Introduction: Historical Foundation for Public Health Information Management

The United States of America (US) was created as a confederation of independent states; its Constitution reflects this by limiting the powers of the federal government. Police power, including the establishment and enforcement of public health laws, is reserved to states. Initial federal responsibilities included national defense, the regulation of international and interstate commerce, and taxing and spending power. As a result, there has been a fairly high level of variation among states in the organization and 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 three ways: interstate agreement, expanding federal influence using national constitutional powers, and adoption of voluntary industry standards for electronic health information systems.

Learning Objectives
1. Describe the historic framework of state, local, and federal public health and the influence on the public health information supply chain.
2. List and describe the function of several national public health information systems.
3. Describe challenges faced by public health authorities in meeting its need for timely, high quality data to respond to health threats and protect the public’s health.
**Interstate Agreements**

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 to Centers for Disease Control and Prevention (CDC) of cases of reportable communicable diseases and other conditions [2, 3]. Federal agencies played important coordinating and enabling roles for both of these national programs as well as for many newer systems and programs listed in Table 24.1.

**Federal Authorities**

Federal authority for protecting the public’s health began over 200 years ago when John Adams signed into law the “Act for the Relief of Sick and Disabled Seamen”. This gave rise to the US Public Health Service (PHS) that performed port quarantine and other duties, and its modern progeny including CDC [18]. The PHS’s role in regulating interstate commerce evolved to include oversight of food, drug, and environmental safety through the Food and Drug Administration (FDA). Other departments like the Department of Agriculture and the Environmental Protection Agency also regulate specific areas of interstate concern. The taxing and spending authority have 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). As of 2017, federal funds (excluding those for Medicare and Medicaid) account for 48% of state and 24% of local health department budgets [19, 20]. This illustrates that, while states retain authority, the power of the purse gives federal public health agencies real influence on public health data and information collection and exchange 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 [21, 22] created national minimum regulations for privacy and security of electronic healthcare information, but states may have stricter controls, which vary from state to state (see Chap. 9).

**Public Health Information Standards**

In the last few decades, there has been a quickening evolution of national systems and frameworks for public health data and information collection and exchange, built partly by consensus among states, and partly by coordination and funding from federal agencies (see Chap. 8). As a consequence of the history and organization of the United States, 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 accelerating, pushed by legislation and regulations described below.

