

Chapter 29

National Public Health Informatics, United States

Seth Foldy

Abstract Informaticians looking at national public health information management in the US may ask, “Who designed it this way?” Most systems are not straightforward or easy to understand, in part due to their historical evolution in a decentralized federal structure that located most public health authority at the state level. Thus, many national systems have been built from the bottom-up in a heterogeneous fashion based on voluntary cooperation, sometimes induced through federal funding. In other cases, federal powers related to interstate commerce or national defense gave rise to centralized systems. More recently, federal agencies have played an important role in convening stakeholders, coordinating practice and information standards, and using funding to support implementation and induce conformance to standards. This chapter describes local, state and federal public health roles in the United States, points to collaborative products defining information requirements for various public health activities, outlines the evolution toward national information exchange standards, and describes health informatics roles (highlighting several important regulations) played by several federal and national agencies.

Keywords Federal government • Local health department • State health department • Police power • Interstate commerce • Taxing and spending authority • National vital statistics • Nationally notifiable conditions • Department of Health and Human Services • Public Health Service • Centers for Disease Control and Prevention • Food and Drug Administration • World Health Organization • International Health Regulations • Health Insurance Portability and Accountability Act • Centers for Medicare and Medicaid Services • Core functions of public health • Public health essential services • Public Health Accreditation Board • Business

S. Foldy, MD, MPH, FAAFP

Department of Family and Community Medicine, Medical College of Wisconsin,
3061 N. Marietta Avenue, Milwaukee, WI 53211, USA
e-mail: sfoldy@sbcglobal.net

process • Public health emergency preparedness • Information supply chain • Situational awareness • Passive surveillance • Electronic health record systems • Clinical Laboratory Improvement Act • Health Information Technology for Economic and Clinical Health (HITECH) Act • Patient Protection and Affordable Care Act (PPACA, ACA) • Electronic laboratory reporting • Immunization information system • National Electronic Disease Surveillance System • Office of the National Coordinator for Health Information Technology (ONC) • National Healthcare Safety Network • BioSense • Mini-Sentinel • Cancer registry • Environmental Health Tracking Network • Standards and Interoperability Framework • Health Information Technology Policy Committee (HITPC) and Standards Committee (HITSC) • National Committee on Vital and Health Statistics • National Center for Health Statistics • Office of Surveillance, Epidemiology and Laboratory Services • Public Health Information Network (PHIN) • Nationwide Health Information Network • National Academies • Institute of Medicine • Health Resources and Services Administration • Agency for Healthcare Research and Quality • National Institutes of Health • National Library of Medicine • Value Set Authority Center • Veterans Administration • Approved Testing and Certification Body • Federal Health Architecture • CONNECT • Substance Abuse and Mental Health Services Administration • Office of Civil Rights • Office of Management and Budget • Paperwork Reduction Act • All payer claims database

Learning Objectives

1. Describe the historic framework of state, local, and federal public health and its influence on the public health information supply chain.
2. Identify key public health informatics roles and regulations of different federal health and information agencies.
3. Become familiar with several key national health information collection systems.

Overview

Informaticians looking at national public health information management in the US may ask, “Who designed it this way?” Most systems are not straightforward or easy to understand, in part due to their historical evolution in a decentralized federal structure that located most public health authority at the state level. Thus, many national systems have been built from the bottom-up in a heterogeneous fashion based on voluntary cooperation, sometimes induced through federal funding. In other cases, federal powers related to interstate commerce or national defense gave rise to centralized systems. More recently, federal agencies have played an important

role in convening stakeholders, coordinating practice and information standards, and using funding to support implementation and induce conformance to standards. This chapter describes local, state and federal public health roles in the United States, points to collaborative products defining information requirements for various public health activities, outlines the evolution toward national information exchange standards, and describes health informatics roles (highlighting several important regulations) played by several federal and national agencies.

Historical Framework

The United States of America was born as a confederation of independent states; its Constitution reflects this by limiting the powers of the national or “federal” government. Police power, including the establishment and enforcement of public health laws, was reserved to states. Federal responsibilities included national defense, the regulation of international and interstate commerce, and taxing and spending power.

As a result, there historically has been a fairly high level of variation between states in the management of public health (and of public health information). From an information perspective, state governments, and sometimes local governments (depending on state constitutions), have been the major regulators of what information is reportable by law, how it is reported, and how it is used and re-used. In recent decades, variability in such information management has been reduced in two ways: interstate agreement, and expanding federal influence using national constitutional powers.

Examples of interstate agreements include standardized state and territorial birth and death registration and reporting to create national vital statistics [1] and the selection, specification, and notification of Nationally Notifiable Conditions (e.g., cases of communicable diseases) [2, 3]. For those impatient with the pace of developing nationwide informatics standards for public health reporting, it is instructive that it took decades just to achieve comprehensive national reporting of vital and communicable disease statistics. Federal agencies played important coordinating and enabling roles for both of these national systems.

Federal authority for national defense and international trade gave rise to the predecessors of the Public Health Service (PHS) that performed port quarantine and other duties, and its modern progeny including the Centers for Disease Control and Prevention (CDC). The regulation of interstate commerce evolved to include oversight of food, drug, and environmental safety through the Food and Drug Administration, the Department of Agriculture, the Environmental Protection Agency, and other agencies. The taxing and spending authority has been used to support research, to induce adoption and standardization of public health practices through federal grants, and to influence health care delivery through reimbursement systems like Medicare (for elders and disabled) and Medicaid (for low-income individuals). Federal funds (excluding Medicare and Medicaid) now account for 45 %

of state and 20 % of local health department budgets [4, 5]. This illustrates that while states retain authority, the power of the purse gives federal public health agencies real influence if grant and contract requirements are focused and coordinated.

