

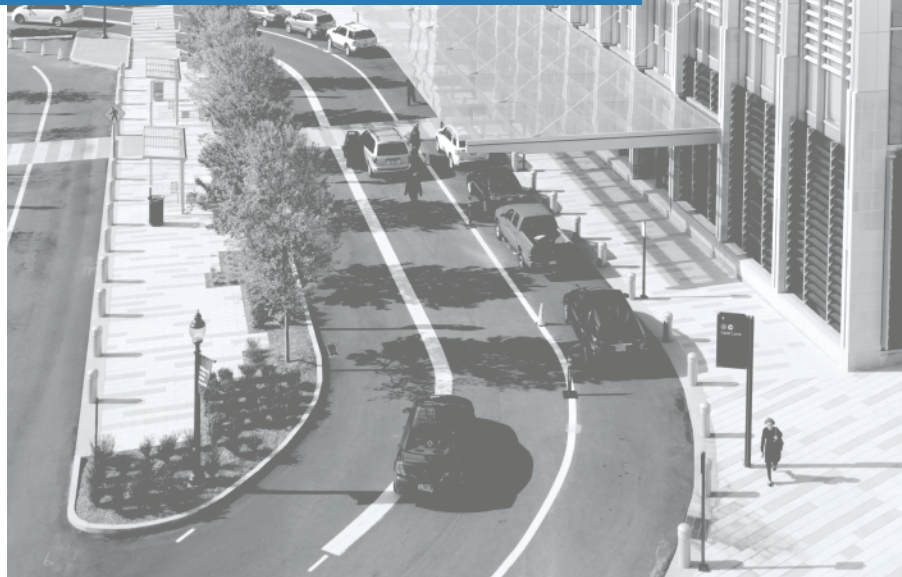
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DATA INTEROPERABILITY AND EXCHANGE TO SUPPORT COVID-19 CONTAINMENT

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May 1, 2020

This Duke-Margolis resource on COVID-19 response policies is intended to inform and help guide policymakers addressing the evolving COVID-19 pandemic in the United States and around the globe, and will be updated as the pandemic and response capabilities change over time.

It contains recommendations for a U.S. Federal response as well as steps and resources for stakeholders across the health care ecosystem. We will add further resources to address a range of related, critical policy challenges.

We thank our many collaborators, co-authors, and reviewers who have contributed significant expertise and guidance on these rapidly evolving issues. Please reach out to us with additional suggestions for resources and effective policies at dukemargolis@duke.edu - we welcome your input.

Executive Summary

The success of COVID-19 containment as the United States reopens will depend on timely sharing of key information related to testing, contact tracing, and detecting and acting on new outbreaks. Containment strategies across the country depend on effective collaboration of public health authorities with health care providers, laboratories, and community-based organizations to conduct testing, support effective contact tracing, quickly discern new patterns in health care use plausibly related to COVID-19, and identify ways to improve all of these activities over time. But public health, health care, and testing organizations have never had to work together with the scale or urgency required for COVID-19 containment. In particular, public health agencies are facing difficulties routinely accessing critical data from these other key participants in the containment effort, despite valiant attempts to cobble together information from many disparate systems.

To address this challenge, the Duke-Margolis Center for Health Policy convened a multi-stakeholder working group to identify feasible, short-term steps to improve interoperability and exchange of key data for COVID-19 containment. This work was guided by two practical principles:

1. **Focus on the next 30-90 days:** While there are many long-term infrastructure projects that could help, immediate needs call for immediate solutions.
2. **Use existing systems rather than building new systems:** Given the time constraints and the availability of substantial pre-existing infrastructure, implementing solutions through existing systems avoids the development work that would be needed for new data flows.

Recommendations

Three immediate, feasible steps will enable public health programs to work more effectively with health care providers, clinical laboratories, and other critical partners in COVID-19 containment efforts. This report details the three steps and specific technical approaches to their implementation:

1. **Improve Commercial Lab Reporting**

To enable timely public health tracing of positive COVID-19 cases, electronic test reporting systems should be expanded to include demographic information provided at the time a test is ordered or immediately thereafter. This standard reporting should include commercial laboratories, point-of-care testing manufacturers, and test implementers. The Centers for Medicare and Medicaid Services (CMS) and other payers should implement payment adjustments and incentives to enable the entities processing COVID-19 tests to obtain and provide the missing information.