**International Influence**

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 (WHO) International Health Regulations (IHR) effective in 2007 [23, 24]. The IHR represents a formal agreement among WHO member states to build their capacities to detect, assess, and report public health events of international concern. The need for a global approach to health security has
| Program name | Primary function | Data | Primary information source | Messaging standards | Infrastructure | Major partners | Program Steward |
|--------------|-----------------|------|---------------------------|---------------------|----------------|----------------|----------------|
| Behavioral Risk Factor Surveillance System (BRFSS) [4] | State-based behavioral risk factor surveillance | Health-related risk behaviors, chronic health conditions, use of preventive services, demographics | Self-reported telephone surveys of US adults | N/A | Varies by jurisdiction | State and local health departments, CDC, federal agencies | CDC National Center for Chronic Disease Prevention and Health Promotion |
| FDA's Sentinel Initiative [5] | Post-market safety surveillance | Performance monitoring for FDA-regulated medical products: drugs, vaccines, biologics, and medical devices | Electronic health records (EHR), administrative claims data, registries | Varies | Distributed data network and common data model | Healthcare, academia, federal agencies | Food and Drug Administration (FDA) |
| Foodborne Diseases Active Surveillance Network (FoodNet) [6] | Active laboratory-based surveillance for foodborne illness | Laboratory results, clinical (hospitalization, patient status), epidemiologic (travel history, food and environmental exposures), demographics | Laboratories, state and local public health investigations | CSV file per standardized data dictionary | Messaging via Association of Public Health Laboratories (APHL) AIMS cloud-based platform and SQL databases on CDC’s network | United States Department of Agriculture (USDA), FDA, CDC, state and local health departments, universities | CDC National Center for Emerging and Zoonotic Infectious Diseases |
| Immunization Information Systems (IIS) [7] | Jurisdiction-based, person-based, consolidated vaccination events | Vaccination records, demographics | Healthcare providers, pharmacies | HL7® V2 | Varies by jurisdiction | Healthcare providers, state and local health departments, CDC | CDC National Center for Immunization and Respiratory Diseases |
| National Ambulatory Medical Care Survey (NAMCS) [8] | Nationally representative survey of ambulatory medical care services | Physician and provider characteristics, visit characteristics (reason for visit, diagnosis, services ordered, treatments, demographics) | Manual abstraction from paper records or EHRs; piloting electronic submission of EHR data | HL7® CDA® R2 implementation guide: National Health Care Surveys Release 1, DSTU release 1.2-US realm | CDC secure server | Healthcare providers, CDC, federal agencies | CDC National Center for Health Statistics |
| Program name                                      | Primary function                                                                 | Data                                                                 | Primary information source                                                                 | Messaging standards                  | Infrastructure                                           | Major partners                                                                 | Program Steward                                                                 |
|--------------------------------------------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------|---------------------------------------------------------------------------------------------|-------------------------------------|----------------------------------------------------------|-------------------------------------------------------------------------------|---------------------------------------------------------------------------------|
| National Environmental Public Health Tracking Network [9] | Environmental health surveillance                                                | Environmental hazards, exposures, health effects, population health  | State and local tracking networks, federal data sources                                     | XML and other                       | SQL databases on CDC network; open API to public          | State and local health departments, CDC, Environmental Protection Agency (EPA), other federal agencies | CDC National Center for Environmental Health                                   |
| National Healthcare Safety Network (NHSN) [10]   | Healthcare associated infections tracking system                                 | Adverse events, demographics                                        | EHRs, commercial infection control surveillance systems                                     | Web-based data submissions using HL7® | SQL databases on CDC network                             | CDC, Centers for Medicare & Medicaid Services (CMS)                            | CDC National Center for Emerging and Zoonotic Infectious Diseases               |
| National Molecular Subtyping Network for Foodborne Disease Surveillance (PulseNet) [11] | National laboratory network using DNA fingerprints for cluster detection of foodborne illness | Laboratory subtyping data, isolate metadata(i.e., patient demographics, food, animal and environmental source information) | State and local public health, agricultural and federal regulatory agency laboratories       | Proprietary messaging in BioNumerics with data dictionary | BioNumerics program interface, SQL databases | USDA, FDA, CDC, state and local health departments, agricultural labs          | CDC National Center for Emerging and Zoonotic Infectious Diseases               |
| National Notifiable Diseases Surveillance System (NNDSS) [12] | Jurisdiction-based, case-based surveillance shared with CDC                     | Clinical, laboratory, vaccine, epidemiologic, demographics          | Healthcare providers, laboratories, public health investigations                            | Transitioning from NETSS legacy standards to HL7® 2.5.1 | SQL databases on CDC network                             | State and local health departments, Council of State and Territorial Epidemiologists (CSTE), CDC | CDC Center for Surveillance, Epidemiology and Laboratory Services              |
| National Program of Cancer Registries (NPCR) [13] | Jurisdiction-based, disease registration shared with CDC                         | Cancer occurrence, treatment, outcomes, demographics               | Hospitals, healthcare providers, laboratories, EHRs                                     | Hospitals (XML); healthcare providers (HL7® CDA); laboratories (HL7® 2.5.1) | SQL databases on cloud-based computing platform          | National Cancer Institute, College of American Pathologists, North American Association of Central Cancer Registries, American Joint Committee on Cancer | CDC National Center for Chronic Disease Prevention and Health Promotion         |
| System Name | Jurisdiction-based Information | Data Sources | Data Elements | Interoperability Standards | Database Location | Data Owners | Data Users |
|-------------|--------------------------------|--------------|--------------|-----------------------------|-------------------|-------------|-----------|
| National Syndromic Surveillance Program (NSSP) [14] | Jurisdiction-based, syndromic surveillance | Chief complaint, discharge diagnosis, demographics | EHRs in emergency departments urgent care facilities; some ambulatory care | HL7® 2.5.1 | SQL databases on BioSense cloud-based computing platform | State and local health departments, CSTE, CDC | CDC Center for Surveillance, Epidemiology and Laboratory Services |
| National Vital Statistics System (NVSS) [15] | Jurisdiction-based vital events registration shared with CDC | Births, deaths, marriages, divorces, fetal deaths, demographics | Hospitals, healthcare providers, jurisdictional vital registrars | Transitioning from inter-jurisdictional exchange (IJE) to FHIR | SQL databases on CDC network | State and local vital registration offices, National Association of Public Health Statistics and Information Systems (NAPHSIS), CDC, federal agencies | CDC National Center for Health Statistics |
| Vaccine Adverse Event Reporting System (VAERS) [16] | National vaccine safety surveillance | Demographics, vaccination information, adverse event details, past medical history | Mandatory reports from healthcare professionals and vaccine manufacturers; voluntary reports from patients | On-line reporting or submission of PDF form | CDC secure network | CDC, FDA, healthcare professionals, vaccine manufacturers, general public | Co-managed by CDC and FDA |
| Vaccine Tracking System (VTrckS) [17] | Public vaccine supply chain management | Vaccine orders, shipments, inventory; CDC vaccine contracts | Healthcare providers, state and local health departments, CDC, vaccine manufacturers | Electronic data interchange (EDI) | SQL databases on CDC network | CDC, state and local health department immunization programs, vaccine manufacturers | CDC National Center for Immunization and Respiratory Diseases |
been demonstrated by outbreaks of Middle East Respiratory Syndrome (MERS-CoV) that have occurred since 2012 and the 2014–2015 Ebola epidemic in West Africa. The US experienced imported cases of both MERS-CoV and Ebola, and local, state, and federal public health agencies were involved in surveillance, reporting, and communication to address the health threats and IHR requirements [25, 26].

