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Measuring the HIV care continuum using public health surveillance data in the United States

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Abstract

The HIV care continuum is a critical framework for situational awareness of the HIV epidemic, yet challenges to accurate enumeration of continuum components hamper continuum estimation in practice. We describe local, surveillance-based estimation of the HIV continuum in the United States, reviewing common practices as recommended by the Centers for Disease Control and Prevention. Furthermore, we review some challenges and biases likely to threaten existing continuum estimates. Current estimates rely heavily on the use of CD4 cell count and HIV viral load laboratory results reported to surveillance programs as a proxy for receipt of HIV-related outpatient care. As such, continuum estimates are susceptible to bias due to incomplete laboratory reporting and imperfect sensitivity and specificity of laboratory tests as a proxy for routine HIV care. Migration of HIV-infected persons between jurisdictions also threatens the validity of continuum estimates. Data triangulation may improve but not fully alleviate biases.

Keywords

HIV Cascade; Treatment as Prevention

Introduced in 2009 to describe the HIV epidemic in Washington, DC,[1] the HIV care cascade, now commonly called a continuum, has become a critical framework for program assessment.[2] With guidance from the Centers for Disease Control and Prevention (CDC), most state and large urban health departments use routinely collected surveillance data to provide estimates of the number and proportion of HIV-infected persons living in their jurisdiction at each continuum stage. Given the variable potential for transmission by HIV-

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infected persons depending on their position in (or outside of) the continuum, this framework is appealing.[3]

The most common presentation of the continuum is a series of vertical bars representing the proportion of HIV infected persons in a particular area who have been diagnosed, ever linked to HIV care, who are currently retained in care, and who are virally suppressed. For examples of the use of the HIV continuum, we refer the reader to Greenberg (2009),[1] Gardner (2011)[4] and Cohen (2014).[5] Although seemingly intuitive, in practice the HIV continuum is difficult to estimate accurately. In the United States (US), estimates are typically based on surveillance data that are often incomplete. However, despite such limitations, public health agencies rely on the continuum estimates to plan and respond to the HIV epidemic. In this paper, we first describe local (i.e., state or Metropolitan Statistical Area) estimation of the HIV continuum using surveillance data, reviewing common practices. Subsequently, we review challenges and biases likely to threaten existing continuum estimates, and we provide suggestions for improvement. We use examples from North Carolina's (NC) continuum estimation efforts to illustrate our points.

METHODS

We interviewed public health practitioners and epidemiologists responsible for HIV surveillance and programmatic activities at the NC Division of Public Health to gain understanding about local continuum estimation practices and relevant surveillance data. We also reviewed programmatic guidance and HIV continuum estimates from other jurisdictions published in the scientific literature and on state health department websites. Finally, we conducted simple analyses of NC surveillance data to illustrate the existence and magnitude of potential biases in continuum estimation.

CURRENT ESTIMATION PRACTICES

Data sources

All 50 states, the District of Columbia, and US dependent areas collect reports of new HIV and AIDS diagnoses made by physicians, hospitals and laboratories in their jurisdictions and store these data in the enhanced HIV/AIDS Reporting System (eHARS).[6] These surveillance data are used in the estimation of every stage of the HIV continuum (including the total number of infected persons, diagnosed and undiagnosed, in at least some settings). Increasingly, states have updated reporting rules to also mandate laboratory reporting of CD4 cell count and HIV RNA viral load results.[7]. Public health agencies participating in the Routine Interstate Duplicate Review (RIDR) forward HIV and AIDS case reports to CDC with the date of HIV or AIDS diagnosis, Soundex name-based code, birth date, and sex at birth, which CDC uses to compare to previously reported cases and identify possible duplicate cases (persons who have previously been HIV-diagnosed in another jurisdiction). CDC alerts the agencies of possible duplicates and the agencies resolve them using identifiable information.[8] Other data sources, including the Medical Monitoring Project, Medicaid and Medicare billing data, and Ryan White Program data (e.g. AIDS Drug Assistance Program and CAREWare) can provide supplemental information about the HIV

continuum, but are not necessarily available in all jurisdictions. Brief descriptions of these data sources are available in table 1.

