

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

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.

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.

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.

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 1.7: Examples of Public Health Domains – Birth and Death Registries

### Vital Statistics (Birth and Death Registration)
### [Delton 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.[52]

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[53]. 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.

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[54], especially when electronic health records are adopted by hospitals.[55] 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 information are supplied by physicians, medical examiners or coroners. The death certificate is

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[52] Rothwell C, Sondik E, Guyer B. 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, 2004. 114(6):1671-1672.
[53] Martin J, Kochanek K, Strobino D, Guyer B, MacDorman, M. Annual summary of vital statistics - 2003. Pediatrics, 2005. 115: 619-634.
[54] Starr P, Starr S. The impact of changes in information technology, welfare policy, and health care. Public Health Report, 1995.110: 534-544.
[55] U. S. Department of Health & Human Services, Public Health Service, Centers for Disease Control & Prevention, National Center for Health Statistics, Division of Vital Statistics. *Report of the working group to improve the quality of birth data*, 1998: 1-3

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.[56] 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.[57]

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.[58] 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.

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[56] National Association for Public Health Statistics and Information Systems.. Background on electronic death registration. 2007. URL: http://www.naphsis.org/projects/index.asp?bid=391.

[57] National Association for Public Health Statistics and Information Systems. Characteristics of an electronic death registration system. 2007. URL: http://www.naphsis.org/projects/index.asp?bid=390.

[58] National Association for Public Health Statistics and Information Systems.. NCHS Recommendation for entry of cause of death data. 2007. URL: http://www.naphsis.org/projects/index.asp?bid=409.

## Appendix 1.8: Examples of Public Health Domains – Obesity

**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 Institute of Medicine (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.

## Appendix 1.9: Example of Interaction of Public Health Domain with Consumer Health Informatics – Personal Health Record (PHR)

**Personal Health Records' Interoperability Between Public Health and Consumer Health Informatics**
**[Dave McCord, Wu Xu and Walton Sumner]**

Internet-based Personal Health Record (PHR) is a relatively new domain of consumer health informatics[59]. The PHR is the longitudinal electronic health record owned, accessed, and managed by a patient or consumer.[60] PHR empowers patients to better manage their fragmented personal health information from themselves, multiple providers and payers for their own healthcare use.

PHR has evolved from electronic medical records and electronic health record applications and has different models. Some health plans, employers, providers, or independent vendors began to provide PHR applications to their patients, members or clients. For example, Kaiser Permanente health plan developed an online PHR, called "My Medical Record," for their members.[61] Recently, Verizon, an employer, provided an initial 40,000 employees with lifelong access to WebMD's electronic PHR application.[62] The Center for Medicare & Medicaid Services (CMS) awarded demonstration projects to pilot Medicare and Medicaid beneficiaries' uses of PHR.[63] The Commonwealth Fund conducted a state survey and reported that "eight states (Alabama, Georgia, Iowa, Massachusetts, Louisiana, Oregon, Texas, and West Virginia) reported having implemented personal health records (PHRs) for state health benefit plans, where as only five Medicaid programs and no pubic health program had implemented a PHR initiative."[6] As the priority of their e-health initiative, the state of Oregon is developing a health record bank for Medicaid beneficiaries to access their own health information to coordinate their care with private and public health systems and Medicaid managed care plans. [64]

Though PHR is developed as a self-management tool for patients to manage personal health, and a supplementary tool for providers to obtain additional information at the point of care, interaction between PHR and public health information systems within a public health jurisdiction could enhance public health's functions to protect population health and further empower residential consumers to take an active role in their personal health and wellbeing in following ways:

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[59] Mullner, Ross M. and Kyusuk C.. Current Issues in Health Care Informatics. Journal of Medical System. 2006. 30(1): 1-2.
[60] Ball MJ and Gold J,. Banking on Health: Personal Records and Information Exchange. Journal of Healthcare Information Management, 2006. 20(2): 71-83.
[61] Kaiser Permanente. URL www.kaiserpermanente.org
[62] Verizon CEO Announces Implementation of New Online Personal Health Records Program for Company Employees URL: http://sev.prnewswire.com/telecommunications/20070509/NYW10309052007-1.html,
[63] Medicare-Encouraging Beneficiary Use of Personal Health Records. URL: http://www.cms.hhs.gov/PerHealthRecords/
[64] Smith VK, Gifford K, Kramer S et al.. State E-Health Activities in 2007: Findings From a State Survey. The Commonwealth Fund, February 2008. URL: http://www.commonwealthfund.org/usr_doc/1104_Smith_state_e-hlt_activities_2007_findings_st.pdf?section=4039

First, public health has population-based clinical information, such as immunization history or cancer treatment, in various registries. With patient direct requests and data sharing agreements, public health registries could securely populate a patient's PHR account with any available health information in a registry.

Second, public health spends considerable resources to promote preventive care in the general population and provide specific preventive interventions to special populations. PHR provides opportunities for public health to send preventive care reminders to eligible patients and conduct cost-effective population-based patient education within participating PHRs, if a PHR user elects to participate in this type of public health services.

Third, PHR's direct outreach to individual residents has tremendous potential value for public health preparedness for health disasters and other crises. Through PHR systems, public health can disseminate recalls of particular medications and medical devices, announce public services in a disaster and help individuals to gain situational awareness, as long as the network is working. Most important, the web-based PHR users can continue to have access to their personal health information regardless of their changed geographic location in a disaster. In the aftermath of Hurricane Katrina, when clinicians and patients throughout the impacted areas in Louisiana, Mississippi, and Florida suffered without access to paper patient records, more than 38,000 veterans and their doctors accessed to their personal health records through the Veterans Health Administration's PHR - MyHealth*e*Vet.[65] In the worst case scenario where Internet is not accessible, the ability of downloading data from a PHR to portable media or printing summary record in a peaceful time are valuable as well. These backup copies of personal health information can help patients to coordinate care after a regional disaster.

However, PHR development is still in its early stages. Payers, employers, providers, independent vendors, and the Health Record Banking Alliance have been exploring various models, strategies and solutions. To our knowledge, public health has not actively participated in the PHR development yet, except for the state of Oregon. Key challenges for PHR's interoperability with clinical and public health information systems include establishing standards for:

- Data, repositories, and exchanges. The common medical informatics challenges of record architecture, terminology standards, and message structure are all relevant to PHR.
- Privacy Policies. Wide variation in vendor policies regarding basic privacy issues was documented in early 2007[66]. PHR vendors are not necessarily beholden to the requirements of the Health Insurance and Portability and Accountability Act (HIPAA), for instance. Privacy advocates have raised concerns about the business models of PHR vendors.
- Security models for patient control of access. In addition to basic privacy rights, the access rights of parents and minors, the mentally ill, and individuals suffering cognitive decline and their caretakers are important concerns. Expectations may differ by state, or even by family. For instance, opinions will vary widely on whether parents should have access to

[65] Ball MJ and Gold J,. Banking on Health: Personal Records and Information Exchange. Journal of Healthcare Information Management, 2006. 20(2): 71-83.

[66] Altarum Systems Research for Better Health. 2007. Review of the Personal Health Record (PHR) Service Provider Market: Privacy and Security. White Paper, available at http://www.patientprivacyrights.org/site/DocServer/Privacy_Review_of_PHRs_Altarum_2007_1_.pdf?docID=1181

the reproductive history data in a 14 year old daughter's PHR. Individuals may want to set their own security levels.

