A Catalog and Review of Public Health Reporting Burden in the U.S.

John Bender, MS

Office of the Chief Technology Officer of Department of Health and Human Services

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Author Note

John Bender, University of Texas Health Science Center at Houston

Contact: john.bender@hhs.gov

Abstract

Several programs across the United States Department of Health and Human Services (HHS) agencies and offices require healthcare organization or provider reporting for public health monitoring activities. The 21st Century Cures Act amended the Health Information Technology for Economic and Clinical Health Act to direct healthcare organizations to reduce provider regulatory and administrative burden. There is not an enterprise-wide system in U.S. HHS for tracking the public heath monitoring programs, digital systems, measures, and tools in the department. Maintaining a reference system for all federally-directed public health monitoring activities could help to reduce duplicative data collection, and enable providers to spend more time caring for patients. We provide results of our review of public health reporting programs in the U.S., recommendations for organizing and maintaining a reference system of public health monitoring activities, highlights of effective programs, and describe the future effort needed from U.S. HHS to expand this work.

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Introduction

Background

A shifting health system has created a heavy toll on healthcare organizations and providers in the U.S. New health models, an ageing population, new technology, limited resources, and changing policy has made it challenging for healthcare organizations to keep up. Faced with these realities, the U.S. federal government amended the Health Information Technology for Economic and Clinical Health Act to include a "Reduction in burdens goal" as part of the 21st Century Cures Act (114th Congress, 2016). The act directs organizations to establish recommendations, a goal, and strategy to address the reduction in provider burden.

Public health reporting enables health departments to monitor the prevalence and incidence of disease, informs the impact of health interventions, and can stimulate research (DeSalvo et al., 2017). There are several methods to collect data for public health, including national and local surveys, active and passive surveillance, and research studies. The federal government awards funds to states across the U.S. for various public health initiatives, some of which include mandated reporting requirements. Although essential, clinical public health reporting has the potential to distract healthcare organizations and providers from patient care. Aligning public health reporting activities across the U.S. has the potential to reduce the administrative burden for healthcare organizations. In this report, we investigated public health reporting for healthcare providers in the U.S., in order to partially address the reductions in burdens goal of the 21st Century Cures Act. The findings from this report can help inform policy activities and reduce the administrative burden for providers in the U.S.

Study Goals and Objectives

The goals of this report were to: (1) Study the public health monitoring activities of the U.S. Health and Human Services (HHS), (2) Provide a catalog of public health programs, registries, and surveillance systems in HHS, and (3) Describe initial findings and recommendations for monitoring and mitigating provider public health reporting burden in the U.S.

Methods

Overview

In order to begin the work of identifying the provider public health reporting burden in the U.S., we conducted interviews with leaders from agencies across HHS, analyzed catalogs of health programs and measurement tools, and analyzed programs nationally and internationally to identify best practices to reduce provider public health reporting burden.

Interviews

We interviewed 10 leaders from U.S. agencies, including the HHS Centers for Disease Control and Prevention (CDC), HHS Health Resources and Services Administration (HRSA), HHS Administration for Children and Families (ACF), HHS Food and Drug Administration (FDA), and the U.S. Department of Agriculture (USDA) Office of Policy Support to understand public health activities within each agency. We conducted the semi-structured interviews by asking for an overview of the work responsibilities of the participants and function of their agency, followed by questions about the public health monitoring activities being conducted by the agency, and concluding with questions regarding any activities to catalog public health programs in the agency. We specifically excluded public health activities associated with the Indian Health Service, due to the limited nature of this project.

Public Health Catalog

Using the results from the interviews, agency websites, and publications, we identified

and created a large inventory of public health programs managed by the U.S. We utilized several

data sources to compile a database of "Data Sets", "Surveys", "Programs", "Registries",

"Surveillance Systems", and "Tools" from U.S. HHS. Sources included: (1) Centers for Disease

Control and Prevention (CDC) Informatics Lab, (2) HHS Enterprise Data Inventory, and (3)

National Quality Forum (NQF): Positioning System (Centers for Disease Control and

Prevention, 2017; National Quality Forum, 2018; United Stated Department of Health and

Human Services, 2018). We used the inventory to identify relevant public health programs that

included provider reporting, and categorized these by public health reporting type. We manually

reviewed the list of domestic public health reporting programs, and additionally reviewed

international programs to make recommendations for monitoring and mitigating public health

reporting provider burden in the U.S. Additionally, we reviewed the metadata schemas

associated with catalogs identified during our interviews, and provided suggestions for a future

enterprise-wide catalog.

Listening Session

During a provider listening session hosted by Kelly Cronin, MS, MPH Director of the

Office of Care Transformation at the U.S. HHS Office of the National Coordinator for Health

Information Technology (ONC), fifty healthcare providers were administered a question

regarding provider public health reporting burden recommendations in the U.S. The providers

were asked, "How much time and effort do hospital and ambulatory care practices spend on

various public health reporting requirements?" and "How could public health reporting required

by federal programs be less burdensome?" Comments were analyzed, and issues and recommendations were extracted for analysis.