**Public Health Department Variability**

Few US states enjoyed statewide systems to protect public health in the eighteenth and most of the nineteenth centuries. City health departments, developed 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. Programs typically offered include communicable disease control, environmental health, emergency preparedness, nutrition, registration of vital events (births, deaths, marriages, and divorces), maternal and child health, and chronic disease prevention and management [27, 28]. However, there is interstate variability in laws authorizing and regulating public health functions. These functions are performed by the state health department in some states, by local public health in others, and by governments of some US territories. They may be performed by different departments (e.g., environmental health programs may be managed by environmental protection departments instead of public health) or by private organizations like public health institutes and academic institutions under contract or government charter. Some activities rely almost entirely 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. 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 (see Chap. 15). All of these factors have led to a lack of uniformity across local and state health departments. Consequently, it is difficult to generalize with assurance about the informatics requirements and work of health departments.

A catalytic report in 1988 by the Institute of Medicine [29] helped establish a national vision of a public health system with three core functions of assessment, policy development, and assurance. These functions were further elaborated into ten essential services in 1994 (Fig. 24.1) [30].

A 2003 Institute of Medicine report on the Future of the Public’s Health in the twenty-first Century [31] recommended the exploration of public health department accreditation to enhance standardization and quality, and in 2007, the Public Health Accreditation Board (PHAB) was established as the national public health accrediting body [32]. Accreditation is assessed based on standards and measures that address the ten essential services as well as management and administration, and governance [33, 34]. As of 2019, approximately 275 out of nearly 3,000 local, state, and tribal health departments have received national accreditation [35]. The establishment of a

![Fig. 24.1 The ten essential public health services](image)
vision for public health and the subsequent accreditation process are critical to understanding the context of public health information management [36].

The Public Health Information Supply Chain

The information supply chain makes up the organizations, people, processes, and technologies used to collect and exchange data and information across the public health enterprise (Fig. 24.2). As a result of the historical evolution of public health authorities, state or local health departments, rather than federal agencies, are usually the first recipients and users of public health information for their jurisdiction.

Data Sources

The data sources that feed the public health information supply chain are derived from four major sources:

1. Clinicians, hospitals, laboratories, and pharmacies sending mandated or voluntary reports including case reports and laboratory results about reportable conditions, birth and death certification, newborn screening results, immunization events, cancer and other disease registry reports, and controlled prescriptions. Many health departments also collect and analyze administrative healthcare records, such as in an all-payer claims database (more about these below in Claims Databases) or hospital discharge databases.

![Simplified schema of national public health information supply chain](image-url)
2. Information received from citizens responding to surveys, reporting complaints, or using health department services.
3. Environmental information, for example, from licensing and inspection and monitoring systems.
4. Information for managing functions such as public health laboratory test orders and results, and medical countermeasures for natural and terrorist threats.

This information is used at the local and state level for activities like case management, outbreak detection and management, program planning and evaluation, and enforcement of sanitary regulations. Some 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 information about the results ultimately reach the professional who placed the order. Clinical laboratory tests are regulated in part by The Centers for Medicare and Medicaid Services (CMS) Clinical Laboratory Improvement Act (CLIA), which covers all laboratory testing (except research) performed on humans in the United States [37]. Systems to manage supply chains of federal assets, like the Vaccine Tracking System (VTrckS) that integrates publicly-funded vaccine supplies from purchasing and ordering through distribution to participating state, local, and territorial health departments; and the Inventory Management and Tracking System (IMATS) that manages medical countermeasures from the Strategic National Stockpile requested by state and local responders during an emergency response, are a prominent part of the information system landscape of health departments [17, 38].

