Public Health Data Strategy

Public Health Data Goals and 2-Year Milestones

April 2023
Executive summary

The Public Health Data Strategy (PHDS) outlines the data, technology, policy, and administrative actions essential to exchange critical core data efficiently and securely across healthcare and public health.

The strategy is designed to describe a path to address gaps in public health data, helping the nation become response-ready, promote health equity, and improve health outcomes for all.

To advance core public health missions (Detect and Monitor, Investigate and Respond, Inform and Disseminate, and Be Response-Ready), the PHDS addresses the CDC Moving Forward imperative to consistently deliver public health information and guidance to Americans in near real-time.

Through the PHDS, public health decision-makers (e.g., the public; labs; providers; other healthcare partners; state, tribal, local, and territorial health departments; CDC programs; federal agencies) will have a clear, streamlined vision of near-term priorities.

The Public Health Data Strategy outlines four Public Health Data Goals:
1. Strengthen the core of public health data
2. Accelerate access to analytic and automated solutions to support public health investigations and advance health equity
3. Visualize and share insights to inform public health action
4. Advance more open and interoperable public health data

Accomplishing 2-year milestones associated with these goals requires collaboration and partnership with state, tribal, local, and territorial health departments; healthcare partners; and other federal agencies.

CDC will create accountability for these Public Health Data Goals and 2-year milestones through the new Office of Public Health Data, Surveillance, and Technology (OPHDST), which will lead and strengthen engagement and collaboration with jurisdictions, CDC programs, and private partners, and focus the execution of data modernization activities.

1. Ensure Core Data Sources are more complete, timely, rapidly exchanged, and available to support the integrated ability to detect, monitor, investigate, and respond to public health threats
What the Public Health Data Strategy (PHDS) is and why it matters

Public Health Data Goals and 2-year milestones

How CDC will help achieve these goals and milestones
What the Public Health Data Strategy is

The Public Health Data Strategy (PHDS) outlines the **data, technology, policy, and administrative actions** essential to exchange critical core data efficiently and securely across healthcare and public health.

The strategy is designed to describe a path to address gaps in public health data, helping the nation become **response-ready, promote health equity, and improve health outcomes** for all.
Why the Public Health Data Strategy matters

To advance core missions of robust public health data aimed at improving health outcomes equitably…

…the Public Health Data Strategy …

- Addresses the imperative of the CDC Moving Forward effort to consistently deliver public health information and guidance to Americans in near real-time

- Builds on lessons learned from the COVID-19 pandemic and other recent public health threats to be more response-ready

- Aligns data modernization efforts at all levels of public health and across partners, focusing on near-term priorities

- Measures success with specific 2-year milestones

- Creates accountability for public health data with CDC’s newly established Office of Public Health Data, Surveillance, and Technology

Source: CDC Moving Forward website
The Public Health Data Strategy aims to address challenges currently experienced across healthcare and public health.

- **Illustrative:**
  - ~70% of healthcare organizations using fax to send or receive care records
  - Up to 80% of epidemiologists' time spent cleaning data because of non-interoperable systems
  - 30%+ of COVID-19 cases missing data on race and ethnicity early in the pandemic

- **Example challenge:**
  - High-level data flow

**Public Health Ecosystem:**

- **Healthcare (labs, providers):**
  - 6+ months often needed to develop and potentially rework Data Use Agreements

- **Public:**
  - 12+ months for data on some reportable conditions to become available in national datasets or be disseminated in accessible and interoperable formats

- **States, tribes, localities, and territories (STLTs):**
  - ~3 months between first reported domestic mpox case and CDC data access agreements with STLTs


Source: New York Times, NEJM Jan 2022, GAO, ONC, CDC + USDS Virginia prototype findings, CDC estimates
Successfully achieving the Public Health Data Goals and 2-year milestones addresses critical public health challenges by 2025

1. Data on demand enables health disparities analysis across geographies, conditions, and settings.
2. Time saved on data cleaning and analytics, through reusable technologies, enables epidemiologists to focus on core public health missions.
3. American public has near real-time awareness of the status of high-consequence diseases through a centralized data dissemination platform.
4. Faster sharing of data through language and terms for data protection and use.