- Records update and maintenance. Competing important challenges are to encourage thorough documentation of health history, and to protect the integrity of the information that is recorded. Early PHR efforts have not met either challenge well.[67]
- Legislation and regulation will be needed to enable this emerging PHR industry and prevent abuses. Legislative efforts in the 110th congress that address personal health records include:
    - The Health Information Privacy and Security Act (S.1814) and TRUST in Health Information Act of 2008 (H.R. 5442), which propose an Office of Health Information Privacy to protect various privacy rights, and incentives for sharing de-identified information.
    - The Federal Employees Electronic Personal Health Records Act of 2007 (S.1490), which provides "for the establishment and maintenance of electronic personal health records for individuals and family members enrolled in Federal employee health benefits plans."
    - The Personalized Health Information Act of 2007 (H.R. 1368), which proposes to pay physicians for each qualifying patient enrolling in a Qualifying Personal Health Record. Funds would come from Medicare and other insurers, who presumably recover the cost through improved and less expensive health outcomes resulting from patient engagement with the PHR.

PHR is a promising domain of health informatics, and could be an empowering technology for citizens. Public health agencies and vendors of health informatics need to pay attention to and actively participate in the PHR development as opportunities arise.

Acknowledgement: The Utah Research Center for Excellence in Public Health Informatics made public input to this appendix.

[67] Kim MI, Johnson KB. Personal health records: evaluation of functionality and utility. J Am Med Inform Assoc. 2002. 9(2):171-180.

## Appendix 1.10: Examples of Public Health Domains - Pharmacovigilance (Surveillance) Domain

### What is the Pharmacovigilance (Surveillance) Domain?
**[Alecia Hathaway]**

To receive FDA approval for marketing and clinical use in the United States, medicines and devices must meet rigorous criteria for safety and efficacy for specific indications of medicinal application. Approval is followed by launching the product for market uptake and begins Phase IV or post marketing surveillance.[68] While, extensive research clinical trial data are submitted for review during the approval process, longer term effects of medicines must be closely tracked following their release for patient utilization. Ten's of thousands of outpatient drug related adverse events, including fatalities, are reported every year in the United States.[69] Many other significant drug side effects often go undetected or unassociated that may either adversely impact the quality of life for patients, or may positively affect their health in some other unanticipated fashion. Adverse events, side effects, drug to drug and bio-interactions, genetic factors & special population effects along with potential new indications for the treatment and management of disease may be discerned only with careful tracking of market entry of new drug & devices.

Currently, manufacturers purchase health data through vendors, such as DataFrame, that provide slices of aggregate claims data approximately 6 months old. Manufacturers and academic institutions then conduct various epidemiological studies. The United States drug surveillance system utilizes MedWatch, which relies on voluntary reporting by providers, patients or hospitals of potential adverse outcomes or side effects. This is entered into the FDA's computerize information database Adverse Event Reporting System (AERS).[1] Public health is most familiar with the VAERS, the database dedicated to vaccine event reporting. Thus, the overarching drug safety monitoring system of today relies upon a sporadic, slow and passive surveillance methodology.

The FDA and CDC continue to seek ways in which to enhance surveillance of outpatient drug safety and have engaged in select projects, such as the National Electronic Injury Surveillance System-Cooperative Adverse Drug Event Surveillance project (NEISS-CADES) in which 63 hospitals participated.[2] Most recently, the FDA is engaging in collaborative projects with CMS, the VA, large private health plans and the DoD for ongoing data collection, review and surveillance for potential biopharmaceutical effects and threats.[70,71] Though, these collaborations represents a good next step in proactively providing earlier warning signals for closer scrutiny, it is still population sampling and is does not employ 'real time' data. Furthermore, most of the

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[68] U.S. Food and Drug Administration. Center for Drug Evaluation and Research. URL: http://www.fda.gov/cder/regulatory/applications/postmarketing/

[69] Budnitz DS et al. National Surveillance of Emergency Department Visits for Outpatient Adverse Drug Events. JAMA. 2006. 10(18): 1858-1866.

[70] Fuhrmans V. Insurers, FDA Team Up to Find Problem Drugs. WSJ. 2008. 4(15): D.

