



An End-User Participatory Approach to Collaboratively Refine HIV Care Data, The New York State Experience

Carol-Ann Swain^{1,4}  · Steven Sawicki² · Diane Addison³ · Benjamin Katz³ · Kelly Piersanti³ · Abigail Baim-Lance³ · Daniel Gordon¹ · Bridget J. Anderson¹ · Denis Nash³ · Clemens Steinbock² · Bruce Agins²

Published online: 2 April 2018
© Springer Science+Business Media, LLC, part of Springer Nature 2018

Abstract

Existing data dissemination structures primarily rely on top-down approaches. Unless designed with the end user in mind, this may impair data-driven clinical improvements to Human Immunodeficiency Virus (HIV) prevention and care. In this study, we implemented a data visualization activity to create region-specific data presentations collaboratively with HIV providers, consumers of HIV care, and New York State (NYS) Department of Health AIDS Institute staff for use in local HIV care decision-making. Data from the NYS HIV Surveillance Registry (2009–2013) and HIV care facilities (2010–2015) participating in a Health Resources and Services Administration (HRSA) Systems Linkages and Access to Care project were used. Each data package incorporated visuals for: linkage to HIV care, retention in care and HIV viral suppression. End-users were vocal about their data needs and their capacity to interpret public health data. This experience suggests that data dissemination strategies should incorporate input from the end user to improve comprehension and optimize HIV care.

Keywords HIV · Participatory process · End-user · Data visualization

Introduction

HIV public health data are used by program staff and policy makers to describe the epidemic, monitor and evaluate program metrics and allocate resources. In the United States, federal and state funders often mandate dissemination of HIV data, but provide little guidance on effective methods to communicate findings. Effective data dissemination strategies consider: (1) the message to be delivered, (2) the source of communication, (3) the mechanism of communication, (4) the audience, and (5) the context of communication [1,

2]. Existing data dissemination structures primarily rely on top-down approaches for data sharing where health officials and researchers determine the content and presentation of the material [3–6]. This approach may limit data-driven clinical improvements to HIV prevention and care if the information is not compatible with the needs and training of end-users [7]. It is also inconsistent with existing literature which indicates that interaction with end-users improves understanding, acceptance and subsequent integration of research findings [4, 8–10].

In 2011, the New York State (NYS) Department of Health (DOH) received funding through the Health Resources Services Administration (HRSA) Special Projects of National Significance, Systems Linkages and Access to Care project for populations at high risk of HIV infection. These funds supported New York Links (NYLinks), a statewide initiative designed to improve linkage to HIV care, retention in HIV care, and viral suppression through collaboration with organizations within geographically defined regions. Consistent with the International Association of Physicians in AIDS Care recommendation that multiple data sources be integrated to improve HIV healthcare utilization [11], a key requirement of the funding was to coordinate HIV epidemiologic surveillance with prevention and treatment resources

✉ Carol-Ann Swain
carolann.swain@health.ny.gov

¹ Bureau of HIV/AIDS Epidemiology, New York State Department of Health, Albany, NY, USA

² Office of the Medical Director, New York State Department of Health, New York, NY, USA

³ Institute for Implementation Science in Population Health, City University of New York, New York, NY, USA

⁴ Bureau of HIV/AIDS Epidemiology, Division of Epidemiology, Evaluation and Partner Services, New York State Department of Health, ESP, Corning Tower, Albany, NY 12237, USA

to improve access to and retention in quality HIV care statewide. This paper describes how the NYLinks evaluation team, researchers at the City University of New York School of Public Health and the NYSDOH, engaged end-users of HIV care data in a participatory process to inform the design and content of tailored HIV data packages.

Methods

NYLinks Regional Groups

NYLinks was organized geographically into regions. Each regional group included clinical and non-clinical representatives from agencies funded by NYS, New York City (NYC) and the Ryan White HIV/AIDS Program. Each participating organization was ideally represented by a project lead, clinician lead, data analyst, at least one consumer of HIV care, and an executive staff member who could approve change within the organization. These representatives were joined by staff from the NYS and NYC HIV surveillance units and HIV prevention programs. Regional groups, comprised of between 5 and 25 individuals, met every 3 to 4 months in daylong face-to-face meetings to discuss progress on the testing or implementation of new linkage and retention strategies. Participants shared data from the NYS HIV surveillance registries as well as clinic-based data on intervention strategies and HIV care outcomes.

Data Packages

NYLinks HIV data packages are a collection of PowerPoint slides designed to convey information about HIV diagnoses, prevalence and care outcomes to users with a range of data expertise. These users included HIV-infected individuals who were consumers of HIV care, staff members from organizations that provide HIV clinical care and NYSDOH AIDS Institute staff (NYLinks and non NYLinks affiliated). The data packages were conceptualized as a tool that could be used by clinicians and executive staff to: (1) understand the quality of HIV care within their organization, (2) develop future goals, and (3) visualize the performance of NYLinks participant organizations on linkage and retention measures within their geographic region and across NYS. The data packages could also be used by organizations to foster data-driven decisions, to conduct targeted outreach, monitor quality improvement (QI) projects, develop internal and external presentations and submit data for grant proposals.

Data Sources and HIV Care Measures

HIV-related data were obtained from the NYS and NYC HIV surveillance registries and from NYLinks organizations.

The NYS HIV registry receives all laboratory test results for HIV-diagnosed individuals who reside in NYS or receive their HIV-related care within the state [12, 13]. Reporting began in 2005 for all confirmed positive HIV antibody tests, HIV nucleic acid tests, HIV viral loads, CD4 counts and percent (unless unrelated to HIV), and genotype nucleotide sequences [14], enabling population-level monitoring of HIV-related healthcare utilization. The NYS HIV registry data requires 12–18 months for data reporting and processing to ensure quality and completeness, especially when examining data for newly diagnosed persons [15, 16]. Reported CD4 and HIV viral loads (January 2009 through December 2013) were used as proxies for HIV medical care encounters for registry-based HIV care measures [17, 18].

The NYSDOH HIV Surveillance program computes five measures of HIV care as part of annual reporting: linkage to care among newly diagnosed persons, the estimated number of those infected with HIV but are unaware of their status, the number of persons living with diagnosed HIV infection who received any HIV-related medical care during the calendar year, a measure of retention in HIV-related medical care and viral suppression among people living with diagnosed HIV infection based on a single HIV viral load test. Thirteen registry-based HIV care measures were computed as part of NYLinks (Table 1). This expanded set addressed existing gaps in knowledge by evaluating viral suppression among newly diagnosed persons and over time among people living with diagnosed HIV infection. Stratification by factors such as HIV transmission risk group (e.g., history of injection drug use or male-to-male sexual contact) and history of sexually transmitted infections was not a component of data analysis. Rather, outcomes were summarized by: participation in the NYLinks initiative (Yes/No), at the Ryan White regional level and, where appropriate, by United Hospital Fund (UHF) neighborhoods, which are organized around community planning districts in NYC [19–21]. Updates to the registry-based measures were prepared annually.