Results and Discussion

Overview

We present the results and discussion of this study, which includes an updated and usable catalog of public health programs, tools, registries, health surveys, and surveillance systems in the U.S., a catalog of the relevant public health reporting programs that impact provider burden, a list of the types of ongoing public health monitoring activities in the U.S., a listing and analysis of metadata from program inventories in the U.S., and highlights of programs and practices that may reduce provider public health reporting burden.

Catalog

We updated the Neo4j graph database prepared by the CDC Public Health Informatics Lab and made it publicly available via this URL: https://github.com/johnnybender/jupiter-api. Background and usage instructions for the Neo4j database are included in the GitHub repository. Additionally, the GitHub repository contains original, unmodified copies of the three source files (CDC Jupiter, HHS Enterprise Data Inventory, and NQF Measures Inventory), and a separate modified neo4j database with all source files combined. The combined database can be used to identify the relationships between programs and organizations, programs and surveillance systems and registries, and how data are collected for each system. A screenshot of the visualized graph database is included in Figure 1.

We used this catalog and results from interviews with U.S. agency leaders to create a consolidated list of approximately 500 health programs, registries, surveillance systems, tools, and health surveys in the U.S. We further refined the list to approximately 200 *public health*

programs, registries, health surveys, and surveillance systems. We reviewed documentation on agency websites and online publications for the 200 programs to identify whether public health monitoring programs had the potential to impact providers. If healthcare organizations or providers were mentioned in any methods or standard operating procedures documentation for the public health program, we included it in the catalog. The final catalog of approximately 100 public health monitoring programs that may impact providers are included in Tables 1a – d. This catalog includes: (1) The agency responsible for the activity, (2) Metadata for whether the item is the primary data source for the monitoring activity, (3) Public health monitoring type, and (4) Labels from the CDC Informatics Lab database: "Programs", "Tools", "Health Surveys", "Surveillance Systems", and "Registries". Data source annotations include: (1) "Primary data source" for public health monitoring activities where the item is the primary mechanism for collecting data; (2) "Compiled data from other systems" for public health monitoring activities that use a collection of public health monitoring activities, like the Influenza Surveillance Program, which contains seven public health data sources; and (3) "Component of Primary data source" for monitoring activities that rely on a separate tool for data submissions, like the National Vital Statistics System – Fetal Death, which relies on the National Vital Statistics System as the primary data source. This catalog can be used by staff and committees to understand the ongoing public health activities in the U.S.

We include a list of the twelve types of public health reporting activities in the U.S. from the catalog (Tables 1a – d) in Table 2. Categories include (1) Adverse Event Surveillance, where programs monitor adverse events to identify things like drug or vaccine defects, like the Vaccine Safety Datalink Project; (2) All Patient Reporting, where programs document all patients who receive a service, like the Early Hearing Detection and Intervention program, which uses birth

records to identify the percentage of patients screened for birth defects after birth; (3) Case

Reporting, which includes morbidity reporting and mandatory infectious disease reporting, like

reporting to the National Notifiable Diseases Surveillance System using the National Electronic

Disease Surveillance System; (4) Clinical Quality Measures, where programs routinely measure

outcomes using pre-defined clinical outcome measures that are typically included and auto-

calculated in electronic health record systems, like the Million Hearts initiative; (5) Laboratory

Reporting, where reporting originates from public health laboratories, but may have impact on

provider public health reporting burden; (6) Recurrent Programmatic Reporting, where

healthcare organizations report on a recurring basis to the state or federal government on an

outcome measure being monitored, like the Ryan White program; (7) Registries, which are

created at the local, state, or federal level to create lists of patients for upkeep of longitudinal

records or to measure outcomes over time, like the Fragile X registry; (8) Sentinel Surveillance,

where a sample of organizations report on things like cases of disease to estimate the national

burden of disease or to monitor for emerging patterns, like the Autism and Developmental

Disabilities Monitoring Network; (9) Served Patient Reporting, where only the patients served

are reported for tracking, like the HIV Prevention Program Evaluation and Monitoring System;

(10) Surveys, where healthcare providers must complete surveys or reporting to the state or

federal government, like the National Ambulatory Medical Care Survey; (11) Syndromic

Surveillance, which serves to identify diseases prior to diagnosis, like the National Syndromic

Surveillance Program; and (12) Vital Statistics, where birth and death records are reported to

health authorities, like the National Vital Statistics System. These categories are not mutually

exclusive. For example, the Birth Defects Surveillance effort by the CDC is an example of both

Case Reporting and Sentinel Surveillance, included in Table 1a.

A pertinent finding from the review of public health surveillance activities in the U.S. is that most programs either rely on sentinel surveillance – extrapolating estimates of public health burden or monitoring the U.S. for disease incidence using data from a small sample of organizations – or limited voluntary partner data submission, rather than conducting comprehensive or near-comprehensive public health monitoring activities. Leveraging the widespread adoption of electronic health records, U.S. HHS has the opportunity to replace or supplement many existing programs with clinical indicators to provide a more holistic picture of public health in the U.S. (Brady et al., 2016). However, clinical indicators are impractical for some programs, like the Gonococcal Isolate Surveillance Project to measure the state of antibiotic resistance in *N. gonorrhoeae* in the U.S.