Laws and regulations related to information privacy and, to a lesser extent, telecommunication, have also been subject to this mix of state and national authority. For example, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 [6, 7] created national minimum regulations for privacy and security of electronic health information, but states may have stricter controls, which vary from state to state.

A casual observer may decide there is no such thing as a “national system” in the United States, but in fact, there has been a gradual evolution of a national framework, built partly by consensus from below, and partly by coordination and funding from above. There has been no central authority to design the best information systems from scratch to meet the nation’s public health needs; what exists today is the result of many actors struggling toward similar goals over time. It is important for public health informaticians to recognize this state of affairs, to consider local, state, *and* national laws and requirements, and to encourage further harmonization whenever possible. The pace of change toward national standards is quickening, pushed by legislation and regulations described below.

International influence on domestic public health information management expanded after the 2002–2003 Severe Acute Respiratory Syndrome (SARS) outbreak and the ensuing revision of World Health Organization International Health Regulations (IHR) effective in 2007 [8, 9]. The IHR, by treaty, established expectations regarding prompt detection, investigation, and international reporting of Public Health Emergencies of International Concern. US systems of local, state, and federal surveillance and communication address IHR requirements [10].

Variability of Health Departments and Public Health Work

Few US states enjoyed statewide systems to protect public health in the eighteenth and most of the nineteenth centuries. City health departments developed rapidly during the rapid urbanization and associated epidemics in the early twentieth century, and their practices were adopted unevenly across local and state governments. Even today, there is wide variation in services offered. Widely offered programs include communicable disease control, environmental health, nutrition, registration of vital events (births, deaths, marriages, and divorces), maternal and child health programs, and chronic disease prevention and management programs [11, 12]. However, there is great interstate variability in laws authorizing and regulating public health functions. These functions are performed by the state health department in some states and the local level in others. They may be performed by different departments (for example, environmental health programs may be managed by environmental protection departments instead of public health) or by private organizations under contract or government charter. Some activities rely almost entirely

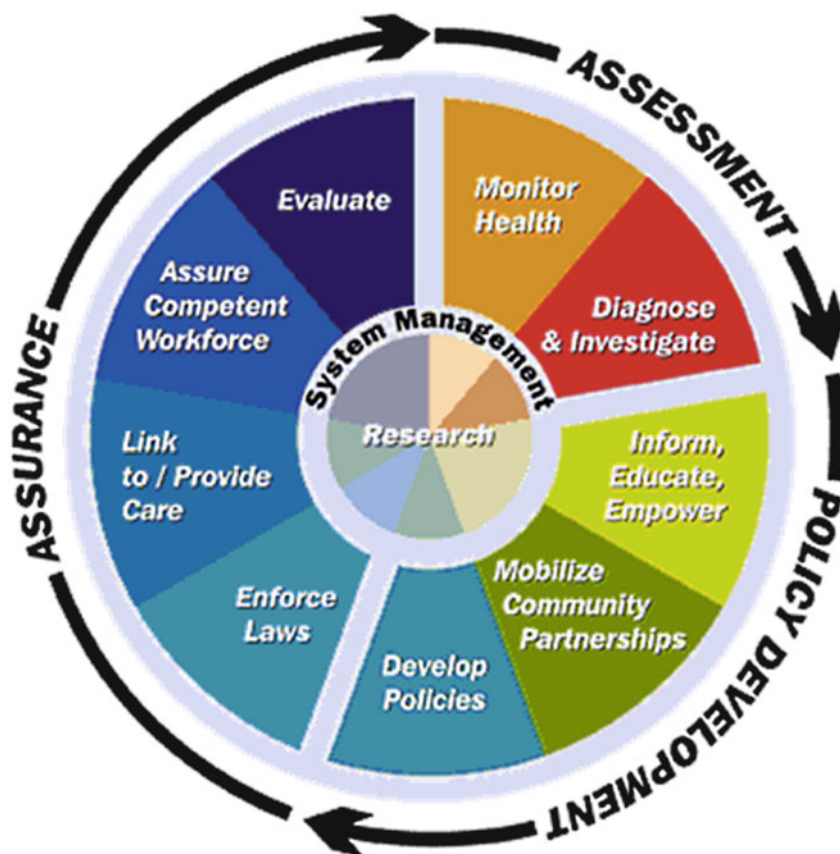


Fig. 29.1 The ten essential services and their relationship to three core functions [13]

on federal grants and contracts, which may not be available or awarded to all jurisdictions.

Public health laboratories are another critical part of the public health system. Virtually every state and territory has a designated state public health laboratory, but its location and governance (whether inside or outside the state health department) vary from one jurisdiction to the next.

All of these factors have led to a common complaint: “If you’ve seen one health department, you’ve seen one health department.” Consequently, it is difficult to generalize with assurance about the work and the informatics requirements of ‘health departments.’

A catalytic 1988 report by the Institute of Medicine [13] helped establish a national vision of a public health system with three core functions of assessment, policy development, and assurance, which were further elaborated into ten essential services [14] (Fig. 29.1), and more recently into an operational definition of local health departments [15] and voluntary Public Health Accreditation Board (PHAB)

standards for local and state health departments [16, 17]. These are critical documents to understand the context of public health information management, but remain too abstract to guide most application and system development.

Recently several collaborations have sought to categorize and describe with greater richness and precision the business processes associated with domains of public health work across many different health departments, and their associated information system requirements (Table 29.1). For example, the Common Ground collaboration on public health emergency preparedness identified similar business processes and information needs that affect most health departments and their information management systems [18].

The Information Supply Chain

As a result of this historical evolution, state or local health departments, rather than national systems, are typically the first recipients and users of public health information for their jurisdictions. This information is derived from four major sources:

1. Clinicians, hospitals, and laboratories sending mandated or voluntary reports including case reports and/or laboratory results about reportable conditions, birth and death certification, newborn screening results, immunization events, cancer and other disease registry reports, etc. Many health departments also collect and analyze administrative healthcare records, such as in an all-payer claims database or hospital discharge database.
2. Information received from members of the public responding to surveys, reporting complaints, or using health department services
3. Environmental information from licensing and inspection, monitoring systems, etc.
4. Information associated with the logistics of public health laboratory test management and medical countermeasures for natural and terrorist threats.

