

# Building Health IT Capacity to Improve HIV Infection Health Outcomes

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The ability to monitor the engagement of individuals living with HIV/AIDS in each stage of the HIV care continuum<sup>1</sup> is important to quality and responsiveness of services, as well as to identify potential opportunities for improving continuity of care. As of December 2015, there were over 19,071 individuals known to be living with HIV/AIDS in Massachusetts,<sup>2</sup> and 86% of those engaged in HIV medical care in Massachusetts achieved viral suppression. This achievement makes Massachusetts's long-term goal of eliminating new infections of HIV a real possibility, as a non-detectable viral load renders the infected individual virtually noninfectious. In order to achieve this goal, Massachusetts is working to engage all who are living with HIV/AIDS in HIV medical care, keep them retained in care, and render their viral load non-detectable.

The HIV care continuum is comprised of 5 main stages: HIV diagnosis, linkage to HIV medical care, retention in HIV medical care, receiving antiretroviral therapy, and achieving sustained viral suppression.<sup>1</sup> Currently, in Massachusetts, the data elements necessary to monitor the HIV care continuum are documented in siloed health information systems that do not communicate with each other (Table). Through Special Projects of National Significance<sup>3</sup> funding support provided by HHS, Health Resources and Services Administration (HRSA), and the HIV/AIDS Bureau, Massachusetts engaged in a pilot project to enhance their health information technology (IT) capacity to monitor the HIV care continuum and identify gaps in care.

## The HIV Continuum of Care as Currently Monitored

The Massachusetts Department of Public Health partners with community health centers to improve care for patients infected with HIV. The current system to identify individuals with HIV who are "out of care" at community health centers requires analyzing and reconciling Massachusetts surveillance data with patient records via time-intensive monthly telephone conference calls with health centers. A case is initially assumed as being out of care if laboratory data identifies an absence of a viral load or a cluster of differentiation

## ABSTRACT

Eighty-six percent of those engaged in HIV medical care in Massachusetts achieved viral suppression, making Massachusetts's long-term goal of eliminating new infections of HIV a real possibility. In order to achieve this goal, Massachusetts is working to engage all individuals living with HIV/AIDS in HIV medical care, keep them retained in care, and render their viral load non-detectable. Currently, in Massachusetts, the data elements necessary to monitor the HIV care continuum are documented in siloed health information systems that do not communicate with each other. Massachusetts has engaged in a pilot project to enhance their health information technology (IT) capacity to monitor the HIV care continuum and identify gaps in care. Massachusetts Virtual Epidemiologic Network (MAVEN) will be enhanced to perform as a consolidated electronic system to document and triage clinic-, laboratory-, and patient-level surveillance, field epidemiology and HIV care continuum data. The consolidation will enhance identification of patients infected with HIV and provide timely, actionable data for engagement and retention in HIV medical care.

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TAKE-AWAY POINTS

Massachusetts is integrating HIV surveillance and leveraging electronic health record (EHR) clinical data into their electronic disease case management system to enhance monitoring the HIV continuum of care. The information contained in this article can be used to inform:

- ▶ Methods for electronic HIV surveillance.
- ▶ Strategies for electronically monitoring the HIV continuum of care.
- ▶ Challenges surrounding standardization of EHR data capture.

4 (CD4) cell count result within a specified period of time. Cases are then reconciled against the clinic data, which may result in a finding that an individual has moved out of state, or is still in care and has an upcoming scheduled HIV care visit. Cases that remain on the out-of-care list will be followed up on by field staff to encourage and provide assistance for re-engagement in HIV medical care.

