

Data Packages Created Collaboratively with Consumers and Providers

Improve Local HIV Decision Making

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NYLinks

ABSTRACT

Introduction

Broad involvement of stakeholders strengthens data-related processes.

Methods/Activities

Data (2009-2014) from the New York State HIV Surveillance Registry and HIV care facilities participating in a HRSA SPNS, systems linkages and access to care initiative were used to calculate surveillance and facility-based HIV care measures. Ryan White region-specific data packages (n=7), updated bi-annually, were created in consultation with HIV providers, consumers, and AIDS Institute staff for use in local HIV care decision-making.

Results

Each data package promoted visualization of linkage to care, retention in care, and HIV viral suppression among HIV-infected persons. Participants reported that the overall process improved their ability to interpret and understand data.

Lessons Learned

Involvement of consumers and providers in creating HIV data presentations increased comprehension and utility of the data and identified gaps along the care continuum.

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INTRODUCTION

Recent editorials call for broad dissemination of HIV surveillance data from public health registries¹

Such data are increasingly used to measure progress toward improved quality of HIV care in the United States²

Theoretical frameworks posit that interaction with the end user supports better understanding and use of data³. 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 with data from:

- NYS HIV Surveillance Registry (2009-2014)
- 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.

Objectives	Step 1	Step 2	Step 3	Step 4
End-User Engagement	Internal review and initial packaging of data by NYLinks staff	Technical assistance to develop agency and consumer capacity to interpret epi. data	Internal review by NYLinks member organizations; external review with area agencies	Comment period for consumer, state staff and NYLinks member organizations
Feedback Mechanism and Data Compilation	Conduct in-person meetings and webinar series	Determine intended use of the data product	Identify elements to include or modify in data displays	Compile regional data packages available at: http://www.newyorklinks.org/measures-and-data/

RESULTS

The end-user participatory process:

Required participants to evaluate practical uses of the data

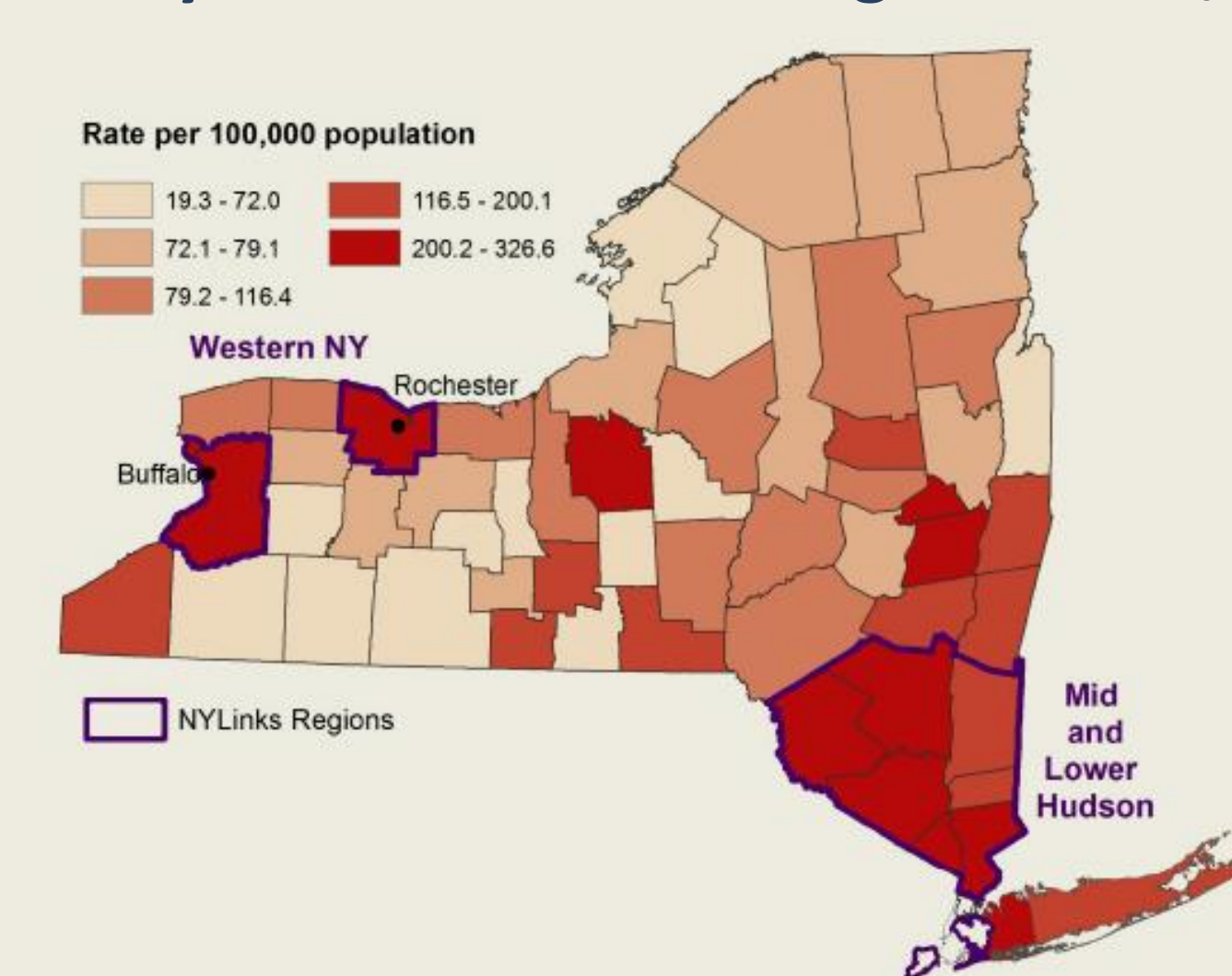
Increased ownership and level of engagement (Figure 1.)

