UC San Diego

UC San Diego Previously Published Works

Title

Detecting Disengagement From HIV Care Before It Is Too Late: Development and Preliminary Validation of a Novel Index of Engagement in HIV Care.

Permalink

https://escholarship.org/uc/item/81v3k4g2

Journal

JAIDS Journal of Acquired Immune Deficiency Syndromes, 81(2)

ISSN

1525-4135

Authors

Johnson, Mallory O Neilands, Torsten B Koester, Kimberly A et al.

Publication Date

2019-06-01

DOI

10.1097/qai.0000000000002000

Peer reviewed



Published in final edited form as:

Detecting Disengagement from HIV Care Before It's Too Late: Development and Preliminary Validation of a Novel Index of Engagement in HIV Care

Mallory O. JOHNSON, Ph.D. [Professor],

Department of Medicine, University of California, San Francisco, 550 16th Street, 3rd Floor, San Francisco, CA 94158, USA

Torsten B. NEILANDS, Ph.D. [Professor],

Department of Medicine, University of California, San Francisco, 550 16th Street, 3rd Floor, San Francisco, CA 94158, USA

Kimberly A. KOESTER, Ph.D. [Assistant Professor],

Department of Medicine, University of California, San Francisco, 550 16thStreet, 3rdFloor, San Francisco, CA 94158, USA

Troy WOOD, M.A. [Clinical Social Worker],

Department of Medicine, University of California, San Francisco, 550 16thStreet, 3rdFloor, San Francisco, CA 94158, USA

John A. SAUCEDA, Ph.D. [Assistant Professor],

Department of Medicine, University of California, San Francisco, 550 16thStreet, 3rdFloor, San Francisco, CA 94158, USA

Samantha E. DILWORTH, M.S. [Senior Statistician],

Department of Medicine, University of California, San Francisco, 550 16thStreet, 3rdFloor, San Francisco, CA 94158, USA

Michael J. MUGAVERO, M.D. [Professor],

Division of Infectious Diseases, University of Alabama at Birmingham, 908 20th St S, Birmingham, AL 35205, USA

Heidi M. CRANE, M.D. [Professor].

Department of Medicine, University of Washington, 325 9th Ave, Seattle, WA 98104, USA

Rob J. FREDERICKSEN, Ph.D. [Senior Research Scientist],

University of Washington, Department of Medicine, 325 9th Avenue, Seattle WA 98104, USA

Kenneth H. MAYER, M.D. [Medical Research Director],

The Fenway Institute, Fenway Health, 1340 Boylston Street, Boston, MA 02215, USA

William Christopher MATHEWS, M.D. [Emeritus Professor of Clinical Medicine, Co-Director],

Clinical Investigation Core, UCSD CFAR, UCSD Owen Clinic, UC San Diego Health System, UCSD Medical Center, 8681, 200 W. Arbor Dr., San Diego, CA 92103, USA

Richard D. MOORE, M.D. [Professor],

Department of Medicine, Johns Hopkins University, 1830 E. Monument St, Room 8059, Baltimore, MD 21287, USA

Sonia NAPRAVNIK, Ph.D. [Associate Professor], and

Department of Medicine, University of North Carolina, Chapel Hill, 130 Mason Farm Rd, 2101 Bioinformatics Building, Chapel Hill, NC 27599-7215, USA

Katerina A. CHRISTOPOULOS, M.D. [Associate Professor]

Department of Medicine, Zuckerberg San Francisco General Hospital, University of California San Francisco, 995 Potrero Ave, 4th Floor, San Francisco CA 94110, USA

Abstract

Background: Engagement in care is critical to achieving and sustaining optimal benefits of efficacious antiretroviral therapies (ART) for HIV infection. Current metrics of engagement in care, including problematic patterns of retention in care, adherence to treatment, and viral suppression, are often detected late in the disengagement process. We sought to develop and validate a patient-centered screener of engagement in care that can be used to identify deficits in patient perceptions of engagement prior to the development of poor outcomes, including loss to follow-up, treatment nonadherence, virologic failure, and the resulting increased likelihood of HIV-associated morbidity and mortality and onward transmission of HIV.

Setting and Methods: Using input from patients, providers, and researchers through in-person focus groups and an online Delphi process, we developed a self-report measure of engagement in care that was validated with 3,296 patients from seven clinics across the U.S.

Results: Results supported a single dimension of engagement in care measured by ten items. Lower scores on the HIV Index were related to higher depression and anxiety symptoms, greater use of alcohol and stimulants, and increased likelihood of reporting internalized HIV stigma. Higher Index scores were positively associated with self-report measures of ART adherence, corroborative clinic records documenting appointment attendance, and increased likelihood of recent viral load suppression.

Conclusion: The HIV Index offers promise as a patient-centered diagnostic and prognostic screener for engagement in care that can be used to trigger interventions to promote better clinical outcomes for persons living with HIV.