The siloed nature of health department and clinical care data (Table) presents a challenge for efficiently monitoring and responding to patients who have not yet linked to care, or who have fallen out of HIV care. The reason for this siloed approach lies in the historical segregation of reportable conditions by program or funding source in the health department and separation of relevant clinical data at the site of care. HIV surveillance data—including demographic, risk, clinical, and laboratory data known at the time of diagnosis—are currently managed and reported utilizing a CDC supported system: Enhanced HIV/AIDS Reporting System (eHARS); the CDC also directly supports the HIV/AIDS Surveillance Program. The Massachusetts Virtual Epidemiologic Network (MAVEN), an electronic disease surveillance and case management system,<sup>4</sup> collects electronic laboratory reports (ELR) of positive HIV tests, as well as CD4 counts and viral load results. These electronic lab

results in MAVEN are extracted into a separate database so that they may be appended to cases that already exist in eHARS. Patient interviews, partner services, and HIV care engagement assistance information, captured by field epidemiologists (staff of the Division of STD [sexually transmitted disease] Prevention), are documented separately in MAVEN.

MAVEN itself is supported by a variety of categorical funding streams from infectious disease surveillance programs. The HRSA project funding offered the opportunity to address the siloed HIV systems within the health department and integrate HIV data collection and triage into MAVEN.

Addressing Internal Silos: MAVEN

Massachusetts began integrating reportable infectious disease conditions into MAVEN in 2005. The funding for this project supports the full integration of HIV surveillance and field epidemiology information. MAVEN will be enhanced to perform as a consolidated electronic system to document and triage clinic-, laboratory-, and patient-level surveillance, field epidemiology, and capture HIV care continuum data. HIV infection is the last of infectious disease conditions under surveillance to be incorporated into the consolidated electronic disease surveillance and case management system. The consolidation will enhance identification of patients infected with HIV and provide timely, actionable data for engagement and retention in HIV medical care, including health department assistance through field epidemiologist outreach. MAVEN workflows and reports will be augmented to enable the identification and triage of patients who are not linked to care, who are not receiving treatment,

TABLE. HIV Continuum of Care-Related Measures

Data Collected and Used to Monitor HIV Care Continuum		Source		
HIV Care Continuum Measures	Data Elements	HIV/AIDS Surveillance	Field Investigation	Clinical Records
HIV infection	Number of unique patients screened and those with positive results by health center, date, race, sex, age, housing status and insurance type	X		X
HIV assessment	Date of HIV supplementary test, type of HIV supplementary test, physician reported diagnosis	X		X
Linkage to care	Date of diagnosis, date of CD4 and viral load tests, date of HIV medical care visits, date of field epidemiologist engagement, time lapse between diagnosis and linkage to care	X	X	X
Engaged or retained in care	Date of diagnosis, date of CD4 and viral load tests, date of HIV medical care visits, date and outcome of field epidemiologist engagement, methods of retention in care, time lapse between diagnosis and care engagement	X	X	X
Prescribed antiretroviral therapy	Antiretroviral therapy prescriptions and date of prescription	X		X
Virally suppressed	Quantitative viral load laboratory results	X		X

CD4 indicates cluster of differentiation 4.

who appear to be out of care, or who appear to be receiving suboptimal treatment. The health department can then conduct follow-up and provide feedback to health centers to inform clinical quality improvement efforts. The capacity to electronically receive timely data to characterize individuals infected with HIV within 1 consolidated system will enhance Massachusetts's ability to allow stratification by subpopulation at risk both for HIV infection and falling out of care.

### Addressing Communication and Clinical Data Collection: ESPnet

HIV clinical data captured by the primary care providers at community health centers are documented in electronic health records (EHR). These EHRs can directly provide information about HIV medical care visits, laboratory test results, clinical status, and more. In order to open an electronic pathway between the clinic EHRs and the health department system (MAVEN), Massachusetts has enhanced the capacity of ESPnet (Electronic medical record Support for Public health), an open-source software application that uses EHR data to automatically identify and report cases of notifiable diseases to health departments.<sup>5</sup> ESPnet has been augmented to utilize a case detection algorithm developed to detect HIV infection using EHR data, and it follows this reporting specification for electronic case reports to MAVEN for surveillance purposes. This algorithm scans the EHRs for a combination of laboratory test results, prescriptions for HIV or opportunistic infection medications, and diagnostic codes (specifically *International Classification of Diseases, Tenth Revision, Clinical Modification [ICD-10-CM]*) to identify and report a case of HIV infection. This algorithm was developed in collaboration with clinical HIV care partners and has undergone extensive validation processes in order to improve accuracy. This electronic access to the HIV clinic data housed in EHRs allows for more timely and efficient identification of cases that appear to be out of HIV care.