Led to the development of longitudinal data monitoring systems and locally developed data-driven quality improvement programs and goals (Table 2.)

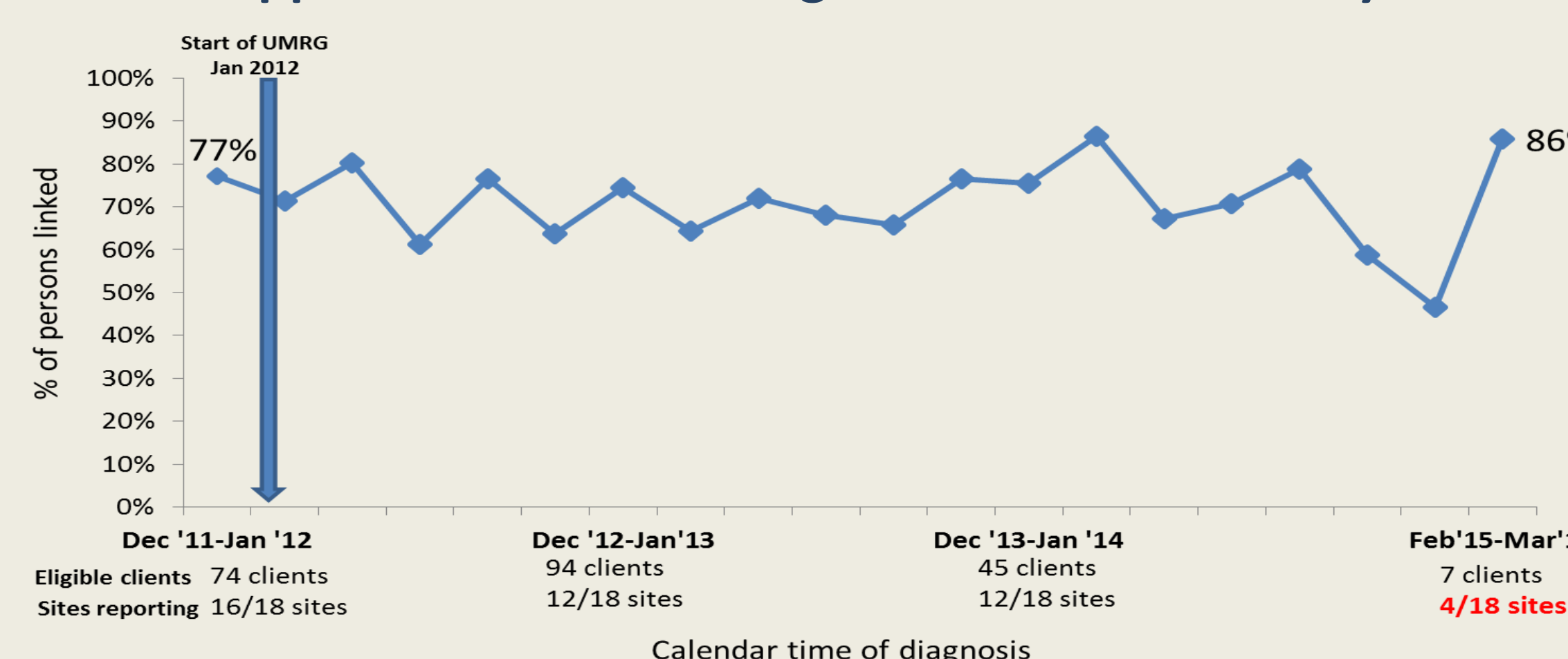
End-user feedback incorporated; data packages included multiple data display formats