HIV prevalence

The CDC uses back-calculation methods to estimate the number of HIV-infected persons living in the US, which is then used as the denominator of national continuum estimates.[9] CDC recommends jurisdictions skip reporting overall prevalence, and use HIV-diagnosed persons as the denominator when producing local continuum estimates. CDC releases incidence estimates (linked to undiagnosed prevalence) for states that contribute sufficient serologic data (at least 15% completeness of Serologic Testing Algorithm for Recent HIV Seroconversion [STARHS] results); these estimates are based on the same back-calculation approach used for national incidence and prevalence estimation. NC is one such state and briefly used those state-specific estimates to scale their number of reported HIV cases to estimate local HIV prevalence.

HIV diagnosis

To estimate proportions of HIV-diagnosed persons at each stage of the continuum (except linked to care) CDC recommends defining the HIV-diagnosed population (the denominator for those proportions) as persons who are alive, HIV-diagnosed for at least 12 months by the date of analysis and thought to be residing in the jurisdiction based on last known address. This estimate excludes persons who die within a year of their HIV diagnosis and persons who were diagnosed in the jurisdiction but are known to have then emigrated. It includes persons diagnosed in another jurisdiction who are known to have immigrated. Only persons newly diagnosed within the jurisdiction (excluding persons previously diagnosed in another jurisdiction) during a given period are included in the denominator when estimating the proportion of HIV-diagnosed persons linked to care.

Linkage to HIV care

Linkage to care is estimated using reported CD4 cell count or viral load results as a proxy for receipt of HIV-related outpatient medical care (where such laboratory data are reported to surveillance). Linkage to care is defined in this context as having had a least one HIV-related medical care visit within 3 months of HIV diagnosis,[9–11] and CDC recommends jurisdictions operationalize this definition by calculating the proportion of patients diagnosed within a given year who have at least one CD4 cell count or viral load measurement within 3 months of HIV diagnosis. Another family of measures has been used to identify patients whose linkage to care is more stable, although such measures are not included in the CDC guidance. These measures are typically operationalized as having had at least two laboratory results within some short interval following HIV diagnosis.[12]

Retention in HIV care

Surveillance-based metrics for measuring retention in care again rely on the use of routinely reported laboratory results (where available) as a proxy for an HIV-related medical visit. The CDC has endorsed the National HIV/AIDS Strategy (NHAS) metric of two or more routine HIV-related medical visits at least three months apart within a calendar year[2] (where

laboratory test results are substituted for visits in the CDC guidance). The U.S. Department of Health and Human Services and the Health Resources and Services Administration, HIV/AIDS Bureau, use a different definition of at least one routine medical visit during each 6-month period over a 24-month observation period, with a minimum of 60 days between the first visit in one period and the last visit in a subsequent period.[10,11,13]

States participating in the Medical Monitoring Project (MMP), a CDC-funded initiative to monitor HIV patients who are in care,[14] also have the option of using weighted MMP data to estimate retention in care. The number of patients in the MMP known to have had at least one medical visit from January through April of the MMP surveillance year (the Population Definition Period) is weighted by the probability of MMP sample selection, adjusted for nonresponse, to get a population estimate of the number of HIV-infected adults who attended at least one medical visit during the same period.[9]

Viral suppression

The proportion of people living with HIV with suppressed viral load is most commonly based on the number of patients whose most recently reported viral load test within a specified period of time was below the limit of detection,[12] which is commonly, although not universally, set at <200 copies/mL (also the CDC recommended threshold).[11,15] States participating in the MMP can also estimate the proportion of patients in care whose most recent viral load was below the limit of detection.

LIMITATIONS OF CURRENT ESTIMATION APPROACHES AND SUGGESTIONS FOR IMPROVEMENT

While each stage of the continuum presents unique challenges for estimation, common threats to surveillance-based estimation of all stages (beyond diagnosis) include reliance on laboratory reporting of CD4 cell count and viral load results to public health agencies, and potential for bias due to missing data. The completeness of laboratory reporting is heterogeneous across jurisdictions[16,17] and is changing rapidly over time due to changing reporting rules and the adoption and implementation of electronic laboratory reporting. The completeness of laboratory reporting can dramatically alter estimates of the HIV continuum.