NYLinks clinical organizations in the NYSDOH HIV surveillance registry were identified from a list of current and historical organizational addresses as well as physician affiliation information. Cleaning and standardization of provider data for consistent and reliable identification in the registry enabled NYLinks to examine outcomes by provider using surveillance data and triangulation with HIV care measures reported by NYLinks participating organizations, thus linking clinical performance data to public health surveillance data.

Data were also collected from NYLinks participant organizations through routine provider reporting of de-identified, aggregated HIV-related patient care data. Similar to registry-based measures the provider-based data addressed a gap in knowledge as no routine method to collect and evaluate clinic-level HIV care outcomes data existed among

Table 1 NYLinks HIV surveillance registry- and clinic-based HIV care measures

Variable name	Definition
HIV registry-based measures: newly diagnosed persons	
Linkage to HIV care (30 days)	Newly diagnosed PLWDHI ^a with evidence of HIV care reported within 30 days of the date of diagnosis
Linkage to HIV care (60 days)	Newly diagnosed PLWDHI ^a with evidence of HIV care reported within 60 days of the date of diagnosis
Linkage to HIV care (3 months)	Newly diagnosed PLWDHI ^a with evidence of HIV care reported within 3 months of the date of diagnosis
Linkage to HIV care (12 months)	Newly diagnosed PLWDHI ^a with evidence of HIV care reported within 12 months of the date of diagnosis
Concurrent HIV/AIDS diagnosis	An AIDS diagnosis that occurred within 30 days of the HIV diagnosis
Median CD4 at HIV diagnosis	Median CD4 cell count of patients newly diagnosed based on the first CD4 cell count within 3 months of diagnosis
Retention in HIV care	Newly diagnosed persons with evidence of care at least three times during the 12 months following diagnosis, with at least one event occurring in each 4-month period
HIV viral suppression (6 months)	Newly diagnosed persons whose last viral load (VL) in the 6 months following diagnosis was <200 copies/mL
HIV viral suppression (12 months)	Newly diagnosed persons whose last VL in the 12 months following diagnosis was <200 copies/mL
HIV registry-based measures: persons living with diagnosed HIV Infection	
Evidence of recent care	Percentage of PLWDHI with any evidence of care ^b during the reporting period of interest
Retention in HIV care	Percentage of PLWDHI who were in care during the reporting period of interest who had evidence of additional care 45-180 days after the initial care event
HIV viral suppression	PLWDHI alive as of a specific point in time whose most recent VL during the prior 6 months was <200 copies/ml.
Sustained HIV viral suppression	PLWDHI at a specific point in time with ≥ 1 VL test, whose VL quantities reported during the next 12 months were all <200 copies/ml
NYLinks organization-based measures	
Linkage	Percentage of newly diagnosed patients in the reporting period who had their first HIV clinical care visit within 30 days of the date of their confirmatory HIV test result
Retention	Percentage of patients with at least one clinical care visit during the first 6 months of the 24-month measurement period who had at least one clinical care visit in each 6-month period of the remaining 18 months of the measurement period with a minimum of 60 days between clinical care visits
New patient retention	Percentage of new patients who have their initial clinical care visit during the first 4 months of the 12-month measurement period who had a clinical care visit in each of the subsequent 4-month periods in the measurement period

^aPLWDHI- persons living with diagnosed HIV infection

^bCD4 or HIV viral load in the specific time period

participant providers outside of annual reporting requirements to NYSDOH prior to NYLinks. Counts of patients linked, retained or engaged in HIV-related care, as established through the analysis of visit dates were submitted bi-monthly via a secure web portal to the NYLinks evaluation team. Reported data were de-identified, aggregated and did not include protected health information. The data encompassed visits to 38 HIV care providers from 2010 through 2015 for three regional groups, representing Western NYS (WNY), Upper Manhattan and Queens (Fig. 1). These geographic areas represent roughly 40% of the 3500 newly diagnosed cases of HIV in NYS in 2013 and 15% of the 133,300

persons who were living with diagnosed HIV infection by the end of the calendar year [15, 16]. Organizations participating in NYLinks could query the data portal to generate performance graphs for each provider-reported measure. Performance graphs included regional and initiative-wide trends, as well as statewide averages. Local Institution Review Boards (IRBs) considered this activity to be non-research, related to public health surveillance.

Three quality of care measures, defined by the NYSDOH AIDS Institute HIV Quality of Care Program, and consistent with Ryan White clinical quality measures, were computed by NYLinks clinical organizations. These metrics