Examples of Data Displays

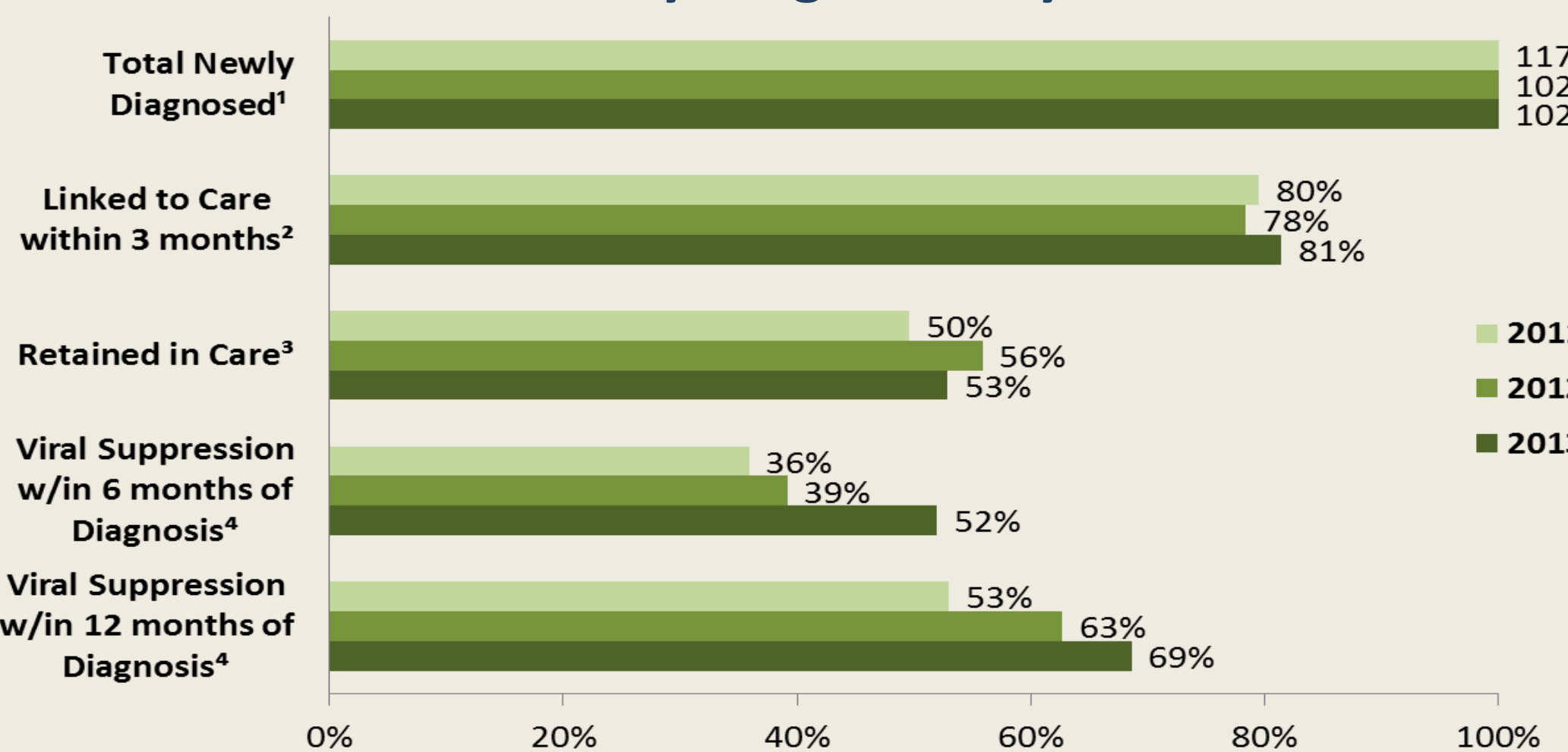
NYLinks Regions and HIV/AIDS Prevalence by County of Residence of Diagnosis NYS, 2013



Upper Manhattan Linkage to care within 30 days



Western NYS Persons Newly Diagnosed by NYLinks Providers



¹ New HIV diagnoses 1/1/2013–12/31/2013; NYS HIV Surveillance data as of 04/2015.
² ≥1 CD4/VL reported to the NYS HIV Surveillance system 90 days post diagnosis.
³ ≥1 CD4/VL test reported to the NYS HIV Surveillance system during each 4 month period in the 12 months following diagnosis.
⁴ Most recent viral load in 6 or 12 months following diagnosis is < 200 copies/mL.