The non-homogenous nature of public health monitoring in the U.S. presents a challenge for estimating provider public health reporting burden for all U.S. providers. Programs funded through Cooperative Agreements, like the Emerging Infections Program, Early Hearing Detection and Intervention, Sexually Transmitted Diseases Surveillance Network, and Sentinel Event Notification System for Occupational Risk are frequently focused on a sample of willing U.S. state participants. Other programs are focused on specific geographical locations, like the Border Infectious Disease Surveillance Project and the National Sentinel Site Surveillance System – Haiti. Additionally, some public health programs are short-term, like the 122 Cities Mortality Reporting System, while others are semi-permanent, like immunization reporting. Short-term and semi-permanent public health programs may have differing administrative burden for providers and healthcare organizations. In order to accurately measure public health reporting burden for providers in the U.S., investigators would need to intimately understand all

the transient and permanent public health programs, their procedures, administrative burden, and participation from healthcare organizations.

Provider Reporting Mechanisms

U.S. laws grant states statutory public health authority over the populations they serve. This makes it challenging to reduce provider burden due to the inability of the federal government to mandate compliance with electronic tools or standards across all public health programs. Federally-funded public health programs that require reporting frequently allow states to coordinate data collection within the state prior to submissions to government agencies. For example, the USDA Women, Infants and Children (WIC) program requires periodic reporting and surveillance from the approximately 11,000 WIC clinics to USDA, but the approximately 1,800 local WIC agencies are required to submit data to state agencies who compile the data to be submitted to the federal government. Although the USDA suggests a reporting tool, state agencies have the autonomy to use the tool of their choice, which creates reporting differences across states. This type of practice is especially burdensome for providers on state borders, since they frequently treat patients from different states. We have documented all the feasible public health reporting mechanisms in Figure 2. These include: (1) Reporting from the provider to the state, which reports to the federal government, like with the National Notifiable Diseases Surveillance System; (2) Reporting from the provider to a local organization, which reports to the state, which reports to the federal government; (3) Reporting from the provider directly to the federal government, like with the Assisted Reproductive Technology (ART) Surveillance program, or (4) Reporting from the provider to a local organization, which reports to the federal government. In addition, public health programs and state policies vary regarding whether providers should report to the state in which the patient resides or the state in which the provider

practices. These inconsistencies contribute to the confusing ecosystem of public health surveillance activities across the U.S. and highlight the need for increased coordination and alignment across programs.

Provider Listening Session Summary

The results of the provider listening session are presented in Tables 3 and 4. Some responses had multiple issues and recommendations listed, thus the count of issues and recommendations does not equal the participant sample size of 50 respondents. Providers overwhelmingly reported burdensome reporting requirements. Common themes were the need to automate reporting, align requirements across all programs and levels of government, a lack of understanding for what the reported information is being used for, technology burdens, desire for standardization of fields in EHRs, and a suggestion to use machine learning techniques to reduce the need to standardize submissions for reporting.

Effective Programs that Reduce Provider Burden

The Million Hearts initiative is an example of a public health monitoring program that has reduced potential provider reporting burden by integrating with existing programs and measures. It is the first of its kind to demonstrate the use of quality measures for public health monitoring purposes aligned with other federal reporting initiatives. Other public health monitoring programs should use the Million Hearts initiative as an example to reduce public health reporting burden by avoiding measuring duplicative metrics and requiring different user interfaces for data entry (Centers for Disease Control and Prevention, 2015). The Million Hearts initiative has been recognized by several organizations, including the Institute of Medicine, as an example of best practice for using a clinical measure for public health monitoring and reporting (Landon, Grumbach, & Wallace, 2012).

As electronic health records and data exchange become more widely leveraged, and standards like Health Level 7 (HL7) Fast Healthcare Interoperability Resources become more widely adopted, much of the duplicative public health reporting activities can be reduced and coordinated. Instead of creating new HL7 implementation guides for electronic health record vendors to accommodate every time a new data set is required, organizations like the CDC should adopt a common means of extracting information using standards like HL7 FHIR via application programming interfaces, align on a set of data to extract, and use a subset of the extracted data for public health purposes.

The National Notifiable Diseases Surveillance System (NNDS) is a great example of consolidating mandatory reporting for reduced provider public health burden. In the early 1990s, several components of NNDS were not yet streamlined to one reporting system, including the Vital Hepatitis Surveillance System. CDC implemented a tool, the National Electronic Telecommunications System for Surveillance (NETSS), which allowed all notifiable conditions to be submitted via a single interface, and paper to be eliminated from the reporting process in 2002. NETSS has since been upgraded to the National Electronic Disease Surveillance System (NEDSS), which continues to allow notifiable disease submission to the federal government via a single user interface. However, it is important to note that despite the existence of a single interface for CDC submissions, states have the autonomy to implement their own processes for notifiable conditions reporting. If a state deviates significantly from consolidated user interfaces like NEDSS, they may be contributing to unnecessary provider public health reporting burden.

Efforts like the Digital Bridge initiative by the Robert Wood Johnson Foundation, the de Beaumont Foundation, the Public Health Informatics Institute, Deloitte, CDC, ONC, electronic health record vendors, and others to create a bidirectional information flow between health care

and public health are important to advance the integration of clinical and public health. The

Digital Bridge initiative is initially focusing on creating an integrated approach to electronic case

reporting, with the first pilot site expected to be live in 2018.