Keywords

HIV/AIDS; engagement in care; adherence to care; retention in care; clinical assessments

INTRODUCTION

The increasing availability of potent antiretroviral therapies (ART) offers the promise of decreased HIV-associated morbidity, mortality, and substantially lower likelihood of HIV transmission to others [1–4]. However, many health care systems tasked with providing ART

and ongoing care for HIV-infected patients can improve to achieve and sustain optimal outcomes [5].

Because treatment success of ART in the current "treat all" era emphasizes rapid uptake, ongoing adherence, and lifelong persistence with ART [5], promoting sustained engagement in care is paramount [6]. Historically, engagement in HIV care has been defined through indicators such as self-reported medication adherence, appointment attendance/retention in care, and ultimately virologic suppression [6–9]. However, we contend that these indicators are better seen as distal outcomes of engagement in care rather than defining dimensions of the care engagement process.

To better understand and support patients in achieving optimal clinical outcomes, patient perspective on the process and dimensions of engagement in care must be defined and measured. Existing measures have attempted to capture the patient role in health promotion, such as the Patient Activation Measure [10] and the Patient Health Engagement Scale [11]. However, the complicated social environment of HIV creates unique challenges characterized by social stigma and the disproportionate concentration of HIV in racial, ethnic, sexual and gender minority communities and people who use drugs. Further, these social factors were not directly considered during the development of other measurement approaches. To meet these challenges, we developed and validate a patient-centered measure of engagement in HIV care that would allow the detection of deficits in perceived engagement in care prior to the emergence of problematic clinical outcomes such as poor ART adherence, non-persistence, suboptimal retention in care, virologic failure and subsequent onward HIV transmission.

We describe the development and preliminary validation of the HIV Index of Engagement, a 10-item self-report, patient-centered screener of engagement in care. In developing and validating the instrument, we ensured high representation among groups disproportionately impacted by HIV and the researchers and providers who work with them. Such a measure could be used to identify problematic levels of engagement in care, thereby triggering efforts to mitigate poor engagement before clinical outcomes are negatively impacted.

METHODS

Overview

We present the HIV Index of Engagement, or HIV Index for short, which is a 10-item, unidimensional scale that was developed using an iterative process of online consensus building, Delphi Process [12] and focus groups with patients in three U.S. cities. Items were tested through cognitive interviews and then validated with patients from seven HIV clinics affiliated with the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) [13, 14].

Item Development

The procedures for the Delphi and focus group methods are described in detail elsewhere [12, 15]. The Delphi methodology comprised four iterative rounds of online surveys administered to 66 experts in three categories: HIV clinical care providers, engagement in

HIV care researchers, and researchers focused on engagement in care and clinicians working in non-HIV fields. Twelve focus groups with patients in San Francisco, CA, Birmingham, AL, and Seattle, WA were conducted between Delphi rounds, with findings fed back into subsequent data collection. Inquiries started with broad, open-ended questions, such as "How would you describe patients who are well-engaged in health care?" responses to which led to a distinction between historical components of engagement in care (i.e., appointment attendance, adherence to treatment, and optimal clinical outcomes) and the patient-centered perceptual and experiential aspects of care. This, in turn, resulted in a working definition of engagement in care to capture the patient-centered facets to describe someone who is "fully engaged in care": 'Engagement in care is the ongoing interaction of patients, their providers, and care settings that is characterized by a patient's sense of connection to and active participation in care." This structure promoted the generation of a large number of topics related to the broader construct of full engagement, which were subsequently ranked for importance by the Delphi panelists. The research team then drafted candidate Index items. Of note is that one item, "My provider really understands me as a person," came directly from prior published work in the area of HIV treatment adherence [16].

Analysis and discussion resulted in refinement, combination, and elimination of some items based on the following criteria: (1) Candidate items were retained if they were universally applicable to all patients; we removed items that were relevant only to subsets of patients, such as topics related to unmet childcare needs and the need for substance abuse treatment, (2) items were removed if they were operationalized as correlates of engagement e.g. substance use, psychiatric symptoms or outcomes of engagement (e.g. ART adherence, retention in care, and virologic control), and(3) we conducted twenty-five cognitive interviews with patients in three clinics to assess clarity and interpretation of 21 candidate items. Items that were not consistently understood by patients were revised or eliminated. This process resulted in 13 items for subsequent factor analysis and validation.

Validation Procedures

From April 2016 to March 2017, the 13 candidate items were added to the clinical assessment of patient reported measures and outcomes (PROs) [17–19] completed as part of routine clinical care visits at seven academic HIV clinics affiliated with CNICS. The inclusion criteria for a patient to be enrolled in the CNICS cohort are at least 18 years old, HIV-positive, and having at least two HIV primary care visits at a CNICS site. The assessment includes brief self-administered assessments of depression, ART adherence, alcohol and drug use, and internalized HIV stigma, among other areas. The CNICS data repository links data from the clinical assessment, electronic health record (EHR), and other sources, including demographic characteristics, laboratory, medication, and visit data. *A priori* comparisons were planned between scores on the new HIV Index and PRO and EHR variables hypothesized to correlate with engagement in care.