Continuum estimates vary considerably across jurisdictions, even among those that claim to have laboratory reporting compliance ≥95%.[11] While access to and retention in HIV care are likely to truly differ, some variation is undoubtedly artifactual, arising from differences in data collection procedures and reporting completeness. CDC does not recommend jurisdictions attempt local estimation of the care continuum until over 95% of laboratory results are reported. However, estimating the total number of expected results and completeness of reporting is not straightforward. Even in states where laboratory reporting is mandated, some laboratories may lack the time or technological capacity to comply with the reporting rule. Furthermore, internal and external stakeholders may press for continuum estimates despite data quality issues. Interpretation of individual continuum estimates and comparisons of estimates across jurisdictions would greatly benefit from clear disclosure of data quality and completeness, as well as reporting of methods used to calculate

completeness. With such information, bounds of continuum estimates given the missing data are easily calculated and reported. Limitations and suggestions related to stage-specific continuum estimates are outlined below.

HIV prevalence

Currently, jurisdictions are discouraged from starting their HIV continuum with the number of HIV-infected persons, which limits comparisons of HIV continua across jurisdictions. If local jurisdictions are able to collect and submit sufficient serum samples and data to get local prevalence estimates using the STARHS algorithm, or other algorithms for recency testing, differences in the prevalence of HIV and the proportion of HIV-infected persons who are undiagnosed would be illustrative regarding the penetration of HIV testing locally. The use of the BED assay and back-calculation approach currently relied on to estimate HIV incidence may not perform uniformly across place and time[18,19] and improvements on the algorithm are possible.[20] Regardless of the specific method used to estimate HIV prevalence, however, bounds representing the uncertainty in that estimate should be presented, and carried forward through all future stages of the continuum.

HIV diagnosis

Several biases threaten the accuracy of estimates of the number of HIV-diagnosed persons living in a jurisdiction. First, full enumeration of HIV diagnoses (whether new diagnoses or the first diagnosis for an HIV-infected person after immigrating to a new jurisdiction) depends on the level of resources allocated to active surveillance, providers' knowledge of their legal obligation to report, completeness of laboratory reporting (enhanced by the adoption of automated electronic laboratory reporting), and the accuracy of the information contained in the final case report. Around 2003, CDC estimated that nationally, completeness of case ascertainment was between 72% and 95%.[21] In 2012, NC estimated that statewide, case ascertainment was between 90% and 95% complete.[22]

Second, estimates of the number of HIV-diagnosed persons living in a jurisdiction may be biased by unrecognized migration into and out of the jurisdiction. For an HIV-positive migrant to be properly accounted for by surveillance, the case must: 1) interact with the healthcare system and have their HIV infection recognized; 2) be reported in the new state (some providers do not recognize their obligation to report HIV infection in a person who is not newly diagnosed); and 3) be identified as a duplicate (already reported to CDC by another state) by the RIDR matching algorithm. Emigration from a jurisdiction that goes unrecognized results in overestimation of HIV-infected persons in the old jurisdiction and underestimation of HIV-infected persons in the new jurisdiction. If the case is identified as HIV-positive in the new jurisdiction but not recognized as a duplicate, the number of HIV-infected persons is only overestimated in the old jurisdiction. Given these challenges to migrant recognition and de-duplication, as well as high rates of migration between counties and states,[23] local estimates of the number of HIV diagnosed people living in a given jurisdiction are likely inaccurate, with subsequent effects on "downstream" cascade stage estimates. For example, in King County, WA, 16% of persons presumed to be living with HIV in the county over a 4-year period were found to have emigrated, and accounting for emigration reduced the estimated proportion of patients out of care from 27% to 16%.[24]

Services like Accurint (http://www.accurint.com/) reduce (but do not eliminate) the resources required for such case investigation. If case investigation of persons not known to be in care is not feasible, at the very least, immigration and emigration rates as detected through the RIDR process should be reported across time to monitor migration trends. Furthermore, sensitivity analyses based on different assumptions about the proportion of chronically out-of-care patients who have actually emigrated would be informative as to the potential impact of migration on continuum estimates.