2. **Supplement Case Investigations with Clinical Data**

State and local health officials should use their existing public health legal authority to define the minimum data necessary for the COVID-19 containment “use case” as a routine part of onboarding into widely-used clinical data exchanges

The trust framework governance entities that oversee secure data exchange should adopt policies necessary for universal responses to authorized public health queries, in a manner that is fully transparent to all participants and fully auditable.

State and local public health officials should evaluate and choose a portal-based connector as an “on-ramp” to access data, ensuring they meet key functional and security criteria.

3. **Enhance Use of the National Syndromic Surveillance Program (NSSP)**

Federal, state, and local public health officials — convened by the Association for State and Territorial Health Officials (ASTHO) and the Centers for Disease Control (CDC) — should agree on a consensus set of protocols governing which data from NSSP state “lockers” can be used for Federal surveillance and how that data may be used at the Federal level.

The Federal Department of Health and Human Services Office of the National Coordinator for Health IT (HHS ONC) and the CDC should convene a joint working group with state,

territorial, and local health officials and syndromic surveillance managers to conduct a focused review of the Syndromic Surveillance Messaging Guide and produce updated guidance for COVID-19 related syndromes. This revision should expand the use of the admission, discharge, and transfer (ADT) transactions for syndromic surveillance by encouraging activation of inpatient ADT feeds and sending of additional ADT message types, such as A06 (“change an outpatient to an inpatient”).

COVID-19 Interoperability & Data Exchange Recommendation 1: Improve Commercial Lab Reporting

Rationale & Background

Reporting from laboratories of test-positive individuals is a cornerstone of public health surveillance. Electronic reporting from clinical laboratories now constitutes the bulk of reportable disease notifications, including for COVID-19, comprising 83% of all positive tests [reported by the Centers for Disease Control and Prevention \(CDC\)](#) for most recent time period (4/12-4/18).

State and local public health investigations of COVID-19 cases are most often triggered by an electronic laboratory result. However, many of these laboratory results are missing key contact information. While there is variation by state, commonly up to 50% of laboratory reports submitted to public health can lack patient address or zip code, which is often a key demographic data element used in identifying infection clusters, localizing disease hotspots, contacting cases to complete investigations, and matching patient information, including for clinical queries through the CommonWell Health Alliance or the Carequality network.

Recommendation

There is an opportunity to use existing data systems to improve the flow of critical information to public health. Our working group investigated multiple potential strategies for supplementing or addressing the completeness of this information, from addressing failure points between electronic health records, laboratory information management systems, and commercial laboratories, to establishing prior authorization, or “ask at order entry” fields for capture of the key demographic data. While “ask at order entry” questions would further support the public health response, our priority was to select a solution that has broad applicability to all data sources and that does not require a software release timeframe nor action to be taken on behalf of every individual hospital or provider.

Our recommendation is therefore to provide policy levers that rely on the entities processing COVID-19 laboratory testing (the private and commercial laboratories and point of care (POC) testing manufactures and implementers, such as pharmacy chains and device manufacturers) to obtain and provide the missing information to ensure that initial result reporting to public health will be timely and complete.

In order to support rapid case investigation and contact tracing, we define “timely” as availability to public health within 24 hours of test resulting, and we define “complete” as containing given and family name, date of birth, gender, race/ethnicity, sufficient information to initiate contact tracing (address and/or telephone number), and sufficient information to identify the patient at the primary point of care (such as medical record number, or MRN). This information is often included in secure test orders for billing purposes, but not always. Timely reporting to public health should ideally occur at the same time as medical reports are returned to ordering providers.

Our investigation revealed multiple potential avenues for testing facilities to obtain more complete demographic information if it is missing from the initial requisition, including manual processes (e.g., immediately contacting providers at the time of submission or using software for individual information searches), internal records queries, and working upstream with sending systems to transmit demographic data at the time of initial order. However, these systems will be hard to scale.

A more scalable solution would be for testing facilities to be able to query a secure information service that can return the required data elements that are commonly missing:

- a. race / ethnicity
- b. telephone number
- c. address

By using data elements that are commonly available to testing facilities for secure billing and unique to the patient:

- d. medical record number + date of birth
- e. payer + subscriber number

Such data service provider(s) would offer an application programming interface (API) enabling laboratories to transmit commonly available data from the laboratory order to the API and receive back the commonly missing data that can be appended to the COVID-19 results prior to submission to the states.²

We believe that such an information service could feasibly be established in a matter of weeks by leveraging the existing infrastructure for clinical queries (e.g., the [CommonWell Health Alliance](#) Master Patient Index), existing [information service providers](#), and/or claims clearinghouses. Furthermore, we believe that testing facilities supported by payment incentives would be in the best position to appropriately select and support effective commercial solutions for supplementing missing demographic information, and are authorized as covered entities to request this information.