Data and Information Exchange

Managing the information supply chain is complex and requires coordination and agreements with many data sharing partners. The nationwide information supply chain includes diverse healthcare-related entities; spans the local, state, and federal public health enterprise; and may involve data collected directly from the public or environmental monitors. Figure 24.2 illustrates that the transmission of large numbers of different types of transactions would benefit greatly from interoperable information systems that could receive, reuse, and send information with minimal human effort. The numbers of exchanges between clinical care providers and state or local health departments are particularly numerous and complex. For example, each year over 2.6 million death records are processed, 20 million laboratory reports are received by health departments, and nearly 1 billion messages from emergency room and urgent care visits are transmitted to public health [39]. These data are used by local and state public health to fulfill their essential services. Despite these needs, federal funding for information technology that supports data exchange for health departments has not kept pace with investments in technologies used by the healthcare sector. In addition, much federal investment in the information supply chain has focused on the transfer of information to national levels, rather than day-to-day information management at local and state levels. There are some notable exceptions.

Nationally Supported Information Supply Chain Activities

Since 2006, CDC has funded the implementation of electronic reporting of anatomic pathology
reports from national and regional laboratories to state cancer registries [40]. Similarly, since 2010, CDC has provided funding to state and local health departments to assist with implementation of electronic laboratory reporting (ELR) associated with reportable conditions [41]. Of the 20 million test reports sent from clinical and public health laboratories to public health agencies each year, as of 2018, 80% were transmitted electronically compared to 54% in 2014 [39]. For both pathology and reportable conditions ELR, the federal government has provided not only funding, but worked with the laboratories on the technical solution and provided guidance on messaging standards for electronic transmission of reports. Federal, state, and private institutions have provided support for state and local immunization information systems (IIS) that enable healthcare providers and public health to track administration of vaccines to patients. This national effort includes establishment of functional standards, core data elements, and clinical decision support capability [42]. Another promising initiative is electronic case reporting (eCR), the automated generation and transmission of disease case reports (clinical data that goes beyond simple laboratory results, for example, the treatment used for a reportable infection) from the electronic health record (EHR) to public health agencies. Work on establishing the technical infrastructure for eCR began with the Public Health Community Platform (PHCP) initiative in 2014 led by the Association of State and Territorial Health Officials (ASTHO) and funded through a cooperative agreement with CDC [43]. PHCP emerged as a shared service entity that aimed to address the technology challenges faced by public health agencies. The initiative also resulted in a community driven governance committee that chose eCR as one of the first use cases for the PHCP. Over time, the concept grew to include technology on the Association of Public Health Laboratories’ (APHL) Informatics Messaging Services (AIMS) platform and a Council of State and Territorial Epidemiologists’ (CSTE) built decision support tool that determines whether conditions encountered by healthcare are reportable by state. However, due to limited funding, there was a need to pivot to demonstrating the value of such an approach. Consequently, a new partnership emerged, Digital Bridge, a governed forum that brings together three clusters of partners from healthcare, public health, and health IT. Discussion of the challenges of information sharing and has led to collaboration on ideas and solutions for bidirectional information exchange between health care and public health [44]. Under the Digital Bridge, eCR is its first use case, which aims to establish a durable governance structure and establish a technical architecture that will be nationally scalable with code sets and systems that can be used nationwide for an integrated and interoperable public health enterprise [45]. Pilot studies to test the technology are underway in a handful of states and look promising. The reality is that scaling eCR across the country will require major investments at the local, state, and federal level.

Public Health Access and Use of Healthcare Data

In the last decade, there has been an explosion of health data availability through digitalized EHR systems, billing, quality measurement, and other health information systems. State, local, and federal public health agencies are establishing information systems to harness the potential value in electronic health data to better track and monitor population health.

Distributed Queries

The FDA launched a post-market safety surveillance initiative for healthcare products in 2008 in response to a legislative mandate [5]. The first phase of the initiative was Mini-Sentinel, a system of distributed queries to administrative claims data, EHRs, and other electronic data systems of large healthcare providers and payers to investigate the safety of regulated drugs, vaccines, and other biologics [46, 47]. Distributed queries enable data providers to assemble and report aggregate, de-identified data, thus improving data security and simplifying data use
agreements. In 2016, based on the success of Mini-Sentinel, the FDA launched the full-scale Sentinel System. A core feature of the Sentinel architecture is the Sentinel Common Data Model (and subsequent systems that borrowed the same distributed query structure), a quality-checked distributed network and suite of analytic tools that protect patient privacy, allow collaborators to maintain control of their data, and enable data to be integrated from disparate sources [48]. The same approach has been replicated many times, typically using an open source platform called PopMedNet [49]. As of 2019, data accessible to query through the Sentinel Distributed Database includes 15 billion medical encounters, 12 billion pharmacy prescriptions filled, and over 668 million person-years of data [50].