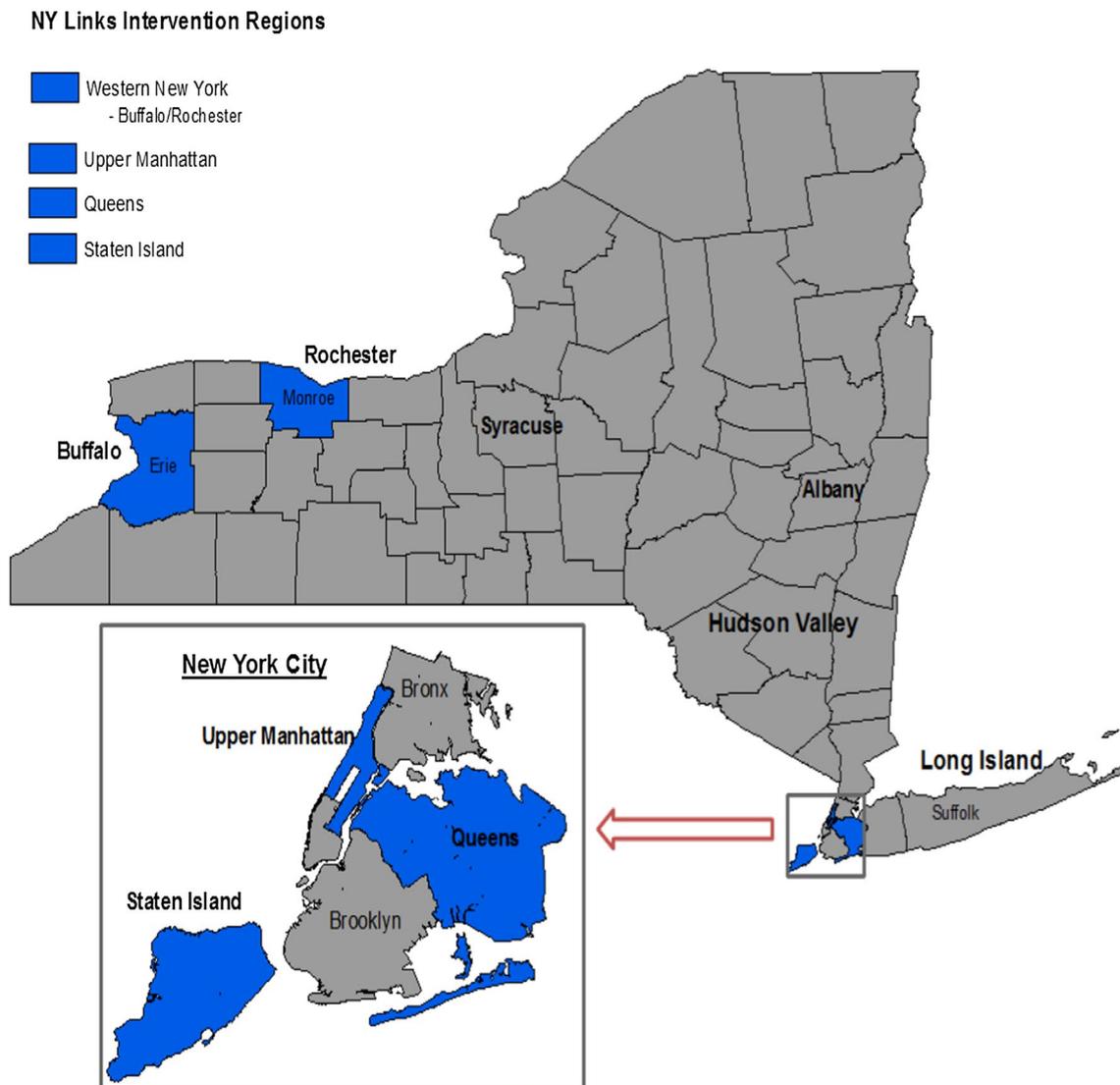


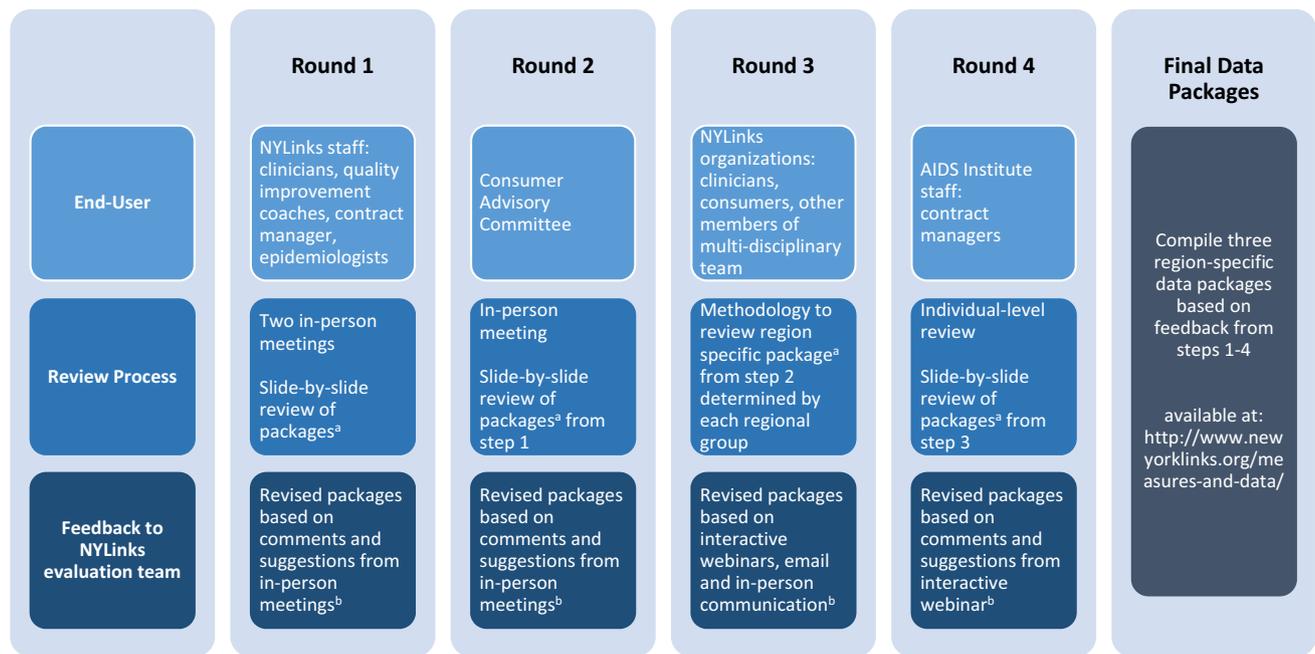
Fig. 1 NYLinks regional groups

focused on linkage to HIV-related care for newly diagnosed patients and retention in HIV-related care for new and existing patients (Table 1). Individual clinic data were aggregated into regional totals by the NYLinks evaluation team. Updates to regional trends were presented at quarterly regional group meetings.

End-User Engagement

End users of the data packages included consumers of HIV care, staff members from organizations that provide HIV clinical care and staff of the NYSDOH AIDS Institute staff (NYLinks and non NYLinks affiliated) (Fig. 2). We sought input from these users over a 10-month period (January through October of 2015) on the usefulness of content, clarity, and relevance of the data packages to inform quality

improvement (QI) and program planning. The participatory process for this one-time activity was part of the broader NYLinks approach to build consensus through ongoing learning networks and regional groups where participant organizations worked toward common improvement goals. A noteworthy contribution to this data dissemination project was the availability of NYSDOH HIV Quality of Care Program QI coaches who were also part of the NYLinks staff. QI coaches facilitate the capacity for quality management, including performance measurement and improvement activities. Part of QI implementation includes the use of data to identify gaps in care and target improvements to address them, while strengthening numeracy skills and the infrastructure for on-going QI activities [22, 23]. QI coaches and the evaluation team provided technical assistance at regional meetings, through in-person interactions



^a Packages reviewed for content, format and clarity; identify elements to include or modify in data visualizations.

^b Determine intended use of the data packages.

Fig. 2 Process to create the data packages

and phone consultations with organizational staff throughout the 10-month data activity period. End-user feedback on the data packages was provided to QI coaches and the evaluation team through structured in-person meetings, interactive webinars, and email communication. The meetings were recorded in the form of field notes and semi-structured tabular charts. From these notes, themes were identified and trends summarized to evaluate differences across regional groups and data users.