The Interconnected Public Health Ecosystem

Increased ability for STLTs to automatically exchange data with CDC creates a reliable national common operating picture.
The Public Health Data Strategy supports partners across the public health ecosystem

The Public Health Data Strategy will help...

...To...

- **Have greater access** to critical information on public health emergencies, risks, trends, and resources

- **Identify and adopt ready-to-use tools** that enable easier and faster sharing of critical core public health data

- **Prioritize data and technology investments** to enable the most critical public health systems to be scalable, flexible, interoperable, sustainable, reusable, and intuitive

- **Streamline ongoing and planned efforts** to support measurable and concrete 2-year milestones

- Understand where and how to **access richer public health data on demand** to inform decision-making

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**Enabling greater response readiness and progress toward health equity**

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1. STLT: States, Tribes, Localities, and Territories
Public Health Data Strategy strengthens the core of public health data

Core Data Sources are essential to identify diseases and conditions, detect emerging public health threats, and understand disease burden and severity across different populations. The PHDS decreases the burden to securely report these critical data, and improves dissemination to ensure the right data are available at the right time.

Core Data Sources…

- **Case data** represent comprehensive disease and condition information used by public health to understand disease burden, know who is at risk, and identify outbreaks.

- **Laboratory data**, including test results and test type, enable public health agencies to track disease trends and identify outbreaks or exposures, and help frontline providers diagnose and treat health conditions.

- **Emergency department data**, including clinical diagnoses, signs, and symptoms, help identify near real-time trends for new, emerging, and developing public health threats to inform faster detection and response.

- **Vital statistics data** include birth and death data and are essential to understand disease severity, mortality, trauma, and toxicity that might signal a larger public health emergency.

- **Immunization data** capture vaccine doses administered (both routinely recommended and response-related) to support calculating vaccination coverage levels and trends.

- **Healthcare capacity and utilization data** assess availability of healthcare resources, including staff, beds, and equipment, aiding understanding of health system stresses and disease severity to inform resource allocation.

1. Core Data Sources as defined in CDC Advisory Committee to the Director (ACD) Data and Surveillance Workgroup (DSW) Report; non-exhaustive of all data sources critical to public health awareness and response (e.g., advanced molecular detection data).
What the Public Health Data Strategy (PHDS) is and why it matters

Public Health Data Goals and 2-year milestones

How CDC will help achieve these goals and milestones
Four major Public Health Data Goals enable the core public health missions

**Public Health Data Goals**

1. **Strengthen the core of public health data**
   - Ensure Core Data Sources\(^1\) are more complete, timely, rapidly exchanged, and available to support the integrated ability to detect, monitor, investigate, and respond to public health threats

2. **Accelerate access to analytic and automated solutions to support public health investigations and advance health equity**
   - Make tools available so STLTs and other public health decision-makers can better use public health data to address health disparities

3. **Visualize and share insights to inform public health action**
   - Serve as a trusted source for near real-time visualizations and offer situational awareness for the public and decision-makers to understand risks, make decisions, and direct resources

4. **Advance more open and interoperable public health data**
   - Enable exchange of interoperable data so that healthcare, STLTs, federal agency partners, and CDC programs can access and use data they need, when they need it

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\(^1\) Case (including electronic case reporting [eCR]), lab (including electronic lab reporting [ELR], Electronic Test Orders and Results [ETOR]), emergency department (including National Syndromic Surveillance Program [NSSP] emergency department data), vital statistics, immunization, healthcare capacity (including National Healthcare Safety Network [NHSN] data)
Public Health Data Goals drive key outcomes over the next 2 years