Internationally, the Challenging Burden Service of NHSDigital is an excellent example of

a program that works to reduce the ongoing reporting burden of providers. They have

implemented standard operating procedures and practices to review any new request for data

reporting to ensure it is not repetitive and is integrated into the existing clinical workflow. A

high-level overview of the reporting request process is included in Figure 3. In order for new

healthcare-driven data reporting to be added, NHSDigital requires all organizations to go through

a burden assessment, which includes a Burden Advice and Assessment Service form and survey

or site-visit, depending on the level of burden identified. In addition to reviewing and judging

future data requests, the Challenging Burden Service also manages an alphabetical list of all Data

Coordination Board and Information Standards Board standards and collections. The

alphabetical list is updated monthly by the Data Coordination Board, and its items are

categorized into "Information Standard", "Collection", "Extraction", or a mix of the three,

depending on how the data are accessed. The list is publicly available, and is a centralized

resource to be used by individuals prior to making any new data request (NHS Digital, 2018). A

summary table of the public metadata elements are included in Table 5. This authoritative list is

helpful for NHSDigital and participating partners, like providers, to keep track of the data being

collected for planning purposes. Maintaining a list allows them to constantly monitor the data

being collected, and provides a clear path to reducing redundant and unnecessary data collection.

Metadata synthesis

If a list of collected data were maintained by HHS, we recommend limiting the metadata to a small essential list of elements, so it is easily maintainable, and providing functionality to extend the core metadata if necessary to support each program. We believe the complexity of the metadata collected for the CDC Informatics Lab made it unwieldy and difficult to maintain. Using the metadata collected by the NHSDigital Challenging Burden Service as a start (Table 5), we recommend a committee create a list of metadata elements that capture the essential features of the U.S. public health monitoring programs with linkages to semi-permanent Uniform Resource Locators for additional information, to keep track of all public health monitoring programs at HHS. A review committee should consider the specific use for each of the metadata elements, and consider whether some of the elements may be better suited in an extension of the core profile, or should be added in future versions, after metadata maintenance is widely adopted in HHS. Furthermore, if possible the metadata schema should be consistent across items to avoid confusion and facilitate querying, which was not the case for the CDC Informatics Lab database.

Limitations

Time was the biggest limitation during the Spring 2018 semester. The catalog included in Tables 1a, 1b, 1c, and 1d does not include healthcare provider-driven public health reporting from the state and local levels independent of the U.S. government. We were only able to interview representatives from CDC, HRSA, ACF, FDA, and USDA, and only included these, the Office of Population Affairs (OPA), and the Agency for Healthcare Research and Quality in our review of federal agencies for public health monitoring activities. Future studies should consider Centers for Medicare and Medicaid Services, Assistant Secretary for Preparedness and Response, Indian Health Service, Substance Abuse and Mental Health Services Administration, ONC, Agency for Toxic Substances and Disease Registry, and the National Institutes of Health

in their review of federal programs to identify ongoing public health monitoring activities to include in the catalog and provider public health reporting burden assessment.

Conclusions and Future Work

We have conducted the initial work necessary to understand the burden of public health reporting for providers in the U.S. Leveraging new technology standards and encouraging adoption of new technology may reduce the public health reporting burden for providers in the U.S. We believe HHS would substantially benefit from an enterprise public health program / registry / surveillance monitoring tool. It would allow the department to quickly understand the current reporting landscape, provide holistic recommendations for reducing provider burden, reduce duplicative activities, and provide a clear path for measure alignment across programs. We also believe HHS should form a service similar to the Challenging Burden Service at NHSDigital in the United Kingdom. Ideally, this group would audit new reporting requirements prior to implementation in order to provide recommendations for duplicative work reduction, measure alignment, or automation. The myriad of public health reporting activities and lack of alignment regarding submission mechanism in the U.S. illustrates the importance of an oversight committee to monitor and coordinate provider reporting across U.S. HHS. The government cannot wholly rely on agencies to perform due diligence on understanding the provider burden of new monitoring programs, and ensuring reduction of redundancy. A centralized service, like the NHSDigital Challenging Burden Service, and centralized data collection inventory like the one managed by the NHSDigital Challenging Burden Service (Table 5) will be necessary for us to move forward with digital health and population health monitoring and allow us to achieve a learning healthcare system, like the one included in the Office of the National Coordinator for

Health Information Technology shared nationwide interoperability roadmap (The Office of the

National Coordinator for Health Information Technology, 2016).

We recommend forming a committee to continue this investigation. The committee can

work to: (1) Validate and expand the catalog identified in Tables 1a, 1b, 1c, and 1d through

additional research and expert interviews; (2) Conduct interviews with a sample healthcare

organizations across the U.S. to identify the estimated burden of each program; (3) Review the

public health programs in-depth given findings from healthcare organizations; (4) Provide

recommendations for consolidation of reporting and reduction of provider burden; (5) Create a

catalog of public health reporting burden reduction best practices domestically and

internationally; (6) Investigate creating an administrative burden control and programmatic

monitoring service to reduce provider burden; (7) Investigate creating a comprehensive public-

facing catalog of federal public health monitoring activities that impact healthcare providers; and