Measures

Index of Engagement in HIV Care.—The 13-item version of the HIV Index was administered to patients completing PRO assessments at each of the seven sites.

Background and demographic variables

Patient characteristics were extracted from the CNICS data repository and included age, gender, race, ethnicity, sexual orientation, and time since enrollment in the CNICS cohort (Table 1).

Hypothesized correlates of engagement in care.—Relevant data were evaluated for associations with domains expected to be negatively related to scores on the HIV Index. Symptoms of depression and anxiety were operationalized as continuous indicators measured using the Patient Health Questionnaire-9 (PHQ-9) [20, 21]. Alcohol and stimulant use were assessed using AUDIT-C and the ASSIST [22–24], respectively, with alcohol use/dependence/abuse measured on a continuous scale and stimulant use as any reported cocaine, crack, or methamphetamine use in the prior 3 months, in the distant past, or no prior use. Internalized HIV stigma was assessed with a four-item version of a validated sixitem scale [25].

Hypothesized outcomes of engagement in care.—There were three main categories of variables that were hypothesized to be related to the HIV Index: ART adherence, retention in HIV care, and HIV viral load.

HIV medication adherence.: We coded each patient as currently taking ART or not as per self-report. Because treatment guidelines strongly support that all patients with HIV initiate ART [26], we hypothesized that not being on ART would be related to lower HIV Index scores. Second, self-reported adherence to HIV medications for those on ART was hypothesized to be positively associated with HIV Index scores and was assessed using two validated measures. The HIV Adherence Rating Scale asks patients to rate their ability to take HIV medications as prescribed over the prior 30 days [27], with response choices from Excellent to Very Poor. The Visual Analog Scale (VAS) asks from 0–100, of the amount they were supposed to take, the proportion of prescribed medications taken over the prior 30 days [28].

Retention in HIV care.: We hypothesized that better retention in care would be related to higher HIV Index scores. As an indicator of retention in care, we constructed the following variables from clinic attendance data during the 18 months prior to administration of the HIV Index: (1) two or more missed visits in the prior 12 months, (2) the proportion of kept primary care visits in the 12 months prior to HIV Index administration, and (3) a visit constancy measure based on whether the patient attended at least one HIV care visit in each of the two six-month intervals starting 180 days prior to the HIV Index administration. Note that this operationalization necessitated the restriction of analyses focused on retention to patients who had been in care at the site for at least the reporting period for each retention variable so that all cases had the opportunity for appointment attendance during a comparable retention window.

HIV viral load.: Virologic suppression is a key outcome of HIV clinical care and hypothesized to be related to HIV Index scores. We used EHR records to identify the HIV viral load results closest in time to the collection of HIV Index data. Because viral load is

not assessed at each clinical care visit, we included those patients with a test result within 90 days before or after the HIV Index administration. We defined suppressed viral load as fewer than 200 copies per mL.

Data Analysis.: SAS 9.4 [29] was used to generate frequency tables to characterize the sample and responses to the 13 HIV Index items as well as to perform the reliability, predictive validity, and convergent validity analyses described below. The sample was randomly split into two approximate halves, a factor extraction (i.e., exploratory) subsample and a factor structure testing (i.e., validation) subsample, stratified by recruitment site to maintain balance by site. In the factor extraction subsample, items were initially screened using FACTOR 10.8.03 [30] to determine the number of factors to retain via the Hull method [31] and to examine items' unidimensionality via the explained common variance (ECV) and mean of residual absolute loadings (MIREAL) statistics [32]. Corresponding item-level statistics, I-ECV and I-REAL, were used to identify individual non-unidimensional items, which were dropped from further analyses.

Following item screening, exploratory factor analyses (EFAs) were performed on the remaining items in the factor extraction subsample. Then confirmatory factor analyses (CFAs) were performed on the validation subsample. Global model fit was assessed using the chi-square test of exact fit and the following well-studied measures of approximate fit: the Root Mean Square Error of Approximation (RMSEA), Bentler's Comparative Fit Index (CFI), and the Standardized Root Mean Square Residual (SRMR). Satisfactory model-data fit was determined by: a) RMSEA .06 and SRMR .08 or b) CFI .95 and SRMR .08 [33].

"Don't know" and "not applicable" responses were treated as missing data, resulting in 25% of cases having missing values. As a sensitivity analysis the EFA and CFA analyses were repeated using 50 data sets with missing values imputed via multiple imputation (MI) [34]. Mplus version 8.1 was used to perform EFAs and CFAs [35].

Internal reliability for the HIV Index for the factor extraction and validation data subsets was assessed by computing Cronbach's coefficient alpha [36]. Predictive validity analyses were then performed on the entire sample to assess the associations of the HIV Index scale score with HIV detectable viremia, HIV care appointment attendance (i.e., retention), and HIV medication adherence-related measures (e.g., being on ART, adherence quality). Binary logistic regression was used for dichotomous clinical and adherence outcomes, ordinal logistic regression was used for the ordinal adherence rating scale, and the Spearman rank-order correlation coefficient was used for the continuous non-normally distributed proportion of HIV care visits attended variable. For the analysis of the adherence rating scale, the proportional odds assumption was tested. For all logistic regression analyses, the HIV Index scale score was rescaled in standard deviation units so that odds ratios reflected changes in the odds of each level of the outcome relative to next lowest level of the outcome per standard deviation increase in the Index score.

