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Health information exchange interventions can enhance quality and continuity of HIV care

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ABSTRACT

Purpose: The purpose of this article is to describe how comprehensive HIV care is delivered within Ryan White Program (RWP)-funded clinics and to characterize proposed health information exchange (HIE) interventions, which employ technology to exchange information among providers, designed to improve the quality and coordination of clinical and support services.

Methods: We use HIV patient care quality and coordination indicators from electronic data systems to describe care delivery in six RWP demonstration sites and describe HIE interventions designed to enhance that care.

Results: Among patients currently in care, 91% were retained in care in the previous six months (range across sites: 63–99%), 79% were appropriately prescribed antiretroviral therapy (54–91%) and 52% had achieved undetectable HIV viral load (16–85%). To facilitate coordination of care across clinical and support services, sites designed HIE interventions to access a variety of data systems (e.g. surveillance, electronic health records, laboratory and billing) and focused on improving linkage and retention, quality and efficiency of care and increased access to patient information.

Discussion: Care quality in RWP settings can be improved with HIE tools facilitating linkage, retention and coordination of care. When fully leveraged, HIE interventions have the potential to improve coordination of care and thereby enhance patient health outcomes.

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1. Introduction

During the past 30 years, dramatic progress has been made in the reduction of morbidity and mortality associated with HIV [1]. However, considerable deficiencies remain in the public and private health systems that have been developed to identify HIV-infected individuals, engage and retain them in care and improve the quality and effectiveness of care and

treatment. In the United States, it is estimated that only 19% of those with HIV are on effective treatment [2]. Due to the complex nature of the disease, effective HIV care is multi-disciplinary. Primary care for people with HIV includes not only treatment of an infectious disease (via prescription of antiretroviral therapy and treatment of opportunistic infections and malignancies), but also treatment of the long-term effects of immune activation and the side effects of antiretroviral therapy (heart disease, diabetes, and metabolic

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abnormalities). Additionally, this care must address the psychosocial factors which impact patients' ability to engage and remain in care [3].

Recently, policy makers, clinicians and researchers have emphasized the importance of expanding the continuum of care for people with HIV to include not only primary HIV care and support services, but also linkage, engagement and retention in HIV care [4,5]. Previous research has identified many barriers to optimal linkage, engagement and retention in care [6–13]. These include structural barriers (e.g., housing, location of clinic and competing subsistence needs such as housing, food and transportation) [14–16], financial barriers (e.g., cost of services, lack of insurance) [17,18], personal and cultural barriers (e.g., attitudes and beliefs, racism, language, sexism, and homophobia) [19,20], co-morbidities such as mental illness and substance abuse [21,22], stigma, fear of confidentiality violations [23,24] and healthcare provider attitudes [25].

The Ryan White Care Program (RWP) was developed to address these barriers and associated deficiencies in HIV-related healthcare through the funding of quality HIV care and treatment for those who cannot afford it, provision of support services (e.g. transportation and housing) for those who experience challenges and/or obstacles in entering and remaining in care, and coordination of care (e.g. medical case management) for those who have co-occurring conditions that impact the effectiveness of HIV care [26,27]. Previous research in RWP-funded health clinics suggests receipt of care and support services in RWP-funded health clinics are associated with better engagement in care, retention in care and patient health outcomes [28–32]. However, these same findings also indicate that the improved engagement, retention and health outcomes are not yet at levels that would be considered ideal [30]. For example, only 45% of patients in RWP-funded clients reported any primary HIV care visits in the past year [28]. Among those in care, 61–74% were on recommended antiretroviral therapy [33].

Recent literature, as well as the National HIV/AIDS Strategy, has suggested that both individual and system-level interventions have the potential to improve linkage and retention in care and the quality of HIV care and support services [3,5,34]. These include case management, patient navigators, integration of care and support services and use of electronic health information to facilitate and coordinate care and services. For example, Mugavero et al. demonstrated that receipt of case management prior to an initial visit with a provider can improve linkage to care for newly identified HIV-infected individuals [5]. Several demonstration projects, funded under an initiative from the US Health Resources and Services Administration's (HRSA) Special Projects of National Significance (SPNS) demonstrated that case management and patient navigators can improve engagement in care, retention in care, adherence to care and treatment for at-risk HIV-infected individuals [28,30]. Integration of HIV primary care, specialty care and support services, as occurs within the Veterans Administration and Kaiser Permanente, has been shown to improve the quality of care across the entire continuum of care for people with HIV [34–36].

To date, few studies have explored to what extent sharing patient information across geographically disparate HIV surveillance, primary care and support service organizations

can enhance linkage to care, retention and adherence to care and treatment, the quality of core and support services, as well as health outcomes for people with HIV. Health information exchange (HIE) is the process of electronic multi-directional transfer of identifiable, patient-level information between different organizations. HIE has been previously implemented in the context of other diseases to link public health surveillance programs to primary care services; laboratory and pharmacies to primary care; and primary and specialty care [37–41].