[71] FDA, Defense Department Share Data to Enhance Medical Product Safety Reviews. FDA News. 2007. 8(2).

data relies upon medical claims coding, nor does it contain sufficient detail or clinical context for specificity.

Nevertheless, timely discernment of potential threat or additional medicinal benefit demands a robust and integrated EHR system from which relevant patient utilization and symptom data points may be captured. Specific triggers or flags may be set to comprise an overarching real-time and active syndromic surveillance system, and specific queries may be conducted to elicit trends that can lead to new health information and more tailored patient therapeutics.

At present, we rely upon crude population public health indices upon which to guide appropriate utilization (such as traditional risk factors, gender, age, race, etc. And, we accrue more clinical experience in the postmarketing setting to further determine more specific patient selection parameters for best drug therapies.

Real-time interconnected/operable comprehensive EHR systems will enable substantially more timely discernment of new population group effects and uncover specific genetic indicators. This will drive new scientific understandings, advancing the field of Proteogenomics/ Pharmagenomics and permit more precise targeting and tailored therapies for individuals. Such real-time sophisticated data systems will be based upon EHRs that employ state-of-the-art clinical science and decision making tools, reminders and caveats to greatly enhance patient safety.

Together pharmaco-surveillance and EHRs would greatly power the envelop of discovery and applications, particularly in critically important and expanding areas, such as oncology, congenital and newborn diseases, environmental health exposures and the major diseases of public health importance,.

**Pharmacovigilance is a central part of all bio-surveillance** and should be incorporated into such an overarching domain. Relational query would permit pro-actively eliciting specific relevant aggregate data indicators. Because, pharmaco-surveillance is a critical public health activity in protecting millions of patients, as well as holding the promise of providing insights into addressing many public health challenges, it must be owned by the public health community and assured as a vital component of the bio-surveillance equation in its forward design of data capturing domains.

Public health has the opportunity, through its bio-surveillance responsibilities, to take the sophistication of the art and science that began as application of herbs and botanicals to its next level of refinement, as bio-genetic medicine evolves. This becomes critical, as the nation's 75 million baby boomers (the senior surge) and future generations are living and working longer and relying more upon the life saving, curative and enabling properties of drugs and devices for health and well-being.[72]

[72] Opinion. Readying for the Senior Surge. AMA News. 2008. 5(12): 18.

Appendix 2.

GLOSSARY OF TERMS

(In Alphabetical Order)

| Acronym | Name/Description |
|---|---|
| AAP | American Academy of Pediatrics |
| ACIP | Advisory Committee on Immunization Practice |
| ACS CoC | American College of Surgeons Commission on Cancer<br><br>A consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard-setting, prevention, research, education, and the monitoring of comprehensive quality care.[73] |
| AHRQ | Agency for Healthcare Research and Quality<br><br>The nation's lead Federal agency, within the Department of Health and Human Services, for research on health care quality, costs, outcomes, and patient safety.[74] |
| AIRA | American Immunization Registry Association<br><br>A membership organization that promotes the development and implementation of immunization registries. AIRA provides a forum to share knowledge that promotes registry activities as a resource for immunization information systems and immunization programs.[75] |
| BT | Bioterrorism |
| CAP | College of American Pathologists<br><br>The leading organization of board-certified pathologists, serves patients, pathologists, and the public by fostering and advocating excellence in the practice of pathology and laboratory medicine.[76] |
| CCD | Continuity of Care Document |
| CCHIT | Certification Commission for Healthcare Information Technology<br><br>The Certification Commission for Healthcare Information Technology is a recognized certification body (RCB) for electronic health records and their networks, and an independent, voluntary, private-sector initiative. The CCHIT mission is to accelerate the adoption of health information technology by creating an efficient, credible and sustainable certification program**.** [77] |