Goals

1 Strengthen the core of public health data

- States, tribes, localities, and territories (STLTs) have reduced reporting burden as case data are electronically reported in a consistent format, using a CDC Front Door concept
- Public health labs can forecast needs better with integrated, electronic ability to see test orders before samples arrive and ensure faster exchange of orders and test results with submitters
- STLTs can access lab reports more quickly and through multiple pathways, enabling faster public health action (e.g., case investigation, contact tracing)
- CDC can access lab, case, and mortality data faster, enabling robust situational awareness that informs decision-making across the nation
- STLTs and CDC programs have access to more early warning signals from emergency departments (EDs), with up to 80% participation by US non-federal EDs in the National Syndromic Surveillance Program (NSSP)

2 Accelerate access to analytic and automated solutions to support public health investigations and advance health equity

- STLTs and CDC can identify emerging threats in all parts of the nation in a timely way as more critical access hospitals in rural communities send case data electronically
- STLTs can address gaps in the public health workflow such as linking case, lab, and immunization records to enrich data and inform public health action through reusable technologies
- STLTs and communities can identify, prevent, and mitigate disproportionate impact on populations through use of automated reports provided by CDC, using CDC public health databases

3 Visualize and share insights to inform public health action

- STLTs and CDC programs receive quicker access to data and insights from Core Data Sources
- Americans can access near real-time data and visualizations made available via a centralized data dissemination platform (e.g., a Public Health Data Channel like the National Weather Service) to improve understanding and inform decisions about public health risks

4 Advance more open and interoperable public health data

- CDC establishes a strategic pathway of data exchange with providers’ electronic health records (EHRs) through at least 2 initial Trusted Exchange Framework and Common Agreement (TEFCA) for public health use case pilots
- CDC and STLTs increase data exchange back to healthcare providers, helping to inform clinical decision-making
- Data use and access are easier through established, standardized agreements (e.g., for sharing emergency department data with CDC programs, STLTs), enabling quicker access to minimal data necessary for response during a public health emergency
- CDC has measurably and securely increased the number of accessible open public health data sets for timely use and faster insights

By the end of 2024, 2-year milestones strive to ensure…

1. Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies

1. Case (including electronic case reporting [eCR]), lab (including electronic lab reporting [ELR]), Electronic Test Orders and Results [ETOR], emergency department (including National Syndromic Surveillance Program [NSSP] emergency department visit data), vital statistics, immunization, healthcare capacity (including National Healthcare Safety Network [NHSN] data)
## Success is measured by 2-year milestones (for Goal 1)

