State and Territorial Issue Brief:
COVID-19 Data Reporting and Technology

Background
The U.S. public health information technology infrastructure is a complex network of local, state, and national databases, data systems, and legal authorities used to support disease surveillance, case investigation, disease reporting and analysis, vaccination event tracking and reporting, and many other events. While this infrastructure is comprehensive, it is challenged by a lack of interconnectivity among programs, partners, and—most importantly—the healthcare sector. State and territorial health agency information systems are comprised of both outdated legacy systems and newer technologies, which are often deployed by available resources in a particular program area versus a comprehensive IT plan. For example, during the pandemic, we continue to see state and territorial health agencies receiving faxes from clinical partners and facilities because IT systems do not connect with these vital partners.

A series of “fixes” have been made to improve real-time data reporting of COVID-19 laboratory testing, but these are short-term solutions to long-standing problems. Individual state statutes and policies shape differences in how data are collected and what is reported federally. There is urgent need to improve the existing infrastructure and bring 21st century technology to the work of governmental public health at all levels during the COVID-19 response and beyond.

Issues and Considerations

- State immunization information systems (or immunization registries) routinely collect data on vaccine doses distributed and administered on child, adolescent, teen, and adult immunization schedules. While states routinely collect personally identifiable patient data for these vaccine events, aggregate data is only typically reported to CDC. For COVID-19 vaccine administration reporting and tracking, CDC and Operation Warp Speed have requested personally identifiable information for each American receiving the vaccine, including name, address, data of birth, and ethnicity, without clearly and adequately articulating the purpose of such data. Further, many states have laws prohibiting or limiting data sharing with other entities, including the federal government. At this time, many states are removing or heavily altering such requirements from the vaccine Data Use Agreement with CDC.
- The current COVID-19 data and technology strategy relies on several new, yet-to-be-tested or scaled systems to track vaccine distribution and administration, including CDC’s Vaccine Administration Management System (VAMS), the Immunization Gateway, Immunization Data Lake, Tiberius, and Privacy-Preserving Record Linkage (PPRL). Introducing new systems or methods without adequate testing for functionality, security, and privacy introduces significant risk, especially for a vaccine event of this magnitude.
- The unprecedented nature and scale of the COVID-19 pandemic has exposed strains and weaknesses in the country’s public health data infrastructure. For the last decade, the public health community has made a shift to modernize its systems to create a core enterprise-level infrastructure that breaks down silos, sets standards for interoperability, and cultivates an environment of innovation. While the CARES Act made a down payment towards public health
data modernization, this shift will require unprecedented investment over the next decade, as well as leadership at all levels of government.

Solutions and Ideas for Improvement

- Support the submission of either deduplicated and deidentified or aggregate COVID-19 vaccine administration data from state immunization information systems to CDC. If the collection of personally identifiable data is necessary, provide a clear purpose for such data and a comprehensive list of any federal agencies to receive it.
- Support immediate piloting and scalable testing of new, yet-to-be-tested or scaled systems or products to track vaccine distribution and administration, including VAMS, the Immunization Gateway, Immunization Data Lake, Tiberius, and PPRL.
- Support immediate, continued investment in public health data system modernization. This next-generation approach will include building a world-class data workforce and data systems that are ready for the next public health emergency. Significant investments must be made to build real-time, automated, electronic, enterprise public health data systems.

Further Resources

- Letter to CDC Director on Critical COVID-19 Vaccine Infrastructure and Rollout
- Public Health Organizations Request $450 Million for CDC's Data Modernization Initiative
- ASTHO Joins Data Elemental to Health Letter Thanking Congressional Leadership for the CARES Act and Requesting $450 Million for CDC's Data Modernization Initiative
- ASTHO Joins Data Elemental to Health Letter Requesting $100 Million in FY2021 Appropriations for Public Health Data/IT Systems Modernization Within CDC
- ASTHO Joins Letter Requesting Funding for Data Modernization to Grow CDC Data Infrastructure and Respond to COVID-19
- Driving Public Health in the Fast Lane: The Urgent Need for a 21st Century Data Superhighway Report by the Council for State and Territorial Epidemiologists

Contact

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