End-users reviewed the data packages in four successive rounds, refinements were made after each round (Fig. 2). The first round of review included NYLinks staff. This review team members were epidemiologists, contract managers (i.e., NYSDOH employees responsible for oversight of funded contracts or grants), program staff and QI coaches. In the second round, recommended changes from round one were incorporated and the data packages were presented to consumers of HIV care, many of whom were active in the New York State Consumer Advisory Committee, a group of persons living with diagnosed HIV infection who advise the NYSDOH about policies and priorities related to the quality of HIV care in NYS [24].

In round three, we sought input from 12 NYLinks organizations known to provide content-related input; 11 agreed to participate. Clinical providers were predominant (n=9) but the group also included one county Department of Health and one supportive services provider. The estimated patient load at entry to NYLinks ranged from approximately

400–2000 HIV infected individuals. Each regional group determined its own method for reviewing the region-specific data package. In the Buffalo Ryan White region in WNY, agencies submitted individual responses from within their organizations; the QI coach used these responses to develop a single organizational response. An organization in the Rochester Ryan White region created a survey tool which participating agencies used to guide their review of the data. The survey instructed participants to rank the utility of each data slide (i.e., “can use, may use, will not use”) and to attain organizational consensus. The various agencies then met to discuss and submit one set of recommendations. In the Upper Manhattan region, the QI coach conducted an in-person meeting with participants from member organizations. Each slide within the package was reviewed, qualitative information was documented and collated and consensus attained on the usefulness of each slide. In the fourth round of review, staff within the NYSDOH AIDS Institute reviewed the updated slides. The data packages were distributed to stakeholders and remain available at the NYLinks website [25].

Results

Three region-specific data packages were created based on feedback from end users [26–28]. Section one provided an overview of the HIV epidemic in NYS while sections two

(a)

United Hospital Fund (UHF) areas

HIV prevalence in 2012 as % of UHF population



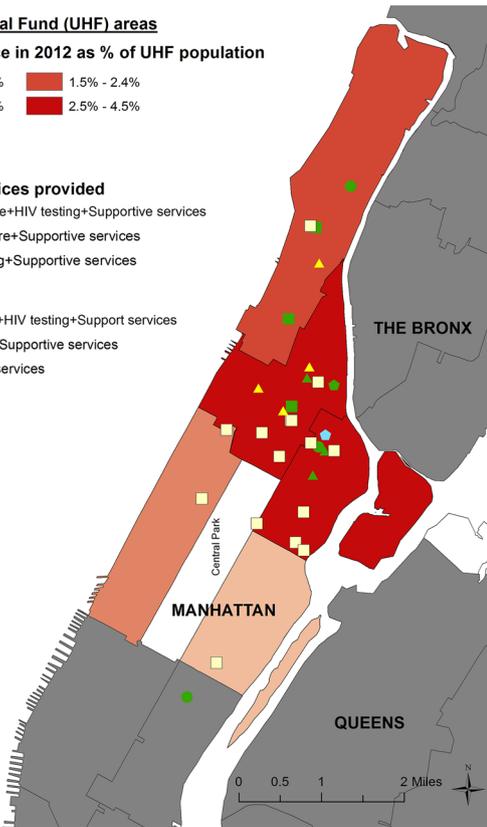
UMRG Sites

Types of services provided

- Clinical care+HIV testing+Supportive services
- Clinical care+Supportive services
- ▲ HIV testing+Supportive services

Inactive Sites

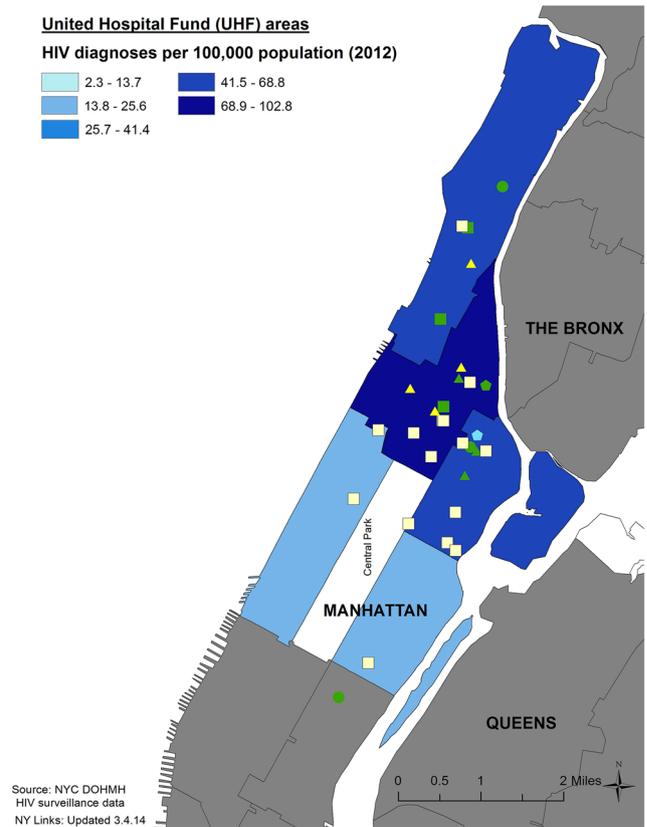
- Clinical care+HIV testing+Support services
- ▲ HIV testing+Supportive services
- Supportive services
- ◆ HIV testing



Source: NYC DOHMH HIV surveillance data NY Links: Updated 3.4.14

United Hospital Fund (UHF) areas

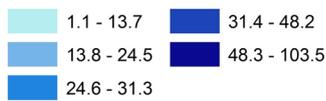
HIV diagnoses per 100,000 population (2012)



Source: NYC DOHMH HIV surveillance data NY Links: Updated 3.4.14

(b)

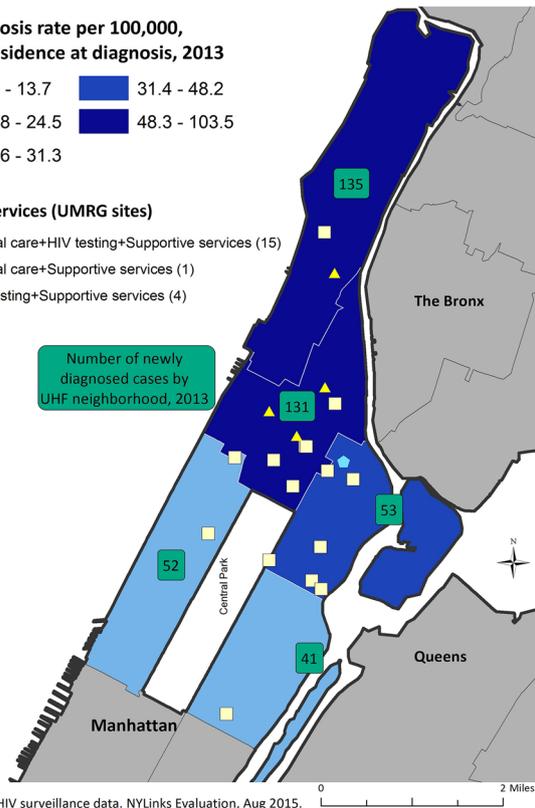
HIV diagnosis rate per 100,000, by UHF residence at diagnosis, 2013



Types of services (UMRG sites)

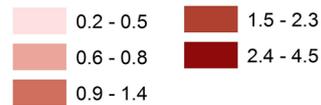
- Clinical care+HIV testing+Supportive services (15)
- Clinical care+Supportive services (1)
- ▲ HIV testing+Supportive services (4)

Number of newly diagnosed cases by UHF neighborhood, 2013



NYC DOHMH HIV surveillance data. NYLinks Evaluation, Aug 2015.