Finally, convergent and discriminant validity were assessed by correlating the HIV Index scores with the existing measures described above. These correlations were calculated using

Spearman's rank-order method. As a sensitivity analysis, the correlations were recomputed based on 50 multiply-imputed datasets.

RESULTS

Sample and HIV Index Item Characteristics.

More than half (51.6%) of the sample of 3,296 patients were older than 50 years, four-fifths were male (79.6%), 40.7% Black/African American, 44.7% White, and 67.0% identified as sexual minority (i.e., gay, lesbian, bisexual, other). Most participants were on ART (94.3%) and virologically suppressed (89.7%).

The average number of individuals who did not respond to any single item was 3.4%, with a median of 2.5% (Table 2). One item, "How often do you refill HIV medications on time?", permitted a "not applicable" response, resulting in 15.6% having not applicable or missing responses, due to 5.7% not being on ART and others likely due to those respondents obtaining automatic prescription refills. In general, the sample consisted of very well engaged patients, with the majority of respondents endorsing the top two levels of engagement for all questions (Table 2).

Item Screening Step.

The Hull method indicated that a single factor best represented the shared variance among the 13 HIV Index items. The scale ECV (.904) and MIREAL (.210) exceeded the recommended thresholds for unidimensionality. The item-level I-ECV and I-REAL indices of unidimensionality exceeded the recommended thresholds for all items except for: "How important is it for you to set goals for your health?" (I-ECV = .734; I-REAL = .387), "How often do you refill your HIV medications on time?" (I-ECV = .719; I-REAL = .233), and "How important is it for you to stay informed about new HIV research findings?" (I-ECV = .573; I-REAL = .518). These three items were removed, yielding a reduced 10-item scale with one latent factor (see Table 3 for the retained items).

Exploratory Factor Analyses (EFA).

EFA of the 10 retained items indicated excellent fit for the one-factor solution: $\chi^2(35) = 273.06$, p < .001; RMSEA = .064; CFI = .990; and SRMR = .032. Factor loadings indicated strong factor-variable relationships with most items' loadings exceeding .70 (Table 3). Refitting the one-factor EFA using MI datasets yielded highly similar global model fit results (mean $\chi^2(35) = 288.90$, SD = 9.79; RMSEA = .066; CFI = .989; and SRMR = .022), factor loadings, and 95% confidence intervals, suggesting robustness of these results under different missing data mechanisms (Table 3).

Confirmatory Factor Analyses (CFA).

CFA using the validation subsample yielded highly similar values of global model fit statistics to those found in the factor extraction subsample and indicated strong support for the one-factor structure of the HIV Index: $\chi^2(35) = 282.06$, p < .001; RMSEA = .065; CFI = .988; and SRMR = .031. Re-fitting the CFA using MI datasets yielded highly similar global model fit results (mean $\chi^2(35) = 294.97$, SD = 9.79; RMSEA = .067; CFI = .988; and

SRMR = .020). As shown in Table 3, the pattern of factor loadings was also highly consistent to that found in the EFA analysis for both the original and imputed datasets. Taken collectively, our factor analysis results indicate robust support for a single engagement in HIV care latent factor that represents the shared variance among the 10 retained items.

Reliability Analyses.

Cronbach's alpha for the 10-item scale in the factor extraction subsample was .886. The corresponding alpha value in the validation subsample was .878. Alpha did not increase appreciably if any items were removed from the reliability analysis in either subsample. These results indicate the proposed 10-item HIV Index has strong and consistent reliability.

Predictive Validity Assessment.

Logistic regression analyses revealed negative associations between the HIV Index scale score and detectable viremia (OR = 0.66; 95% CI = 0.60, 0.74), such that the odds of detectable viremia were 34% lower for each standard deviation increase in the Index score. In addition, the HIV Index score was negatively associated with missing two or more HIV-related medical appointments in the past year (OR = 0.75; 95% CI = 0.69, 0.83). The HIV Index score was positively associated with attending one or more HIV care visits in each of the two six-month windows prior to 180 days before the Index measurement was taken (OR = 1.11; 95% CI = 1.02, 1.21). The HIV Index score was also positively correlated with the proportion of HIV care appointments kept in the year prior to Index (r = .13, p < .0001). Additionally, positive associations were also observed with increases in the HIV Index scale score and being on ART (OR = 1.43; 95% CI = 1.27, 1.62), 100% VAS adherence (OR = 1.37; 95% CI = 1.25, 1.51), and self-rated ART medication adherence (OR = 1.72; 95% CI = 1.60, 1.85; proportional odds test χ^2 (4) = 3.01, p = .55).