Another initiative built on distributed queries and a common data model is the Patient-Centered Outcomes Research Network (PCORnet). It was created by the Patient-Centered Outcomes Research Institute (PCORI), a non-profit organization that was authorized by Congress to fund research on the comparative effectiveness of different clinical options [51]. PCORnet consists of nine Clinical Data Research Networks (CDRN), two Health Plan Research Networks (HPRN), and a coordinating center [52]. The CDRNs and HPRNs are centered within healthcare delivery systems and can query records across multiple states with diverse patient populations for research purposes. A similar approach is used to enable geographically-focused public health surveillance by combining EHR data of multiple providers in a geographic area, such as the Massachusetts’ MDPHnet [53] and the Colorado Health Observations Regional Data Service (CHORDS) [54]. CDC’s Childhood Obesity Data Initiative is leveraging both the PCORNet and CHORDS data models in association with a platform of shared research tools to study disparities in child obesity screening and the effectiveness of weight management programs [55, 56]. There is increasing interest in using EHR data for population health surveillance with the promise of lower data collection costs and richer, more timely data. While there have been studies validating disease prevalence estimates from EHRs for localized jurisdictions [57], methodologies for creating robust national estimates have yet to be developed.

**Claims Databases**

All-Payer Claims Databases (APCDs) is another effort aimed at using existing data to support health system measurement and improvement activities. As of early 2018, at least 18 states had established APCDs, state run data repositories that include either voluntary or mandatory submissions from Medicaid, state employee health programs, commercial insurers, and self-insured employer plans. The data include medical claims, pharmacy claims, dental claims, and eligibility and provider data from private and public payers [58]. To help states get more value from their APCDs, the Agency for Healthcare Research and Quality (AHRQ) compiled an inventory of recommended measures related to cost, utilization, and quality [59] and several organizations including the National Association of Health Data Organizations (NAHDO), the Public Health Data Standards Consortium, the APCD Council, and America’s Health Insurance Plans (AHIP) have collaborated on the development of national APCD reporting standards and policies [60]. States have used their APCDs to examine variation in prices for high-volume inpatient treatments, compared prescription prices for commercial plans and Medicaid plans, studied the conditions most commonly associated with high-dose opioid prescriptions, and estimated the population prevalence of chronic conditions such as diabetes and hypertension [61]. There have been a number of efforts over the years to create national all-payer claims databases, but success has been limited. What exists today are public payer databases such as Medicare and Medicaid claims, federal initiatives such as AHRQ’s Healthcare Cost and Utilization Project (HCUP) that brings together all-payer hospital discharge data [62], and a growing number of public and private vendor offerings such as FAIR Health [63], MarketScan [64], and IQVIA [65]. Medicare claims data are 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). The Centers for Medicare and Medicaid Services (CMS) data can now be accessed and analyzed through a Virtual Research Data Center (VRDC) [66]. Besides offering greater protection for patient-level data, the VRDC is more efficient and cost effective for managing and analyzing large complex data. Similarly, data products offered by vendors are increasingly being found on platforms and virtual data centers. Some of these products provide access to a variety of data sources (e.g., claims, pharmacy transactions, laboratory data, EHRs), as well as to analytic tools for data linkage and more advanced analytics such as machine learning. While these data offerings have allowed for more complex analysis of patient-level data, the sampling of data from the healthcare providers and EHR vendors is fluid making it difficult to infer population estimates.

**Federal Role in Establishing and Promoting Information Management Standards**

Local variation in public health practices is less of 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 FDA operates centralized and nationally funded information systems under the FDA MedWatch program for adverse event reporting [67]. 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 programs with less legacy of state-level systems), a single predominant and nationally-funded system has been created, for example, CDC’s National Healthcare Safety Network (NHSN), a national platform used by healthcare providers and health departments to track and improve healthcare-associated infections [10]. More often, federal agencies support capacity building for state and local public health by defining program requirements and standards, providing implementation tools and technical assistance, and providing funding through programs such as the Epidemiology and Laboratory Capacity for Prevention and Control of Emerging Infectious Diseases (ELC) [68]. Examples of national public health information programs and initiatives are listed in Table 24.1. In some cases, a federal application or information system is offered, but not required, for example, the NEDSS Base System [69] and the BioSense platform [14] are used by some states for case-based surveillance and syndromic surveillance, respectively (see Chap. 16). Unfortunately, local difficulty migrating from legacy approaches often causes new processes, standards, and tools to be adopted slowly and unevenly, sometimes accreting atop old ones, resulting in increased complexity and cost rather than the efficiency of an industry-wide approach.