<table>
<thead>
<tr>
<th>Public Health Data Goal</th>
<th>Milestones within 2 years&lt;sup&gt;1&lt;/sup&gt;</th>
<th>End of 2023</th>
<th>End of 2024</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> Strengthen the core of public health data</td>
<td>STLTs enabled to submit a generic core case data feed that can be used for national disease notification</td>
<td></td>
<td>Core case data for select nationally notifiable conditions are reported using a common format, using a CDC Front Door concept, and shared back in near real-time for CDC programs and STLT partners to access</td>
</tr>
<tr>
<td>Ensure Core Data Sources&lt;sup&gt;2&lt;/sup&gt; are more complete, timely, rapidly exchanged, and available to support the integrated ability to detect, monitor, investigate, and respond to public health threats</td>
<td>32 jurisdictions&lt;sup&gt;3&lt;/sup&gt; are ingesting eCR data into disease surveillance systems</td>
<td></td>
<td>38 jurisdictions&lt;sup&gt;3&lt;/sup&gt; are ingesting eCR data into disease surveillance systems</td>
</tr>
<tr>
<td></td>
<td>90% of ELC recipients are connected to one or multiple intermediaries (e.g., AIMS, ReportStream, HIEs) for lab data</td>
<td>32 jurisdictions&lt;sup&gt;3&lt;/sup&gt; are ingesting eCR data into disease surveillance systems</td>
<td>38 jurisdictions&lt;sup&gt;3&lt;/sup&gt; are ingesting eCR data into disease surveillance systems</td>
</tr>
<tr>
<td></td>
<td>90% of State Public Health Labs have implemented ETOR (e.g., web portal, direct integration, or use of intermediary) with at least 1 healthcare partner for at least 1 lab program</td>
<td>90% of State Public Health Labs have implemented ETOR (e.g., web portal, direct integration, or use of intermediary) with at least 1 healthcare partner for at least 1 lab program</td>
<td>100% of State Public Health Labs have implemented ETOR (e.g., web portal, direct integration, or use of intermediary) with at least 1 healthcare partner for at least 1 lab program</td>
</tr>
<tr>
<td></td>
<td>75% of CDC infectious disease labs send lab test results to external partners electronically (e.g., using ELR, CSTOR, intermediary)</td>
<td>75% of CDC infectious disease labs send lab test results to external partners electronically (e.g., using ELR, CSTOR, intermediary)</td>
<td>50% of lab test order requests received electronically at CDC infectious disease labs (e.g., using ETOR, CSTOR, intermediary)</td>
</tr>
<tr>
<td></td>
<td>Reduced time to send mortality data to and receive coded cause of death data from CDC for 12–15 jurisdictions&lt;sup&gt;3&lt;/sup&gt; through use of FHIR messaging</td>
<td>Reduced time to send mortality data to and receive coded cause of death data from CDC for 12–15 jurisdictions&lt;sup&gt;3&lt;/sup&gt; through use of FHIR messaging</td>
<td>Reduced time to send mortality data to and receive coded cause of death data from CDC for 30 additional jurisdictions (42–45 total)&lt;sup&gt;3&lt;/sup&gt; through use of FHIR messaging</td>
</tr>
<tr>
<td></td>
<td>CDC receives and ensures access to commercial lab data from at least 2 major national commercial labs to enable situational awareness across multiple conditions</td>
<td>CDC receives and ensures access to commercial lab data from at least 2 major national commercial labs to enable situational awareness across multiple conditions</td>
<td>CDC receives and ensures access to commercial lab data from at least 3 major national and regional commercial labs to enable situational awareness across multiple conditions</td>
</tr>
<tr>
<td></td>
<td>Increased participation to 80% (from 73% today) of U.S. non-federal emergency departments to increase representativeness of NSSP data sources and users</td>
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</tr>
<tr>
<td>Potential impact: &lt;7 days needed to detect a suspected disease outbreak and begin nation-wide monitoring, through using faster case, lab, emergency department, mortality data</td>
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</tbody>
</table>

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<sup>1</sup> Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies.  
<sup>2</sup> Case (including electronic case reporting (eCR)), lab (including electronic lab reporting (ELR)), Electronic Test Orders and Results (ETOR), emergency department (including National Syndromic Surveillance Program [NSSP] emergency department data), vital statistics, immunization, healthcare capacity (including National Healthcare Safety Network [NHSN] data).  
<sup>3</sup> Out of the ~64 ELC- or PHI-funded jurisdictions.
### Success is measured by 2-year milestones (for Goal 2)

<table>
<thead>
<tr>
<th>Public Health Data Goal</th>
<th>Milestones within 2 years¹</th>
<th>End of 2023</th>
<th>End of 2024</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
<td>Critical access hospitals in production with eCR increased to <strong>25%</strong>, up from 20% in 2022</td>
<td>Critical access hospitals in production with eCR increased to <strong>35%</strong></td>
</tr>
<tr>
<td>Accelerate access to analytic and automated solutions to support public health investigations and advance health equity</td>
<td>Reusable technologies to link multiple data streams (e.g., case, lab) made available to all jurisdictions and deployed by at least <strong>1 STLT</strong> – saving time for epidemiologists who currently spend up to 80% of their time on data cleaning²</td>
<td>Reusable technologies to link multiple data streams (e.g., case, lab) adopted by <strong>multiple STLTs</strong></td>
<td></td>
</tr>
<tr>
<td>Make tools available so STLTs and other public health decision-makers can better use public health data to address health disparities</td>
<td>At least <strong>2 automated reports using CDC's healthcare databases</strong> available within CDC and across STLTs to identify and address health disparities</td>
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</tr>
</tbody>
</table>