Convergent and Discriminant Validity Assessment.

Table 4 displays the sample and imputation-based Spearman correlations. The HIV Index score, computed as a single score representing the sum of the ten individual items, was significantly negatively associated with depressive symptoms, stimulant use, problem drinking, HIV-related stigma and anxiety. The HIV Index score was not associated with age, Black race, gender minority status, nor the time that the participant was in the CNICS cohort. Sample-based correlations and MI-based correlations differed little, suggesting robustness of the correlation results under different missing data mechanism assumptions.

DISCUSSION

HIV Index scores were associated with estimates of retention in care, self-reported recent treatment adherence, and viral suppression. Findings support the existence of a single factor of perceived engagement in care that was associated in expected directions with symptoms of depression, alcohol and substance use, and HIV-related stigma. Our findings underscore the multi-faceted experience of engagement in care that considers nuanced perspectives of patients living with HIV. The final items included in the HIV Index reflect the central features of patient centeredness, as reflected in the literature and including recognition of the patient as a unique person, the importance of patient involvement in care, and the centrality

of patient-provider communication [37, 38]. The current study represents a first but critical step in identifying and addressing suboptimal engagement in HIV care. Next steps will determine how well the HIV Index performs longitudinally and will explore its potential use in clinical care settings to identify patients who are feeling disengaged in care but before suboptimal outcomes occur, including ART non-adherence or non-persistence, missing appointments, or dropping out of care altogether. The resulting failure to suppress HIV viral load can lead to increased morbidity, elevated likelihood of HIV transmission, and decreased survival.

Our work to date, while promising with robust findings, is introductory. We used concurrent and retrospective data to provide evidence of the preliminary validity of the HIV Index. Therefore, it is not possible to determine causal relationship to other factors such as depression or outcomes such as retention in care and viral suppression. The next test of the HIV Index will be whether it accurately predicts outcomes over time. To that end, prospective studies are needed to carefully evaluate the predictive value of the HIV Index over time.

Other future work will evaluate how the HIV Index performs with sub-populations disproportionately impacted by HIV, including sexual and gender minority individuals from racial and ethnic minority backgrounds and people who use drugs. As people living with HIV live longer, we are interested in exploring how engagement in HIV care varies in the presence of comorbidities, such as diabetes, cardiovascular disease, hepatitis C, and cancer. We also plan to explore empirically-supported clinical cut-off scores for use in clinical screening settings and will evaluate potential short forms of the HIV Index. Finally, we see the HIV Index as an opportunity to embed timely interventions into clinical care for patients who indicate low perceived engagement in care, so that real-time responses can be triggered to address actionable concerns before clinical outcomes are adversely affected.

There are other considerations that should be taken into account when interpreting the current findings. First, although we included a diverse sample of patients from a range of sites in several geographic regions in the US, these sites were HIV specialty care clinics affiliated with research universities, and they tended to serve more urban patient populations. The sample had a high proportion of viroloigic suppression (90%) compared with other US samples, which show estimates closer to 81% [39]. Data reflecting how the HIV Index performs in other settings with other patient groups are needed. Second, the use of the CNICS infrastructure meant that all patients included in analyses had been in care at the site for at least two clinic visits, and therefore they might be described as well-linked to care. Similarly, to be able to compare sufficient time periods to detect clinic visit patterns, the appointment attendance analyses were only conducted on data from patients who had at least a 12-month history at the clinic. Given this consideration, some of the items may not be relevant to patients who are newly diagnosed or new to care and may not have sufficient exposure to the clinic and their provider to have formed impressions. Third, at most sites patients complete the clinical assessment as part of routine care so refusal rates are low; however, patients who arrive very late, intoxicated, or acutely ill are not asked to complete the assessment, which may have resulted in the exclusion of some patients, including potentially those who may have been at greatest risk of poor outcomes. Finally, our ART

adherence assessment relied on self-report, which is prone to reporting biases [40]. However, the viral load outcome was extracted from laboratory assays and appointment attendance from the electronic health record, eliminating recall and other reporting biases.

Overall, there is encouraging support for the HIV Index, a ten-item self-administered approach to assessing patient perceptions of engagement in HIV care. Preliminary evidence provides support for the HIV Index's association with modifiable factors such as depressive symptoms, substance use, and HIV-related stigma and with relevant clinical variables including ART adherence, retention in care, and HIV viral suppression. The HIV Index offers a potentially powerful patient-centered diagnostic tool that can strengthen efforts to combat the HIV epidemic through successfully and meaningfully engaging patients in care, and identifying prevalent, modifiable psychiatric and psychological intervention targets, towards the goal of improving the quality and span of the lives of people living with HIV.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements.

This work was supported by the following grants from the National Institutes of Health: R01MH102198, R24AI067039, P30AI027763, K24DA037034 (MOJ), K01MH113475 (JAS), P30AI027757 (HMC), U01AA020793 (RJF), P30AI027767 (MJM), P30AI094189 (RDM), DA036935 (RDM), P30AI50410 (SN). The authors have no conflicts of interest to report.