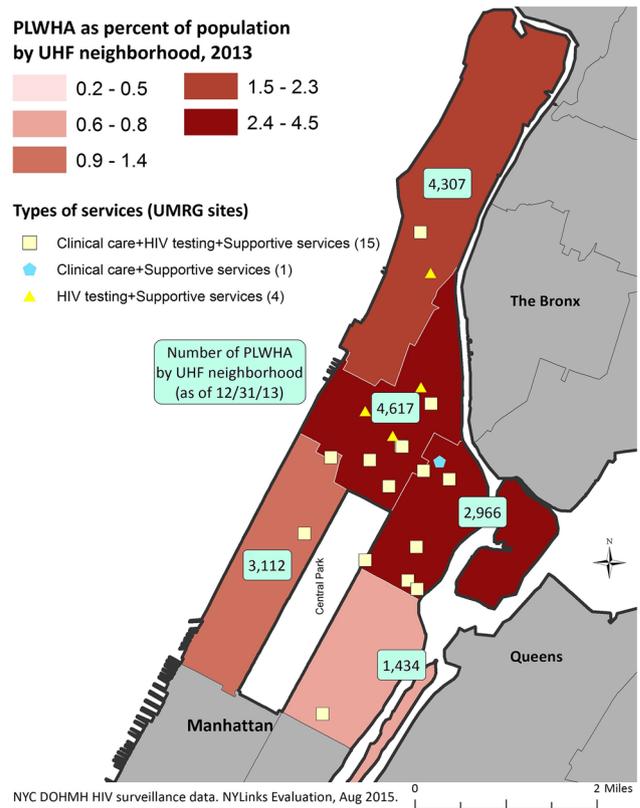
PLWHA as percent of population by UHF neighborhood, 2013



Types of services (UMRG sites)

- Clinical care+HIV testing+Supportive services (15)
- Clinical care+Supportive services (1)
- ▲ HIV testing+Supportive services (4)

Number of PLWHA by UHF neighborhood (as of 12/31/13)



NYC DOHMH HIV surveillance data. NYLinks Evaluation, Aug 2015.

Fig. 3 a Upper Manhattan Regional Group: HIV Prevalence & New Diagnoses (2012) Display before Data Review Activity. **b** Upper Manhattan Regional Group: HIV Prevalence & New Diagnoses (2013) Display after Data Review Activity. Upper Manhattan Sites: The Addiction Research and Treatment Corporation, African Services Committee Inc., AIDS Service Center, Beth Israel-Methadone Maintenance Treatment Program, Boriken Neighborhood Health Center, Center for Comprehensive Health Practice, Columbia Presbyterian, Community Healthcare Network, Harlem Hospital, Harlem United, Institute for Family Health, Iris House, Lenox Hill, Metropolitan Health Center, Mt. Sinai Medical Center, Renaissance Healthcare, Safe Horizon, Settlement Health, St. Luke's Hospital, William F. Ryan Community Health Center. Compared to (a), case counts were added to improve clarity

and three focused on clinic- and surveillance-based data, respectively. Each data package contained a variety of data visualizations including tables, maps and trend graphs, which could be used to benchmark regional performance with national HIV care goals (Figs. 4, 5). The size and focus of the final packages varied by region. In the Rochester Ryan White Region, NYLinks organizations noted that 27% of content slides could be used for program planning and patient care activities, 47% may be useful and 8% were not useful; the remaining 18% were not content related (e.g., title and transition slides) [29]. Based on this feedback the content changed significantly to have a more local focus. The size of the package remained relatively unchanged at approximately 50 data slides. In Upper Manhattan, the number of slides increased from 51 to 67 slides while the number in the Buffalo Ryan White Region also remained relatively unchanged, with 75 in the pre-review slide set and 73 in the final package.

Participants indicated a preference for a range of different data displays. For example, maps of HIV diagnoses and prevalence were identified as an important complement to tabular and other graphical data displays. End-users also preferred visualizations that included both counts and percentages for each data point. However, they recommended that slides be judicious in the amount of data presented; cluttered slides were considered less useful for evaluating the magnitude of HIV disease burden, gaps in care, or progress toward HIV care goals.

Participants expressed their short- and long-term data needs including content that could be used to improve local HIV decision-making and technical assistance to better understand and interpret data. A priority of NYLinks staff was the separation of data slides into distinct regional packages. Consumers of HIV care were interested in data interpretation while NYSDOH staff focused on using the data for public health and contractual purposes, such as tracking work plan deliverables. Regional groups preferred data packages that highlighted local data, such as new diagnoses and HIV prevalence in the context of the surrounding geographic area. The scale of geographic comparisons differed

by region. In WNY, state level displays that showed regional or county-level outcomes relative to other NYS jurisdictions were a priority. NYLinks participating organizations preferred data visualizations that focused on HIV care outcomes in their own geographic area when provider-collected data were shown. A similar finding was observed for the Upper Manhattan and Queens groups, with the caveat that geographic data at the zip code level was deemed most relevant to local needs given the high population density.

End users suggested a variety of content changes that were incorporated without significant delay. These included the addition of: a list of region-specific NYLinks organizations, a summary of findings for clinic-based measures, demographic characteristics of infected persons in each region in tabular format, and a region-specific HIV care cascade for newly diagnosed persons. Data visualizations were also tailored based on specific feedback. For example, providers requested that case counts be added to maps to quantify the magnitude of the epidemic (Figs. 3a, b). They also requested the addition of data slides that simplified trend graphs (Figs. 4, 5).

Some suggested content changes could not be accommodated. For example, clinical providers requested the number of individuals in state correctional facilities by calendar year. This would have required substantial updates to the HIV surveillance registry, which was not feasible within the project timeframe. Although identified as important, zip code-level maps were not included in the data packages because these data were less stable compared to the UHFs. Small numbers in some zip codes would have required a large amount of data suppression to ensure patient confidentiality. External factors that could impact data reporting and observed outcomes, such as severe weather (e.g., hurricane Sandy in 2012) and policy or service delivery changes, were outside the scope of the project. While these could not be feasibly incorporated into the packages, end-users were encouraged to interpret the data in the context of these factors, where appropriate.