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**Potential impact:** Improved data available to epidemiologists (e.g., 2x critical access hospitals sending case data electronically), enabling faster health equity analyses

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1. Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies.
2. ‘A Prototype of Modernized Public Health Infrastructure for all: Findings from a Virginia Pilot’ – CDC (2022)
### Success is measured by 2-year milestones (for Goal 3)

<table>
<thead>
<tr>
<th>Milestones within 2 years&lt;sup&gt;1&lt;/sup&gt;</th>
<th>End of 2023</th>
<th>End of 2024</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Health Data Goal</strong></td>
<td><strong>3</strong> Visualize and share insights to inform public health action</td>
<td><strong>Minimum viable product for centralized data dissemination platform</strong> developed in partnership with CDC’s Office of Readiness and Response to share timely and actionable data publicly</td>
</tr>
<tr>
<td></td>
<td><strong>Data and visualizations available within 2–3 days</strong> (from 5–90+ days) for CDC programs and STLTs since time of receiving case data at CDC for at least 1 nationally notifiable condition (i.e., viral hepatitis)</td>
<td><strong>Data and visualizations available within 2–3 days</strong> (from 5–90+ days) for CDC programs and STLTs since time of receiving case data at CDC for multiple nationally notifiable conditions</td>
</tr>
</tbody>
</table>

**Potential impact:** Faster, actionable insights available to the public in near real-time (2–3 days from 5–90+ days) through a centralized data dissemination platform.

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<sup>1</sup> Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies.
## Success is measured by 2-year milestones (for Goal 4)

<table>
<thead>
<tr>
<th>Public Health Data Goal</th>
<th>Milestones within 2 years&lt;sup&gt;1&lt;/sup&gt;</th>
<th>End of 2023</th>
<th>End of 2024</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advance more open and interoperable public health data</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enable exchange of interoperable data so that healthcare, STLTs, federal agency partners, and CDC programs can access and use data they need, when they need it</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Milestones within 2 years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>End of 2023</strong></td>
<td>CDC selects a QHIN and has identified at least 2 public health use cases for TEFCA, establishing a pathway for data exchange with healthcare systems and providers</td>
<td></td>
<td>CDC launches pilots for at least 2 public health use cases with TEFCA (e.g., query data from healthcare settings for urgent public health investigations)</td>
</tr>
<tr>
<td></td>
<td>Standard language and terms for data protection and use agreed upon with public health partners for Core Data Sources, consistent with ACD DSW recommendations</td>
<td></td>
<td>Data access and use under established language and terms across at least 15% of funded states and territories for Core Data Sources, including case data</td>
</tr>
<tr>
<td></td>
<td>New data access agreement established to enable easier sharing of emergency department data from NSSP across STLTs and CDC programs</td>
<td></td>
<td>At least 50% of existing NSSP jurisdictions adopt new data access agreement to enable easier sharing of emergency department data across STLTs and CDC programs</td>
</tr>
<tr>
<td></td>
<td>Minimal data elements necessary for public health response defined for at least case and lab data, in collaboration with STLT partners and CDC programs</td>
<td></td>
<td>Minimal data elements necessary for public health response defined for multiple data sources, in collaboration with STLT partners and CDC programs</td>
</tr>
<tr>
<td><strong>End of 2024</strong></td>
<td>Number of public health data sets published by CDC with metadata utilizing FAIR open data principles increased by 10%</td>
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</tr>
</tbody>
</table>

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**Potential impact:** Standardized language and terms for data use introduced across healthcare and public health, enabling greater data quality and easier data sharing

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<sup>1</sup> Accomplishing the Public Health Data Goals requires collaboration and partnership with STLTs, healthcare partners, and other federal agencies
What the Public Health Data Strategy (PHDS) is and why it matters