This information is used at the local or state level for activities like case management, outbreak detection and management, program planning and evaluation, and enforcement of sanitary regulations. Information is also sent up to the national level, typically without identifiers, for national-level surveillance, situational awareness (tracking multiple aspects of fast-moving outbreaks or emergencies), grant and contract management, supply chain management, and evaluation and research.

In addition to information used for surveillance purposes, clinical laboratory specimens and their associated information are sent to and from reference laboratories at health departments, CDC, and other federal agencies for specialized public health laboratory tests. Environmental laboratory specimens (for example, well water, food, or air samples) are also analyzed in public health laboratories. Laboratory information management must ensure the right tests are performed, the source, type and circumstances of the specimen are identified, that chain of custody is documented for tests with legal significance, and that meaningful, accurate

Table 29.1 Examples of collaborative public health business analyses and related specifications

Topic	Title	Organization	Website
Chronic disease management	Common Ground: Chronic Disease Management Toolkit: Tools and Methodology for Business Process Analysis and Redesign, 2011	Public Health Informatics Institute	http://phii.org/sites/default/files/resource/pdfs/ChronicToolKit_web-site.pdf
Diabetes management and surveillance	Standards for Public Health Data Exchange: Functional Requirements Standard for Diabetes Care Management and Surveillance, 2008.	Public Health Data Standards Consortium	http://phdsc.org/health_info/pdfs/Standards-for-Public-Health-PHDSC-FINAL-Report.pdf
Emergency preparedness	Common Ground: Public Health Preparedness Toolkit: Tools and Methodology for Business Process Analysis and Redesign, 2011.	Public Health Informatics Institute	http://phii.org/sites/default/files/resource/pdfs/PrepToolKit_forwebsite.pdf
Newborn screening	Newborn Dried Bloodspot Screening Business Process Analysis Report of the NDBS Workgroup: Screening through transition to Long-term Follow-up, 2008.	Public Health Informatics Institute	http://phii.org/sites/default/files/resource/pdfs/NDBSReportFinal.pdf
Syndromic Surveillance	Electronic Syndromic Surveillance Using Hospital Inpatient and Ambulatory Clinical Care Electronic Health Record Data: Recommendations from the ISDS Meaningful Use Workgroup, 2012.	International Society for Disease Surveillance	https://s3.amazonaws.com/ISDS/Meaningful+Use/ISDS_2012-MUse-Recommendations.pdf
Immunization registries	Defining Functional Requirements for Immunization Information Systems, 2012.	Public Health Informatics Institute	http://www.phii.org/sites/default/files/resource/pdfs/IIS%20FINAL%2010302012.pdf
Clinical Care and Case Management	Public Health EHR Requirements, 2012.	Public Health Informatics Institute	http://www.phii.org/sites/default/files/resource/pdfs/EHR_Requirements.pdf

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Table 29.1 (continued)

Topic	Title	Organization	Website
Surveillance	Redesigning Public Health Surveillance in an eHealth World, 2012.	Public Health Informatics Institute	http://www.phii.org/sites/default/files/resource/pdfs/Requirements%20Lab_Final%20Deliverables_RWJ%20Sureveillance.pdf
Case Reporting	Public Health Reporting Initiative Lead Team. Public Health Reporting Initiative Functional Requirements Description, 2012.	Public Health Reporting Initiative, Standards and Interoperability Framework	http://wiki.siframework.org/file/view/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf/367698936/PHRI%20Functional%20Requirements%2009252012%20Consensus%20Approved.pdf

information about the results ultimately reach the professional that ordered them. (For clinical laboratory tests, these are regulated in part by the Clinical Laboratory Improvement Act [CLIA] [19]). Systems to manage supply chains of federal assets, like the Vaccine Tracking System (VTrckS) and Countermeasure Tracking System (CTS) are also becoming a more prominent part of the information system landscape of health departments [20, 21].

A simplified schema of information exchange is presented in Fig. 29.2 with examples. What is clear from the diagram is that (1) state and local health departments are a critical part of a national information supply chain, receiving and transmitting large numbers of different types of transactions, and as a result, (2) they would benefit greatly from interoperable information systems that could receive, reuse, and send information with minimal human labor. The numbers of exchanges between clinical care providers and state or local health departments are particularly numerous and complex. For example, each year over 6.5 million vital records are processed, 1.5 million nationally notifiable conditions are reported, and two million infants screened [22]. These transactions may trigger multiple local actions, of which reporting to the federal level is but one. Despite these needs at the health department level, CDC funding for information technology distributed to other entities such as health departments (extramural funding) has been almost halved since 2004, after a surge of funding following the major 2001 terror attacks (Fig. 29.3) [23]. Not surprisingly, much federal investment has focused on the transfer of information to national levels, rather than day-to-day information management at local and state levels. Concerns have been raised about whether funding is sufficient and focused enough to assure a beginning-to-end supply chain for biosurveillance and other information needs [24–26].