Other potential biases are inherent in the denominator for estimation of subsequent stages of the continuum. Because patients are required to survive at least 1 year after diagnosis before they are included in continuum denominators for retention and viral suppression, patients who are diagnosed with advanced disease may be underrepresented. Jurisdictions with different 1-year survival rates will not be comparable, and jurisdictions will not be comparable to themselves across time if 1-year survival rates change. If the current continuum estimation framework is used, jurisdictions should report 1-year survival rates in conjunction with continuum estimates. Alternatively, continuum estimation could embrace a competing risk framework to incorporate early deaths more intuitively.[25]

Linkage to HIV care

Laboratory under-reporting issues aside, laboratory results are a sub-optimal proxy for receipt of routine HIV-related medical care, the actual indicator of interest for care attendance in the major recommendations and guidelines. Not all CD4/VL testing is associated with receipt of routine HIV care (e.g., CD4/VL testing on inpatients or during emergency department visits). Furthermore, laboratory testing proximal to HIV diagnosis might be associated with diagnosis and not with initiation of medical care.[26] Some jurisdictions have excluded laboratory results collected within a short time of HIV diagnosis (e.g., 30 days) when estimating linkage to care,[27] which may reduce the number of patients classified as linked who did not initiate care, but increase the number of patients classified as not linked who did.

While CDC recommends measuring linkage to care based on 1 visit after diagnosis, it is not yet clear that this measure is of greater public health importance than a metric based on 2 visits. The two metrics often yield markedly different results. In King County, WA, 90% of people diagnosed between 2007 and 2009 had one laboratory measurement within 3 months, but only 73% had a second reported 3–9 months after diagnosis.[26] We believe that both metrics provide valuable information, and where they differ, jurisdictions should focus on understanding barriers to attending a second visit, and on modifying the first clinical care visit to promote better engagement and retention.

Retention in HIV care

Data triangulation can help identify biases and improve continuum estimates, particularly estimates of retention in care.[28] We compared NC estimates of retention based on laboratory results reported to eHARS only (standard estimates) with results based on triangulating data from eHARS, Medicaid, Medicare, CAREWare and ADAP. The latter databases capture encounters with medical providers and pharmacies, in addition to laboratory data. Using

data triangulation, 77% of HIV-diagnosed North Carolinians were classified as retained in care in 2010. However, only 44% of HIV-diagnosed persons were classified as retained in care using eHARS data alone.[29]

While improvements are possible with data triangulation, however, the availability of external data sources varies across jurisdictions and those sources commonly available often miss patients with private insurance and patients who seek HIV care outside the jurisdiction (i.e., across state or county lines). This is of concern to NC for patients in the Charlotte area, who may seek care across state lines in South Carolina. Furthermore, as HIV treatment has become more effective and less toxic, some physicians have reduced the frequency of laboratory monitoring,[15,30,31] potentially leading to misclassification of retained patients as not retained in care.

MMP is considered one of the best sources of estimates of HIV care in the US,[32] but the validity of estimates of retention in care depends upon the representativeness of the sample. In NC in 2009, the facility-level response rate was only 77% and the adjusted patient-level response rate was 51%.[9] Participants in the MMP are more likely to be from larger clinics (that have the resources to agree to participate if sampled) and to be frequent users of services (higher probability of having a visit in the population definition period). The next round of MMP will sample patients directly (rather than sampling clinics first), which may reduce, but not eliminate, this potential for selection bias. Methods exist for evaluating[33,34] and adjusting for[35] selection bias and should be utilized to address estimation of retention in care and characterization of the in-care population.