Under the HIPAA Privacy Rule, a clinical laboratory (which is a covered entity under the Rule) can access demographic information from an HIE "business associate" under the Rule for purposes of "treatment" (which would include gathering additional demographic data to further assure the lab's ability to match lab test results to the right patient) and for "health care operations," including population health activities related to improving health, customer service activities (assuring the delivery of results on the right patient), and general administrative activities such

² Although this will address the large majority of transactions that are submitted to the states, there will be some scenarios that will not be addressed by this solution. When the patient data that is submitted to the API does not return a unique individual, laboratories and point-of-care testing companies will not be able to supply the required demographic information.

as assuring completeness of its data for other permitted purposes like treatment, payment, or public health reporting..

Looking ahead, the likely surge in testing through point-of-care devices may further challenge reliable public health access to timely and complete information on laboratory-positive COVID-19 cases. As access to diagnostic testing expands with the authorization by FDA of additional platforms, the agency should request that manufacturers of point-of-care tests disclose, as part of the Emergency Use Authorization, how the device can assist in the collection of data for surveillance purposes, including any technology incorporated into the device, or the manufacturer's plans to update the device with such technology.

Policy drivers of electronic data sharing could include public health orders (as recently promulgated by [Massachusetts](#) and [Chicago](#)), or Federal regulations pursuant to [Section 18115](#) of the CARES Act. But the most powerful opportunity is to provide appropriate incentives through payment policy. As described in our [companion report on payment reforms](#) to support health system participation in COVID-19 containment, we recommend that the Centers for Medicare and Medicaid Services provide financial incentives for laboratory, testing facility, and POC device manufacturer compliance with our recommendation, including higher reimbursement for COVID-19 laboratory testing contingent on the provision of timely and complete data submission to public health.

COVID-19 Interoperability & Data Exchange Recommendation 2: Supplement Case Investigations with Clinical Data

Rationale & Background

Public health case investigations often start with attempting to locate clinical information for the patient's course of illness, comorbidities, and demographics. This is currently a burdensome and difficult process that does not scale to meet the demands of the COVID-19 epidemic. Most health departments have to rely on manual queries and faxes of clinical records. Some have been requesting logins to individual hospital EHRs; even in locations where there are local health information exchanges, there may be limitations in patient matching, access to clinical notes, and outpatient data.

There is an opportunity to use existing data systems to improve the flow of critical information to public health. Over the past several years, national interoperability networks have emerged to facilitate secure clinical exchange between providers using automated electronic queries in a trust framework. The most common “use case” for these networks is sharing data in direct support of the treatment of patients. However, the detailed demographic, risk factor, and clinical picture available through these networks is highly relevant for the use case of public health investigations during the COVID-19 outbreak.

The two major trust frameworks used by the majority of hospitals and health systems are governed by the [CommonWell Health Alliance](#) (which includes Cerner, Meditech, and CPSI participants, among other hospital-based electronic health record systems) and [Carequality](#) (which includes Epic participants, among others). These organizations primarily provide standards and governance for data exchange. In addition to these two, the [eHealthExchange](#) provides a trust framework for large Federal providers, such as the Department of Defense Military Health System and the Department of Veterans Affairs Veterans Health Administration and connects approximately half of all state and local health information exchanges. There is the ability for the networks to connect (e.g., a CommonWell query can be distributed to Carequality nodes within a defined geographic radius), but seamless omnidirectional network connectivity between eHealthExchange, CommonWell, and Carequality is not yet at full scale.

The working group's analysis identified three key areas of attention required for public health entities to access these clinical data exchange networks: Privacy Policy; Governance; and Technical. Our recommendations address each of these key areas. While we have sought to minimize the cost and burden of implementation by building directly on existing systems, payment adjustments to health care providers participating in these systems could offset these costs.