REFERENCES

- Cohen MS, et al., Prevention of HIV-1 infection with early antiretroviral therapy. N Engl J Med, 2011 365(6): p. 493–505. [PubMed: 21767103]
- Lifson AR, et al., Improved quality of life with immediate versus deferred initiation of antiretroviral therapy in early asymptomatic HIV infection. AIDS, 2017 31(7): p. 953–963. [PubMed: 28121710]
- 3. Group ISS, et al., Initiation of Antiretroviral Therapy in Early Asymptomatic HIV Infection. N Engl J Med, 2015 373(9): p. 795–807. [PubMed: 26192873]
- 4. Rodger A, et al., Risk of HIV transmission through condomless sex in MSM couples with suppressive ART: The PARTNER2 Study extended results in gay men, in 22nd International AIDS Conferece 2018: Amsterdam, The Netherlands.
- 5. Fox MP and Rosen S, A new cascade of HIV care for the era of "treat all". PLoS Med, 2017 14(4): p. e1002268. [PubMed: 28399160]
- International Advisory Panel on, H.I.V.C.C.O., IAPAC Guidelines for Optimizing the HIV Care Continuum for Adults and Adolescents. J Int Assoc Provid AIDS Care, 2015 14 Suppl 1: p. S3–S34. [PubMed: 26527218]
- Mugavero MJ, et al., Beyond core indicators of retention in HIV care: missed clinic visits are independently associated with all-cause mortality. Clin Infect Dis, 2014 59(10): p. 1471–9. [PubMed: 25091306]
- 8. Mugavero MJ, et al., Measuring Retention in HIV Care: The Elusive Gold Standard. Journal of acquired immune deficiency syndromes, 2012.
- 9. Mugavero MJ, et al., From access to engagement: measuring retention in outpatient HIV clinical care. AIDS Patient Care STDS, 2010 24(10): p. 607–13. [PubMed: 20858055]
- Hibbard JH, et al., Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res, 2004 39(4 Pt 1): p. 1005–26. [PubMed: 15230939]

11. Graffigna G, et al., Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. Front Psychol, 2015 6: p. 274. [PubMed: 25870566]

- 12. Johnson MO, et al., Development of an Index of Engagement in HIV Care: An Adapted Internet-Based Delphi Process. JMIR Res Protoc, 2017 6(12): p. e224. [PubMed: 29208589]
- Kitahata MM, et al., Cohort profile: the Centers for AIDS Research Network of Integrated Clinical Systems. Int J Epidemiol, 2008 37(5): p. 948–55. [PubMed: 18263650]
- Nance RM, et al., HIV Viral Suppression Trends Over Time Among HIV-Infected Patients Receiving Care in the United States, 1997 to 2015: A Cohort Study. Ann Intern Med, 2018.
- 15. Wood TJ, et al., If someone cares about you, you are more apt to come around: improving HIV care engagement by strengthening the patient-provider relationship. Patient Prefer Adherence, 2018 12: p. 919–927. [PubMed: 29872277]
- 16. Beach MC, Keruly J, and Moore RD, Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? J Gen Intern Med, 2006 21(6): p. 661–5. [PubMed: 16808754]
- 17. Crane HM, et al., Routine collection of patient-reported outcomes in an HIV clinic setting: the first 100 patients. Curr HIV Res, 2007 5(1): p. 109–18. [PubMed: 17266562]
- 18. Kozak MS, et al., Patient reported outcomes in routine care: advancing data capture for HIV cohort research. Clin Infect Dis, 2012 54(1): p. 141–7. [PubMed: 22042879]
- Lawrence ST, et al., Routine, self-administered, touch-screen, computer-based suicidal ideation assessment linked to automated response team notification in an HIV primary care setting. Clin Infect Dis, 2010 50(8): p. 1165–73. [PubMed: 20210646]
- 20. Kroenke K, Spitzer RL, and Williams JB, The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med, 2001 16(9): p. 606–13. [PubMed: 11556941]
- Spitzer RL, Kroenke K, and Williams JB, Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. Jama, 1999 282(18): p. 1737–44. [PubMed: 10568646]
- 22. Higgins-Biddle JC and Babor TF, A review of the Alcohol Use Disorders Identification Test (AUDIT), AUDIT-C, and USAUDIT for screening in the United States: Past issues and future directions. Am J Drug Alcohol Abuse, 2018: p. 1–9. [PubMed: 29215917]
- 23. Humeniuk R, et al., Validation of the Alcohol, Smoking And Substance Involvement Screening Test (ASSIST). Addiction, 2008 103(6): p. 1039–47. [PubMed: 18373724]
- 24. Saunders JB, et al., Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption--II. Addiction, 1993 88(6): p. 791–804. [PubMed: 8329970]
- 25. Earnshaw VA, et al., HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. AIDS Behav, 2013 17(5): p. 1785–95. [PubMed: 23456594]
- 26. Cohen T, & Corbett EL, Test and treat in HIV: success could depend on rapid detection. The Lancet, 2011 378: p. 204–6.
- 27. Lu M, et al., Optimal recall period and response task for self-reported HIV medication adherence. AIDS Behav, 2008 12(1): p. 86–94. [PubMed: 17577653]
- 28. Walsh JC, Mandalia S, and Gazzard BG, Responses to a 1 month self-report on adherence to antiretroviral therapy are consistent with electronic data and virological treatment outcome. Aids, 2002 16(2): p. 269–77. [PubMed: 11807312]
- 29. SAS Institute, BASE SAS 9.4 Procedures Guide. 2013, Cary, NC: SAS Institute, Inc.
- 30. Ferrando PJ and Lorenzo-Seva U, Program FACTOR at 10: Origins, development and future directions. Psicothema, 2017 29(2): p. 236–240. [PubMed: 28438248]
- 31. Lorenzo-Seva U, Timmerman ME, and Kiers HA, The Hull Method for Selecting the Number of Common Factors. Multivariate Behav Res, 2011 46(2): p. 340–64. [PubMed: 26741331]
- 32. Ferrando PJ and Lorenzo-Seva U, Assessing the Quality and Appropriateness of Factor Solutions and Factor Score Estimates in Exploratory Item Factor Analysis Educational & Psychological Measurement, 2017.
- 33. Hu L. t. and Bentler PM, Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. Structural Equation Modeling, 1999 6(1): p. 1–55.

