

The Nation's Public Health Laboratories (PHL) perform critically needed services to protect the public's health and support patient treatment. The ability for PHLs to maintain their current capacities is being challenged by the economic landscape locally and nationally. Information collected from PHLs are important to not only gain a thorough understanding of the PHL community from both a macro and micro point of view, but to also tell the story of the important role PHLs fulfill from a public health perspective. Currently, State and local PHL service data on test services and volumes are collected in a disparate fashion by APHL through its various surveys and by a number of separate CDC programs that support laboratory testing. Aggregate data on State and local test services is shared through APHL's annual report; however, a comprehensive annual report of State by State test service and volume has not been published since 2000.

Dr. Thomas Frieden, CDC Director, made the following observation regarding this situation, *"CDC is committed to working to help mitigate State, Federal, and local budget cuts and reduce the impact on testing services. Information on State and local testing services and associated test volume provide a baseline measure to address the current economic situation."*

Laboratory test service data is critical in order to give PHL Directors and political decision-makers a comprehensive view of test services. APHL and CDC convened key members of their constituencies for a two-day meeting to develop a framework for a jointly implemented data collection and reporting process. Participants included State and local PHL Directors, APHL senior and survey staff, and CDC program leadership. The participants were tasked with establishing guiding principles for the analysis and reporting of the data as well as transparency and access to the data collected.

The group developed principles and frameworks around three objectives through the following process:

1. Discuss specified questions related to each objective as a large group to gain a common understanding of the objective and address challenges related to the objective
2. Break into small groups to develop additional thoughts around each question and begin development of guiding principles and frameworks for each objective
3. Reconvene the large group to discuss the results from each small group to determine which principles and frameworks will be applied to the objective

The following objectives and related questions guided the two-day meeting. Each question contains key points generated by the group. The guiding principles and framework created by the group are highlighted after each objective question.

Objective 1: Develop Guiding Principles for the Analysis and Reporting of Data for the Joint Data Collection Process

Who are the key users of the data and what information would be most useful?

- The core users of the data will be public health officials at the local, State and Federal level. Other users include the Director of CDC, State Legislators, APHL (staff and members), Federal Officials, Congress, Office of Management and Budget (OMB), State budget office, other federal agencies (EPA, FDA, etc.), consumer groups, clinical labs, laboratory suppliers, general public, media, Academia, State regulators
- Useful information to collect include metric related to: Infrastructure, IT Capabilities, Performance Measures, Personnel, Test Volumes, State Mandates, and Sole Provider Information

What are the benefits and potential sensitivities of identifying testing services/capabilities by state or local laboratory?

- Benefits include increased communication between programs and States, identification of programmatic gaps or problems, and creation of a baseline for performance measures
- Sensitivities include a certain subset of data may have national security issues associated with sharing it, “low performing” laboratories could be subjected to lower funding instead of additional assistance, and laboratories may be considered a “black box” that could be outsourced instead of being viewed as a core function of State/local government

Should we adopt standard formats to display data and will this differ for the user?

- A standard format will create consistency for historical analysis and should include standard timeframes

What are key data points to include in a standard format?

- Workforce demographics, Public Health Functions, Test List and Methodologies, Instrument Lists, IT Capabilities, and Test Volumes

Draft Guiding Principles

- Coordinate data requests and responses
- Standardize terms, definitions, and data format
- Identify and address areas of sensitivity
- Articulate clear data collection purpose
- Investigate the use of Data Use/Sharing Agreements

Objective 2: Develop Guiding Principles for Access to and Transparency of the Data

What are the benefits and risks of consolidating data and increasing access: 1) between CDC programs, 2) between state and local laboratories, and 3) between APHL and CDC?

- Benefits include the reduction of isolated data in programs and agencies as well as better informed decision makers at the Federal, State, and local level
- Risks include the need to validate data before sharing and for standardized data definitions to assure high value data

What are the risks, benefits, and costs of public web-based data versus controlled access?

- Benefits include an increase in public knowledge and awareness of PHL functions, a minimization of data collection duplication, and the ability to identify programmatic gaps in State/local public health systems
- Risks include the publishing of cost per test data which does not calculate uniformly across jurisdictions

Will increased access and transparency impinge on the willingness to share data with CDC or APHL?

- Aside from cost per test data, PHLs are willing to share test service data and understand that sharing this information benefits themselves and the system as a whole

Draft Guiding Principles:

- Broad process allowing for the most technologically feasible transparency and access
- “If you contribute, you should have access”
- User-friendly

- Access and collaboration between CDC and APHL and among their programs; internally and externally

Objective 3: Develop a Framework for Improving the Data Collection Process

What are the benefits and barriers of unifying data collection across CDC programs?

- Benefits include better evaluations of data processes and capabilities, a decreased administrative burden on State and local PHLs, an increase in collaboration across various public health disciplines
- Barriers include the development of standard formats and vocabulary for data collection, the integration of various systems across CDC and APHL members, resistance to cultural change, and sufficient staff, funding, and access to reach the desired outcomes

How can APHL improve the data sharing process with state and local members and CDC?

- Identified improvement include a review of the APHL data sharing policy with CDC, archiving of previous surveys and responses, and improved coordination between all submitters of information to APHL

What processes are necessary to implement recommendations and establish coordination between CDC and APHL to reduce duplication, increase efficiency, and harmonize mechanisms?

- Analyze what data collection models may have already been developed to aggregate data in the private sector
- Form a joint committee consisting of members from APHL Knowledge Management Committee and CDC's Laboratory Program Forum to serve as the central governance body to drive this process forward

Draft Guiding Framework:

- Develop governance structure and charter for the group that will manage improving the data collection process
- Foster a culture of change at CDC, APHL, and amongst APHL's members; engaging stakeholders from all three groups
- Knowledge exchange; sharing data beyond the current audience in user friendly interfaces and making available inventories of past questions and responses
- Enterprise business plan of where public health laboratories should be focusing their efforts in the future and what efficiencies they can realize in the near term (continuous improvement)
- Sustained involvement from both CDC and APHL leadership as well as APHL's members to keep momentum and allocate appropriate resources

Next Steps:

- Identify data sharing "quick wins" that the joint CDC Laboratory Program Forum and the APHL Knowledge Management Committee can address in the near term such as developing standard formats for collection and display of data.
- Address and change as necessary the APHL data sharing agreement with CDC
- Utilize the APHL annual meeting in May to highlight the activities and progress of this joint committee towards a more unified and useful data collection and sharing process