Recommendation #1 – Privacy Policy

State/local public health department assertion of existing authority, minimum data necessary, and cross-jurisdictional permissions

Covered entities such as health care providers (hospitals, most physician practices, and laboratories) and health plans are permitted to share identifiable health information (otherwise known as protected health information or PHI) with public health authorities under the HIPAA Privacy Rule (45 CFR 164.512(b)). However, contractors to covered entities (business associates) were only able to share PHI with public health authorities if their contracts with covered entities (business associate agreements) included language allowing them to do so. Health information exchange networks are business associates under HIPAA, and this provision has had the unfortunate and unintended effect of inhibiting the use of these networks by state and local public health agencies. On April 2, the Federal Department of Health and Human Services (HHS) Office of Civil Rights (OCR) announced in a [notice of enforcement discretion](#) that it “will not impose penalties for violations of certain provisions of the HIPAA Privacy Rule against health care providers or their business associates for the good faith uses and disclosures of protected health information (PHI) by business associates for public health and health oversight activities during the COVID-19 nationwide public health emergency.” This announcement enables health information exchange networks to be leveraged to share data with public health in a way that may not have been possible in the past.

However, hospitals and other covered entities responding to these queries may want assurances that their disclosures are authorized by state/local statute and meet the “minimum necessary” requirements under HIPAA. **Our recommendation is for state and local health officials to assert existing legal authority and minimum data necessary as a routine part of onboarding into the data exchanges.**

The [Network for Public Health Law](#) has agreed to draft a model template (“boilerplate”) that could be easily appended with the necessary reference to state/local laws granting public health authority, along with clarification that the standard clinical query payload (the “[Common Clinical Data Set](#)”³) constitutes the minimum data necessary for public health investigations ([see Appendix on page 13](#)). The city of Chicago provided [a model](#) for this assertion of authority and minimum data necessary in their April 6 order. In addition, to maximize utility in cross-border investigations, the template addresses public health authority queries to hospitals and health information networks outside of their jurisdictions for information on the authority’s residents and also addresses sharing of information among public health departments.

Recommendation #2 – Governance

The establishment of policies from trust framework governance entities ensuring universal response to authorized public health queries

The Trust Frameworks (CommonWell Health Alliance and Carequality) are currently assuring universal responses from each framework participant to “Treatment” queries. Each responding site has configured their local servers to automatically respond to queries with the Treatment

³ Defined in 45 CFR 170.102 and specified in ONC’s 2015 Edition certification requirements

indicator. However, queries for Operations or Research—or Public Health—have not been set to automatic response.

Our recommendation is for the trust framework governance entities to rapidly and transparently adopt policies that would ensure universal responses to authorized public health queries. These may be enabled in the short term through the authorized and audited “translation” of a Public Health query into a Treatment query during the current public health emergency. Such translations, whether through the centralized machinery of the exchange network or through an intermediary (see below), must be fully transparent to all participants, and fully auditable. These business associates must inform the participating provider organizations of the date on which these authorized disclosure to a public health jurisdiction commence, and must also be able to provide covered entities with a list of any applicable disclosures upon the event of an “accounting of disclosures” request.

Recommendation #3 – Technical

Access to portal-based connectors (“on-ramps”) that satisfy key functional and security criteria

There are several potential technical “on-ramps” for public health to access these clinical query networks. The querying entity can be an existing participant in the network (e.g., a public hospital that is also part of a health department); the querying entity can be a state or local health information exchange (HIE) that has already been onboarded to the networks, often via the eHealthExchange; or the querying entity can be an intermediary (“connector”) – a service provider that offers portal- or API-based access to one or both networks.

Since most health departments have strained or limited ability or resources to establish and ingest new API-based data feeds, our recommendation is for one or more portal-based connectors to be established for easy and rapid onboarding of state/local public health jurisdictions.

Where there are pre-existing relationships between public health and state/ local HIEs that have broad coverage, the public health agency may choose to use those entities either directly, or as “on-ramps” to other trusted exchanges. Where that option is not available, or coverage is inconsistent, and matching is inadequate, public health jurisdictions should consider portal-based connectors. After a review of current options, **our current recommendations are for state/local public health departments to consider and evaluate two intermediaries that offer the greatest chance of meeting public health utility based on our key selection criteria ([see Appendix on page 12](#)).**

1. [Health Gorilla](#), which is both a Member of CommonWell and an Implementer on Carequality, currently provides query access to all acute-care sites on both networks, and maintains its own set of services (MPI and RLS) and capabilities (event notifications) that could increase utility for public health.

