



## Meeting Summary

### Consultation on Monitoring and Use of Laboratory Data Reported to HIV Surveillance

March 9-10, 2011

#### Background

The Division of HIV/AIDS Prevention (DHAP), National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), in collaboration with the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB), sponsored a *Consultation on Monitoring and Use of Laboratory Data Reported to HIV Surveillance*, March 9-10, 2011, in Atlanta, Georgia.

The purpose of the consultation was to explore science, program, and ethical considerations for collection and use of laboratory indicators in HIV surveillance for public health action and monitoring. Approximately 40 external consultants including state and local HIV surveillance staff, ethicists, HIV community advocates, care providers, and representatives from laboratories and relevant national organizations participated in the 2 day meeting with CDC and HRSA staff.

Initial presentations by CDC and HRSA provided an overview of laboratory data reported through HIV surveillance and uses of CD4+ T-lymphocyte (CD4) counts and percentage and viral load test results as clinical indicators of disease progression and proxy indicators of whether a person with HIV infection has received care related to HIV. Use of these indicators both at the individual and community levels (e.g. community viral load or percentage decrease in decrease viral suppression) have been proposed to ensure and monitor access to and quality of care and treatment. Aggregate surveillance data on community viral load and percentage decrease in viral suppression serve as key indicators in the National HIV/AIDS Strategy (available at <http://www.whitehouse.gov/administration/eop/onap/>).

Presentations from state and local areas highlighted a broad range of innovative examples of how state and local programs are using surveillance data at both the individual and aggregate levels. These included analyses demonstrating why surveillance is the primary data source for monitoring national strategy outcomes, including monitoring of viral load suppression in communities, monitoring the extent to which expanded HIV testing in test and treat initiatives increase new diagnoses of HIV, examining concurrent diagnosis as missed opportunities for earlier detection, using surveillance to distinguish between rapid progression and late diagnosis, and determining the proportion of newly diagnosed persons who initiate care within 3 months. Presenters also highlighted efficiencies gained by using HIV data at the individual level to initiate partner services, to help medical providers re-engage persons living with HIV who have dropped out of care, to establish linkages to enhance CD4 cell count and viral load information for clients receiving services from a Ryan White Part B programs, and the use of surveillance data in a health information exchange partnership to reach people needing important public health follow-up.

Participant presentations also identified key technical issues with regard to gathering and reporting necessary data elements and identifying mechanisms to improve quality and completeness of laboratory data obtained through HIV surveillance. After these presentations and discussion, small groups

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discussed key questions related to the ethical and logistical implications of collecting these laboratory data over time and obligations and cautions for using these data to follow-up with individuals and/or providers to ensure people receive care and treatment.

### Outcome

Presentations and discussion made clear how the National HIV/AIDS Strategy (NHAS) relies on HIV surveillance data for most of the measures and important outcomes which brings with it great responsibility to ensure high quality data are produced in a timely manner. Within the implementation plan for NHAS there is a call for Federal agencies to improve reporting of lab results. Experts emphasized the need to standardize reporting of data elements and address reporting completeness and timeliness. CDC will need to continue to work in collaboration with state partners, with HRSA, and other Federal agencies to address these issues.

Presentations highlighted innovative examples of how state and local programs are using surveillance data at both the individual and aggregate levels. While the aggregate level uses discussed were relatively uncontroversial, the individual level uses spurred the most dynamic discussion. Participants generally supported the uses of the data at the individual level; some cautioned that more work was needed with broader representation of affected communities regarding these approaches. Participants identified areas where continued work is needed to ensure data quality and appropriate use of data including assuring security and confidentiality.

Regarding reporting of lab measures and data quality, standardization and differences in required elements were mentioned as issues. Different reporting requirements and formats for each state/jurisdiction and each disease complicate laboratory compliance with reporting efforts. Furthermore, laboratories do not get reimbursed for the extensive staff time and effort required to respond to the varied reporting requirements.

Small group discussions emphasized that improving data quality was important and if data are not of sufficient quality they should not be used. Defining appropriate uses for data and activities that are consistent with a public health mission were discussed. There was some discussion about what the scope of the public health mission is. Although the proper uses of data at the individual level need further examination, discussions generally underscored the overarching responsibility to use the data once collected. Participants suggested some checks and balances need to be put in place regarding the data uses and public health must do a better job of specifying the purpose and uses of the data.

Small group discussions examined questions regarding how information could best be used to follow-up with physicians regarding their patients, and to trigger follow-up with individuals to ensure that they receive care. While some areas are piloting these activities, more deliberation will be needed as programs gain experience in this area and share what they have learned with others.

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Participants emphasized that this is not just about the laboratory data, such as CD4 and viral load, but all of our data should be used to guide prevention and evaluate public health efforts. Successful approaches to using data at the individual level involved thoughtful stepwise multidisciplinary consideration of ethical, legal, and privacy issues as well as state of the art information technologies for securing and sharing data. Participants identified areas where continued work is needed including additional guidance on successful methodologies and model approaches being used in areas that ensure appropriate use of data.

### Conclusion

Participants identified areas where continued work is needed, including additional guidance on successful methodologies, model approaches, and best practices that ensure appropriate use of data. There was strong interest in the health information exchange project in Louisiana and participants suggested additional demonstration projects should be considered. Some HIV surveillance workgroups (e.g., community viral load) are already considering implementation of measures and how to use the data. In addition, solutions are needed to enhance electronic reporting, use new and/or additional technologies for information exchange, and increase standardization of reporting requirements.

Continued engagement with laboratories and other partners to improve standardization of lab data will be critical to enhancing data quality and reporting from labs. Continued workgroup efforts to address issues of analytic methodology and reporting of CD4 and Viral load test results will assist areas in using their lab data. CDC will collaborate with HRSA on additional guidance on successful methodologies, model approaches, and best practices that ensure appropriate use of data for individual intervention. Finally, promoting best practices for securing data and maintaining confidentiality through support and implementation of the Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs will assist in programs using and sharing surveillance data.

### Follow Up

CDC will provide support for the collection of laboratory data, develop guidance and provide technical assistance on methods for data analyses, work with states and laboratories to improve standardized reporting and information exchange, and promote best practices for securing data and maintaining confidentiality. CDC is also collaborating with the Department of Veterans Affairs (VA) to improve reporting of laboratory results from VA medical facilities. Finally, CDC will provide assistance for data use and demonstration projects. CDC will collaborate with HRSA and surveillance programs to provide additional guidance on successful methodologies, model approaches, and best practices that ensure appropriate use of data for individual intervention.