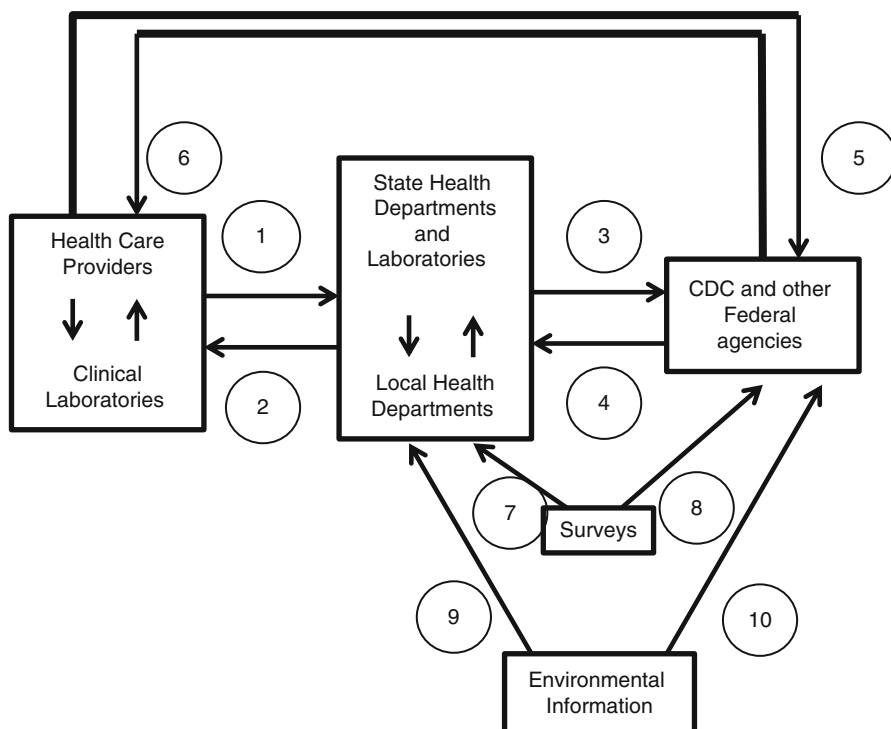


Fig. 29.2 A schematic of U.S. public health information flow. Examples (keyed to circles) include: 1. disease case reports (lab results and/or clinical information), birth and death reports; newborn screening results, jurisdictional syndromic surveillance systems; 2. jurisdictional disease and outbreak statistics, alerts and guidance, reference lab results; 3. National Notifiable Disease Surveillance reports, vital statistics summaries, Public Health Laboratory Interoperability Project (PHLIP) reports; 4. National statistics and guidance; reference lab results, National Healthcare Safety Network (NHSN) jurisdiction level reports; 5. NHSN reports, FDA MedWatch adverse event reports, 6. Health Alert Network alerts and guidance, national statistics, institution-level information from NHSN; 7. Behavioral Risk Factor Survey, local surveys; 8. National Health and Nutrition Examination Survey; 9. license inspections, lead poisoning hazard assessments, BioWatch bioterrorism assays; 10. BioWatch event notifications, FDA inspections, US Department of Agriculture inspections. NOT REPRESENTED: Information exchange with members of the public (e.g., websites, publications, press releases); international notifications of Public Health Emergencies of International Concern

Apart from surveillance systems based on reports (sometimes described as *passive surveillance*, with public health relying on another actor to initiate a report), there has been an explosion of health data availability through digitalized electronic health record (EHR) systems, billing, quality measurement, and other systems. The Food and Drug Administration has developed Mini-Sentinel, a system of distributed queries to EHR and other electronic data systems of large healthcare providers and payers to investigate the safety of regulated healthcare products [27]. Data accessible to query include administrative and claims data from 2000 to 2011 for over 300 million person-years, 2.4 billion encounters, 38 million inpatient hospitalizations,

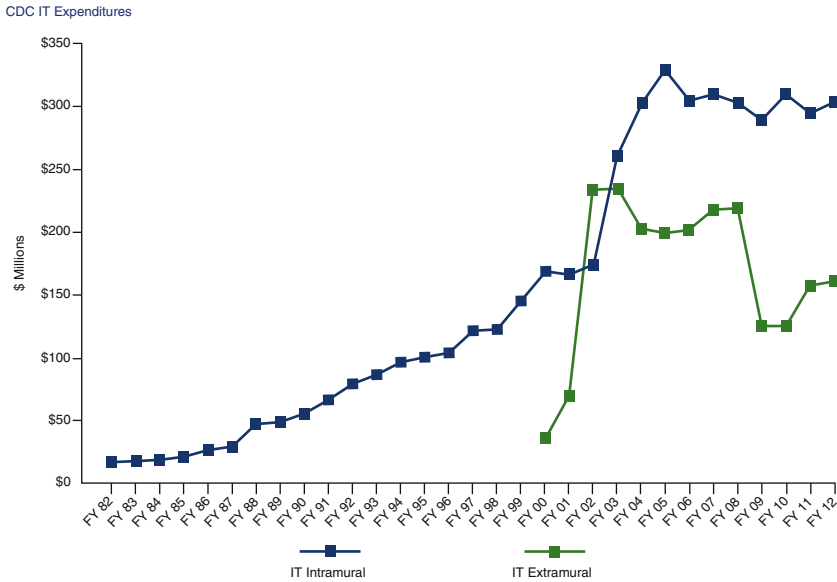


Fig. 29.3 Trends in CDC spending on intramural and extramural information technology [24]

and 2.9 billion dispensings of medication. For example, FDA's Center for Biologics Evaluation and Safety is using Mini-Sentinel to assess the incidence of rare adverse events for vaccines after they have entered general use [28]. Mini-Sentinel is one initiative in a larger FDA program to leverage newly available electronic health information [29].

Many states have established voluntary or mandated all-payer hospital discharge and claims data systems that have been used to track the impact of policy changes, to characterize care-seeking patterns, and to assess variations in medical costs among many other uses. An important evolving feature of such databases is the capability to track the care of individuals across multiple providers and payers over time, for example, to aggregate and compare the services and costs of a longitudinal episode of care, like pregnancy and childbirth, or acute myocardial infarction [30]. A similar national-level database is being developed to support comparative effectiveness research (see below) [31]. Medicare claims data is frequently used in research on utilization, outcomes, and disparities (such as the incidence of clinical preventive services, or the association of products or services with health outcomes). Further information on access to Centers for Medicare and Medicaid Services (CMS) data can be found at the Research Data Assistance Center [32]. Quality measures submitted by health care providers to the federally funded Medicare and Medicaid programs are another emerging source of public health information. These include measures of the prevalence of preventive screenings and vaccination [33]. Federal authority to use healthcare reimbursement to incentivize changes in information collection, reporting, and analysis has accelerated with the Health Information Technology for Economic and Clinical Health Act (HITECH 2009)

[34] and the Patient Protection and Affordable Care Act (2010) [35], and promises to make larger amounts of more standardized information available over time (described below).

