

Future Preparedness: Data Collection & Monitoring Recommendations to Support Public Health and Health Care Response During Emergencies

Greater New York Hospital Association | May 2021

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GOAL

To establish a single, national data collection and monitoring framework for emergency events that supports operations and decision-making at all levels of government, meets the needs of both public health and health care entities, reduces reporting burden, and produces reliable data. This framework would align with the Executive Order signed by President Biden on his first day in office (January 20, 2021) titled: *Ensuring a Data-Driven Response to COVID-19 and Future High Consequence Public Health Threats*. It also responds to a gap first documented in 2001 in the aftermath of the 9/11 attacks and reiterated after every major public health emergency. Congress has directed the Department of Health and Human Services (HHS) to develop a national public health situational awareness capability since 2006 as part of the Pandemic All Hazards Preparedness Act and subsequent reauthorizations in 2013 and 2019 (i.e., Pandemic All Hazards Preparedness Reauthorization Act and Pandemic All-Hazards Preparedness and Advancing Innovation Act).

RATIONALE

The Greater New York Hospital Association (GNYHA)—which represents 160 hospitals and health systems across New York, New Jersey, Connecticut, and Rhode Island—has been deeply involved in the COVID-19 response. To meet the combined COVID-19 data collection requirements of local, State, and Federal agencies, hospitals within our membership have needed to dedicate significant staff resources to collecting, organizing, and submitting a constellation of data elements. At the height of the two patient surges (in spring 2020 and winter 2020-2021), our larger health systems estimate using over 500 staff hours per day to meet these combined demands. Frequent additions of new questions and lack of clarity regarding data definitions have resulted in confusion about and low confidence in the resulting data, compromising its usefulness and adding to the time required to identify and supply information. GNYHA and its members offer the principles and summary data collection topics and data points below to help develop an improved data collection framework.

DATA COLLECTION PRINCIPLES

1. There should be a single Federal data collection framework that is coordinated across agencies that interact with public health and health care entities. States and localities should have the operational latitude to collect data, but the systems and data elements used should be automated and interoperable with the Federal system. In this way, national data collection standards could be achieved, and local and state data can be sent to the Federal system, thereby reducing reporting burden and creating alignment. During the COVID-19 response, at least 10 states collected and sent data to HHS's TeleTracking system on behalf of their hospitals. Use of jurisdictional systems that automate data collection via mapping to electronic health records, bed management, or inventory systems should be encouraged as such systems reduce data collection burden and increase data quality.
2. Topics, content areas, data elements, definitions, intended uses of the data (including metrics and thresholds), reportable time intervals, and frequency of data collection should be established ahead of time, with minimal adjustments, to meet a particular event's specificity. Frontline users must be involved in developing the data collection elements and processes to ensure relevance and accuracy, with standardized definitions used across the country. Providers can also



GNYHA is a dynamic, constantly evolving center for health care advocacy and expertise, but our core mission—helping hospitals deliver the finest patient care in the most cost-effective way—never changes.

characterize what values are within a normal range, as many hospitals routinely manage a high census. Particular attention must go to collection of bed census and availability data. Successful regional examples can serve as models. Based on known hazards and predictable areas of concern, 90% of the needed content could likely be developed in advance and grouped into hazard-specific modules. While real-time adjustments to data collection should only be made if truly warranted, the framework and systems used should be able to accommodate such changes.

3. The burden of data collection on public health departments and health care organizations should be balanced with the need for data to establish disease prevalence and burden, characterize impacts, and inform operational actions. There should be a clear rationale for every element collected.
4. Additions of data elements, changes in frequency, or other alterations should be communicated as far in advance as possible and should involve frontline users in development and decision-making whenever possible. Additionally, the necessity/pertinence of each data element should be constantly evaluated, with the goal of removing elements whenever feasible to reduce data collection and reporting burden.
5. Data that is collected should be visible to stakeholders at multiple levels, including hospital and health system leaders, associations, and government agency staff, providing a common operating picture to inform current and future decision-making and actions. Where metrics are calculated or trends are shown, use of these data should be clear and transparent. Where possible, data collection systems should provide reports on data completeness, accuracy, and integrity to data users.
6. Data elements and formulas for resource allocation—including equipment, personal protective equipment (PPE), and medications—should be predetermined to the greatest extent possible and made transparent to impacted stakeholders. These data elements and formulas should guide Federal allocations, with states and localities strongly encouraged to use or minimally adapt these guidelines.
7. Thought should go to which data elements are required at the hospital level vs. the health system level. The involvement of frontline providers in determining this is critical, with flexibility built into the system to account for differing organizational structures.
8. Key agency points of contact at all levels of government for supporting data collection, validation, and addressing issues regarding use of the data should be clearly communicated and readily available.
9. The Federal data collection framework should fully leverage existing, broadly adopted technologies to reduce input burden. For example, a single product is already used in 23 states, and the product owner has facilitated automated reporting and maintained alignment with the various HHS data collection systems throughout the COVID-19 response.
10. Because many emergency events are localized, counties and states should maintain the ability to activate data collection systems in line with activations of emergency plans and/or emergency declarations. With interoperability, Federal agencies could access situational awareness of such localized events, increasing their ability to provide support as requested.