(8) Identify ways to educate providers about the use and outcomes of public health reporting
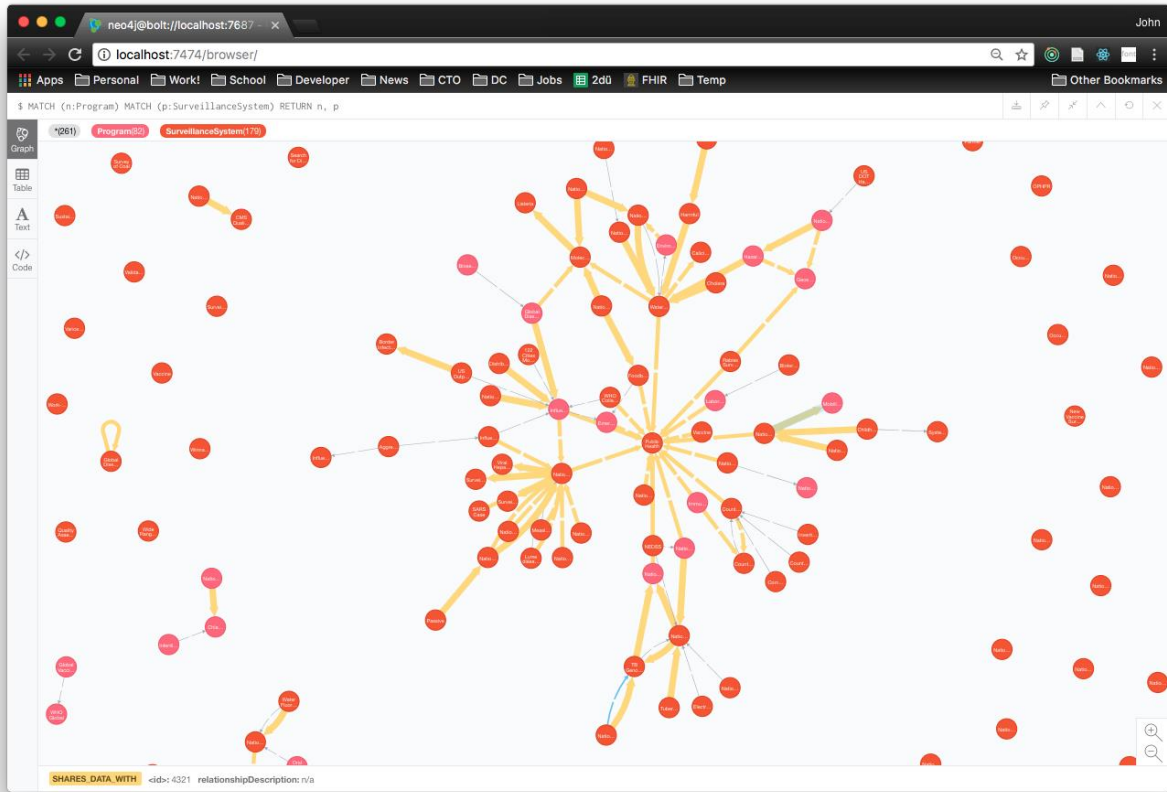
activities.

Appendix: Figures and Tables

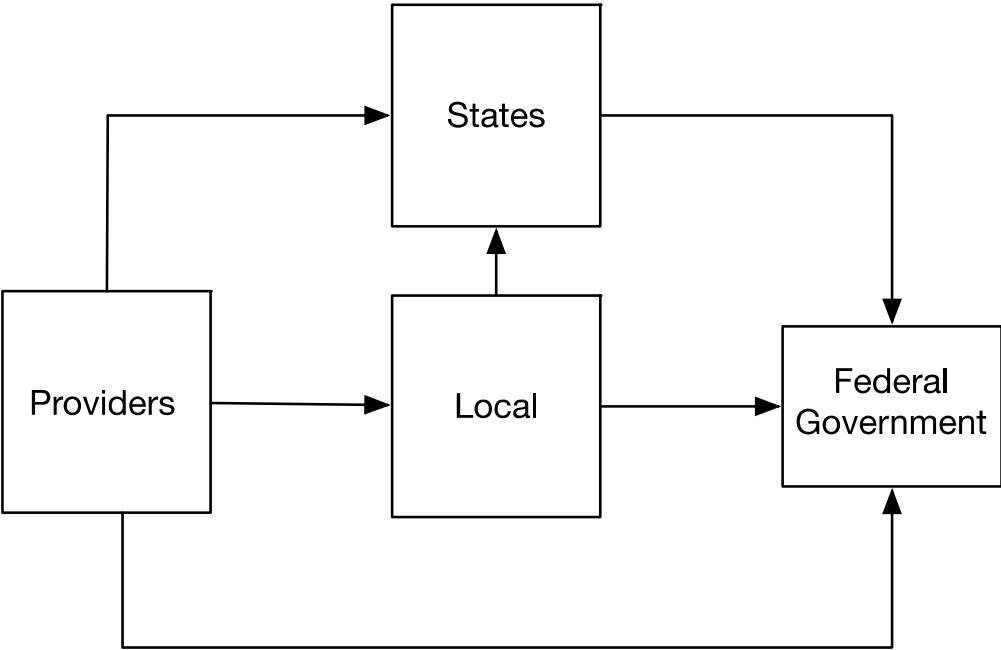Figure 1: Screenshot of the Neo4j database linking Programs to Surveillance Systems