ESPnet also enables aggregate queries of EHR data, such as HIV screening rates. These aggregate-level queries report rates of HIV screening and positivity, and are stratified by clinical site, as well as by sex, race/ethnicity, and age group. These aggregate queries are expected to lead to improved monitoring of the implementation of national HIV testing guidelines.<sup>6</sup> Reporting functionality for HIV screening and positivity rates also supports continuous quality improvement at the health center level. By stratifying these data by location, the Massachusetts Department of Public Health will have the ability to monitor program performance and identify opportunities for quality improvement.

The data and communication capacity provided by ESPnet will help both the public health department and health centers to identify high-priority areas for targeted interventions to improve care and outcomes for individuals at risk for, and living with, HIV/AIDS. Leveraging automated clinical care data collection will give Massachusetts the opportunity of a richer, timelier, and more

complete picture of HIV testing, care, and clinical events within the populations served by community health centers.

### Lessons Learned

The goal of the pilot project was to create the integrated system illustrated in the **Figure**. Throughout the first 2 years of the pilot project, there were challenges related to the EHRs themselves and in the collection and integration of EHR data (through ESPnet) into the public health surveillance and disease case management system (MAVEN). The following are some key lessons that may be used to assist other health departments or jurisdictions interested in adopting a similar model.

**High variability in data structure within and across EHRs.** Community health centers in Massachusetts use a number of different EHR products, including GE Centricity, Epic, NextGen, and others. Through surveys and in-depth review of a sample of 6 community health centers, it became clear that there was high variability in data collected, the format of data, and where data are located within the EHRs. Not all EHRs documented the data elements for monitoring the HIV care continuum; or if the variables did exist, they did so without a consistent convention or format.