Public Health Data Goals and 2-year milestones

How CDC will help achieve these goals and milestones
How CDC will help achieve the Public Health Data Strategy goals and milestones

Increase engagement, collaboration, and continual feedback

Increase engagement and collaboration with:

- **STLTs**: Collaborate on and continually provide feedback on progress towards key 2-year milestones (e.g., DUAs, reusable technologies); engage directly with STLTs to understand priority needs
- **Providers and labs**: Gather feedback from the frontlines on how CDC can better support progress towards 2-year milestones
- **CDC**: Establish internal steering committee to provide guidance on longer term PHDS, monitor and provide input on progress; establish mechanisms to solicit programmatic input and identify priority needs
- **Private partners**: Organize Industry Days and promote data exchange pilots to work toward modernization together
- **Federal agency partners**: Collaborate with partners such as ONC and CMS to advance shared understanding of activities needed to support 2-year milestones, including TEFCA for public health

Establish accountable office within CDC

Ensure accountability for the Public Health Data Goals sits with CDC’s Office of Public Health Data, Surveillance, and Technology (OPHDST):

- Structure the organization to support **core public health missions**
- Identify owners within **OPHDST and across the agency to drive progress** for specific 2-year milestones
- **Update the agency regularly** on Public Health Data Strategy goals and milestones
The Public Health Data Strategy is an ambitious but necessary plan to improve the exchange of core data across healthcare and public health.

Successful implementation of the strategy—and achievement of the Public Health Data Goals over the next two years—will require collaboration with STLTs, healthcare partners, and other federal agencies, as well as sustained resources.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACD</td>
<td>Advisory Committee to the Director (ACD), Centers for Disease Control and Prevention</td>
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<tr>
<td>AIMS</td>
<td>Association of Public Health Laboratories (APHL) Informatics Messaging Services platform</td>
</tr>
<tr>
<td>CSTOR</td>
<td>CDC Specimen Test Order and Reporting</td>
</tr>
<tr>
<td>DMI</td>
<td>Data Modernization Initiative</td>
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<td>DSW</td>
<td>Data and Surveillance Workgroup (within the Advisory Committee to the Director)</td>
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<tr>
<td>DUA</td>
<td>Data Use Agreement</td>
</tr>
<tr>
<td>eCR</td>
<td>Electronic Case Reporting</td>
</tr>
<tr>
<td>EHR</td>
<td>Electronic Health Records</td>
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<td>ELC</td>
<td>Epidemiology and Lab Capacity Cooperative Agreement</td>
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<tr>
<td>ELR</td>
<td>Electronic Laboratory Reporting</td>
</tr>
<tr>
<td>ETOR</td>
<td>Electronic Test Orders and Results</td>
</tr>
<tr>
<td>FAIR</td>
<td>Findability, Accessibility, Interoperability, and Reuse (of digital assets)</td>
</tr>
<tr>
<td>FHIR</td>
<td>Fast Healthcare Interoperability Resources</td>
</tr>
<tr>
<td>HIE</td>
<td>Health Information Exchange</td>
</tr>
<tr>
<td>NBS</td>
<td>NEDSS Base System</td>
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<tr>
<td>NHSN</td>
<td>National Healthcare Safety Network</td>
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<tr>
<td>NSSP</td>
<td>National Syndromic Surveillance Program</td>
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<tr>
<td>OCIO</td>
<td>Office of the Chief Information Officer</td>
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<tr>
<td>OKR</td>
<td>Objectives and Key Results</td>
</tr>
<tr>
<td>PHDS</td>
<td>Public Health Data Strategy</td>
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<tr>
<td>QHIN</td>
<td>Qualified Health Information Network</td>
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<tr>
<td>SPHL</td>
<td>State Public Health Laboratory</td>
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<tr>
<td>STLT</td>
<td>States, Tribes, Localities, and Territories</td>
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<tr>
<td>TEFCA</td>
<td>Trusted Exchange Framework and Common Agreement</td>
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</table>