Discussion

This activity utilized an end-user participatory approach to collaboratively refine an HIV data dissemination product that included epidemiologic HIV surveillance data. The review process resulted in data packages that were tailored to the needs of HIV care data end users in different geographic regions allowing users to select data based on their unique preferences and skills. End users were vocal and specific about their short- and long-term data needs. They identified both content and delivery preferences to improve local HIV program activities and technical assistance that enhanced their capacity to interpret public health data. At

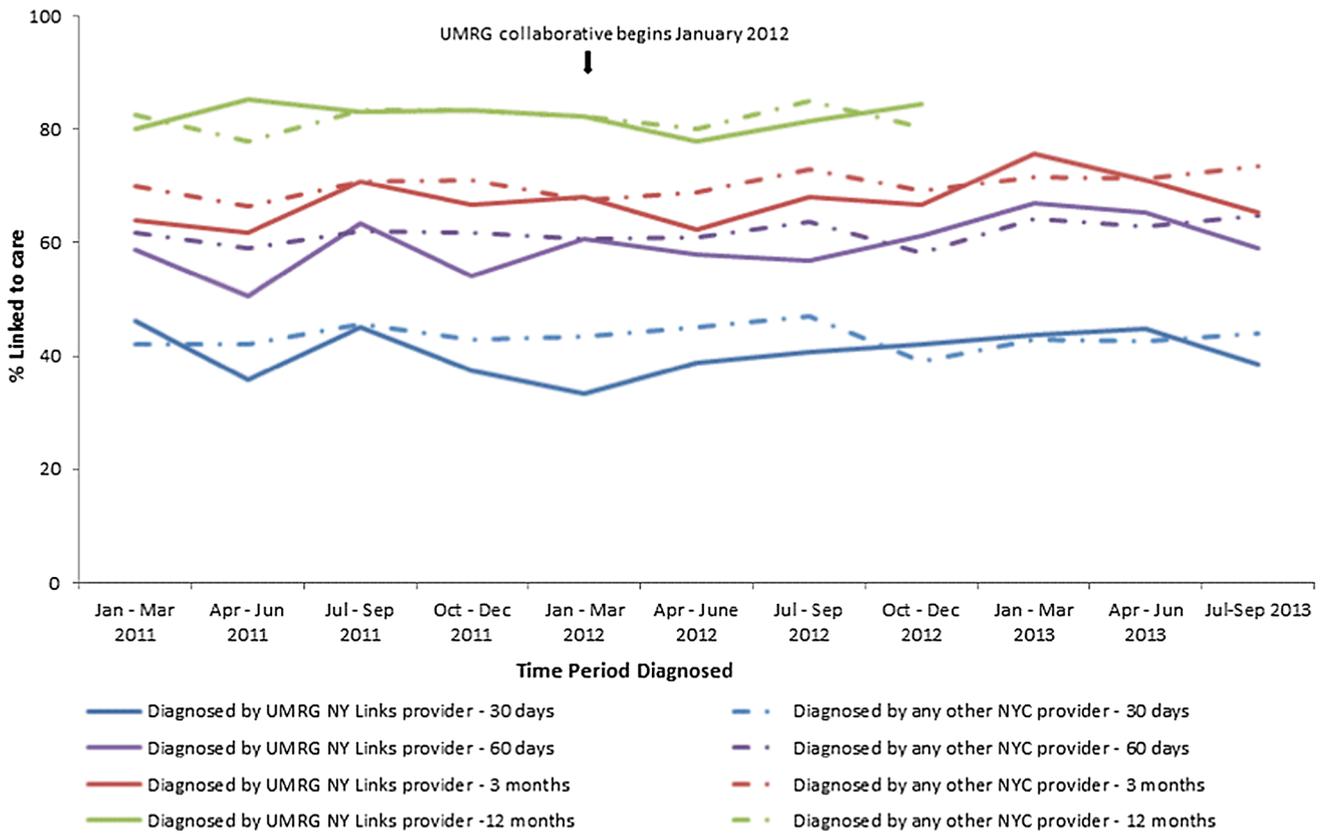
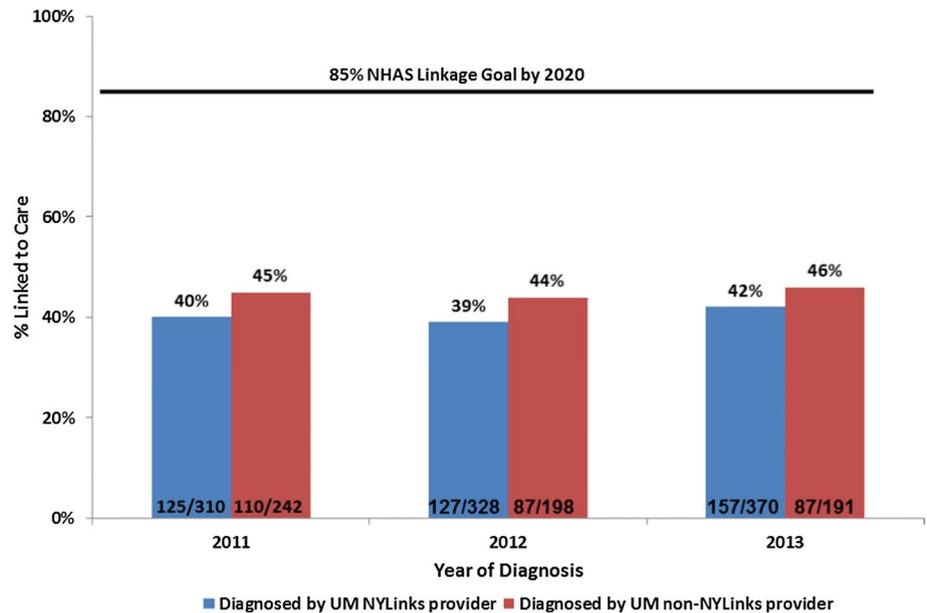


Fig. 4 Linkage to care within 30 days, 60 days, 3 months, and 12 months Post Diagnosis. Data Source NYC HIV/AIDS Registry, updated January 2015 with data reported by April 30, 2014

Fig. 5 Linkage to care within 30 days Post Diagnosis by Year of Diagnosis new slide based on comments received during the review activity (Labs (CD4/VL) within 7 days of diagnosis removed. Bottom numbers = (# linked by providers/total # diagnosed by providers); Data Source: NYC HIV/AIDS Surveillance data, updated March 2015 with data reported through June 30, 2014). Compared to Fig. 4a, data are shown in annual versus quarterly increments to simplify appearance and improve comprehension. Case counts were added as well as benchmarking to the National HIV/AIDS Strategy target



the state level, staff learned about end-user preferences and how data are used in the field allowing them to create simple and informative data displays.