Figure 2: Public health reporting paths from providers to the federal government
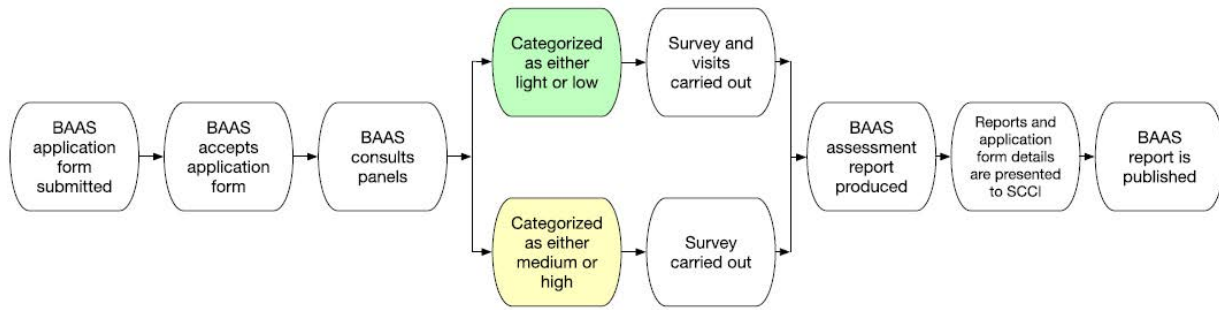
Figure 3: Standard operating procedure of NHSDigital Challenging Burden Service to review requests for data submission

Table 1a

Catalog of public health programs that may impact provider public health reporting

Name	Agency	Data source	Public health type	Category
Medical Expenditure Panel Survey: Medical Provider Component	AHRQ	Primary data source	Surveys	HealthSurvey
Healthcare Cost and Utilization Project	AHRQ	Primary data source	Recurrent Reporting	Program
Medical Expenditure Panel Survey	CDC	Primary data source	Surveys	HealthSurvey
National Ambulatory Medical Care Survey	CDC	Primary data source	Surveys	HealthSurvey
National Hospital Ambulatory Medical Care Survey	CDC	Primary data source	Surveys	HealthSurvey
National Vital Statistics System - Fetal Death	CDC	Component of Primary data source	Vital Statistics	HealthSurvey
National Vital Statistics System - Linked Birth/Infant Death	CDC	Component of Primary data source	Vital Statistics	HealthSurvey
National Vital Statistics System - Mortality	CDC	Component of Primary data source	Vital Statistics	HealthSurvey
Million Hearts	CDC	Primary data source	Clinical Quality Measures	Program
Autism and Developmental Disabilities Monitoring Network	CDC	Primary data source	Sentinel Surveillance	Program
Birth Defects Surveillance	CDC	Primary data source	Case Reporting, Sentinel Surveillance	Program
Chlamydia and Gonorrhea Prevalence Monitoring Program	CDC	Compiled data from other systems	Group of Surveillance Methods	Program
Early Hearing Detection and Intervention	CDC	Primary data source	All Patient Reporting	Program
Emerging Infections Program	CDC	Primary data source	Case Reporting, Sentinel Surveillance	Program
HIV Prevention Program Evaluation and Monitoring System	CDC	Primary data source	Served Patient Reporting	Program
Influenza Surveillance Program	CDC	Compiled data from other systems	Group of Surveillance Methods	Program
National Syndromic Surveillance Program (formerly BioSense)	CDC	Primary data source	Syndromic Surveillance	Program
Perinatal Hepatitis B Prevention Case Management Data	CDC	Primary data source	Case Reporting	Program
Vaccine Safety Datalink Project	CDC	Primary data source	Adverse Event Surveillance, Sentinel Surveillance	Program
Cardiac Arrest Registry to Enhance Survival	CDC	Primary data source	Registry	Registry
National Amyotrophic Lateral Sclerosis Registry (ALS)	CDC	Primary data source	Registry	Registry
National Congenital Rubella Syndrome Registry	CDC	Primary data source	Registry	Registry
National Program of Cancer Registries	CDC	Primary data source	Registry	Registry
National Spina Bifida Patient Registry	CDC	Primary data source	Registry	Registry
NCIRD Registry Sentinel Project	CDC	Primary data source	Sentinel Surveillance	Registry
Paul Coverdell National Acute Stroke Registry	CDC	Primary data source	Registry	Registry
State Based Surveillance for Silicosis	CDC	Primary data source	Sentinel Surveillance	Registry

Note. Continued on next page

Table 1a: Catalog of public health programs that may impact provider public health reporting

Table 1b

Catalog of public health programs that may impact provider public health reporting