Federal Role in Information Management and Standardization

Local variation in public health practices is less an issue when the Federal Government has the predominant authority for a program, as in the case of drug and medical device safety. In that case, the Food and Drug Administration has been able to establish centralized and nationally funded information systems like MedWatch for adverse event reporting [36]. In other domains where state authority reigns, federal programs have worked with health departments and other partners to develop more standardized processes and information systems. In some of these cases (particularly for newer programs with less legacy of state-level systems), a single predominant and nationally-funded system has been created: for example, the National Healthcare Safety Network (NHSN), a national platform used by healthcare providers and health departments to track and improve healthcare-associated infections [37]. More often, federal agencies support evolutionary efforts to define program requirements, standards, and implementation tools for state and local levels, as for example, the National Electronic Disease Surveillance System (NEDSS) [38], electronic laboratory reporting (ELR) of results for reportable condition [39], immunization information systems [40], cancer registries [41], vital statistics [42], syndromic surveillance [44] and environmental health metrics (Environmental Health Tracking Network) [44]. In some cases a federal application or information system is offered, but not required (for example, the NEDSS Base System and the BioSense syndromic surveillance system) [45]. In most cases funding is made available to help some, if not all, health departments adopt national standards of practice and information management. Unfortunately, local difficulty migrating from legacy approaches often causes new processes, standards, and tools to be adopted unevenly, sometimes accreting atop old ones, resulting in increased complexity and cost rather than the efficiency of an industry-wide approach [46]. Examples of several national public health information systems are listed in Table 29.2.

Several initiatives, particularly at CDC, have sought to increase public health migration to electronic information management and more system interoperability [47, 48]. The concept for a National Health Information Infrastructure (NHII) to support health information transactions emerged from the National Committee on Vital and Health Statistics, affiliated with the CDC National Center for Health Statistics [49]. Efforts accelerated after the 2001 September 11 terror attacks. In 2004, the Public Health Information Network (PHIN) initiative at CDC sought to implement greater interoperability in six domains related to public health emergency preparedness: early event detection; outbreak management; connecting laboratory systems; countermeasure and response administration; partner communications and alerting;

Risk Factor Surveillance	Behavioral Risk Factor Surveillance System (BRFSS)	State-based random telephone survey of public	State/territorial	By agreement, funding requirement	Questionnaire and sampling design, stakeholder conferences	CDC Office of Surveillance, Epidemiology and Laboratory Services ^d (www.cdc.gov/brfss/)	
Syndromic surveillance	BioSense Program (national tool); Public Health Emergency Preparedness cooperative agreement	Electronic surveillance of healthcare utilization data (most often admission/discharge/transfer system data)	State/territorial ^b (CMS/ONC ^c established incentives and associated standards for syndromic surveillance reporting in 2010)	Voluntary adoption of BioSense system, or data sharing agreement, funding requirement	Provision of BioSense platform, electronic reporting guides and standards, stakeholder conferences	CDC Office of Surveillance, Epidemiology and Laboratory Services ^d (OSELs) and Office of Public Health Preparedness and Response (OPHPR) www.cdc.gov/biosense/	International Society for Disease Surveillance; Council of State and Territorial Health Officials; Association of State and Territorial Health Officials
Health status measurement	National Health and Nutrition Examination Survey (NHANES)	National-level random survey with physical/laboratory examination	Federal	NA	NA	CDC National Center for Health Statistics www.cdc.gov/nchs/nhanes.htm	National Institutes of Health, Food and Drug Administration, Department of Agriculture, Environmental Protection Agency

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Table 29.2 (continued)

Function	Name	Primary information source	Primary authority/ mandate for data collection	Enablers of national collection	Federal approaches to state standardization	Current Federal agency and website	Major Partners
Immunization registration	Immunization Information Systems (at state or local level, often called Immunization Registries)	Healthcare provider reports of immunization events	State/territorial ^a (CMS/ONC ^c established incentives and associated standards for reporting to immunization information systems in 2010)	Funding requirement to report system characteristics (not immunization prevalence)	Electronic reporting guides and standards, funding requirements, stakeholder conferences	CDC National Center for Immunization and Respiratory Diseases (NCIRD) Immunization Information Services Support Branch and CMS/ONC www.cdc.gov/vaccines/programs/iis/index.html	American Immunization Registry Association
Immunization prevalence	National Immunization Survey	Random telephone and follow-up mail survey of immunization prevalence	Federal	NA	NA	CDC NCIRD and NCHS www.cdc.gov/nchs/nis.htm	
Vaccine supply chain	Vaccine Tracking System (VTrckS)	Systems to manage ordering, use and inventory of publicly-funded vaccines	Federal	NA	Software applications, funding requirement, stakeholder conferences	CDC NCIRD www.cdc.gov/vaccines/programs/vtrcks/	Association of Immunization Managers and other associations