34. Ibrahim JG, et al., Missing Data Methods for Generalized Linear Models: A Review. Journal of the American Statistical Association, 2005 100(469): p. 332–346.

- 35. Muthén LK and Muthén BO, Mplus User's Guide: Eigth Edition. 1998–2017, Los Angeles, CA: Muthén and Muthén.
- 36. Cronbach LJ, Coefficient alpha and the internal structure of tests. Psychometrika, 1951 16: p. 297–334.
- 37. Zill JM, et al., Which Dimensions of Patient-Centeredness Matter? Results of a Web-Based Expert Delphi Survey. PLoS One, 2015 10(11): p. e0141978. [PubMed: 26539990]
- 38. Scholl I, et al., An integrative model of patient-centeredness a systematic review and concept analysis. PLoS One, 2014 9(9): p. e107828. [PubMed: 25229640]
- 39. CDC, Understanding the HIV Care Continuum, N.C.f.H.A. CDC, Viral Hepatitis, STD, and TB Prevention, Division of HIV/AIDS Prevention, Editor. 2018.
- 40. Stirratt MJ, et al., Self-report measures of medication adherence behavior: recommendations on optimal use. Transl Behav Med, 2015 5(4): p. 470–82. [PubMed: 26622919]

Table 1.

Sample characteristics

Characteristic		N = 3296
Characteristic		N (%)
Site		
UCSD		521 (15.8)
UAB		600 (18.2)
UW		511 (15.5)
UNC		466 (14.1)
FENWAY		341 (10.4)
JH		541 (16.4)
UCSF		316 (9.6)
Age at HIV Index		
19-29 years		232 (7.0)
30-39 years		544 (16.5)
40-49 years		823 (25.0)
50 or more years		1697 (51.5)
Current gender		
Cis-male		2625 (79.6)
Cis-female		610 (18.5)
Gender minority		61 (1.9)
Race		
Black/AA		1337 (40.7)
White		1468 (44.7)
Latino		310 (9.4)
Asian/Pacific Islande	er	87 (2.7)
Other		81 (2.47)
Sexual orientation		
Heterosexual		1072 (33.0)
Sexual minority		2177 (67.0)
Current ART use		3063 (94.3)
Detectable viral load (>	200 copies/mL) †	274 (10.3)
CD4 *	(median, IQR)	586 (383 – 818)
Years in CNICS	(median, IQR)	7.1 (3.2 – 12.5)

 $^{^{\}dagger}$ VL closest to Index from +/- 90 day window.

 $^{^{*}}$ CD4 closest to Index from -180 days before to 90 days after Index.

Author Manuscript

Author Manuscript

Table 2.

Frequencies of 13 HIV Index Items (Total N = 3296)

	Total (N)			Percent (%)		
How much do you/does your		Not at all	A little	A moderate amount	A lot	A great deal
Trust your HIV care provider	3209	0.53	1.34	3.46	20.22	74.45
HIV provider respects what you say	3213	0.78	1.40	4.33	23.44	70.06
HIV provider really understand you	3204	1.00	2.81	10.02	29.09	57.08
Clinic helps meet health needs	3228	0.87	1.77	6.04	26.15	65.18
Ном		Not at all	Slightly	Moderately	Very	Extremely
Open can you be with HIV provider	3203	0.87	1.28	5.56	25.98	66.31
Well does HIV provider explain things	3216	0.37	1.06	3.33	25.12	70.12
Important to set goals for health	3215	1.37	3.20	12.85	35.30	47.28
Comfortable asking questions during appt	3226	0.99	1.43	4.62	26.53	66.43
Well do you follow through on HIV care when things in your life get tough	3208	2.37	3.96	13.31	32.48	47.88
Important to stay informed about new HIV research	3250	1.60	4.62	12.15	29.75	51.88
How much of a		None	Small	Medium-sized	Big	Very big
Role in making decisions about your HIV care do you have	3250	3.17	2.68	6.37	26.46	61.32
How often do you		Never	Sometimes	Half the time	Most of the time	Always
Leave your HIV care appointments feeling like you got really good care	3236	2.60	3.31	2.35	23.33	68.42
Refill HIV medications on time	2749*	0.62	1.83	1.69	15.40	80.46