[73] American College of Surgeons. Commission on Cancer. URL: http://www.facs.org/cancer/
[74] Agency for Healthcare Research and Quality (AHRQ). URL: http://www.ahrq.gov
[75] American Immunization Registry Association. URL: http://www.immregistries.org
[76] College of American Pathologists. URL: http://www.cap.org
[77] Certification Commission for Healthcare Information Technology (CCHIT). URL: http://www.cchit.org/about/index.asp

| Acronym | Name/Description |
|---|---|
| CDA | Clinical Document Architecture |
| CDC | Centers for Disease Control and Prevention<br><br>The nation's premier public health agency, within the Department of Health and Human Services, whose mission is to promote health and quality of life by preventing and controlling disease, injury, and disability.[78] |
| CR | Cancer Registry |
| CVX | Vaccines Administered Code Set<br><br>The CDC's National Center for Immunization and Respiratory Diseases (NCIRD) maintains the HL7 external code set CVX.[79] |
| Domain | A problem or subject area within the healthcare enterprise or other associated areas such as the public health domain (including , but not limited to, vital statistics, cancer registries and immunization). |
| EHR | Electronic Health Record<br><br>A subset of each care delivery organization's EMR which is owned by the patient and has patient input and access that spans episodes of care across multiple care delivery organizations within a community, region, or state (or in some countries, the entire country).[80]<br><br>The National Alliance for Health Information Technology is leading an important effort for the Office of the National Coordinator for Health Information Technology (ONC) to develop consensus-based definitions for key health information technology terms including EHR.[81] |
| EHR-PH | Electronic Health Record-Public Health Information Systems<br><br>The bi-directional health information exchange of electronic health record information between clinical care and public health. |
| EHR-S | Electronic Health Record System |
| EIS | Entity Identification Services |

[78] Centers for Disease Control and Prevention (CDC). URL: http://www.cdc.gov
[79] Health Level Seven (HL7). IIS: HL7 Standard Code Set CVX. URL: http://www.cdc.gov/vaccines/programs/iis/stds/cvx.htm
[80] Garets D and Davis M, Electronic Medical Records vs. Electronic Health Records: Yes, There is a Difference. A HIMSS Analytics White Paper, January 26, 2006. URL: http://www.himssanalytics.org/docs/WP_EMR_EHR.pdf
[81] National Alliance for Health Information Technology (NAHIT). URL: http://definitions.nahit.org/

| Acronym | Name/Description |
|---|---|
| EMR | Electronic Medical Record<br><br>An application environment composed of the clinical data repository, clinical decision support, controlled medical vocabulary, order entry, computerized provider order entry, pharmacy, and clinical documentation applications. This environment supports the patient's electronic medical record across inpatient and outpatient environments, and is used by healthcare practitioners to document, monitor, and manage health care delivery within a care delivery organization.[82]<br><br>Note: The National Alliance for Health Information Technology is leading an important effort for the Office of the National Coordinator for Health Information Technology (ONC) to develop consensus-based definitions for key health information technology terms including EMR.[83] |
| EPA | Environmental Protection Agency |
| EPSDT | Early Periodic Screening, Diagnosis and Treatment |
| FDA | Food and Drug Administration |
| HIE | Health Information Exchanges<br><br>The mobilization of health information electronically across organizations within a region or community.[84]<br><br>Note: The National Alliance for Health Information Technology is leading an important effort for the Office of the National Coordinator for Health Information Technology (ONC) to develop consensus-based definitions for key health information technology terms including HIE.[85] |
| HIPAA | Health Insurance Portability and Accountability Act |
| HIT | Health Information Technology<br><br>Allows comprehensive management of medical information and its secure exchange between health care consumers and providers.[86] |
| HITSP | Health Information Technology Standards Panel<br><br>A cooperative partnership between the public and private sectors for the purpose of achieving a widely accepted and useful set of standards specifically to enable and support widespread interoperability among healthcare software applications, as they will interact in a local, regional and national health information network for the United States.[87] |