HIE interventions have the potential to close many of the gaps that lead to sub-optimal care for people with HIV. For example, if we share information between surveillance systems and primary HIV care, we can identify individuals with delayed entry or incomplete engagement in care. If we share information between laboratory and primary care settings, we can improve receipt of appropriate laboratory testing and reduce redundant testing. If we share information between primary HIV care and support services, we can enhance coordination of care.

To test the potential of HIEs for supporting better coordinated care in RWP settings, HRSA initiated a SPNS initiative within which six demonstration projects were funded to initiate bi-directional HIE which would enhance linkage to care, quality of HIV care and support services and enhance access to information and coordination of comprehensive care for people with HIV. This paper presents baseline information on patient characteristics and the quality of comprehensive HIV care within the six demonstration sites in the initiative in order to understand the clinical environment in which HIEs can be deployed. We also describe the HIE interventions proposed by each site to address deficiencies in linkage and retention in care, quality of care and access to information to enhance coordination of care. The results of this paper will help define the range of settings and data systems within, which HIE interventions can be implemented to improve comprehensive HIV care for people with HIV.

2. Methods

2.1. Description of the initiative

In 2007, HRSA funded the Information Technology Networks of Care Initiative to assess whether the use of health information technology to enhance sharing of information across public health surveillance programs, primary care programs and support service providers could improve the linkage of HIV-infected individuals into HIV care, as well as the quality, coordination, and effectiveness of that care. The initiative provided support for four years to six organizations (hereafter referred to as "demonstration sites") to promote the implementation of HIE interventions for people living with HIV in underserved communities. These six demonstration sites were: Bronx-Lebanon Hospital Center in Bronx, NY; the City of Paterson (Department of Human Services), NJ; Duke University (Center for Health Policy) in Durham, NC; Louisiana State University Health Services Center in New Orleans, LA; New York-Presbyterian Hospital in New York, NY; and St. Mary Medical Center Foundation in Long Beach, CA. In addition, one Evaluation and Support Center (hereafter referred to as the

“Center”) at the University of California, San Francisco (UCSF) was funded to conduct a cross-site evaluation of the HIE interventions and provide technical assistance and support to the demonstration sites. The protocol for the cross-site evaluation was approved by the Internal Review Board at UCSF.

2.2. Data collection

2.2.1. Quantitative data collection

As part of a broader evaluation plan, the center collected de-identified quantitative data from electronic patient records from each of the demonstration sites for the six-month period preceding the implementation of the HIE interventions. This six-month interval varied among sites and ranged from May 2008 to December 2009. The six demonstration sites provided data from a simple random sample of at least 100 patients from their patient population. The present analyses are based on the combined data from all sites.

2.2.2. Qualitative data collection

Information on proposed HIE interventions was collected through interactions with the demonstration sites and through presentations made during semi-annual grantee meetings.

2.3. Measures

Each agency funded by the RWP is required to submit standardized data for each client to HRSA on an annual basis. This report is known as the Ryan White Services Report (RSR). The data elements used for this evaluation followed the specifications of this report (<http://hab.hrsa.gov/manageyourgrant/clientleveldata.html>), although data were submitted for the previous six months, rather than the required 12 month period to facilitate evaluation of the HIE interventions. The present analyses utilized the following subset of RSR data elements:

2.3.1. Patient characteristics

The patient sample was described using age, gender, ethnicity, race, socio-economic status (as measured by the annual household income as a percent of the federal poverty level), risk behavior for HIV infection (transmission category), housing status and type of health insurance.

2.3.2. HIV-related health status

For new patients was, HIV-related health status characterized by their median CD4 count at first test. New patients were those who utilized HIV care at the reporting clinic for the first time during the reporting period. For all patients, HIV-related health status was characterized by the presence of CDC-defined AIDS and median CD4 cell count at last test.

2.3.3. Engagement in HIV care

Since the data were drawn exclusively from HIV care clinics, the entire sample was considered to be linked into HIV care. Retention in HIV care was defined as at least one outpatient/ambulatory care visit or at least one laboratory test – CD4 or viral load – during the six-month reporting period. The need for antiretroviral therapy was defined as a nadir

CD4 count of ≤ 350 cells/ μ L or an AIDS diagnosis or being on antiretroviral therapy. Similar definitions have been used in previous research and this definition corresponds to clinical practice guidelines in place during the study period [1,9]. The percentage of patients who were prescribed antiretroviral therapy in the reporting period was calculated. A viral load at last test of less than 75 copies/ML was considered as undetectable.

2.3.4. Utilization of non HIV-related health care services

This was assessed using the following:

- screening for tuberculosis, hepatitis B and hepatitis C at least once since the time of HIV diagnosis;
- screening for syphilis, chlamydia and gonorrhea in the six-month reporting period;
- screening for alcohol and drug use, oral health and mental health in the six-month reporting period; and
- completion of vaccinations for hepatitis A, hepatitis B, pneumonia (in the past five years) and influenza (in the past year).