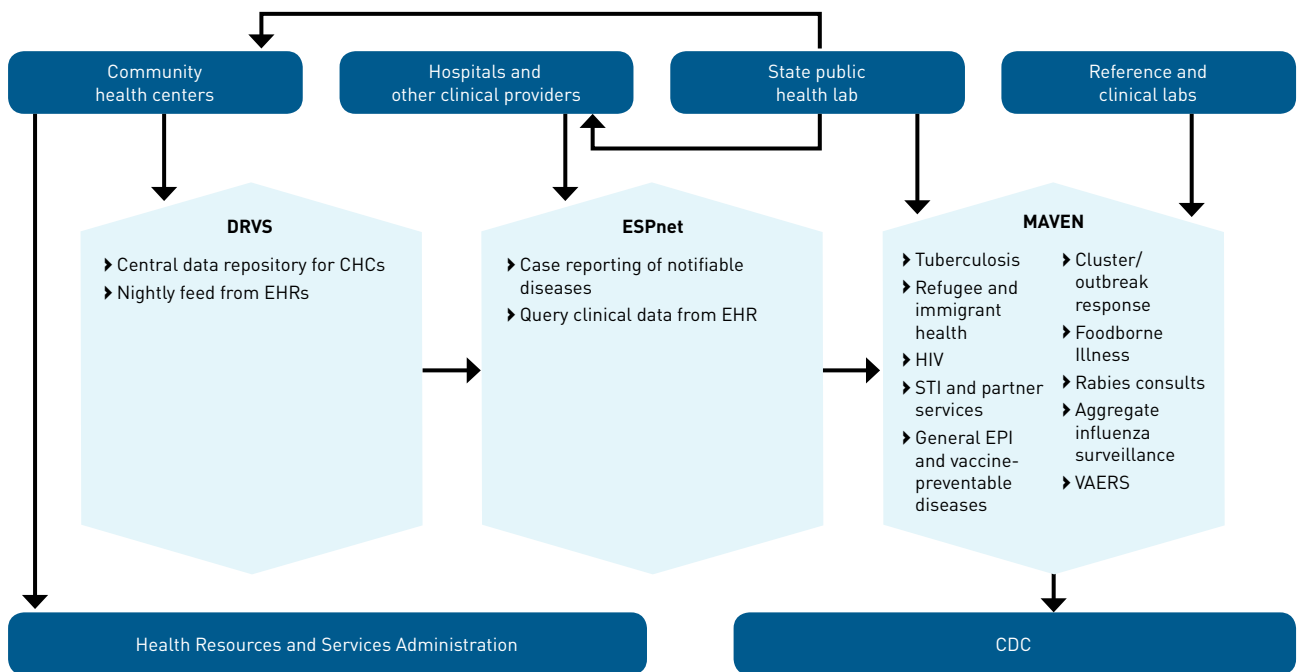
Many of the HIV data elements of interest that identify potential correlates of care disparities (eg, gender, HIV risk classification, housing status, income, country of birth, health insurance) are difficult to obtain from EHRs. When available, these data elements are often not in structured fields (eg, HIV risk exposure, income), or vary significantly in terms of variable definition (eg, local definitions of clinical encounters), consistency of collection, or location within EHRs (eg, within the HIV patient panel only, as in the case of HIV risk exposure). Provider practice, with regard to where recorded in the EHR data and the consistency of collection, presents a particular challenge. Specifically, some clinical providers have recorded key data elements (eg, HIV risk) in notes, rather than in structured fields, making these data unavailable to extract. Significant mapping efforts, coupled with provider education and workflow changes, will be required to collect these data in a clean, complete, and analyzable way.

**Utilizing clinical visit data to identify an HIV-related medical visit.** HIV medical care visits are an HIV/AIDS Bureau performance measure used to assess the quality of HIV medical care in the context of national treatment guidelines.<sup>7</sup> An HIV medical care visit is defined by HRSA as a medical visit with a provider who has antiretroviral (ARV) prescribing privileges.<sup>7</sup> HIV medical care visit data from EHRs are a measure of retention in care for individuals living with HIV/AIDS; primary care visit data provide parameters for evaluating the screening of those not known to be living with HIV/AIDS. Utilizing EHR data to identify the nature of clinical encounters has proven to be difficult; in addition to identifying the primary reason for a clinical encounter in a primary care setting.

In community health centers in which HIV medical care is integrated fully into primary medical care, it is difficult to assess

## TRENDS FROM THE FIELD

**FIGURE.** Proposed Flow of Health Information to Public Health



CHC indicates community health center; DRVS, Data Reporting and Visualization System; EHR, electronic health record; EPI, Expanded Program on Immunization; ESPnet, Electronic medical record Support for Public health; MAVEN, Massachusetts Virtual Epidemiologic Network; STI, sexually transmitted infection; VAERS, Vaccine Adverse Event Reporting System.

whether HIV medical management (eg, medication adherence) was addressed based on EHR data (*ICD-9* and *ICD-10-CM* codes on problem lists; *ICD-9* and *ICD-10-CM* codes and or procedure codes used in conjunction with clinic visits). Unless a viral load was ordered or an antiretroviral prescription was generated, it is difficult to define the primary reason for the clinical encounter. HIV medical care is changing rapidly, and for stable patients, guidelines have changed<sup>8</sup> and many clinicians are choosing to order viral loads annually or even less frequently, and may be renewing antiretroviral prescriptions without viral load testing. This change in practice results in clinical visits that do not involve viral load orders or ARV prescriptions less valuable in predicting medication adherence or ongoing viral suppression.