RESULTS CONTINUED

Figure 1. Thinking Beyond the HIV Care Facility

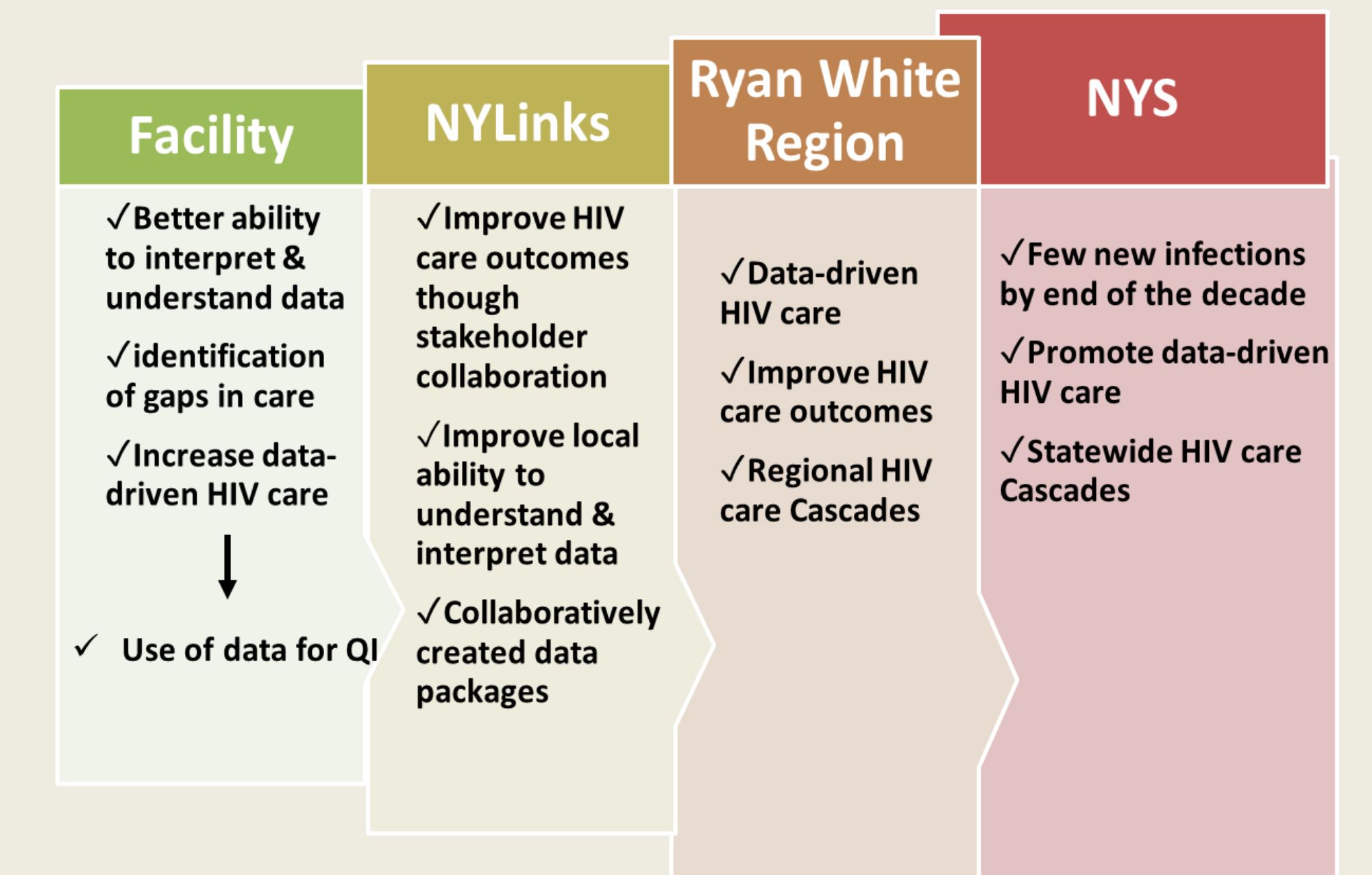


Table 2. Example of Local Action Plan*

Clinical and non-clinical stakeholders	Goals
<ul style="list-style-type: none"> • County Department of Health • State Department of Health • Community-based organizations • Consumers 	<ul style="list-style-type: none"> • Decrease number of undiagnosed HIV+ individuals • Link newly diagnosed individuals to care within 3 business days of diagnosis • Increase patient retention in HIV care • Re-engage out-of-care patients • Increase HIV viral suppression

*Monroe County Partnering to End the Epidemic

LESSONS LEARNED

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

REFERENCES

1. Fairchild A., Bayer R.; HIV Surveillance, Public Health, and Clinical Medicine — Will the Walls Come Tumbling Down?. NEJM 2011 (365)8: p. 685-687.
2. Mahle-Gray K, et al. Using the HIV Surveillance System to Monitor the National HIV/AIDS Strategy. AJPH 2013 (103)1: p. 141-147.
3. Wilson et al.; Disseminating research findings: what should researchers do? A systematic scoping review of conceptual frameworks. Implementation Science 2010 5:91.