

HEALTH INFORMATICS, DATA MANAGEMENT AND STATISTICS: INTEGRATING DATA IN SUPPORT OF HIV PROGRAMS

OVERVIEW

The U.S. Centers for Disease Control and Prevention (CDC) integrates information to achieve health impact in global HIV programs. CDC's data analysts, data visualization specialists, database designers and managers, software engineers and developers, strategic systems planners, evaluators, informatics trainers, data modelers, and statisticians work with multilateral organizations, partner-country governments, and civil society to understand and improve data and health systems in order to reach the goals of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR).

CDC'S ROLE

With increased focus on transparency and accountability, data is critical for both PEPFAR and its partners. Through technical assistance and capacity building, CDC helps country-led HIV programs improve data collection, management, and availability; integrate data from different sources; ensure consistent data quality; facilitate the use and statistical analysis of data for program planning; and measure progress towards national and global health goals.

- **Integrating data for impact** – CDC advances the management, integration, and use of routinely collected data, including data visualization, data modeling, and geographic information system use – serving the agency and PEPFAR's Interagency Collaborative for Program Improvement (ICPI) – experts from PEPFAR's six interagency partners, including the CDC, U.S. Agency for International Development (USAID), Department of Defense (DoD), Peace Corps, Health Resources and Services Administration (HRSA), and Substance and Mental Health Service Administration (SAMSHA) – in Washington, DC.
- **Facilitating data management best practices** – CDC develops and promotes data management methods, standards, and systems for the agency's headquarters, field offices, and partners to assure robust, cost-effective, and sustainable data management and information system infrastructure for PEPFAR activities and other global HIV projects.
- **Ensuring statistical integrity for scientific endeavors** – CDC promotes statistical integrity of divisional protocols and products through robust technical review, supportive technical response, and capacity building (via technical assistance and training) in study planning and analytic methods. CDC also promotes best practice statistical principles and methodologies in HIV-related activities across headquarters, field offices, and multilateral agencies by providing guidance, building capacity, advancing innovative methods, and applying new approaches to surveillance activities, evaluation studies, and the estimation and modeling of HIV epidemics and programs.
- **Growing and integrating local health information systems for present and future needs** – CDC assists PEPFAR-supported countries in the design, implementation, use, and evaluation of sustainable, locally-owned health information systems. This includes building workforce capacity, developing policies and guidance, and utilizing standards-based tools to support implementation of HIV services to monitor and evaluate program results, enable timely disease surveillance, and improve data sharing.

ACCOMPLISHMENTS / RESULTS

- **Supporting PEPFAR's ICPI at the Office of the U.S. Global AIDS Coordinator** – CDC leads ongoing interagency efforts to integrate and coordinate processes needed to deliver quantitative analyses, data modeling, and visualizations of HIV and TB program data.
- **Improving key data management systems** – CDC has implemented a new method for capturing data from site-level service provision assessments electronically, in real-time. CDC has streamlined the agency's process of reviewing and verifying program performance indicators by eliminating manual data exchange. CDC has also created a data warehouse at headquarters to consolidate, integrate, and analyze data from CDC-supported HIV drug-resistance surveys.
- **Improving sub-national estimation** – CDC leads ongoing efforts to estimate HIV indicators (e.g., people living with HIV, HIV incidence, etc.) in small geographic areas. This helps PEPFAR to prioritize those areas with highest HIV burden and to build in-country capacity for future estimates.
- **Automating PEPFAR and ministry of health (MOH) indicators** – CDC field-tested and published a new standard for automatically calculating PEPFAR and MOH indicators from electronic systems at clinical facilities, and electronically transmitting these to PEPFAR's Data

for Accountability Transparency Impact (a database used to analyze PEPFAR program effectiveness and efficiency) or MOH systems. This has improved both efficiency and accuracy of reporting.

- **Promoting standards-based approaches** – CDC is helping countries adopt and practice standards-based approaches to information system building, training, and governance/policy development.
- **Building informatics capacity** – CDC is helping to build informatics capacity in its partner countries through leadership training, such as Intergovernmental Learning Exchange to Advance Data-based Decision Making and Growing Expertise in E-health Knowledge and Skills – a front-line worker training program.
- **Improving the quality of HIV studies** – A CDC training module on ‘Protocol Development with a focus on Statistical Components’ was developed and rolled out in 2018.

FUTURE EFFORTS

In the future, CDC plans to:

- Support sub-national estimation of HIV viral load suppression and viremia (the presence of viruses in the blood), which involves developing and applying methods to quantify viral load suppression and viremia from survey and routine programmatic data.
- Extend and apply methods for indirect estimation of HIV incidence from trends in CD4 cell counts and HIV testing history data.
- Extend methods developed by PEPFAR’s ICPI to better support country-specific data management, data integration, and visualization needs.
- Increase technical assistance and training to PEPFAR-supported countries to build their capacity to design and implement information systems, to improve the efficiency of data flow and quality assurance, and to improve the analysis and interpretation of data.
- Increase efforts to automate PEPFAR and MOH reporting across PEPFAR-supported countries.
- Improve efforts to manage global HIV data for accountability, and extend CDC headquarters operations with greater use of business automation tools (e.g. SharePoint).
- Provide training on ‘Protocol Development with a Focus on Statistical Components’ to more CDC country offices and develop a web-based version as a refresher and for those unable to attend the training in person.
- Develop a training on how to prepare public release data sets and develop associated documentation.

BENEFITS OF OUR WORK

High quality, timely data is key to achieving PEPFAR accountability and transparency goals. CDC enhances PEPFAR productivity by improving access to and use of information to achieve health impact. CDC integrates multiple data sources, develops consolidated data structures to standardize and improve data quality and availability, and improves the efficiency of data collection and analysis. CDC also coordinates and integrates data analyses, assures methodologic soundness of data collection and analysis, builds local capacity to design and understand data and systems, and evaluates the effectiveness of solutions. Data management and statistical reviews provide mission-critical support to ensure that PEPFAR-supported study protocols and manuscripts and other documents are of the highest quality and integrity.

CDC has improved the estimation of key HIV indicators--such as the number of people living with HIV and HIV incidence – at granular, sub-national levels by age and sex. These estimates undergird PEPFAR’s Impact Action Agenda, as they are used to identify the geographic areas in greatest need for treatment and prevention, further enhancing PEPFAR’s ability to do the right things, in the right places.