2.3.5. Support services

Support services whose utilization was measured for the six-month reporting period included non-medical case management, treatment adherence counseling, health education/risk reduction, psychosocial support, transportation, outreach, referral for health care/supportive services, housing assistance, emergency financial assistance and food bank or home-delivered meals.

2.3.6. Availability of information to coordinate care and services

The extent of availability of referrals-related data in each of the sites' exchange networks was evaluated. The specific types of data considered were the referrals made and the referrals fulfilled from the primary HIV care provider to other providers (outpatient specialty care, pharmacy, case manager, substance use treatment, mental health provider and others) – as well as the referrals made and those fulfilled from these other providers to the HIV primary care provider.

2.4. Analyses

2.4.1. Quantitative analysis

The demonstration sites provided samples of varying sizes exceeding the minimum requirement of 100 records. We present sample characteristics within each demonstration site using descriptive statistics. To prevent the undue influence of data from sites with higher numbers of records, we weighted the data from each site based on sample size [weight assigned to a given site = $100/(\text{number of data records from that site})$]. These weighted data were used to describe overall sample characteristics, engagement in care, and the utilization of core and support services by the patients. We conducted sensitivity analysis to assess the potential effect of differing patient populations on the quality and continuity of care within each site. For these analyses, data for each site were weighted such that the distribution of patient characteristics resembled the overall patient characteristics for all

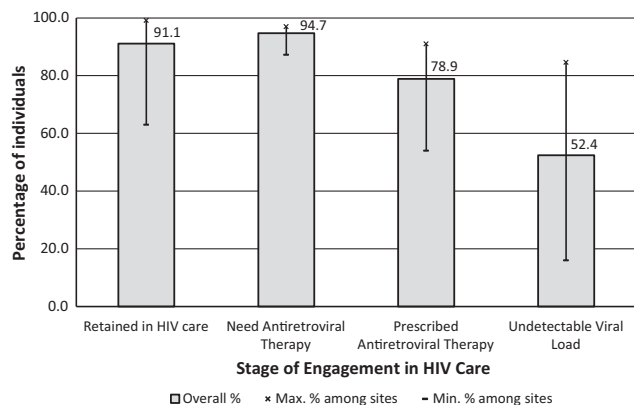


Fig. 1 – Engagement in HIV care.

sites. These analyses employed inverse probability weighting [42,43]. Final weights for the sensitivity analysis include weighting for both varying sample size and distribution of patient characteristics.

2.4.2. Qualitative analysis

We summarize information about the existing data systems and the proposed HIE interventions in tabular form. We describe proposed HIE intervention which target linkage and retention in HIV care, quality of primary HIV care and support services and increased access to information and coordination of care.

3. Results

3.1. Sample characteristics

The sample characteristics for each site are presented in Table 1. Overall, the sample was demographically diverse and patient characteristics varied by site. Most patients were African American/Black (56%) or Caucasian/White (38%), while 25% were Hispanic/Latino. Women made up approximately 40% of the sample and the average patient age was 45 years. The most frequently reported risk factor for HIV was heterosexual contact (38%) followed by MSM (21%). While 36% were at or below the federal poverty level, almost two-thirds (65%) had stable housing. Including Medicaid (42%), a total of 58% of the patients had public health insurance whereas 12% had no insurance in the reporting period. Of the 106 new patients in the sample, CD4 data was available for 84 patients and their median CD4 count at first test was 334 cells/ μ L. A little over half the sample (54%) had CDC-defined AIDS. At the last test in the reporting period, the median CD4 count was 451 and 52% had an undetectable HIV viral load. Roughly 9% of the sample had neither an outpatient/ambulatory care visit nor laboratory tests done in the reporting period.

3.2. Engagement in HIV primary care

Fig. 1 shows the percentage of patients at different stages of engagement in HIV care based on information collected in the preceding six months. Ninety one percent (range across sites

63–99%) were retained in HIV care. Ninety five percent (range 87–97%) were found to be in need of antiretroviral therapy while 79% (range 54–91%) had been prescribed antiretroviral therapy in the reporting period, and HIV viral load was undetectable in 52% (range 16–85%) of the patients. Results were similar when we weighted data to adjust for differences in patient characteristics across sites: 94% were retained in care (range 63–99%); 94% needed ART (range 92–100%); 80% had been prescribed ART (range 54–91%) and 47% had undetectable HIV viral load (range 3–74%).