**Federal Regulations for Health Data Exchange**

In 2004, the Office of the National Coordinator for Health Information Technology (ONC) was established to promote a national health information technology infrastructure with a focus on adoption of electronic health records and electronic information exchange [70]. 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 (HIT) Standards Panel (HITSP); and software was certified for interoperability by a Certification Commission for HIT [71]. Progress was underfunded and slow until 2009 when Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act [72, 73]. 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. Federal authority to use healthcare reimbursement and regulations to incentivize changes in information collection, reporting, and analysis expanded as a result of HITECH and the Patient Protection and Affordable Care Act of 2010 [74]. More recently, the twenty-first Century Cures Act of 2016 established a legal framework for strengthening interoperability and preventing information blocking, which is the use of technological or contractual mechanisms to thwart exchanges of health information between vendor systems [75]. The most influential program to come out of HITECH might be the 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 [76].

Meaningful Use

The high stakes engendered by Meaningful Use has been driving the US toward national adoption of syntactic, semantic, and transport standards for health data faster than previous efforts. Because healthcare providers were required to perform certain types of standardized public health reporting to receive incentives, the program has been both creating de facto national standards for reporting and radically increasing the numbers of providers wishing to implement exchange with health departments. Meaningful Use rules affected electronic laboratory reporting of results for state reportable conditions, reporting to immunization registries, syndromic surveillance systems, and cancer registries. The regulations also addressed other matters of public health interest, such as mandating EHR recording of race and ethnicity and smoking status, quality measurement reporting of preventive clinical services, and affecting how public health laboratory results may be received and displayed in electronic health records [77–79]. In 2018, CMS renamed the EHR Incentive Programs to the Promoting Interoperability Programs. The prior requirements of meaningful use have evolved to a new focus on EHR measurement with an increased emphasis on interoperability and improving patient access to health information [80]. Under this current incentive program, the public health requirements are reporting to two different public health agencies or clinical data registries for any of the following: immunization registries, electronic case reporting, public health registry, clinical data registry, or syndromic surveillance [81]. 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.

Future Directions in National Public Health Informatics

Public health informatics has grown and evolved in the last quarter century as is evidenced by the variety and depth of topics in this book. New technologies are producing rich sources of digital data from mobile phones, wearable devices, and other wireless technology. As of 2017, 96% of acute care hospitals and 86% of physician offices have adopted EHR systems that are capturing the majority of data public health needs to monitor and protect the nation’s health [82]. Advances in nucleic acid (initially mostly DNA) sequencing, are providing public health scientists with timely insight into disease causing pathogens and ways to stop them. Technology is also making it easier to collect, store and analyze large amounts of data and new analytic methodologies such as machine learning are helping to turn complex data into action-
able information (see Chap. 12). Public health is poised to benefit from all of these advances. However, the exchange of data and information among public health entities and between public health and primary sources of data, such as healthcare, continue to be challenging. There are a number of reasons why, and there are a number of national efforts underway to address the challenges.

**Laws and Authorities That Enable Sharing of Health Data**

In health care and public health, protecting the privacy of individuals and data security are paramount. As described earlier, states have the primary authority to protect the public’s health and states have laws that require reporting of some health information from healthcare to public health. The laws and the types of information that are considered “reportable” vary by state. There are also numerous federal laws that protect the privacy and confidentiality of health information. Notably, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [83] and the HIPAA Privacy Rule (2004) [84] established national standards to protect individually identifiable health information. The Privacy Rule allows covered entities (e.g., health plans and healthcare providers) to share protected health information (PHI) with authorized public health agencies (non-covered entities) such as local and state health departments [85]. The Public Health Service Act [86] provides additional protection for sensitive data collected by the US Department of Health and Human Services. There are additional federal laws such as the Federal Information Security Modernization Act (FISMA) of 2014 [87] that requires an information security program to protect data resources in compliance with applicable public laws, federal regulations, and Executive Orders. Despite the many state and federal laws aimed at protecting health data, or perhaps because of the many different laws, there is often uncertainty about what individual-level data can be shared among public health entities. This can be particularly challenging during national public health emergencies when state and federal public health agencies are collaborating on a response to stop the spread of infection or identify the source of an outbreak and need to share timely data.

