ABSTRACT

INTRODUCTION

Recent editorials call for broad dissemination of HIV surveillance data from public health registries. Such data are increasingly used to measure progress toward improved quality of HIV care in the United States. Theoretical frameworks posit that interaction with the end user supports better understanding and use of data. However, dissemination of state and national HIV data products rarely includes input from these stakeholders.

Objective: Package HIV data to meet the needs of HIV-related services organizations in New York State (NYS) using a participatory process.

METHODS/ACTIVITIES

NYS received HRSA Special Projects of National Significance, funding and created the New York Links (NYLinks) initiative, a systems linkages and access to care project. One goal was to increase use of existing data among HIV-related service providers. HIV Surveillance (n=14) and facility-based (n=5) quality of HIV care measures were calculated from: NYS HIV Surveillance Registry (2009-2014) and NYLinks participating providers (2012-2015).

Outcomes for NYLinks regions (Fig. 1) were compiled and presented using PowerPoint. The process to create data packages is summarized in Table 1.

RESULTS

The end-user participatory process: Required participants to evaluate practical uses of the data. Increased ownership and level of engagement (Figure 1.) Led to the development of longitudinal data monitoring systems and locally developed data-driven quality improvement programs and goals (Table 2.) End-user feedback incorporated; data packages included multiple data display formats.

RESULTS CONTINUED

End-user participatory process: Strengthened relations between agencies and between agencies and state-level partners

Varied across regions; highly dependent on regional and organizational structure which influenced approach, level of engagement and final data package content and design

Required timely data dissemination and structured review to sustain momentum and collaboration

Increased usage and comprehension of the data as well as consumer advocacy; motivated data-driven goals to address regional gaps in HIV care

LESSONS LEARNED

Table 1. Creating the Data Packages

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
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</thead>
<tbody>
<tr>
<td>End-User Engagement</td>
<td>Internal review and initial packaging of data by NYLinks staff</td>
<td>Technical assistance to develop and consumer capacity to interpret data</td>
<td>Internal review by NYLinks member organizations; external review with area agencies</td>
<td>Comment period for consumer, state staff and NYLinks member organizations</td>
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<tr>
<td>Feedback Mechanism and Data Compilation</td>
<td>Conduct in-person meetings and webinar series</td>
<td>Determine intended use of the data product</td>
<td>Identify elements to include in or modify in data display</td>
<td>Compile regional data packages available at: <a href="http://www.nylinks.org/measurements-end/data/">http://www.nylinks.org/measurements-end/data/</a></td>
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</tbody>
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Table 2. Example of Local Action Plan*

<table>
<thead>
<tr>
<th>Clinical and non-clinical stakeholders</th>
<th>County Department of Health</th>
<th>State Department of Health</th>
<th>Community-based organizations</th>
<th>Consumers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals</td>
<td>Decrease number of undiagnosed HIV individuals</td>
<td>Link newly diagnosed individuals to care within 3 business days of diagnosis</td>
<td>Increase patient retention in HIV care</td>
<td>Re-engage out-of-care patients</td>
</tr>
</tbody>
</table>

*Monroe County Partnering to End the Epidemic

REFERENCES


Carol-Ann Swain, Steven Sawicki, Diane Addison, Ben Katz, Kelly Piersanti, Denis Nash, Clemens Steinbock, Bruce Agins, New York State Department of Health, Albany, NY; City University of New York, New York, NY.