3.3. Utilization of non HIV-related primary care

Patients' receipt of non HIV-related care is summarized in Table 2. A majority of patients (between 63% and 74%) had been screened for each of tuberculosis, hepatitis B and hepatitis C since their HIV diagnosis. However screening for STDs in the past six months was lower with 43% having been screened for syphilis and only roughly 17% and 19% been screened for chlamydia and gonorrhea, respectively. Furthermore, in the same period, a quarter of the patients had been screened for alcohol and drug use and a third received mental health screening. Less than 20% of patients had completed their hepatitis A and/or B vaccines, 47% had the pneumonia vaccination in the past five years and 57% had an influenza vaccine in the past year.

3.4. Utilization of support services

There was low documented utilization of support services by patients (Table 2). Less than a quarter of the patients were reported to have received non-medical case management and health education/risk reduction services; 31% received treatment adherence counseling. Outreach services and referral for health care/supportive services was utilized by 33% each, psychosocial support services by 21% and transportation services by 14%. Less than 3% used food bank or home-delivered meals, emergency financial assistance and housing services.

3.5. Availability of information to coordinate care and services

While sites usually had complete records related to the utilization of HIV-related and non-HIV-related primary care within their existing data systems, few sites were able to track referrals from HIV primary care to outside specialty care or support services. Only two demonstration sites had information on referrals made to HIV specialty care and support services. However, these sites did not have information on whether patients received these services. Two other demonstration sites had information on specialty care and support services provided. However, these sites did not have information about whether this care was needed or the result of a referral from primary HIV care. None of the demonstration sites had any data in their existing data systems about referrals into HIV primary care from other providers.

Table 1 – Patient characteristics.

Characteristics	Demonstration site					
	1 n = 100	2 n = 117	3 n = 78	4 n = 500	5 n = 196	6 n = 100
Mean age (95% CI)	39.7 (37.7, 41.7)	48.3 (46.4, 50.1)	48.2 (45.3, 51.2)	43.8 (42.9, 44.6)	44.3 (42.9, 45.7)	45.9 (44.1, 47.8)
Gender						
Male	43.0	66.7	48.7	85.8	63.3	46.0
Female	55.0	33.3	50.0	10.6	35.7	54.0
Transgender	2.0	0	1.3	0.4	1	0
Unknown	0	0	0	3.2	0	0
Ethnicity						
Non-Hispanic/Latino	100.0	60.7	61.5	66.4	95.4	60.6
Hispanic/Latino	0	39.3	38.5	30	4.6	38.4
Unknown	0	0	0	3.6	0	0
Race						
Black or African-American	84.0	41.9	71.8	17.2	63.9	59.0
White	16.0	54.7	28.2	60.2	33.5	37.0
Other	0	3.42	0	22.6	2.58	4.0
Income						Not recorded
Equal to or below the Federal poverty level	5.0	67.5	33.3	44.6	68.4	–
Above the Federal poverty level	1.0	32.5	3.9	52.2	23.5	–
Unknown	94.0	0	62.8	3.2	8.2	–
Risk factors for HIV						
Heterosexual contact	31.0	30.8	64.1	10.8	47.5	42.0
MSM	6.0	9.4	7.7	68.4	31.1	5.0
IDU	7.0	4.3	7.7	6	5.6	4.0
Other/unknown	56.0	55.6	20.5	14.8	15.8	49.0
Stable/permanent housing	18.0	92.3	94.9	81.4	81.6	20.0
Health insurance						
Medicaid	23.0	35.7	53.9	16.06	18.9	100.0
Other public	0	35.7	19.2	3.05	0	0
Private	1.0	10.4	1.3	20.5	19.4	0
Other, multiple, unknown	75.0	17.4	25.7	27.2	21.1	0
No insurance	1	0.9	0	33.1	40.6	0
HIV-related health status						
CDC-defined AIDS	49.0	51.3	74.4	60.6	53.6	36.0
Median CD4 cell count						
For new patients (at first test)	No new patients	249.0	358.0	417.0	330.0	323.0
For all patients (at last test in reporting period)	296.0	403.0	451.0	451.0	415.0	470.0

Results are presented as proportions (%) for each column.

3.6. Proposed HIE interventions

Each of the six demonstration sites proposed one or more HIE interventions in order to increase patient linkage and retention in care, the quality of primary HIV care and support service and/or access to information to improve coordination of care. These interventions are summarized in Table 3 and described below.

3.6.1. HIE to increase linkage and retention in HIV care

Two sites proposed HIE interventions, which employed data from surveillance and other systems to engage HIV-infected individuals in care. Site 1 proposed to use information from surveillance systems and electronic medical records within the public health system to create a list of individuals who had been identified as HIV-infected but were not currently in HIV primary care (had not ever received a CD4 or viral load test or had not received one in at least the past year). When individuals on this list present for care at an emergency room

within the public health system, the provider is sent an alert that this person is HIV-infected and not receiving HIV primary care. The provider is also sent a list of tailored instructions for next steps to take with each person. Site 2 proposed to use surveillance data to notify providers when an individual tests positive for HIV. In addition, Site 2 proposed to supplement this notification by creating an alert within its web-based electronic medical record which notifies case managers if a patient does not enter care within two weeks of receiving their test results.