*
Note: 514 participants responded "not applicable," due to not being on ART (n=188) or a combination of receiving automatic refills or other reasons.

Author Manuscript

Author Manuscript

Table 3.

Factor Loadings (95% Confidence Intervals) from Exploratory (EFA) and Confirmatory (CFA) Factor Analyses

Item	EFA	EFA (MI)	CFA	CFA (MI)
How much do you trust your HIV care provider?	.904 (.886, .922)	.904 (.886, .922)	.904 (.886, .922)904 (.886, .922)889 (.868, .910)891 (.870, .911)	.891 (.870, .911)
How open do you feel you can be with your HIV provider?	.860 (.839, .881)	.862 (.842, .883)	.860 (.839, .881) .862 (.842, .883) .823 (.799, .846) .823 (.799, .846)	.823 (.799, .846)
How much does your HIV care provider respect what you have to say?	.905 (.887, .923)	.905 (.889, .922)	.905 (.887, .923) .905 (.889, .922) .881 (.861, .900) .882 (.863, .902)	.882 (.863, .902)
How well does your HIV care provider explain things in a way that is easy to understand?	.901 (.884, .917)		.901 (.885, .918) .889 (.870, .907)	.890 (.871, .908)
How much of a role do you have in making decisions about your HIV care?	.555 (.511, .600)	.560 (.516, .604)	.540 (.495, .585)	.536 (.491, .581)
How much does your HIV care provider really understand you as a person?	.836 (.816, .857)	.836 (.815, .857)	.836 (.816, .857) .836 (.815, .857) .850 (.831, .869) .851 (.831, .870)	.851 (.831, .870)
How often do you leave your HIV care appointment feeling like you really got good care?	.736 (.705, .766)	.740 (.709, .770)	.736 (.705, .766) .740 (.709, .770) .760 (.731, .789) .759 (.731, .788)	.759 (.731, .788)
How much does the clinic help you meet your most important health needs?	.759 (.728, .789)	.762 (.731, .792)	.759 (.728, .789) .762 (.731, .792) .771 (.743, .800) .773 (.744, .802)	.773 (.744, .802)
How comfortable do you feel asking questions during your HIV care appointments?	.845 (.821, .868)	.847 (.824, .870)	.845 (.821, .868) .847 (.824, .870) .827 (.803, .851) .828 (.804, .852)	.828 (.804, .852)
How well do you follow through on your HIV care when things in your life get tough?	.606 (.567, .645)	.610 (.571, .650)	.606 (.567, .645) .610 (.571, .650) .569 (.529, .608) .570 (.529, .611)	.570 (.529, .611)

resulting in N = 1,645 and 1,649 for EFA and CFA analyses, respectively. Results in the EFA and CFA columns were obtained using the Mplus 8.1 diagonally weighted least squares estimator (WLSMV) under the missing completely at random (MCAR) missing data assumption; results in the EFA (MI) and CFA (MI) columns were obtained via WLSMV estimation based on 50 multiply-imputed datasets Notes: EFA results are based on a random subsample of 1,646 participants; CFA results are based on the remaining 1,650 participants. One participant was missing data for all items in each sample, under the missing at random (MAR) missing data assumption.

Table 4.Spearman Correlations (95% Confidence Intervals) of HIV Index with Other Measures

Page 16

Correlate	Sample N	Sample r	MI r
Depressive Symptoms	2909	204 (239,169)***	202 (237,166)***
Stimulant Use	2830	114 (150,077)***	111 (149,073)***
Alcohol Use	2907	040 (076, -0.004)*	039 (074, -0.003)*
Internalized HIV Stigma	2709	272 (306,237)***	266 (299,231)***
Anxiety Symptoms	2933	096 (131,060)***	097 (132,061)***
Age	2853	0.031 (005, .068)	0.031 (005, .067)
Black Race	2844	.005 (032, .041)	.001 (036, .038)
Gender Minority	2853	.003 (034, .039)	.002 (035, .039)
Time in CNICS Cohort	2853	.033 (003, .070)	.036 (001, .072)

^{*} p < .05,

JOHNSON et al.

Results in the Sample r column are Spearman correlations commented on the Sample N. Results in the MI r column are based on 50 multiply-imputed datasets under the missing at random (MAR) missing data assumption using N=3296

p < .01,

^{***} p < .001.