Background

HIA is a diverse coalition of patient advocates, healthcare providers, consumer organizations, employers, technology companies, and payers who support the adoption and use of data and technology to improve health outcomes and lower costs.

The tools used by our public health service are outdated and the methods for the reporting, collection, analysis, and use of public health data are inadequate, slow, and unreliable. Despite the potential for this data to help slow infection and better treat patients, it is not readily available electronically at the point of care, across electronic medical records, disparate hospital systems, or state databases. Additionally, there is no automated mechanism for sending case reports directly to public health authorities or providers on the front lines.

Congress and the Administration should:

1. **Standardize the Data.** We must expedite the recognition of standards necessary to standardize and enable the sharing of public health and clinical data to fight the COVID-19 pandemic and future potential pandemics by working with existing standards development organizations that have such standards in development/use, such as NCPDP. This should include case reports to local, state, and national authorities, electronic lab results, immunization status and electronic syndromic surveillance data.

2. **Reduce Burdens on Doctors, Nurses, Pharmacists.** Data should be automatically reported from EHRs and pharmacy practice systems to public health authorities, so doctors, nurses and pharmacists don't have to stop, fill out a form, scan and email or fax it in.

3. **Rely on the Private Sector.** Within three months, HHS should contract with a private sector entity with expertise in facilitating the sharing and use of information where it is needed to construct a federal data facilitator. This data hub would make information gleaned from public health reporting and pharmacy transactions available to clinicians at the point of care to help detect and treat COVID-19 and other public health threats.

4. **End Data Hoarding that Limits Emergency Response.** Actions taken to restrict access to information required to ensure the working of the facilitator for both public and clinical health must be considered information blocking and subject to penalties for data hoarding.

5. **Ensure Privacy and Security of Data.** HHS must take appropriate measures to safeguard the privacy and security of the data in the facilitator. Data should be encrypted and not accessible except for those with a legitimate right to know, such as a treating nurse, doctor or pharmacist. Inappropriate use or disclosure of protected health information should be a violation of HIPAA privacy law and subject to stiff penalties.

Additional Information

COVID-19-related health information is reliant on several surveillance systems to track the pandemic. Overall, CDC's COVID-19-related reporting works on a retrospective basis, and lags behind what the current reality is. Thus, due to lack of real-time reporting, the reported data within a certain period can be incomplete. Additionally, the CDC's website reporting of total cases of COVID-19 in the US is based on data confirmed the previous day by 4 PM ET.

- **Virologic Surveillance:** Public Health, Commercial and Clinical laboratories report, on a weekly basis, the number of specimens tested and the number of positives.

- **Outpatient and ED Illness Surveillance:** Data percentage are calculated weekly using health information reported to the following syndromic surveillance systems: U.S. Outpatient Influenza-like Illness Surveillance Network (ILINet) and National Syndromic Surveillance Program (NSSP).

- **Hospitalizations:** According to the CDC, "laboratory confirmed COVID-19-associated hospitalization rate are monitored through the COVID-19-Associated Hospitalization Surveillance Network (COVID-NET). Cases must be a resident of a designated catchment area and hospitalized within 14 days of a positive SARS-CoV-2 test. Testing is performed at the discretion of health care providers. Cases are identified through active review of notifiable disease and laboratory databases and hospital admission and infection control practitioner logs. Data gathered are used to estimate age-specific hospitalization rates on a weekly basis and describe characteristics of persons hospitalized with COVID-19 illness."

- **Death Surveillance:** COVID-19 death count is based on mortality data in the National Vital Statistics System. Actual death count reported by the CDC can lag by an average of 1-2 weeks, based on when a death certificate is submitted and coded by the National Center for Healthcare Statistics (NCHS). Challenges also include COVID-19 being misclassified as pneumonia or influenza.

As scrutiny around what data is reported, how and the ways in which it informs public health and clinical decision making, HIA scrutinized several states' ability to handle the reporting demands required by disease outbreaks. What we found was a disturbing reliance on antiquated approaches, including phone, paper-based reporting and, facsimile. These mechanisms can cause delay of usable information, loss of data, and inaccurate entries. Table 1 provides an overview of the reporting guidelines and surveillance systems in place within several states. It also analyzes the various mechanisms employed by states for the reporting of COVID-19 cases.

Methodology

HIA's *States' Surveillance Guidelines Chart* was designed and analyzed using publicly available sources. A thorough review of states' Department of Health websites was carried out to highlight disease reporting regulatory guidelines set in place by state's public health authorities. Additionally, a broad scope analysis of scientific studies was also conducted to obtain a general understanding of the time lapse between the submission and processing of disease cases by public health authorities.

In this analysis, only the exchange of information between providers/laboratories/hospitals and public health agencies were examined—although states should have a system in place that allows public health agencies to transmit data to the CDC's National Notifiable Diseases Surveillance System (NNDSS).

Conclusion

In light of the coronavirus (COVID-19) pandemic, states' surveillance systems and communicable disease reporting practices are being increasingly scrutinized. Public health authorities require access to quality information that is readily available to inform decision making and clinical response. Leveraging today's health information technologies will allow real-time, interoperable information on patient test results, symptoms, reporting and to support efficient public health responses.