2. The Patient Unified Lookup System for Emergencies, or [PULSE](#), is a project supported by the Sequoia Project and implemented by Audacious Inquiry. It has already established an onboarding process for public health first responders, and Audacious Inquiry is a trusted participant in multiple Federal and state health information exchange initiatives. PULSE is a member of the eHealthExchange and is currently able to access acute care hospitals through that network (often via state and local health information exchanges); they have connected to the Carequality exchange, and expect all Carequality endpoints to be active and accessible by the end of May; there are currently a subset of ~300 hospitals live on CommonWell that could be accessible to PULSE via the Carequality connection, but some technical onboarding and testing work remains. PULSE could also rapidly onboard to CommonWell to increase the potential for use of the RLS, and for greater coverage. These actions should be prioritized to be performed in a matter of days to weeks.

We recommend that rapid pilots be established with both options from several interested health departments, with information sharing and transparency on evaluation against the key selection criteria ([see Appendix on page 12](#)), convened by CSTE and ASTHO. Both connectors have agreed to support health departments with portal-based access to clinical query networks for the duration of the current pandemic at no cost.

Recommendation 2 Appendix 1 - Key selection criteria for a service provider

- **Network reach:** The service provider must be able to demonstrate reliable access to the largest possible number of acute-care endpoints. Over time, as the outbreak—and testing—shifts to ambulatory settings, network reach to ambulatory EHRs will become an emerging priority.
- **Use of Record Locators and Geolocated Queries:** Some networks are configured primarily to submit queries to a single known location. Because public health case investigations start with a positive test result, the ability to discover where the person’s records might be found is important. The ability to use Record Locator Services and “geolocated queries” (e.g., query every setting of care in an MSA) to direct queries to the most relevant institutions will be important.
- **Query completeness:** Many laboratory-confirmed cases reported to public health will have missing demographic information (especially zip codes) used in the patient query standard. Tools to supplement this data through Master-Patient Indices, especially using other data that might be available (e.g., Medical Record Numbers) would help increase the yield of successful queries.
- **Public Health Usability:** There will be features that would increase the utility of the infrastructure for public health workers. Connectors that have already designed front-end tools—or could rapidly develop them—to meet public health’s particular needs should be prioritized. These could include tools for managing and downloading batch data uploads and downloads, and event notifications (e.g., a known case seen in an emergency room, admitted, moved to ICU, discharged, died, etc.)
- **Trusted, secure:** The connector will be accessing and storing large amounts of personal health information on behalf of public health agencies. Prior experience serving as a HIPAA business associate to covered entities, with “clinical grade” security and privacy protections will be an important indicator of the organizational maturity of the connector to serve in this role. While the engagement with public health will be covered primarily by relevant public health law rather than HIPAA, there will need to be clear delineation of data use rights via contractual language. The Network for Public Health Law has volunteered to draft a model DUA/ boilerplate contract.

Recommendation 2 Appendix 2 – Memorandum /Letter/Communication Sample Text

[public health authority letterhead]

Date:

To: All licensed health care providers, clinical laboratories, acute and long-term hospitals and health care facilities or institutions, public health authorities, and health information networks or exchanges⁴ collecting or maintaining health information about persons living or seeking care in the City/County/State of [insert location].

Severe acute respiratory coronavirus 2 (commonly referred to as COVID-19) is a communicable disease that presents a severe and significant threat to persons living in the City/County/State of [insert location]. It is necessary and appropriate to collect health information relevant to COVID-19 in order to protect the health, safety, and welfare of such persons.

The [insert name of public health authority] is a public health authority authorized under [citation to relevant local and or state laws] to request, collect, receive, maintain, use, and disclose patient identifiable information, records, and data, including protected health information (PHI) as defined in the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) Privacy Rule ([45 Code of Federal Regulations \(CFR\) Subpart E](#)), for the purpose of preventing or controlling disease, including COVID-19. “Covered Entities,” as that term is defined in the HIPAA Privacy Rule, may disclose PHI to a public health authority that is authorized to receive such information for the purpose of preventing or controlling disease. ([45 CFR 164.512\(b\)\(1\)](#).) The Office for Civil Rights (OCR) of the Federal Department of Health and Human Services (HHS) recently announced [enforcement discretion](#) clarifying additional circumstances when “business associates,” such as health information networks and exchanges may disclose PHI to public health authorities. Further, data sharing with public health authorities beyond your jurisdiction is also important for disease surveillance and control; a resident of another jurisdiction may seek testing or care while traveling.