[82] Garets D and Davis M, Electronic Medical Records vs. Electronic Health Records: Yes, There is a Difference. A HIMSS Analytics White Paper, January 26, 2006. URL: http://www.himssanalytics.org/docs/WP_EMR_EHR.pdf
[83] National Alliance for Health Information Technology (NAHIT). URL: http://definitions.nahit.org/.
[84] The American Health Quality Foundation. Quality Improvement Organizations and Health Information Exchange, March 6, 2006. URL: http://www.ahqa.org/pub/uploads/QIO_HIE_Final_Report_March_6_2006.pdf
[85] National Alliance for Health Information Technology (NAHIT). URL: http://definitions.nahit.org/
[86] Department of Health and Human Services (DHHS). Health Information Technology. URL: http://www.hhs.gov/healthit/
[87] Healthcare Information Technology Standards Panel (HITSP). URL: http://www.ansi.org/hitsp

| Acronym | Name/Description |
|---|---|
| HL7 | Health Level 7<br><br>HL7, an American National Standards Institute accredited Standards Development Organization (SDO), produces clinical and administrative data standards for the healthcare domain.[88] |
| HRSA | Health Resources and Services Administration<br><br>The primary Federal agency, within the Department of Health and Human Services, for improving access to health care services for people who are uninsured, isolated or medically vulnerable.[89] |
| HSSP | Healthcare Services Specification Project |
| IARC | International Agency for Research on Cancer |
| ICD | International Classification of Diseases<br><br>The classification used to code and classify mortality data from death certificates. The International Classification of Diseases, Clinical Modification (ICD-9-CM) is used to code and classify morbidity data from the inpatient and outpatient records, physician offices, and most CDC/NCHS surveys. The ICD-10 is used to code and classify mortality data from death certificates.[90] |
| ID | Identifier |
| IHE | Integrating the Healthcare Enterprise<br><br>An initiative by healthcare professionals and industry to improve the way computer systems in healthcare share information. IHE promotes the coordinated use of established standards to address specific clinical needs in support of optimal patient care.[91] |
| IHS | Indian Health Services<br><br>A Federal agency, within the Department of Health and Human Services, which is responsible for providing Federal health services to American Indians and Alaska Natives.[92] |
| IIS | Immunization Information Systems<br><br>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.[93] |
| IOM | Institutes of Medicine |
| IT | Information Technology |
| LHD | Local Health Departments |

[88] Health Level Seven (HL7). URL: http://www.hl7.org
[89] Health Resources and Services Administration (HRSA). URL: http://www.hrsa.gov/about/default.htm
[90] Centers for Disease Control and Preventions (CDC). National Center for Health Statistics (NCHS). Disease Classification. URL: http://www.cdc.gov/nchs
[91] Integrating the Healthcare Enterprise (IHE). URL: http://www.ihe.net
[92] Indian Health Service (HIS). URL: http://www.ihs.gov
[93] American Immunization Registry Association (AIRA). Immunization Information Systems. URL: http://www.immregistries.org

| Acronym | Name/Description |
|---|---|
| LOINC | Logical Observation Identifiers Names and Codes<br><br>LOINC codes, maintained by the Regenstrief Institute, Inc., are universal identifiers for laboratory and other clinical observations that facilitate the exchange and pooling of results for clinical care, outcomes management, and research. [94] |
| MIROW | Modeling of Immunization Registry Operations Workgroup |
| MVX | Manufacturers of Vaccines Code Set<br><br>The CDC's National Center for Immunization and Respiratory Diseases (NCIRD) maintains the HL7 external code set MVX.[95] |
| NAACCR | The North American Association of Central Cancer Registries<br><br>A professional organization that develops and promotes uniform data standards for cancer registration; provides education and training; certifies population-based registries; aggregates and publishes data from central cancer registries; and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs, and patient care to reduce the burden of cancer in North America.[96] |
| NCHS | National Center for Health Statistics<br><br>A Federal agency within the CDC and the nation's principal health statistics agency that compiles statistical information to guide actions and policies to improve the health of our people.[97] |
| NCI | National Cancer Institutes<br><br>The Federal Government's principal agency for cancer research and training. NCI is a component of the National Institutes of Health.[98] |
| NCPDP | National Council for Prescription Drug Programs<br><br>NCPDP creates and promotes standards for the transfer of data to and from the pharmacy services sector of the healthcare industry.[99] |
| NCRA | National Cancer Registrars Association<br><br>A not-for-profit association representing cancer registry professionals and Certified Tumor Registrars.[100] |