Name	Agency	Data source	Public health type	Category
State Based Surveillance for Work-Related Asthma	CDC	Primary data source	Sentinel Surveillance	Registry
Tremolite Asbestos Registry	CDC	Primary data source	Registry	Registry
World Trade Center Health Registry	CDC	Primary data source	Registry	Registry
Abortion Surveillance System	CDC	Primary data source	Served Patient Reporting	SurveillanceSystem
Active Bacterial Core surveillance	CDC	Component of Primary data source	Case Reporting, Sentinel Surveillance	SurveillanceSystem
Assisted Reproductive Technology (ART) Surveillance	CDC	Primary data source	Served Patient Reporting	SurveillanceSystem
Asthma Surveillance	CDC	Compiled data from other systems	Group of Surveillance Methods	SurveillanceSystem
Border Infectious Disease Surveillance Project	CDC	Primary data source	Sentinel Surveillance, Syndromic Surveillance	SurveillanceSystem
CaliciNet	CDC	Primary data source	Case Reporting	SurveillanceSystem
Cholera and Other Vibrio Illness Surveillance System	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
Chronic Kidney Disease Surveillance System	CDC	Compiled data from other systems	Group of Surveillance Methods	SurveillanceSystem
Countermeasure Tracking Systems	CDC	Primary data source	Supply management	SurveillanceSystem
EMERGEncy ID NET	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Enhanced Perinatal Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
Foodborne Diseases Active Surveillance Network	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Fragile X Registry	CDC	Primary data source	Sentinel Surveillance, Registry	SurveillanceSystem
GeoSentinel Network Surveillance System	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Gonococcal Isolate Surveillance Project	CDC	Primary data source	Sentinel Surveillance, Laboratory Reporting	SurveillanceSystem
Infectious Diseases Society of America Emerging Infections Network	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Influenza Associated Pediatric Mortality Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
Influenza Hospitalization Surveillance Network	CDC	Primary data source	Case Reporting, Laboratory Reporting	SurveillanceSystem
Listeria Initiative	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
Lyme disease	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem

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Table 1b: Catalog of public health programs that may impact provider public health reporting

Table 1c
Catalog of public health programs that may impact provider public health reporting

Name	Agency	Data source	Public health type	Category
Measles, Mumps, and Rubella Surveillance	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
Molecular Subtyping Network for Foodborne Disease Surveillance	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
Multi-Site Gram-Negative Bacilli Surveillance Initiative (MuGSI) Data Management System	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
National Botulism Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Electronic Injury Surveillance System - Occupational Supplement	CDC	Primary data source	Case Reporting, Sentinel Surveillance	SurveillanceSystem
National Enterovirus Surveillance System	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
National Environmental Public Health Tracking Network	CDC	Primary data source	Case Reporting	SurveillanceSystem
National HealthCare Safety Network	CDC	Primary data source	Case Reporting	SurveillanceSystem
National HIV Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Malaria Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Notifiable Diseases Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Poison Data System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Polio Surveillance System	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
National Respiratory and Enteric Virus Surveillance System	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
National Rotavirus Strain Surveillance System	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
National Sentinel Site Surveillance System - Haiti	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
National Syndromic Surveillance Platform (BioSense)	CDC	Primary data source	Syndromic Surveillance	SurveillanceSystem
National Tuberculosis Genotyping Service	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
National Tuberculosis Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
National Violent Death Reporting System	CDC	Primary data source	Vital Statistics	SurveillanceSystem
National Vital Statistics System	CDC	Primary data source	Vital Statistics	SurveillanceSystem
NEDSS TB Program Area Module	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
New Vaccine Surveillance Network	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Occupational Health Safety Network	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Passive Dengue Surveillance System for Puerto Rico, USVI and US Travelers	CDC	Primary data source	Case Reporting	SurveillanceSystem
Pregnancy Mortality Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
Rabies Surveillance Network	CDC	Primary data source	Case Reporting	SurveillanceSystem
Sentinel Event Notification System for Occupational Risks - Pesticides	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem

Note. Continued on next page

Table 1c: Catalog of public health programs that may impact provider public health reporting

Table 1d

Catalog of public health programs that may impact provider public health reporting

Name	Agency	Data source	Public health type	Category
Sexually Transmitted Diseases Surveillance Network	CDC	Primary data source	Sentinel Surveillance	SurveillanceSystem
Sudden Unexpected Infant Death Case Registry Pilot Program	CDC	Primary data source	Registry	SurveillanceSystem
Surveillance for Trichinellosis	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
US Outpatient Influenza-Like Illness Surveillance Network	CDC	Primary data source	Case Reporting	SurveillanceSystem
Vaccine Adverse Event Reporting System	CDC	Primary data source	Adverse Event Surveillance	SurveillanceSystem
Varicella Active Surveillance Project	CDC	Primary data source	Case Reporting	SurveillanceSystem
Varicella Deaths Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
Viral Hepatitis Surveillance Program	CDC	Component of Primary data source	Case Reporting	SurveillanceSystem
Waterborne Diseases Outbreak Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
WHO Collaborating Laboratories	CDC	Primary data source	Laboratory Reporting	SurveillanceSystem
Work-Related Lung Disease Surveillance System	CDC	Primary data source	Case Reporting	SurveillanceSystem
Electronic Disease Notification	CDC	Primary data source	Served Patient Reporting, Case Reporting	Tool
Enhanced HIV/AIDS Reporting System	CDC	Primary data source	Case Reporting	Tool
Metropolitan Atlanta Developmental Disabilities	CDC	Primary data source	Case Reporting	Tool
National Program of Cancer Registries Registry Plus	CDC	Primary data source	Case Reporting	Tool
Public Health Laboratory Information System	CDC	Primary data source	Laboratory Reporting	Tool
Patient Centered Medical Home	HRSA	Primary data source	Recurrent Reporting	Program
Ryan White HIV/AIDS	HRSA	Primary data source	Recurrent Reporting	Program
Title X Funding	OPA	Primary data source	Recurrent Reporting	Program
Special Supplemental Nutrition Program for Women, Infants, and Children	USDA	Primary data source	Recurrent Reporting	Program

Note.