Emergency medical countermeasure supply chain	Countermeasure Tracking System (CTS)	Systems for inventory awareness, management and administration of medical countermeasures	State/territorial	By agreement, funding requirement	Software applications, funding requirement, stakeholder conferences	CDC OSELS and OPHPR www.cdc.gov/phinf/tools/cts/
Post-marketing product adverse event surveillance	MedWatch	Voluntary reporting of adverse events from FDA regulated drugs, devices, biologics and supplements	Federal (voluntary reporting)	NA	NA	Food and Drug Administration www.fda.gov/safety/MedWatch/default.htm
Post-marketing product adverse event surveillance	Mini-Sentinel Pilot program	Distributed queries of electronic health records	Federal (voluntary reporting)	NA	NA	Food and Drug Administration www.fda.gov/safety/FDAsSentinelInitiative/ucm2007250.htm HMO Research Network and other collaborating institutions

(continued)

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Function	Name	Primary information source	Primary authority/mandate for data collection	Enablers of national collection	Federal approaches to state standardization	Current Federal agency and website	Major Partners
Healthcare associated infection reporting	National Healthcare Safety Network	Reporting of data on infections associated with healthcare	State/territorial or voluntary	By agreement (at state or health-care provider level); funding requirement	Provision of NHSN platform, funding requirements, electronic reporting guides and standards, stakeholder conferences	CDC National Center for Emerging and Zoonotic Infectious Diseases www.cdc.gov/nhsn/	Council of State and Territorial Epidemiologists
Cancer registration	National Program of Cancer Registries	Provider and laboratory reports of cancer diagnoses and associated care	State/territorial (CMS/ONC ^c established incentives and associated standards for reporting to cancer registries in 2012)	By agreement, funding requirement	Funding requirement, electronic reporting guides and standards, stakeholder conferences	CDC National Center for Chronic Disease Prevention and Health Promotion www.cdc.gov/cancer/npcr/	North American Association of Central Cancer Registries, National Cancer Institute SEER program

Environment health tracking	National Health Tracking Network	Data on environmental exposures and effects	State/territorial	By agreement, funding requirement	Funding requirement, indicator and metadata standards, stakeholder conferences	CDC National Center for Environmental Health http://ephtracking.cdc.gov/showHome.action	Environmental Protection Agency, National Environmental Health Association and other associations
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^aIn some (“home rule”) states, this authority may devolve to the local jurisdiction

^bCenters for Disease Control and Prevention, US Department of Health and Human Services

^cCenters for Medicare and Medicaid Services/Office of the National Coordinator for Health Information Technology, both parts of the US Department of Health and Human Services with shared responsibility for the Electronic Health Record Incentive (“Meaningful Use”) Program

^dAs of September, 2013 OSELS is proposed to be reorganized as the Office of Public Health Scientific Standards. However OSELS websites still function

and cross-functional capabilities and components [50]. Some standardization was achieved, but support for these initiatives at CDC and in health departments waxed and waned, and was affected by frequent reorganizations and leadership changes.

Also in 2004, US President George W. Bush directed federal agencies to increase the adoption of electronic health records and electronic health information exchange, and established the Office of the National Coordinator for Health Information Technology (ONC) [51]. ONC organized a public-private American Health Information Council (AHIC) which selected and defined high priority use cases (including public health reporting); interoperability specifications were developed by a Health Information Technology Standards Panel (HITSP), and software was certified for interoperability by a Certification Commission for HIT [52]. Simultaneous with these efforts were modest public and private initiatives to create Regional Health Information Organizations (RHIOs, now often called Health Information Exchange Organizations) to facilitate health information exchange [53]. Lack of Congressional authorization and funding, and mal-aligned incentives for the private sector limited progress until the 2009 passage of the Health Information Technology for Economic and Clinical Health (HITECH) Act [54, 55]. HITECH required the Secretary of the Department of Health and Human Services (HHS) to establish standards and rules for HIT interoperability and information exchange, privacy and security, and increased funding of ONC toward these ends. More importantly, it created a multi-billion dollar Medicare and Medicaid Electronic Health Record Incentive Program (better known as “Meaningful Use”) to encourage health care providers to adopt and use nationally certified EHR systems for data capture, care improvement, and information exchange [56]. The high stakes engendered by this program is driving the US toward national adoption of syntactic, semantic and transport standards for health information faster than previous efforts. Healthcare providers must perform certain types of standardized public health reporting to receive incentives, thus the program is both creating *de facto* national standards for reporting and radically increasing the numbers of providers wishing to implement exchange with health departments. As of 2013, Meaningful Use rules affect electronic laboratory reporting (ELR) of results for reportable conditions, and reporting to immunization information systems (sometimes called immunization registries), syndromic surveillance systems, and cancer registries. The regulations also address other matters of public health interest, such as mandating EHR recording of race and ethnicity and smoking status, quality measurement reporting regarding the use of preventive clinical services, and affecting how public health laboratory results may be received and displayed in electronic health records. More requirements will be issued in additional stages of regulation over time [57–60].

Public health and clinical stakeholders are also using the Standards and Interoperability Framework, facilitated by the Office of the National Coordinator (ONC), to harmonize standards and to establish and pilot reference implementations for public health use cases [61, 62]. Unfortunately, the HITECH Act offered little funding for health departments. Since the peak in funding to health departments for technology preceded the new HITECH standards by several years, there has been a mismatch between the standards deployed in health departments and

those cited in Meaningful Use regulations. Health departments have had to migrate to the new standards and digital reporting relationships with limited federal support. However, the emergence of more universal national standards and their incentivized adoption in EHR systems appears to have created momentum for increasing interoperability in the public health information supply chain. In 2010, the CDC Public Health Information Network (PHIN) program was re-oriented to focus on accelerated harmonization and implementation in concert with Meaningful Use standards with renewed input from health departments and other stakeholders [63].