3.6.2. HIE to increase quality of primary HIV care and support services

Three sites proposed HIE interventions to increase the quality and efficiency of HIV primary care and support services. Sites 2 and 3 propose to employ quality improvement methods to encourage providers to address specific health concerns (e.g. out of range laboratory values) or needed services (e.g. screening and vaccination). Site 2 will send reminders, which

Table 2 – Utilization of non-HIV-related primary care and support services.

	Sites with data ^a	Overall %	Range across sites min–max
Non-HIV-related primary care			
<i>Screenings</i>			
Since HIV diagnosis			
Tuberculosis	6	68.3	39.0–92.3
Hepatitis B	6	73.6	27.4–99.0
Hepatitis C	6	63.3	10.7–97.0
During the 6-month reporting period:			
Syphilis	6	42.7	4.0–80.8
Chlamydia	6	16.9	0.9–50.2
Gonorrhea	5	18.7	0.9–85.9
Substance use	6	25.8	0.0–71.0
Mental health	6	33.5	0.0–93.6
Oral health	3	6.0	0.0–18.0
<i>Vaccinations</i>			
Hepatitis A	5	13.1	0.0–29.1
Hepatitis B	6	16.9	0.0–29.5
Pneumonia (5 years)	5	47.1	0.0–77.8
Influenza (1 year)	5	56.5	44.0–79.5
Support services			
Case management (non-medical)	6	23.3	3.0–66.7
Treatment adherence counseling	5	31.2	10.3–90.0
Health education/risk reduction	6	23.8	0.0–100
Psychosocial support services – other	6	21.3	0.0–57.0
Transportation services	6	14.2	0.0–35.7
Outreach services	3	33.3	0.0–100
Referral for specialty care/support services	3	33.7	0.0–82.0
Housing services	3	1.4	0.0–4.1
Emergency financial assistance	2	2.3	0.0–4.6
Food bank/home-delivered meals	4	2.6	0.0–6.4

^a For measures that were reported by a subset of the sites, the presented statistics are based on the data from those sites alone.

Table 3 – Proposed health information exchange (HIE) interventions.

Site	N ^b	Databases included in HIE	Proposed HIE intervention	Anticipated outcomes
1	4800	Surveillance database; electronic medical record	Alert to initiate care for out of care patients who present in emergency rooms and other health care settings	Improved linkage/re-engagement in care; improved health outcomes
2	263	Electronic medical record; support service databases	Web-based electronic health record accessible by all health service providers; quality improvement framework; quality alerts	Improved quality of care; improved efficiency; improved health outcomes
3	350	Electronic medical record	Structured patient summary; quality alerts; expanded access to external case managers	Improved quality of care; improved coordination of care; improved health outcomes
4	1181	Electronic medical record	Electronic prescribing; electronic laboratory test orders and results	Improved linkage to care; improved efficiency of care; improved health outcomes
5	3611	Electronic health record	Electronic health record; expanded access to external support service providers	Improved coordination of care; improved health outcomes
6	5578	Medical claims laboratory data	Structured patient summaries; expanded access to patients and external providers	Improved coordination of care; improved health outcomes

^b N, patient population size within each demonstration site.

need to be addressed to each site/provider on a regular basis. The provider can then explore the global summary of alerts to identify the patient associated with each alert within the web-based electronic medical record. Site 3 will generate a patient summary within each person's electronic medical record, which will indicate specific health concerns or needed services for that individual. Site 4 proposed to implement electronic prescribing and electronic processing of laboratory test orders in order to increase the quality and efficiency of HIV primary care.

3.6.3. HIE to increase access to information and coordination of care

Four sites proposed HIE interventions to increase access to information for support service providers and patients. Site 2 proposed to provide access for all service providers to information on all patient services by implementing a web-based electronic medical record system. Site 5 proposed to export data from an existing electronic medical record system into an external electronic medical record system which could then be accessed by primary, as well as, support service providers. Sites 3 and 6 proposed to generate patient summaries, which would then be accessible to providers (both sites) and/or patient (site 6).

4. Discussion

The quality of HIV care within the six demonstration sites exceeds that of previously published estimates. Previous reviews of engagement in HIV care within the United States suggest that among HIV-infected individuals linked to care, 67% are retained in care, 53% need antiretroviral therapy, 40% are on antiretroviral therapy and 32% have achieved undetectable viral load [2]. In contrast, among patients in the present sample, 91% are retained in care, 95% need antiretroviral therapy, 79% are on antiretroviral therapy and 52% have achieved undetectable viral load.