There are informatics solutions that are being used to protect data privacy while enabling more sharing of data among public health agencies and between healthcare and public health. For example, MDPHnet is a distributed health data network in Massachusetts that allows public health officials to query EHR data from several group practices (see section above on Distributed Queries) [53]. The network includes software that maintains a data repository behind the practices’ firewall and another software called PopMedNet that public health can use to query the participating group practices. The queries return aggregate counts of conditions of interest without personal identifiers. This is particularly useful for obtaining timely data on conditions such as chronic diseases which tend not to be reportable by state law. It remains to be seen whether solutions such as MDPHnet can be scaled and adopted across the country. Another solution for data sharing are tools that can be used for role-based and conditional data access and sharing. CDC’s National Syndromic Surveillance Program’s BioSense platform has an Access and Management Center that allows participating jurisdictions to control who can access and view their data [14]. Jurisdictions can limit visibility to individual level data for routine monitoring while allowing their data to be included in aggregate analysis results at national and regional levels. Most importantly, jurisdictions can allow access to more detailed data for other public health agencies when collaborating on responses to health threats that cross borders. However, the need for agreements to share data more broadly, such as during nationwide outbreaks or epidemics, does complicate and slow down the exchange of data needed for emergency responses.

Earlier in this chapter CMS’ Meaningful Use and Promoting Interoperability Programs were described as enabling more data sharing between healthcare and public health. A number of additional federal initiatives address data
exchange and call for more sharing and public access while protecting privacy and confidentiality. The Foundations for Evidence-Based Policymaking Act of 2018 calls for the development of government-wide best practices for the use, protection, dissemination, and generation of data and for promoting data sharing agreements among agencies [88]. It also requires federal agencies to create an inventory of their data, publish data assets as machine-readable, and allow the public access to agency data.

Interoperability and Data Standards

Perhaps the greatest barriers to data exchange across the public health enterprise is the reality of the current US landscape with fragmented data, independent condition-specific systems, and data repositories that are largely inaccessible [89, 90]. The technical challenges that underlie this landscape are the lack of data standards, and information systems that are not interoperable. Interoperability is the ability of different information systems to exchange data such that the data retain their meaning from system to system. Data can be exchanged between systems with a common architecture, through application programming interfaces (APIs), or when coded using the same coding standards [91].

Office of the National Coordinator for Health Information Technology

In recent years, a number of federal initiatives have sought to address interoperability in healthcare. The Office of the National Coordinator for Health Information Technology issued a Federal Health IT Strategic Plan for 2015–2020 and has a new plan for 2020–2025 in development [92]. The impetus for the strategic plans was the lack of interoperable systems in healthcare that created a market of uncontrolled costs and limits on the quality of healthcare. The plans call for coordinated investments, standards-based APIs for exchanging data, and user focused technologies. The strategies aim to meet the needs for patients, providers, payers, researchers, developers, and innovators. One example of ONC’s work to improve interoperability is an effort to integrate access to Prescription Drug Monitoring Programs (PDMPs) into clinical workflows [93]. PDMPs are state databases that track controlled substance prescriptions [94]. Pharmacists who dispense controlled substances enter the prescription into the state PDMP. Before prescribing a controlled substance, providers are able to see patients’ prescribing histories to monitor and inform their prescribing decisions. To facilitate the use of PDMPs to address the nation’s opioid epidemic, ONC is collaborating with other federal partners to support standards-based approaches for PDMP access and query, and mapping PDMP data elements with Fast Healthcare Interoperability Resources (FHIR) to support APIs for exchanging data (see Chaps. 8 and 18) [93]. Timely capture of prescription information from pharmacists and access to the data by providers are critical to having the right data at the right time. PDMPs are used by state health departments to monitor the opioid epidemic and evaluate population prevention and intervention efforts.

US Food and Drug Administration

In 2019, FDA launched the Technology Modernization Action Plan (TMAP) [95]. The plan focuses on the modernization of their hardware and software in order to improve access, quality and timeliness of the data that they need for carrying out their mission—ensuring the safety and effectiveness of drugs and medical products, and the safety of the food supply. Their plan also calls for improving data exchange through system interoperability, APIs, and data standards. They also plan to explore distributed ledger solutions such as blockchain to support their ability to track and trace products through
increasing amounts and variety of data. Block chain has been proposed as a solution for public health data exchange for a number of years and several pilot projects are underway. For example, Hashed Health, a distributed ledger technology company, is building a prototype for public health surveillance whereby the blockchain serves as an audit log of data transfer of healthcare data from reporting location to centralized data repositories [96]. The transfer logs would be available to all authorized entities and the data might include lab results, clinical data from EHRs, and pathogen genome data. CDC is also exploring block chain for securing data from electronic health records and for exchanging data as part of public health surveillance, but projects are in the very early stages [97].