Our findings support previous research which shows that engaging the end user improves the uptake of data pertaining to systems operations and services to clients [4, 31] as

well as a shift from individual to team decision-making using comprehensible visual tools focused on clinic-level outcomes and broader geographic HIV-related public health data [7, 32]. In a recent investigation designed to promote knowledge translation and data interpretation in a primary care setting, Laycock et al., described efforts to improve healthcare outcomes through an iterative process that engaged clinical experts in data analysis and solicited system-wide input from stakeholders such as health care practitioners, managers, policy-makers and support organizations [4]. The project included reports and online surveys that captured existing and potential priorities as well as barriers to decreasing gaps in care at different levels of the health system. Investigators provided stakeholders with a summary of evidence-based literature to inform local strategies for improving care. The process culminated in a final report that utilized end-user feedback from iterative reviews that could be used to identify and refine their dissemination strategy and improve usability and uptake of research findings. Our project differs from that of Laycock et al., in that we collaborated directly with end users to develop customized data visualization packages, whereas Laycock et al., developed a final report and recommendations.

Data visualizations and prioritization of data elements allow the end user to quickly characterize differences in HIV care outcomes, describe longitudinal trends in the quality of HIV care and evaluate program activities [33]. During the data package review period, several factors influenced the final package content and design: level of engagement in the process, organizational characteristics, geographical context and prior level of participation in NYLinks. For example, we observed that individuals who were familiar with analytics were more active in the review process. It is likely that staff with less expertise may have had different comments on overall needs.

The data review and design was not meant to be sustained over time. Nonetheless, the process could be replicated by producing packages from provider-reported and HIV surveillance data. This “scale up” would require consistent and high-quality data reporting on behalf of providers, person hours from analysts generating regional level data sets over time and ample time for feedback sessions to craft and customize each package. The final slide deck output required processing by NYLinks evaluation team. A web-based interface which allows users to query the database and generate predefined data templates would reduce the workload and make this component of the activity scalable as others have done [34, 35].

Both population- and clinic-based HIV data were used to understand HIV care among infected persons in NYS, offering several advantages. Population-based HIV surveillance data captured engagement with medical service providers regardless of whether visits occurred at one or at multiple

facilities. Population-based data also enabled the distinction between newly diagnosed persons and patients who were simply new to a medical practice. One disadvantage of HIV surveillance-based data was that laboratory reports served as a surrogate for capturing HIV medical care visits. This may have led to misclassification of care status if laboratory tests occurred independently of actual HIV-related medical care visits. In contrast, clinic-based metrics utilized visit data to determine linkage and engagement in care, thus reducing the likelihood of misclassifying individuals who did not actually have an HIV-related medical care visit. However, clinic-based investigations do not typically track patient care outside of specific facilities, limiting the ability to fully evaluate HIV care. The combined presentation of clinic- and population-based data allowed end-users to evaluate HIV care outcomes in the context of these advantages and limitations.

The following were limitations of the data collection and review. Clinic-based data were abstracted from patient records by organizational staff with processing by NYLinks evaluation team. This resulted in delays to receive and process data, which was not always updated quarterly as planned. Participant organizations expressed concern about the age of data from the HIV surveillance registry, citing the need for timely HIV surveillance data which could be compared to organizational data and used to set realistic objectives. The difference in availability of recent clinic- versus surveillance-based data highlights the quality improvement maxim that “data drives improvement” [36]. Specifically, data that are proximate in time and place, such as clinic-based outcome metrics, enhance the process of evaluating gaps in care and service while time-lagged HIV surveillance data are important to the longitudinal evaluation and context of HIV care.

Staff turnover at NYLinks organizations during the project period may have also impacted the level of expertise and participation in the review process. Sustainability of the activities as previously described proved difficult. Although providers reported using information from the data packages, follow-up research did not track their use to foster data-driven decisions, conduct targeted outreach, monitor QI projects or develop internal and external presentations. In addition, the combined effect of time-lagged HIV surveillance registry data, the required collection and processing of provider-collected data and time-limited funding prevented on-going updates as described. Development of the HIV care measures, compilation of the data (some of which existed prior to the data package activity) and design of the initial HIV data packages took approximately 1 year to complete. Our success was a result of broader, on-going NYLinks activities and the ability to incorporate processes and measures into NYSDOH AIDS Institute systems. Some components, such as the definitions and on-going calculation

of HIV care metrics, have been embedded in the NYS Ending the Epidemic Dashboard [30] and regional QI programs.

Conclusions

This effort to refine an HIV care outcomes data package in collaboration with end users was one component of the NYLinks approach to improve HIV care in NYS. This project used multiple visual formats and focused on local relevance to ensure the utility of the data packages among end users with varying levels of analytical expertise. During the data review process, participants were specific about their data needs and their ability to interpret the data. The NYLinks evaluation team developed tailored HIV care data visualizations appropriate for each type of end user, presenting a broad perspective on HIV care, from high-level overviews to more detailed presentations of local HIV care outcomes. Several metrics developed in this process remain embedded in regional QI programs and the state-level HIV care dashboard. Data packages created without input from the end-user may hinder comprehension and impede improvement in HIV care outcomes.

Acknowledgements The authors thank members of the New York Links (NYLinks) team, the New York State Consumer Advisory Committee and NYLinks member organizations. In particular, we thank Erie County Medical Center, Evergreen Health, Trillium Health, Monroe County Department of Health, Catholic Charities, Strong Memorial Hospital, Anthony L. Jordan Health Center, Mount Sinai Hospital, Harlem Hospital Center, St. John's Riverside Hospital and North Shore Long Island Jewish Health System. We also thank Allison Krug, MPH (Artemis Biomedical Communications, LLC), Travis O'Donnell and John Helmeset for their editorial contributions.

Funding This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant Number H97HA22693, Special Projects of National Significance, Systems Linkages and Access to Care for Populations at High Risk of HIV Infection Initiative (CFDA) no. 93.928. The content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government. Support was also provided by the Centers for Disease Control and Prevention 13-1302, National HIV Surveillance System U62PS003966, and the AIDS Institute, New York State Department of Health and the New York City Department of Health and Mental Hygiene.

Compliance with Ethical Standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent This study received a determination of Exempt status (exempt category #5) according to federal regulations, under 45 CFR 46.101(b). For the qualitative assessment, informed consent was obtained from all implementation staff included in the study.