[Name of Public Health Authority] requests that, to the extent permitted by applicable state and Federal law, all health care providers, clinical laboratories, acute and long-term hospitals and health care facilities or institutions, public health authorities, and health information network or exchanges collecting or maintaining health information about individuals who reside or have received care in [insert City/County/State], provide [Name of Public Health authority] with access to health records and other data relevant to COVID-19. Such information should be provided securely and in such form and formats and pursuant to such schedules as we may reasonably specify, in order to enable us, either directly or through a contracted third party, to accurately monitor and interpret COVID-19-related medical information and efficiently and effectively

⁴ A “health information network or exchange” is an individual or entity that determines, controls, or has the discretion to administer any requirement, policy, or agreement that permits, enables, or requires the use of any technology or services for access, exchange, or use of electronic health information.” 45 CFR 171.102

direct the [City/County/State-wide] response. Such information should include demographic data as we may specify, including (but not limited to) name, address, gender, race, ethnicity, date of birth or other indicia of age. Data sharing with public health authorities beyond your jurisdiction is also important for disease surveillance and control; a resident of another jurisdiction may seek testing or care while traveling.

[Name of Public Health Authority] declares that Continuity of Care Documents, as regulated by the HHS Office of the National Coordinator for Health Information Technology (“[CCDS 2015 Edition](#)”) are the minimum data necessary for purposes of meeting the HIPAA Privacy Rule. [HIPAA](#) allows providers to rely upon public health authority’s determination of the minimum data necessary. See [45 CFR 164.514\(d\)\(3\)\(iii\)\(A\)](#).

PHI collected by [Name of Public Health Authority] pursuant to this request will be maintained securely and used or disclosed only for public health purposes [or other purposes expressly permitted by applicable law].

This request remains in effect until [Name of Public Health Authority or Official] determines that the threat to public health posed by COVID-19 is sufficiently diminished to the point that this data request is no longer necessary.

Sincerely,

[Public Health Official]

Name
Title

COVID-19 Interoperability & Data Exchange Recommendation 3: Enhance Use of the National Syndromic Surveillance Program (NSSP)

Rationale & Background

Syndromic surveillance refers to methods that support the detection of individual and population health indicators that are available before confirmed diagnoses are made.⁵ Syndromic surveillance of emergency department (ED) visits provides valuable insights to public health officials and policymakers in tracking the COVID-19 outbreak. In New York City, increases in ED visits for influenza-like illness and respiratory complaints [were apparent](#) in daily syndromic surveillance tracking as early as March 4, when there were only 2 laboratory-confirmed cases. The Federal [Guidelines for Opening Up America Again](#) call for “a downward trajectory of COVID-like syndromic cases” as one of the key regional gating criteria.

While several state and local health departments have published syndromic surveillance visualizations on their own websites, Federal health officials have not yet provided comprehensive visibility into the state of syndromic trends at the state or local level, in part due to challenges with data sharing agreements governing the flow of syndromic surveillance data between state/local and Federal health officials ([see Appendix on page 19](#)). In addition, there have [reportedly](#) been Federal efforts to establish parallel “national coronavirus surveillance systems” tracking the flow of patients into emergency departments from private-sector databases, which could create duplication of effort and data inconsistencies with state and local systems.

Furthermore, one of the challenges with using syndromic surveillance for monitoring the status of the COVID-19 outbreak is that emergency department visits may be impacted by changes in health-seeking behavior, as individuals with symptoms may avoid emergency department visits. The addition of information on emergency department visits for individuals who are ultimately admitted to the hospital (as [demonstrated in New York City](#)) would provide crucial additional information for gauging the course of the epidemic.

There is an opportunity to use existing data systems to improve the flow of critical information to public health. The [National Syndromic Surveillance Program](#) (NSSP) housed at the Centers for Disease Control and Prevention (CDC) is currently receiving data daily from over 4,000 healthcare facilities covering 47 states and the District of Columbia, encompassing roughly 71% of the nation’s emergency department visits, though [coverage](#) is sparse in some areas⁶. Reporting of

⁵ Mandl, K. D., Overhage, J. M., Wagner, M. M., Lober, W. B., Sebastiani, P., Mostashari, F., Pavlin, J. A., Gesteland, P. H., Treadwell, T., Koski, E., Hutwagner, L., Buckeridge, D. L., Aller, R. D., & Grannis, S. (2004). Implementing syndromic surveillance: a practical guide informed by the early experience. *Journal of the American Medical Informatics Association: JAMIA*, 11(2), 141–150. <https://doi.org/10.1197/jamia.M1356>

⁶ There are a [relatively small number of states](#) that are not contributing data to the NSSP (e.g., Iowa, Wyoming, Hawaii, South Dakota) for various reasons related to capacity and establishing connections with their existing data feeds to the syndromic surveillance program. There are an even smaller number of states that were participating but have not historically allowed that data to be further shared beyond the state’s uses. Additionally, a few states

syndromic surveillance visits was one of the Centers for Medicare & Medicaid Services' Health IT incentive program's Meaningful Use (now Promoting Interoperability) requirements, and many state and local health departments chose to direct hospital reporting to the CDC's NSSP platform. The NSSP established "lockers" where states and hospitals can share data that is then viewable by Federal officials.