SUMMARY OF DATA COLLECTION TOPICS

Broad Topics	Content Areas	Involved Stakeholders
Public health detection and monitoring	<ul style="list-style-type: none"> • Syndromic surveillance of symptom clusters/disease • Case counts and rates • Demographic trends • New prescriptions issued/dispensed • Over-the-counter medication purchases • School absences 	<ul style="list-style-type: none"> • Centers for Disease Control and Prevention (CDC) • State and local public health departments • Public health laboratories and partnering academic labs • Assistant Secretary for Preparedness and Response (ASPR)
Disease burden/severity	<ul style="list-style-type: none"> • Health care seeking (including newly scheduled appointment requests, tele-visits, home care services, urgent care center visits, ED and outpatient visits, EMS call volume) • Hospitalizations (early reliance on trends, later on case counts) • Illness and infection rates in residential and congregate care settings (i.e., long term care, supportive housing settings, jails/prisons, detention centers, homeless shelters) • Fatalities (early reliance on trends, later on case counts) 	<ul style="list-style-type: none"> • CDC • Centers for Medicare & Medicaid Services (CMS) • Health Resources and Services Administration (HRSA) • Federal Bureau of Prisons • State and local public health departments • EMS agencies • Medical examiners and coroners • Hospitals, health systems, and hospital associations • Federally Qualified Health Centers and primary care and urgent care networks • Long term care providers and associations • Supportive housing providers • State and local corrections departments • ASPR
Hospital Capacity	<ul style="list-style-type: none"> • Current hospital census, available beds by standardized bed type (<i>HAvBED can serve as a foundation</i>) • Immediate and intermediate bed surge capacity at defined intervals • ED Volume and acuity (using standardized method) • ED bed holds 	<ul style="list-style-type: none"> • CDC • CMS • ASPR • State and local public health departments • EMS agencies • Hospitals, health systems, and hospital associations
Hospital Operations	<ul style="list-style-type: none"> • PPE supply (universal method for calculating burn rate needed) • Supply of specialty clinical equipment (e.g., ventilators, dialysis machines) • Availability of key clinical services, including dialysis, ECMO • Morgue capacity (fixed and surge) • Supply of medications and therapeutics • Supply of any other incident-specific pertinent medical countermeasures • Supply of blood products • Staffing levels 	<ul style="list-style-type: none"> • CDC • CMS • ASPR • Department of Homeland Security (DHS); Cybersecurity and Infrastructure Security Agency (CISA) and Federal Emergency Management Agency (FEMA) • State and local public health departments • EMS agencies • Hospitals, health systems, and hospital associations • Health care group purchasing organizations • Manufacturers and distributors
Broader Health Care System Capacity	<ul style="list-style-type: none"> • <i>Availability/status of primary care services</i> • <i>Blood supply (# of days)</i> • <i>Supply of any shortage items (# of days)</i> • <i>Availability/status of dialysis centers</i> • <i>Availability/status of pharmacies (i.e. Rx Open from Healthcare Ready)</i> 	<ul style="list-style-type: none"> • CDC • CMS • ASPR • DHS: CISA and FEMA • HRSA • IPRO • State and local public health departments • EMS agencies • Hospitals, health systems, and hospital associations • Federally Qualified Health Centers, primary care and urgent care networks • Pharmacy associations • Manufacturers and distributors

Broad Topics	Content Areas	Involved Stakeholders
Residential & Congregate Settings - Operations	<ul style="list-style-type: none"> • PPE supply (universal method for calculating burn rate needed) • Census, availability, and surge capacity • Staffing levels 	<ul style="list-style-type: none"> • Long-term care providers and associations • Supportive housing providers • State and Local Corrections Departments • ASPR

PATH FORWARD

Create a single, unified Federal data collection framework.

Several Federal systems—including the CDC’s National Healthcare Safety Network, HHS’s Protect System, and HHS’s Tele-Tracking—are currently used to collect public health and health care-related data. A single system could be selected as primary and adapted to meet the needs of other agencies. Another option would be to create a one-stop-shop overlay that simplifies data submission, and then pushes it to multiple places. The Federal strategy must facilitate interoperability with jurisdictional systems used at the state and local level.

Pre-build and validate data collection contents.

Based on known hazards and previous events, approximately 90% of the data collection content can be pre-built—including content areas, data elements, definitions, and frequency of data collection—and grouped into hazard-specific modules. To the extent possible, existing, well-established data elements should be used to create consistency in data collection, reduce confusion, increase confidence, and ensure data fidelity. We believe CDC and ASPR are best positioned to lead this effort because they can draw upon existing networks of public health departments and Hospital Preparedness Program (HPP) and Public Health Emergency Program (PHEP) recipients. An Advisory Group comprising current frontline providers and health IT standards experts should support and validate this work. Exercises currently required as part of ASPR HPP funding and other Federal grant programs can be used to continuously stress test the system.

Provide guidance to local and state agencies regarding reporting and additional data collection activity.

The Federal data collection strategy should be clearly communicated to state and local authorities, with the expectation that state and local reporting systems integrate with and complement the Federal framework. State and local authorities should be strongly encouraged to carefully consider the need for and purpose of additional data collection activities and how to integrate their data collection systems with the Federal structure.

Incentivize technical integrations to reduce data collection burden and increase data quality.

The stability created by the above actions will produce an environment where the marketplace can respond. Vendors and organizations that offer situational awareness and data aggregation solutions can adapt their products to integrate with the Federal system. To foster such activity, the primary Federal agency should produce and maintain updated technical information. Additionally, Federal grant programs should require that any monies spent on technical solutions adhere to the Federal framework and interoperability standards.