Federal Agencies with Important Informatics Roles

Cross-Agency Coordination

Because federal roles in health care, information and telecommunication policy, science, and national security (including preparedness for public health emergencies) necessarily span multiple cabinet departments, the Executive Office of the President has become involved in activities affecting public health informatics. The Office of Management and Budget (OMB) includes the Office of Electronic Government headed by the nation's Chief Information Officer (CIO) [64]. Armed with OMB's powers over budget and procurement policies, the office seeks to improve federal efficiency and effectiveness including: adoption of cloud services; data center consolidation; encouragement of shared services across agencies and programs; enhanced cyber security; improved federal enterprise architecture; and improved public access to digital information from government. These policies are developed and executed in conjunction with a council of CIOs across the various federal agencies. Notably, the CIO Council helped develop Data.gov, a data transparency initiative that makes government data sets and application programming interfaces (APIs) available to the public and developers over the Internet. As of early 2013, over 387 health datasets were available at the site, including demographic, survey, reportable condition, and healthcare utilization and cost data [65]. The Office of Management and Budget is also responsible for administering the Paperwork Reduction Act of 1995 (PRA) which establishes important limits on and requires prior review of most federal data collection efforts [66, 67].

The White House Office of Science and Technology Policy (OSTP) supports the President's Council of Advisors on Science and Technology (PCAST), which sought to enlarge the vision for HIT in a 2010 report advocating health record systems standards that enable standardized query for public health and other purposes while preserving record privacy and security [68]. OSTP is also the home of the US Chief Technology Officer, an office created in 2009 and which in 2012 was focused on improving access and use of health data [69]. OSTP also sponsors the Health Information Technology Research and Development Senior Steering Group to coordinate multi-departmental efforts related to big data analytics and health systems interoperability [70].

Biosurveillance is a complex activity involving multiple agencies. Biosurveillance is described as “the process of active data-gathering with appropriate analysis and interpretation of biosphere data that might relate to disease activity and threats to human or animal health – whether infectious, toxic, metabolic, or otherwise, and regardless of intentional or natural origin – in order to achieve early warning of health threats, early detection of health events, and overall situational awareness of disease activity” and is part of an overarching strategy for countering biological threats [71]. The National Security Council, in collaboration with OSTP, has created a high-level biosurveillance strategy and inter-agency team to support implementation [72]. The Department of Homeland Security is responsible for biosurveillance integration across domains like geopolitical intelligence, agriculture, and human health. The Department of Health and Human Services is primarily accountable for human health biosurveillance [73]. Thus public health national notifiable and syndromic disease surveillance systems are envisioned as part of a multi-source information stream directed to federal emergency decision-makers.

The Federal Health Architecture (FHA) initiative, supported by ONC and co-led by the Veterans Administration (VA) and the Department of Defense (DoD), seeks to help 33 federal agencies leverage digital health interoperability and information sharing [74]. Among other initiatives, FHA oversees CONNECT, an open-source solution to support health information exchange.

The Section 508 amendment to the Rehabilitation Act of 1973 requires that Federal information offered electronically must be accessible for those with disabilities. This creates accessibility expectations for websites and other information systems created by (or funded by) federal agencies. The US General Services Administration (GSA) serves as the government-wide resource for 508-compliant services and infrastructure, and these requirements are typically incorporated into agency system lifecycle management and funding requirements for federally supported systems.

The Department of Health and Human Services

HHS includes several agencies now under the umbrella of the Public Health Service, including CDC and FDA, as well as the National Institutes of Health (NIH), the Agency for Toxic Substances and Disease Registry (ATSDR, administered by CDC), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Indian Health Service (IHS) and the Health Services and Resources Administration (HRSA) [75]. The Public Health Service also includes the Surgeon General and a uniformed corps of health professionals (the PHS Commissioned Corps) assigned to these agencies and other health functions. HHS also includes the previously mentioned ONC, CMS, the Office of the Assistant Secretary for Prevention and Response (ASPR), and the Office of Civil Rights, in addition to agencies focused on the welfare of children and families, elders, and the disabled.

The ONC in the Office of the Secretary of HHS provides leadership, program resources, and services needed to guide nationwide implementation and meaningful use of HIT. This work includes: strategic planning [76]; helping the Secretary select information standards for department rules including Meaningful Use; standards harmonization and implementation for health use cases; research on major informatics problems like usability, data mining, and privacy and security; support for state level health information exchange (and the framework for national exchange through a Nationwide Health Information Network, NwHIN); and community-level demonstration projects. The ONC is a relatively new office, with funding that rose from about \$60 million US in 2008 to over \$2 billion US during the economic stimulus of 2009–2010, and back to about \$60 million US in each of 2011 and 2012 [77, 78]. Thus, the long-term portfolio of this office is still being defined. The ONC supports two Federal Advisory Committees (HIT Policy and HIT Standards), which are major forums for discussing and proposing regulation. The HHS Office of Civil Rights is responsible for writing and enforcing information privacy and security rules associated with the Health Insurance Portability and Accountability Act (HIPAA).

CDC supports many public health programs at national, state, and local levels, with major emphasis on surveillance of disease, injury and environmental hazards, prevention services, emergency public health response, and public health laboratory services. CDC is structured as a group of National Centers, with cross-cutting functions performed by Offices [79]. It is the major federal supporter of public health programs at the state and local level. Each National Center and some Offices operate many systems for national collection or management of public health information (see Table 29.2 for examples). As previously described, the agency has worked to support interoperability between local, state, and federal public health information systems, and increasingly to ensure that the implementation of information exchange between health care providers and public health agencies is harmonized, effective, and efficient for both. The key locus of interoperability work has been renamed and reorganized several times, and in 2013 resides at the CDC Office of Surveillance, Epidemiology and Laboratory Services (OSELs) [80]. As of September, 2013 CDC has proposed to reorganize OSELs as the Office of Public Health Scientific Standards, the latest of multiple reorganizations and leadership changes. This Office includes: the PHIN program and associated interoperability efforts (like the PHIN Vocabulary Access and Distribution System and development of public health report implementation specifications); support for public health in the Meaningful Use incentive program; the Public Health Informatics Research Laboratory for research and prototyping [81]; support for notifiable disease and syndromic surveillance (including the BioSense system); the Public Health Informatics Fellowship; the EpiInfo epidemiology software application; the Behavioral Risk Factor Survey; a program for public health clinical decision support; and programs supporting laboratory systems interoperability. Another cross-cutting program, governed elsewhere at CDC, addresses the need to sequence and share information on CDC's large microbial collection [82].