References

1. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009;4:50.
2. McGuire WJ. Input and output variables currently promising for constructing persuasive communications. In: Rice R, Atkin C, editors. *Public communication campaigns*. 3rd ed. Thousand Oaks, CA: Sage; 2001. p. 22–48.
3. Kuruvilla S, Mays N. Reorienting health-research communication. *Lancet.* 2005;366(9495):1416–8.
4. Laycock A, Bailie J, Matthews V, Bailie R. Interactive dissemination: engaging stakeholders in the use of aggregated quality improvement data for system-wide change in Australian Indigenous primary health care. *Front Public Health.* 2016;4:84.
5. Waddell C. So much research evidence, so little dissemination and uptake: mixing the useful with the pleasing. *Evid Ment Health.* 2001;4(1):3–5.
6. Wilson PM, Petticrew M, Calnan MW, Nazareth I. Disseminating research findings: what should researchers do? A systematic scoping review of conceptual frameworks. *Implement Sci.* 2010;5:91.
7. Shneiderman BPC, Hesse BW. Improving healthcare with interactive visualization. *Computer.* 2013;46(5):58–66.
8. Jacobson N, Butterill D, Goering P. Development of a framework for knowledge translation: understanding user context. *J Health Serv Res Policy.* 2003;8(2):94–9.
9. Centre for Reviews and Dissemination. *Undertaking systematic reviews of research on effectiveness: CRD's guidance for carrying out or commissioning reviews*. 3rd ed. York: University of York; 2009.
10. Hughes M, McNeish D, Newman T, Roberts H, Sachdev D. What works? Making connections: linking research and practice. A review by Barnardo's Research and Development Team. Ilford: Barnardo's; 2000.
11. Thompson MA, Mugavero MJ, Amico KR, Cargill VA, Chang LW, Gross R, et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care panel. *Ann Intern Med.* 2012;156(11):817–33, W-284, W-5, W-6, W-7, W-8, W-9, W-90, W-91, W-92, W-93, W-94.
12. Statutory Authority: Public Health Law. Sect. §2786 and Article 21.
13. Statutory Authority: Public Health Law. Sect. §§69–1.2.
14. Part 63 HIV/AIDS Testing, Reporting and Confidentiality of HIV-Related Information [updated January 2002]. <http://www.health.ny.gov/nysdoh/rfa/hiv/full63.htm> Accessed 10 April 2013.
15. New York City Department of Health and Mental Hygiene. *HIV Surveillance Annual Report, 2013; 2013*.
16. New York State Department of Health. *HIV/AIDS Surveillance Annual Report, 2013. 2013*.
17. Hu YW, Kinsler JJ, Sheng Z, Kang T, Bingham T, Frye DM. Using laboratory surveillance data to estimate engagement in care among persons living with HIV in Los Angeles County, 2009. *AIDS Patient Care STDS.* 2012;26(8):471–8.

18. Torian LV, Wiewel EW. Continuity of HIV-related medical care, New York City, 2005-2009: do patients who initiate care stay in care? *AIDS Patient Care STDS*. 2011;25(2):79–88.
19. United Hospital Fund. The Fund at 125 2017 <https://www.uhfny.org/publications/880587>. Accessed 28 Feb 2017.
20. New York City Department of Health and Mental Hygiene. United Hospital Fund Neighborhoods and NYC ZIP Code Areas 2017. https://www1.nyc.gov/assets/doh/downloads/pdf/survey/uhf_map_100604.pdf. Accessed 28 Feb 2017.
21. New York State Department of Health. ZIP Code Definitions of New York City Neighborhoods 2017. <https://www.health.ny.gov/statistics/cancer/registry/appendix/neighborhoods.htm>. Accessed 28 Feb 2017.
22. Taylor EF, Machta RM, Meyers DS, Genevro J, Peikes DN. Enhancing the primary care team to provide redesigned care: the roles of practice facilitators and care managers. *Ann Fam Med*. 2013;11(1):80–3.
23. New York State Department of Health. The HIV Quality of Care Program: Clinical Guidelines Program in the JHU School of Medicine, Division of Infectious Diseases, on behalf of the NYSDOH AIDS Institute; 2017 [cited 2017 11/05/2017]. <https://www.hivguidelines.org/quality-of-care/about-the-program/quality-improvement>. Accessed 11 May 2017.
24. New York State Department of Health. AIDS Institute (AI) Advisory Bodies: New York State Department of Health; 2016 [cited 2016 11/06/2016]. http://www.health.ny.gov/diseases/aids/general/about/advisory_bodies.htm Accessed 11 June 2016.
25. AIDS Institute NYSDoH. NYLinks [cited 2016. Available from: <http://www.newyorklinks.org/measures-and-data>. Accessed 28 Sept 2016.
26. New State Department of Health, AIDS Institute. NYLinks Regional Data Set for Upper Manhattan 2015. <http://www.newyorklinks.org/measures-and-data>. Accessed Sept.
27. New State Department of Health, AIDS Institute. Rochester NYLinks Evaluation Dissemination Slide Set. August 2015. <http://www.newyorklinks.org/files/new-york-links-evaluation-dissemination-rochester-slide-set>. Accessed Sept.
28. New State Department of Health, AIDS Institute. Buffalo NYLinks Evaluation Dissemination Slide Set. August 2015. <http://www.newyorklinks.org/files/new-york-links-evaluation-dissemination-buffalo-slide-set>. Accessed Sept.
29. Monroe County Department of Health. Email Communication. In: Magnani N, editor. 2015.
30. City University of New York, Institute for Implementation Science in Population Health. Ending the Epidemic Dashboard; 2017. <http://etedashboardny.org> Accessed 28 Feb 2017.
31. Heaton J, Day J, Britten N. Collaborative research and the co-production of knowledge for practice: an illustrative case study. *Implement Sci*. 2016;11:20.
32. Ratwani RM, Fong A. ‘Connecting the dots’: leveraging visual analytics to make sense of patient safety event reports. *J Am Med Inform Assoc*. 2015;22(2):312–7.
33. Althoff KN, Rebeiro PF, Hanna DB, Padgett D, Horberg MA, Grinsztejn B, et al. A picture is worth a thousand words: maps of HIV indicators to inform research, programs, and policy from NA-ACCORD and CCASAnet clinical cohorts. *J Int AIDS Soc*. 2016;19(1):20707.
34. Centers for Disease Control and Prevention. 2016 Sexually transmitted diseases surveillance: the state of STDs—infographic; 2017. <https://www.cdc.gov/std/stats16/infographic.htm>. Accessed 28 Sept 2017.
35. Centers for Disease Control and Prevention. 2016 Sexually transmitted diseases surveillance: customizable infographic with instructions; 2017. <https://www.cdc.gov/std/stats16/infographic.htm>. Accessed 28 Sept 2017.
36. Kadom N, Nagy P. Data drives quality improvement. *J Am Coll Radiol*. 2015;12(12 Pt A):1296–7.