We observed substantial variation in the quality of HIV care across the demonstration sites. In one site, retention in care, prescription of antiretroviral therapy and achievement of undetectable viral load was similar to or lower than previously published estimates. This variation is likely due to differences across sites in patient populations, stage of illness and social isolation which all impact the degree of engagement in care [31,44]. This variation may also be due to limitations in the provision of needed support services to enhance engagement and retention in care, limitations in the provision of non-HIV related health services to prevent co-occurring conditions or a lack of information needed to coordinate care and services. Each of these impact patients' ability to engage in care and reduces the effectiveness of HIV care and treatment [2,26,44]. Previous research suggests that between one-fifth and one-third of people with HIV have an unmet need for support services [30]. If patients in lower performing sites have higher needs for support services and specialty care, then the gaps in the engagement in care continuum may be greater than in other sites even though the quality of care is similar.

HIE interventions can play a crucial role in facilitating the sharing of information among providers across the continuum

of HIV care, which in turn can help close each of these gaps [28–32]. For instance, in settings where patients do not engage or remain in HIV care, it is possible to use coordinated information technology systems to identify out-of-care patients when they utilize any type of care (e.g. emergency room visits). Similarly, in settings where patients do not receive optimal care (e.g. antiretroviral therapy, routine screening and vaccination), information technology can be used to facilitate continuous quality improvement activities. In settings where patients have unmet needs for services outside of primary care, HIE can be used to link primary care providers with laboratories, pharmacies, support service providers and specialty care thereby creating a closed loop of information exchange that prevents those in most need of care from falling through the cracks. Each of these types of interventions was implemented by one or more demonstration sites in this initiative. The results from these projects are described in this issue.

The present results should be interpreted in the context of certain limitations. First, since patients were sampled from care sites, the sample is more likely to include individuals retained in care. However, in a previous review, among patients retained in care, 80% needed antiretroviral therapy, 60% were on antiretroviral therapy, and 48% had achieved undetectable viral load [2]. Given these estimates, engagement in care among the six demonstration sites still exceeds that found in previously published reviews. Second, since all data are taken from patients medical records, we do not know whether gaps in reported services are due to deficiencies in care or lack of documentation of care provided. However, since documentation of care provided is required to ensure coordination of efficient care, inclusion of only documented care is valid in this setting. Third, the six SPNS demonstration sites may not represent the broader population of RWP-funded health settings, which may limit the generalizability of these results. Sites that are able to implement HIEs are likely to have more established relationships with support service and/or specialty care providers.

5. Conclusion

Linkage to care, retention in care, appropriate use of antiretroviral therapy and viral suppression are key components of comprehensive HIV care and prevention. However, there are many systemic and individual barriers which limit the provision of comprehensive HIV care for all people with HIV. We believe that HIE can play an integral role in bringing together the fragments of our health system to improve health outcomes for people with HIV as well as those at risk for HIV.

Authors' contributions

SBS: conceived idea, drafted introduction and discussion, led revision of manuscript, reviewed final manuscript. DC: managed data, conducted analysis, drafted methods and results, contributed to revision of manuscript, reviewed final manuscript. KK: led the qualitative evaluation, contributed to revision of manuscript, reviewed final manuscript. WTS: led evaluation, contributed to revision of manuscript, reviewed final manuscript. JJM: conceived study, obtained funding,

Summary points

What was already known on the topic?

- Engagement and retention in HIV care in the U.S. is sub-optimal.
- The Ryan White Care Program was developed to facilitate engagement and retention in comprehensive, multidisciplinary care for people with HIV.
- Health information exchange has potential to improve coordination of comprehensive primary care, specialty care and support services for people with HIV.

What this study added to our knowledge?

- Engagement in HIV care and treatment within the Ryan White funded demonstration sites exceeded previously published estimates.
- However, there was much variation across sites and many gaps in the documented provision of specific services and referrals.
- Health information exchange of surveillance, primary care, laboratory, pharmacy and/or support service data may facilitate linkage to care and improve the quality and coordination of comprehensive care for people with HIV.

contributed to framing and revision of manuscript, reviewed final manuscript.

Conflict of interest statement

The authors have no known conflicts of interest regarding this study.