A related challenge to identifying a clinic visit relevant for HIV medical care is the “missed visit” issue, which is the indicator that clinics are using to generate out-of-care line lists. Missed visits are another indicator of care retention; a missed visit is not always captured in the EHR, but rather in a separate practice management or appointment system that is not interoperable with the EHR. Additionally, even when identifying a missed visit is possible, it has been difficult to define whether that missed visit was HIV-related.

**Unforeseen transition to a new EHR vendor.** Several community health centers were transitioning to a different EHR during the

project. Prior to the transition, the mapping of local codes had been completed between their original EHR reporting portal and its gateway to MAVEN. With the transition to their new EHR systems, the time- and resource-intensive process of building a map between the EHR and MAVEN needs to be repeated. This mapping challenge will almost certainly arise again in the case of an upgrade or update to an existing EHR system that may affect the way certain data are documented, as well as for additional EHR transitions in the future.

**HIV screening to identify undiagnosed infection.** In the context of a primary care setting, and particularly in a multidisciplinary community health center (eg, dental, optical, medical, social services), there are only certain types of encounters appropriate for HIV infection screening. Clinics develop their own local coding for various encounter types, related to organizational factors, grant-funded programs, agency-specific quality improvement initiatives, reporting needs, and other factors. Relative to identifying clinical encounters where HIV screening might be reasonably assumed to be feasible and/or desirable to perform, Massachusetts observed that all local codes must be mapped to characterize the “clinical encounter.” Some health centers identified “HIV testing” as an encounter type because they have a dedicated HIV testing program, while others implemented certain HIV screening in the context of their dental services provided in an “oral health” encounter. Each community health center had to have their

unique codes for various encounter types in which screening might take place mapped into 1 “medical visit” category.

**Other challenges in identifying HIV-related care.** Additional information that may flag a visit as HIV-related is often found in the clinician notes or other free-text entries. At present, text notes cannot easily be extracted to populate a structured field in MAVEN, and data structure changes may not always be the best or most feasible answer to these problems. Direction, consensus, and standardized practice in data entry, as well as use and encoding of information, must be supported at the clinical level.

## Recommendations

Based on our experience with the pilot project, we offer 3 recommendations for health departments interested in a similar approach to enhancing their health IT for HIV surveillance, case management and quality assurance:

- 1. Communication.** Early identification of what is, and is not, available in the EHR system(s)—particularly where multiple systems and clinics are involved—is highly recommended. All project partners should agree on the goals of data capture and flow to establish feasibility and an appropriate timeline for implementation. Explicit communication about standardized data definitions and entry expectations at the clinic level is imperative to capturing robust and useful data.
- 2. Site selection.** Start with only a few sites that use the same EHR vendor and version to become familiar with the system structure and data capture.
- 3. Acknowledge and address the current lack of standardization.** Uniform standards for electronic case reporting that can be the basis for industry standards for EHRs is highly desirable. Similar to Meaningful Use requirements, EHR vendors should be able to incorporate state and local reporting requirements in the design, structure, and functionality of their EHRs.

## Conclusions and Next Steps

The ability to electronically extract key variables from clinical records and integrate the data with public health surveillance and case management systems has implications for many other infectious diseases, and potentially for chronic diseases, as well. A successful electronic system built to extract care information would facilitate public health monitoring and action related to a care continuum for other infections, such as hepatitis C.<sup>9</sup>

Our next steps will include the full implementation of this pilot project and expansion of ESPnet to other facilities offering HIV care. We will further explore HIV reporting requirements and collaborate

with other public health jurisdictions toward the development of a standard for EHR vendors and compliance agencies, such as the Office of the National Coordinator for Health IT. We will continue to work with clinical partners in refining the system and utilization of data collected.

Consolidation of the data elements necessary to monitor the HIV care continuum will provide opportunities for enhancement of public health services and response. EHR data will augment efficient oversight of the HIV care continuum. With enhanced health IT infrastructure, we hope to facilitate engagement and retention in HIV care to maximize the benefits and contribute to prevention. ■

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