**Centers for Disease Control and Prevention**

While the primary focus of many federal initiatives has been on improving interoperability between EHRs and other health IT, CDC has sought to increase public health migration to electronic standards–based information management and more system interoperability across the public health enterprise. In 2014, CDC launched the CDC Public Health Surveillance Strategy to guide efforts to make US surveillance systems more adaptable to rapidly changing technology, more versatile in addressing evolving health threats, more adept at accessing and leveraging healthcare data, and more capable of meeting demands for timely, population-specific, and geographically specific information. The strategy initially focused on modernizing four cross-cutting information systems that would benefit federal, state, and local public health partners. The systems included those for notifiable disease surveillance, syndromic surveillance, electronic laboratory reporting, and electronic death reporting (see Table 24.1). Good progress has been made in these four areas [39], but more work remains. A large part of the remaining effort is the need to build capacity for IT and information management modernization at the state and local level. A new initiative that builds upon the 2014 surveillance strategy is the 2019 CDC Public Health Data Modernization Initiative [98] that aims to transform the way CDC and its partners collect, store, exchange, analyze, and share data and information used to address threats to the public’s health. Details about this initiative are just now unfolding but there will be an emphasis on cloud computing, data standards, system interoperability, increased data sharing, the use of advanced methods (e.g., machine learning) for predictive analytics, and support for state and local health departments for complementary modernization efforts.

**Resources and Workforce Development and Capacity**

Resources for IT and informatics modernization are an ongoing challenge for public health. It is rarely possible to stop a data collection system and use the resources to buy or build new technology. Data must continue to flow so additional resources for modernization must be found. In 2019, the Council of State and Territorial Epidemiologists (CSTE), Association of Public Health Laboratories (APHL), National Association for Public Health Statistics and Information Systems (NAPHSIS), and Healthcare Information & Management Systems Society (HIMSS) joined forces to spearhead a campaign to secure $1 billion over 10 years to modernize the public health surveillance enterprise at CDC and through it, the state, local, tribal, and territorial health departments [99, 100]. As of late 2019, it is not yet known whether this campaign will result in additional resources for public health, but the campaign has raised awareness about the need to strengthen data systems and has coalesced public health partners around some guiding principles for modernization. These principles include taking an enterprise approach to data system modernization, using interoperable
data systems, ensuring the protection and privacy of patient data, building a data science and informatics workforce, and partnering with the public and private sectors [101].

Of particular concern to public health agencies, is a public health workforce that is not prepared for the information age. For example, vocabularists are needed who can apply vocabulary standards to data elements and value sets for sharing data. Informaticians are needed who can create standardized case report messages and use message transport systems to exchange data between agencies. Database managers are needed who can pull data from an SQL or HL7® data structure and transform the data to a flat file for analysts to use. Data scientists (both epidemiologists with additional skills and experience and specialized experts) are needed who can use programming languages like Python to apply machine learning methods to large, complex data. It is difficult to attract and retain persons with these skills to public health given demand and compensation in the private sector. Solutions are being tried such as post-graduate fellowships, professional development, sharing experts across program areas, training-in-place programs, acquiring expertise through contracts, public-private personnel exchanges, and some limited increases in recruitment salaries. It is unlikely that these solutions alone will build the workforce as quickly as is needed. New ideas and strategies will be required to meet the demand for new skill sets as surveillance and information management become more digital, automated, and complex.

Today, this is further accelerated by initiatives seeking national information standards across health care, the major source of information used by public health agencies. One priority challenge is to leverage common approaches so that the network of functions and systems converge around interoperability and standards. Because most public health practice is performed at the local or state level, systems of information collection and exchange must serve both local public health processes and national information needs. US public health informaticians must navigate the intersecting influence of both local and federal requirements, and we must work collaboratively to ensure critical information needs are met at all levels: local, state, and federal in partnership with private entities, whether corporate or non-profit. We 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.

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Summary

The onset of global trade and travel at jet speeds and the potential for rapid spread of emerging and terrorist disease threats, in an ever-expanding information age, has created demand for national information systems for public health surveillance and response likely 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.

Review Questions

1. How does the US Constitution influence the evolution of government public health structures and information systems in the US?
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. What aspects of technology modernization do most of the new federal initiatives have in common?
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