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REFERENCES

- [1] S.M. Hammer, J.J. Eron Jr., P. Reiss, R.T. Schooley, M.A. Thompson, S. Walmsley, P. Cahn, M.A. Fischl, J.M. Gatell, M.S. Hirsch, D.M. Jacobsen, J.S. Montaner, D.D. Richman, P.G. Yeni, P.A. Volberding, Antiretroviral treatment of adult HIV infection: 2008 recommendations of the International AIDS Society-USA panel, *J. Am. Med. Assoc.* 300 (2008) 555–570.
- [2] E.M. Gardner, M.P. McLees, J.F. Steiner, C. Del Rio, W.J. Burman, The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection, *Clin. Infect. Dis.* 52 (2011) 793–800.
- [3] National HIV/AIDS Strategy. Available at: <http://www.whitehouse.gov/administration/eop/onap/nhas/>. Accessed July 24, 2012.
- [4] L.W. Cheever, Engaging HIV-infected patients in care: their lives depend on it, *Clin. Infect. Dis.* 44 (2007) 1500–1502.
- [5] M.J. Mugavero, Improving engagement in HIV care: what can we do? *Top. HIV Med.* 16 (2008) 156–161.
- [6] M.L. Millman, *Access to Health Care in America*, National Academies Press, 1993.
- [7] M.J. Mugavero, H.Y. Lin, J.J. Allison, T.P. Giordano, J.H. Willig, J.L. Raper, N.P. Wray, S.R. Cole, J.E. Schumacher, S. Davies, M.S. Saag, Racial disparities in HIV virologic failure: do missed visits matter? *J. Acquir. Immune Defic. Syndr.* 50 (2009) 100–108.
- [8] M.J. Mugavero, H.Y. Lin, J.H. Willig, A.O. Westfall, K.B. Ulett, J.S. Routman, S. Abrams, J.L. Raper, M.S. Saag, J.J. Allison, Missed visits and mortality among patients establishing initial outpatient HIV treatment, *Clin. Infect. Dis.* 48 (2009) 248–256.
- [9] C. Tobias, W.E. Cunningham, C.O. Cunningham, M.B. Pounds, Making the connection: the importance of engagement and retention in HIV medical care, *AIDS Patient Care STDS* 21 (2007) 3–8.
- [10] L.V. Torian, E.W. Wiewel, Continuity of HIV-related medical care, New York City, 2005–2009: do patients who initiate care stay in care? *AIDS Patient Care STDS* 25 (2011) 79–88.
- [11] L.V. Torian, E.W. Wiewel, K.L. Liu, J.E. Sackoff, T.R. Frieden, Risk factors for delayed initiation of medical care after diagnosis of human immunodeficiency virus, *Arch. Intern. Med.* 168 (2008) 1181–1187.
- [12] A. Tripathi, L.I. Gardner, I. Ogbuanu, E. Youmans, T. Stephens, J.J. Gibson, W.A. Duffus, Predictors of time to enter medical care after a new HIV diagnosis: a statewide population-based study, *AIDS Care* 23 (2011) 1366–1373.
- [13] A. Tripathi, E. Youmans, J.J. Gibson, W.A. Duffus, The impact of retention in early HIV medical care on viro-immunological parameters and survival: a statewide study, *AIDS Res. Hum. Retroviruses* 27 (2011) 751–758.
- [14] W.E. Cunningham, R.M. Andersen, M.H. Katz, M.D. Stein, B.J. Turner, S. Crystal, S. Zierler, K. Kuromiya, S.C. Morton, P. St Clair, S.A. Bozzette, M.F. Shapiro, The impact of competing subsistence needs and barriers on access to medical care for persons with human immunodeficiency virus receiving care in the United States, *Med. Care* 37 (1999) 1270–1281.
- [15] G.J. Huba, L.A. Melchior, G.A.D. Smereck, V.B. Brown, E. Jean-Louis, V.F. German, T. Gallagher, S.S. McDonald, A. Stanton, C. Hughes, Perceived barriers to receiving HIV services in groups of traditionally underserved individuals: empirical models, *Home Health Care Serv. Q.* 19 (2001) 53–75.
- [16] H. Palacio, C.H. Shiboski, E.H. Yelin, N.A. Hessol, R.M. Greenblatt, Access to and utilization of primary care services among HIV-infected women, *J. Acquir. Immune Defic. Syndr.* 21 (1999) 293.
- [17] S.A. Bozzette, S.H. Berry, N. Duan, M.R. Frankel, A.A. Leibowitz, D. Lefkowitz, C.A. Emmons, J.W. Senterfitt, M.L. Berk, S.C. Morton, The care of HIV-infected adults in the United States, *N. Engl. J. Med.* 339 (1998) 1897–1904.
- [18] V.B. Brown, G.A.D. Smereck, V. German, C. Hughes, L.A. Melchior, G.J. Huba, Change in perceived barriers and facilitators to treatment among women with HIV/AIDS as a function of psychosocial service utilization, *AIDS Patient Care STDS* 14 (2000) 381–390.
- [19] L.M. Bogart, S. Thorburn, Are HIV/AIDS conspiracy beliefs a barrier to HIV prevention among African Americans? *J. Acquir. Immune Defic. Syndr.* 38 (2005) 213.