In response to the COVID-19 outbreak, the CDC's NSSP staff worked with ASTHO on a national data-sharing effort led by state health officials (SHOs) whereby participating jurisdictions would share line-level ED visit data with the CDC to improve syndrome definitions that could be used to monitor emergency department (ED) visits that might be associated with COVID-19. The CDC has since informed jurisdictions the data are being integrated with laboratory testing, case reports, and other data to assess what is happening at the national, state, and county levels, and are being made available to the National Response Coordinating Center as well as the CDC. While there is broad support for the need for nationwide surveillance, it is not clear if this sharing and use is consistent with the NSSP data use agreement.

The widely deployed Syndromic Surveillance [Messaging Guide](#) (last updated in April 2015) provides an approach to capturing information about patients who have been admitted to the hospital using standardized admission, discharge, transfer (ADT) data, but, in reality, the data for the field are too inconsistently recorded in terms of frequency and data captured for the NSSP to be able to draw reliable nationwide inferences regarding hospital admissions from the ED.⁷

Our working group's investigation has identified two key areas of attention required to enhance use of the National Syndromic Surveillance Program: **Federal-State Collaboration, and Technical**. Our recommendations address each of these key areas.

Recommendation #1 – Federal-State Collaboration

Permitted uses of state syndromic data; Federal and state transparency on data used to inform decisions

Federal and state/local public health officials must rapidly align on a consensus set of protocols regarding what data from the NSSP state lockers can be used for Federal nationwide surveillance activities, and how that data may be used. Updated protocols and permitted use specifications can be articulated between public health officials, the CDC, and any Federal coordinating bodies as currently outlined in the NSSP data use agreement between the CDC and state/local jurisdictions, and should also adhere to states' policies that require consideration of their respective data use agreements. In the event that data sharing agreements do not align with

(e.g., Colorado, California) collect hospital data at the county level within NSSP "lockers" with no statewide data collection.

⁷ A newer version of the Syndromic Surveillance Messaging Guide was balloted through HL7 in 2019 and reflects a modest update to the 2015 version. It may not necessarily include or reflect in-the-field experiences as a result of the COVID-19 response. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=503

permitted use, Federal partners should engage state and local officials to address these concerns and barriers, which will inform how the data should be used for Federal surveillance activities. As syndromic surveillance data are used to inform decision-making around tightening or loosening physical distancing policies, there must be public transparency at the state and Federal level with respect to key syndromic surveillance indicators, alongside COVID-19 testing, cases, hospitalizations, and deaths, all reported daily.

To achieve near-universal reporting by states and hospitals within the NSSP, the Federal government should:

- **Engage with state and local authorities on an ongoing basis.**
- **Provide sufficient guarantees to states that data will be used according to revised and clearly-defined protocols building on the existing governance and trust framework established over the past decade for Federal-state partnership.**
- **Exclude personally identifiable information from Federal use**
- **Provide state and local officials with real-time access to the same data and visualizations available to Federal officials.**
- **Provide Federal support in the form of funding for data modernization initiatives and technical assistance so all states can create public-facing data visualizations of their aggregate syndromic surveillance data, as many health departments (e.g. [New York City](#), [Michigan](#), [Arizona](#), [Florida](#), and [Idaho](#)) are already doing.**

Furthermore, CSTE and the CDC should collaborate on greater engagement of state epidemiologists and health officials with the syndromic data, including optimal practices on how to interpret and use this information in outbreak-related decision-making.

Recommendation #2 – Technical

Updated data specification and rollout plan

The working group reviewed various options for expanding the utility of the NSSP by including reliable monitoring of trends in hospitalizations for various syndromes. Our priority was to select a solution that has broad applicability to all data sources and that does not require a software release timeframe nor extensive reworking to be done on behalf of every individual hospital.