[94] Logical Observation Identifiers Names and Codes (LOINC). URL: http://www.regenstrief.org/medinformatics/loinc
[95] Health Level Seven (HL7). IIS HL7 Standard Code Set MVX. URL: http://www.cdc.gov/vaccines/programs/iis/stds/mvx.htm
[96] The North American Association of Central Cancer Registries (NAACCR). URL: http://www.naaccr.org
[97] Centers for Disease Control and Preventions (CDC). National Center for Health Statistics (NCHS).. URL: http://www.cdc.gov/nchs
[98] National Cancer Institute (NCI). URL: http://www.cancer.gov
[99] National Council for Prescription Drug Programs (NCPDP). URL: http://www.ncpdp.org
[100] National Cancer Registrars Association (NCRA). URL: http://www.ncra-usa.org/

| Acronym | Name/Description |
|---|---|
| NEDSS | National Electronic Disease Surveillance System<br><br>NEDSS (National Electronic Disease Surveillance System) is an Internet-based infrastructure for public health surveillance data exchange that uses specific PHIN (Public Health Information Network) and NEDSS Data Standards.[101] |
| NHAMCS | National Hospital Ambulatory Medical Care Survey<br><br>The NHAMCS is a CDC/NCHS survey designed to collect data on the utilization and provision of ambulatory care services in hospital emergency and outpatient departments.[102] |
| NHANES | National Health and Nutrition Examination Surveys (NHANES) data provide a snapshot of the health and nutrition of the U.S. population.[103] |
| NHIN | Nationwide Health Information Network<br><br>The critical portion of the health IT agenda intended to provide a secure, nationwide, interoperable health information infrastructure that will connect providers, consumers, and others involved in supporting health and healthcare.[104] |
| NIH | National Institutes of Health |
| NPCR-MERP | National Program of Cancer Registries – Modeling Electronic Reporting Project |
| NPI | National Provider Identifier |
| Omaha | The Omaha System<br><br>The Omaha System is a research-based, comprehensive practice and documentation standardized classification; it can be used by multidisciplinary health care practitioners in any setting from the time of client admission to discharge.[105] |
| OLTP | Online Transaction Processing<br><br>A class of systems that facilitate and manage transaction-oriented applications, typically for data entry and retrieval transaction processing.[106] |
| PDQ | Patient Demographic Query - IHE |

[101] Centers for Disease Control and Preventions (CDC). National Electronic Disease Surveillance System. URL: http://www.cdc.gov/phin/activities/applications-services/nedss/
[102] Centers for Disease Control and Preventions (CDC). National Center for Health Statistics (NCHS). National Hospital Ambulatory Medical Care Survey. URL: http://www.cdc.gov/nchs/about/major/ahcd/nhamcsds.htm
[103] Centers for Disease Control and Preventions (CDC). National Center for Health Statistics (NCHS). National Health and Nutrition Examination Surveys. URL: http://www.cdc.gov/nchs/nhanes.htm
[104] U.S. Department of Health and Human Services (DHHS). Nationwide Health Information Network (NHIN) URL: http://www.hhs.gov/healthit/healthnetwork/background/
[105] The Omaha System. URL: http://www.omahasystem.org/
[106] Online Transaction Processing.Wikipedia. URL: http://en.wikipedia.org/wiki/OLTP