Table 1d: Catalog of public health programs that may impact provider public health reporting

Table 2
Public health monitoring and reporting categories

Categories
Adverse Event Surveillance
All Patient Reporting
Case Reporting
Clinical Quality Measures
Laboratory Reporting
Recurrent Programmatic Reporting
Registry
Sentinel Surveillance
Served Patient Reporting
Surveys
Syndromic Surveillance
Vital Statistics

Note.

Table 2. Public health monitoring and reporting categories

Table 3

Provider listening session reported public health reporting burden issues

Issue Reported	Count
Too much reporting	9
Burden is too high	8
Federal, state, local, and private public health reporting requirements not aligned	7
Don't understand meaning / impact of public health reporting	6
Public health reporting not aligned across states	6
Public health reporting is not automated	4
Manual reporting	3
Public health reporting not standardized or streamlined	3
Measures need improvement	2
Public health reporting is too complex	2
Unnecessary information requested	2
Don't understand cost of measuring quality	1
EHRs make it challenging to produce public health reports	1
Electronic interface burden	1
Every provider makes their own report without vendor assistance	1
Every state and registry requires their own submission format	1
Federal reporting does not accept state as fulfillment	1
Lack of standardized field names across EHR	1
Manual abstraction - especially practices without EHRs	1
No standard user interface for data extraction in EHR	1
Over-reliance on clinical public health reporting; look to other sources	1
Over-reliance on clinicians for public health reporting instead of other staff	1
Providers cannot report once for all programs	1
Public health data not available on EHR dashboard	1
Public health organizations do not use same standards as CEHRT	1
Public health reporting does not use electronic standards	1
Public health reporting requires separate interfaces from claims	1
Public health systems not interoperable	1
Public health systems outdated	1

Note.

Table 3. Provider listening session reported public health reporting burden issues.

Table 4

Listening Session Reported Public Health Reporting Burden Recommendations

Recommendation Reported	Count
Reduce public health reporting	5
Align federal, state, and local reporting	4
Align public health reporting across states	3
Automate public health reporting	3
Communicate the value / use of public health reporting	3
Create a single source of reporting for all programs	2
Standardize fields in EHRs to improve public health reporting	2
Use electronic standards for public health reporting	2
Align EHR vendors for public health reporting automation	1
Align federal and state reporting, or accept state as fulfillment	1
Align public health reporting within states	1
Assist organizations that require manual abstraction	1
Better integrate public health reporting into care team workflow	1
Create standard interface from EHRs to extract data without much human capital	1
Force public health organizations to use same standards as CEHRT	1
Fund study to quantify cost of measuring quality	1
Improve public health reporting from EHRs	1
Improve public health reporting measures	1
Integrate public health reporting into claims reporting	1
Make public health data available on EHR dashboards	1
Make public health systems interoperable with EHRs	1
Make reporting requirements more applicable to patient care	1
Reduce burden of outpatient reporting	1
Remove all public health reporting by clinicians	1
Remove unnecessary information in reporting	1
Report what needs to be reported	1
Require EHRs to have pre-built interfaces for federal public health reporting	1
Simplify added public health reporting requirements	1
Simplify public health reporting data capture in EHRs	1
Standardize public health reporting	1
Standardize formats/transmissions to states and registries	1
Stop making every hospital build their own public health reporting interface	1
Streamline / automate public health reporting	1
Streamline / standardize public health forms	1
Streamline connectivity nationwide	1
Use abstractors instead of clinicians for public health reporting	1
Use artificial intelligence for public health reporting	1
Use examples from other countries to support electronic reporting	1
Use natural language processing for public health reporting	1
Use social media public health surveillance to reduce need for provider reporting	1
Note.	

Table 4. Listening session reported public health reporting burden recommendations.

Table 5

Public metadata for the alphabetical list of all Data Coordination Board and Information Standards Board standards and collections from NHSDigital Challenging Burden Service

Metadata Element	Description
Reference number	The unique identifier; DCB prefix indicates approved by DCB; ISB prefix indicates approved by ISB; SCCI prefix indicates accepted by SCCI
Title	The name of the standard or collection and the name of its current release.
ISCE	Information Standard or Collection (including Extraction). Standard - refers to an information standard. Standard and a collection - refers to an information standard which incorporates a collection. Collection - refers to a data collection or extraction.
Documentation	More information about the current release of the item. Note that a number of the 'Documentation' links for ISB standards will direct you to the ISB website; although this website has been transferred to The National Archives (TNA) please be assured that the links are taking you to the most recent documentation.
Summary	No description
About this information standard	No description
Release date	No description
Release number	No description
Release title	No description
Stage	No description
Key documents	No description
Supporting documents	No description
Further information	No description
Accessible Information web pages	No description

Note.

Table 5. Public metadata for the alphabetical list of all Data Coordination Board and Information

Standards Board standards and collections from NHSDigital Challenging Burden Service (NHS

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