CDC's National Center for Health Statistics (NCHS) performs other major surveys, supports the Vital Records System, and is responsible for adapting the use of the International Statistical Classification of Diseases and Related Health Problems

for recording morbidity in the United States (the latest version is ICD-10-CM) [83, 84]. It also serves as the home for the National Committee on Vital and Health Statistics, which advises the HHS Secretary on health data, statistics, and national health information policy.

The Centers for Medicare and Medicaid Services (CMS) is the largest payer for US personal health care services and thus has considerable influence and access to information. It writes and administers the EHR Incentive Program Meaningful Use regulations (employing information standards endorsed by the ONC), and its claims, quality reporting, and other data are frequently used for public health research. As the driver of new models of healthcare purchasing and delivery, authorized by the 2010 Patient Protection and Affordable Care Act (PPACA) national health care finance reform, CMS will have considerable leverage over the future direction of health information management. CMS and CDC collaborate on enforcement and training associated with the previously discussed Clinical Laboratory Improvement Act (CLIA).

The National Library of Medicine (NLM) at NIH has a long history of developing wide-ranging health-related databases, and developing and/or distributing necessary metadata and semantic standards; examples include the Unified Medical Language System (UMLS), which integrates and distributes key terminology, classification and coding standards, and associated resources [85] and RxNorm, a normalized naming system for generic and branded drugs [86]. In 2013, it was named as the Value Set Authority Center to distribute official value sets for 2014 Meaningful Use quality measures [87]. NLM also supports biomedical informatics training programs at many universities, and access to library resources through the multi-agency Partners in Information Access for the Public Health Workforce [88]. Other NIH Institutes fund internal and extramural research in bioinformatics, diagnostics, and therapeutics.

The CDC, FDA, CMS, AHRQ, NIH, and HRSA each sponsor initiatives to measure and improve various aspects of health care quality and safety, some of which are listed in Table 29.2. An important function of AHRQ is to assess and address gaps in knowledge about the effectiveness of health care. The PPACA also established the Patient-Centered Outcomes Research Institute (PCORI), a non-profit, tax-exempt corporation (with NIH and AHRQ Directors serving as board members) to support and disseminate research that compares effectiveness between two or more medical treatments or services in a way that helps patients, clinicians, purchasers, and policy makers make informed health decisions [89]. The FDA regulates and performs post-marketing surveillance of the safety of drugs, devices, biologics, and some nutritional supplements, and in the case of vaccines, collaborates with CDC on the Vaccine Adverse Events Reporting system (VAERS).

HRSA, IHS and SAMHSA (along with the Veterans Administration and Department of Defense outside HHS), each have programs to support and improve digital information collection and management by the healthcare providers they fund or employ. For example they support electronic health record implementation by their various programs, grantees, and contractors. HRSA is also a federal leader in supporting: rural telehealth programs (electronically-assisted healthcare delivery

at a distance); resources for data sharing and quality measurement by community health centers; and informatics workforce development.

Other Organizations of Note

The National Institute for Standards and Technology (NIST) is a non-regulatory federal agency within the US Department of Commerce that is focused on measurement, including conformance with technical standards. It develops conformance-testing procedures for the Meaningful Use certification of EHRs by private ONC-authorized Testing and Certification Bodies (ATCBs) [90].

The National Academies (National Academy of Science, National Academy of Engineering, Institute of Medicine (IOM) and National Research Council) are private, non-profit but congressionally chartered organizations that serve as independent advisers on scientific matters. They convene expert panels to address specific requests, and the Institute of Medicine has recently issued multiple reports related to public health surveillance, health care information management, and the requirements for developing a “learning health system” based on improved information management practices.

The National Science Foundation is a major funder of research into “big data” (massive scale and high speed) computing and information management. As of this writing, it supports grants addressing scientific, governance, and policy issues addressing large-scale analysis and sharing of biomedical data. National Laboratories (such as Sandia, Los Alamos, and Argonne National Laboratories) supported by the Department of Energy are sources for super-computing systems and expertise for such functions.

Conclusion

The onset of global trade at jet speeds and the potential for rapid spread of emerging and terrorist disease threats has created demand for national systems of surveillance and response unanticipated by federal constitution-writers at the end of the eighteenth century. National information systems are emerging through a combination of consensus building and federal funding and incentives. Today this is further accelerated by initiatives seeking national information standards across health care, the major source of information used by public health agencies. Because most public health practice is performed at the local or state level, systems of information collection and exchange must serve both local business processes and national information needs. US public health informaticians must navigate the intersecting influence of both local *and* federal requirements, and work collaboratively to ensure critical information needs are met at all levels: local, state and federal. They should also seek to identify and leverage relevant national interoperability initiatives, and

prepare to migrate public health information systems to emerging national standards in an orderly way.

Review Questions

1. How did the US Constitution influence the evolution of government public health structures and information systems?
2. Where do local and state health departments fit into the US public health information supply chain? What does this imply regarding their informatics capacity requirements?
3. What levers can federal agencies use to encourage and support standardized public health practice and information systems, even if they do not hold the direct authority for a particular public health activity?
4. Identify the following: (a) the office that advises the Secretary of Health and Human Services on interoperability standards for health information technology; (b) the agency that provides the greatest direct federal support to state health departments; (c) the agency creating a Value Set Authority Center related to Meaningful Use objectives; (d) the home of a federal public health informatics research and prototyping laboratory.
5. Identify at least three Acts that established regulations on whether and how electronic information is gathered or used by federal agencies.

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