While “patient class” values (PV1-2) and “discharge disposition” (PV1-36) as currently specified in the syndromic surveillance message guide could be used to infer hospitalizations⁸, these fields are not always accurate or reported consistently across sites.

⁸ The [current specification](#) suggests that we should be able to infer inpatient hospitalizations from the ED using the A03 segment. It reads “If the patient is admitted directly from the ED without a discharge transaction, the A03 Discharge message may be created by extrapolating from existing transactions such as the ADT^A06 Change from Outpatient to Inpatient or ADT^A02 Patient Transfer”

Our recommendations are therefore to expand the admission, discharge, and transfer (ADT) transactions and data used for syndromic surveillance by activating inpatient ADT feeds and adding the A06 (“change an outpatient to an inpatient”) message type to the existing syndromic data flows.

In order to implement these changes:

- **The CDC and the Council for State and Territorial Epidemiologists (CSTE) should issue coordinated guidance to hospitals that are contributing data to the NSSP.**
- **The Federal Department of Health and Human Services Office of the National Coordinator and the CDC should convene a joint working group, including state and territorial health officials, local county and city health officials, and syndromic surveillance managers, to review the Syndromic Surveillance Messaging Guide with the intent to produce an updated draft implementation guide.**

As discussed in the governance section, any enhanced use of NSSP syndromic surveillance data should maintain health agencies’ needs around data ownership, legal/privacy considerations, and data use and sharing, while working seamlessly with their existing syndromic surveillance workflow.

As part of alignment with a [companion report on payment reforms](#) to support health system participation in COVID-19 containment, we further recommend that the Centers for Medicare and Medicaid Services (CMS) provide financial incentives to encourage more timely (<24 hours) data submission from certain vendors, universal hospital participation in the NSSP, and accelerated availability of inpatient admission data. One avenue would be for CMS to provide extra bonus points for hospitals that use the updated messaging guide in the [Promoting Interoperability Program’s Public Health and Clinical Data Exchange Objective](#), beginning for the 2020 performance year, for hospitals that adopt the updated messaging guide and comply with timely reporting.

Recommendation 3 Appendix 1: Syndromic Surveillance Data Sharing Barriers Identified by Health Officials

The following table summarizes barriers, challenges, or concerns raised by health officials and their staff leadership. ASTHO organized these barriers into categories previously identified in a published systematic review of barriers to data sharing in public health (see below).

Category	Details
Technical B-7 Lack of metadata data standards	<ul style="list-style-type: none"> • Symptoms are both common and non-specific to COVID-19. Details need to be shared on how syndromic surveillance data will be used to refine syndrome definitions • Technical challenges. States/territories that don't participate in NSSP
Economic B-12 Possible economic damage B-13 Lack of resources	<ul style="list-style-type: none"> • Economic cost of sharing data (e.g., SARS outbreak which led to estimated economic loss of \$50 billion) • Consideration for how much involvement is required for health department staff
Political B-14 Lack of trust B-15 Restrictive policies B-16 Lack of guidelines	<ul style="list-style-type: none"> • Cultural and political regarding trust and control of data • Requirement of additional signed data sharing agreements for line-level data to adhere to states' laws and agency policies restricting the sharing of protecting health information • A need to check with staff on the legal and system considerations • No consistent POC with a state authority to efficiently consider and grant approval for sharing data
Legal B-17 Ownership and copyright B-18 Protection of privacy	<ul style="list-style-type: none"> • Concerns with CDC having access to line level data without any input or involvement from health agencies on how it gets used and managed • An endpoint is defined for when data sharing for this collaborative project will end • Details need to be provided for which Federal agency staff would be allowed access to the data • Concerns with CDC making choices on and accounting for small numbers or odd distributions • Concerns with CDC access to free text data, which can contain personal information (patient names, patient phone number, family attending at bedside)
Ethical B-20 Lack of reciprocity	<ul style="list-style-type: none"> • States do participate in NSSP and CDC already has access to some of the free-text data in a special dataset with no demographics that's used for query testing • Health agencies expect to be included as close collaborators on all planned uses and publications of the data

Adapted for COVID-19 data sharing: van Panhuis WG, Paul P, Emerson C, et al., A systematic review of barriers to data sharing in public health. BMC Public Health. 2014;14(1):1-9.

The information in this Appendix was sourced from ASTHO's COVID-19 Syndromic Surveillance Collaborative Project, which supports a state health official (SHO)-led national data sharing effort with CDC's National Syndromic Surveillance Program (NSSP).