| Acronym | Name/Description |
|---|---|
| PHDSC | Public Health Data Standards Consortium<br><br>The mission of the PHDSC is to bring a common voice from the public health community to the national efforts of standardization of health and healthcare information. The PHDSC is a non-profit membership-based organization of Federal, state and local health agencies; national and local professional associations; academia, public and private sector organizations; international members, and individuals. [107] |
| PHI | Public Health Informatics |
| PHIN | Public Health Information Network<br><br>The CDC PHIN is a national initiative to improve the capacity of public health to use and exchange information electronically by promoting the use of standards, defining functional and technical requirements.[108] |
| PHR | Personal Health Record<br><br>An electronic Personal Health Record ("ePHR") is a universally accessible, layperson comprehensible, lifelong tool for managing relevant health information, promoting health maintenance and assisting with chronic disease management via an interactive, common data set of electronic health information and e-health tools. The ePHR is owned, managed, and shared by the individual or his or her legal proxy(s) and must be secure to protect the privacy and confidentiality of the health information it contains. It is not a legal record unless so defined and is subject to various legal limitations.[109]<br><br>Note: The National Alliance for Health Information Technology is leading an important effort for the Office of the National Coordinator for Health Information Technology (ONC) to develop consensus-based definitions for key health information technology terms including PHR.[110] |
| PIX | Patient Identifier Cross-Reference - IHE |
| POIZ | Immunization Domain – HL7 V3 |
| PRPA | Person Registry Patient Administration – HL7 V3 |
| QA | Quality Assurance |
| QC | Quality Control |
| QBP | Query by Parameter – HL7 V2.5 |
| QED | Query for Existing Data Integration Profile - IHE |
| RHIO | Regional Health Information Organizations<br><br>Note: The National Alliance for Health Information Technology is leading an important effort for the Office of the National Coordinator for Health Information Technology (ONC) to develop consensus-based definitions for key health information technology terms including RHIO.[111] |
| RIM | Reference Information Model |

[107] Public Health Data Standards Consortium (PHDSC). URL: http://www.phdsc.org
[108]Centers for Disease Control and Preventions (CDC). Public Health Information Network. URL: http://www.cdc.gov/phin/about.html
[109] Health Information and Management Systems Society (HIMSS). URL: http://www.himss.org/asp/topics_phr.asp
[110] National Alliance for Health Information Technology (NAHIT). URL: http://definitions.nahit.org/
[111] National Alliance for Health Information Technology (NAHIT). URL: http://definitions.nahit.org/

| Acronym | Name/Description |
|---|---|
| RLUS | Resource Location and Updating Service - HSSP |
| SEER | Surveillance Epidemiology and End Results |
| SHD | State Health Departments |
| SNOMED | Systematized Nomenclature of Medicine<br><br>SNOMED CT (Clinical Terms) is a comprehensive, multilingual clinical healthcare terminology for the electronic health record containing more than 357,000 concepts with unique meanings and formal logic-based definitions organized into hierarchies.[112] |
| STD | Sexually Transmitted Disease |
| UML | Unified Modeling Language |
| USAMRIID | U.S. Army Medical Research Institute of Infectious Diseases |
| USDA | United States Department of Agriculture |
| VFM | Vaccine Forecast Module<br><br>Evaluates the completeness of a person's immunizations based upon standard clinical practices. |
| VXQ | Query for Vaccination Record – HL7 V2.5 |
| VXU | Unsolicited Vaccination Record Update – HL7 V2.5 |
| WHO | World Health Organization |
| WIC | Women, Infant & Children |
| X12 | The Accredited Standards Committee (ASC) X12<br><br>ASC X12 brings together business and industry professionals in a cross-industry forum to develop and support electronic data exchange standards and related documents for the national and international marketplace to enhance business processes, reduce costs and expand organizational reach.[113] |
| XDR | Cross-Enterprise Document Reliable Interchange - IHE |
| XDS | Cross Enterprise Document Sharing - IHE |

[112] International Health Terminology Standards Development Organization (IHTSDO). URL: http://www.ihtsdo.org/our-standards/
[113] Accredited Standards Committee (ASC) X12. URL: http://www.x12.org