- [20] R.H. Feldman, R. Fulwood, The three leading causes of death in black Americans: barriers to reducing excess disparity and to improving health behaviors, *J. Health Care Poor Underserved* 10 (1999) 45.
- [21] G.F. Joyce, K.S. Chan, M. Orlando, M.A. Burnam, Mental health status and use of general medical services for persons with human immunodeficiency virus, *Med. Care* 43 (2005) 834.
- [22] W.D. Klinkenberg, S. Sacks, Mental disorders and drug abuse in persons living with HIV/AIDS, *AIDS Care* 16 (2004) 22–42.
- [23] A.L. Gifford, R. Collins, D. Timberlake, M.A. Schuster, M.F. Shapiro, S.A. Bozzette, D.E. Kanouse, Propensity of HIV patients to seek urgent and emergent care, *J. Gen. Intern. Med.* 15 (2000) 833–840.
- [24] S.C. Kalichman, D. Rompa, Functional health literacy is associated with health status and health-related knowledge in people living with HIV–AIDS, *J. Acquir. Immune Defic. Syndr.* 25 (2000) 337.
- [25] J.S. Bodenlos, K.B. Grothe, K. Kendra, D. Whitehead, A.L. Copeland, P.J. Brantley, Attitudes toward HIV health care providers scale: development and validation, *AIDS Patient Care STDs* 18 (2004) 714–720.
- [26] R. Conviser, M. Pounds, Background for the studies on ancillary services and primary care use, *AIDS Care* 14 (2002) 7–14.
- [27] Health Resources and Services Administration: HIV/AIDS Program. Available at: <http://www.hab.hrsa.gov/>. Accessed July 24, 2012.
- [28] J.J. Ashman, R. Conviser, M.B. Pounds, Associations between HIV-positive individuals' receipt of ancillary services and medical care receipt and retention, *AIDS Care* 14 (suppl. 1) (2002) S109–S118.
- [29] D. Chan, D. Absher, S. Sabatier, Recipients in need of ancillary services and their receipt of HIV medical care in California, *AIDS Care* 14 (suppl. 1) (2002) S73–S83.
- [30] C.J. Conover, K. Whetten-Goldstein, The impact of ancillary services on primary care use and outcomes for HIV/AIDS patients with public insurance coverage, *AIDS Care* 14 (Suppl 1) (2002) S59–S71.
- [31] R. Conviser, M.B. Pounds, The role of ancillary services in client-centred systems of care, *AIDS Care* 14 (Suppl 1) (2002) S119–S131.
- [32] D. Karus, V.H. Raveis, K. Marconi, B. Hanna, P. Selwyn, C. Alexander, M. Perrone, I. Higginson, Service needs of patients with advanced HIV disease: a comparison of client and staff reports at three palliative care projects, *AIDS Patient Care STDS* 18 (2004) 145–158.
- [33] P.S. Sullivan, M. Denniston, E. Mokotoff, S. Buskin, S. Broyles, A.D. McNaghten, Quality of care for HIV infection provided by Ryan White Program-supported versus non-Ryan White Program-supported facilities, *PLoS One* 3 (2008) e3250.
- [34] M.J. Mugavero, W.E. Norton, M.S. Saag, Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system, *Clin. Infect. Dis.* 52 (suppl. 2) (2011) S238–S246.
- [35] M.B. Goetz, T. Hoang, C. Bowman, H. Knapp, B. Rossman, R. Smith, H. Anaya, T. Osborn, A.L. Gifford, S.M. Asch, A system-wide intervention to improve HIV testing in the Veterans Health Administration, *J. Gen. Intern. Med.* 23 (2008) 1200–1207.
- [36] M.H.L. Horberg, W. Towner, et al., Antiretroviral therapy (ART) adherence and HIV RNA (VL) control as HIV quality measures in Kaiser Permanente (KP), in: 5th International Conference on HIV Treatment Adherence, Miami, 2010 (abstract # 61795).
- [37] P.J. Branger, A. van't Hooft, J.C. van der Wouden, P.W. Moorman, J.H. van Bommel, Shared care for diabetes: supporting communication between primary and secondary care, *Int. J. Med. Inf.* 53 (1999) 133–142.
- [38] A.R. Hinman, A.J. Davidson, Linking children's health information systems: clinical care, public health, emergency medical systems, and schools, *Pediatrics* 123 (suppl. 2) (2009) S67–S73.
- [39] D.C. Kaelber, D.W. Bates, Health information exchange and patient safety, *J. Biomed. Inform.* 40 (2007) S40–S45.
- [40] R. Kaushal, K.N. Barker, D.W. Bates, How can information technology improve patient safety and reduce medication errors in children's health care? *Arch. Pediatr. Adolesc. Med.* 155 (2001) 1002–1007.
- [41] J.R. Vest, J.S. Jasperson, H. Zhao, L.D. Gamm, R.L. Ohsfeldt, Use of a health information exchange system in the emergency care of children, *BMC Med. Inform. Decis. Making* 11 (2011) 78.
- [42] M.A. Hernan, B. Brumback, J.M. Robins, Marginal structural models to estimate the causal effect of zidovudine on the survival of HIV-positive men, *Epidemiology* 11 (2000) 561–570.
- [43] J.M. Robins, M.A. Hernan, B. Brumback, Marginal structural models and causal inference in epidemiology, *Epidemiology* 11 (2000) 550–560.
- [44] M.E. Lewin, S.H. Altman, *America's Health Care Safety Net: Intact but Endangered*, National Academies Press, 2000.