Finally, while this stage is labeled retention in care, a state of being that is dynamic (unlike diagnosed or linked to care, in which a person only changes states once, i.e., once diagnosed, no one can return to being undiagnosed), the commonly used metrics only capture a static snapshot of the proportion of persons who received care within a set period. Comparisons of the proportion retained in care in one year versus the next does not say anything about how often individuals transition between being in care versus out of care, nor the proportion of persons transitioning between these two states. Because current metrics do not capture transitions directly, they are insufficient for evaluating the effect on the continuum of interventions focused on re-engaging persons in care. Additional HIV continuum metrics should estimate progress through the HIV continuum in addition to the current status of HIV-infected persons. The development of complementary frameworks and approaches is an active area of research, and several have been recently proposed.[36–38]

Viral suppression

Estimation of viral suppression is limited by the lack of a consensus definition and laboratory reporting. The threshold used to define viral suppression for reporting and for surveillance definitions can have a dramatic impact on estimates.[39] Viral suppression, like retention in care, is dynamic and information is lost when it is summarized with only a cross-sectional snapshot, as in the continuum framework. Detectable viral load results may reflect chronic non-suppression, true viral failure or simply a detectable “blip”.[40] In British Columbia, 66% of diagnosed patients were classified as virally suppressed based on one undetectable viral load measurement in a given year, compared to 53% classified as virally

suppressed based on at least 2 undetectable viral load measurements at least 3 months apart.[39] We recommend a more nuanced treatment of viral suppression, and suggest that, as with "retention in care" process is as important as current status; categorizing patients based on a cross-tabulation of ever suppressed and suppressed at the time of the most recent measurement would highlight whether persons classified as having unsuppressed viral load were never treated or rather in need of adherence counseling. The complementary frameworks mentioned in the prior section are relevant here, too.[36–38]

CONCLUSIONS

Estimation of the HIV continuum could be improved with careful consideration of several key issues. Triangulation of data sources (including possible data sharing across jurisdictions and through public-private partnerships) and sensitivity analyses with these considerations in mind are likely to result in a more nuanced understanding of each continuum stage. Quantifying the uncertainty of surveillance estimates, including providing a range of estimates for each stage (e.g., based on results from different sources, varying assumptions about data completeness, or different definitions of "retained" or "virally suppressed"), rather than an artificially precise, single numerical estimate, is informative and should be encouraged, rather than avoided.[41] As data completeness improves, the proportions linked and retained in care calculated using the proxy of a reported laboratory value are likely to increase. Strategies to quantify improvements in cascade outcomes due to improved data quality – and to distinguish these artifactual improvements from true improvements – are needed to ensure scarce public health resources are maximally leveraged. Finally, published continuum estimates should include a detailed description of data collection procedures, data quality, definitions used, and analysis decisions made.

The HIV care continuum is a critical tool for conceptualizing and monitoring the HIV epidemic in the United States and globally. However, the challenges to its accurate enumeration are often given insufficient attention. Given the importance of the continuum in monitoring and evaluating our efforts to control the epidemic and improve the lives of people living with HIV, considerable efforts should be devoted to improving its accuracy and utility. We applaud the work of public health in transforming the paradigms under which HIV surveillance has been done and we encourage public health practitioners to publish their work and further suggestions for and experiences with continuum estimation, which could be aggregated to establish a new standard for estimation.

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References

1. Greenberg AE, Hader SL, Masur H, Young AT, Skillicorn J, Dieffenbach CW. Fighting HIV/AIDS in Washington, D.C. Health affairs. 2009 Nov-Dec;28(6):1677–1687. [PubMed: 19887408]
2. National HIV/AIDS Strategy for the United States. Office of National AIDS Policy; 2010.
3. Mugavero MJ, Amico KR, Horn T, Thompson MA. The State of Engagement in HIV Care in the United States: From Cascade to Continuum to Control. Clin Infect Dis. 2013 Jun 23.
4. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical infectious diseases : an official publication of the Infectious Diseases Society of America. 2011; 52(6):793–800. [PubMed: 21367734]
5. Cohen SM, Hu X, Sweeney P, Johnson AS, Hall HI. HIV viral suppression among persons with varying levels of engagement in HIV medical care, 19 US jurisdictions. J Acquir Immune Defic Syndr. 2014 Dec 15; 67(5):519–527. [PubMed: 25230292]
6. [Accessed January 22, 2015] HIV surveillance supported by the Division of HIV/AIDS Prevention. 2014. http://www.cdc.gov/hiv/statistics/recommendations/publications.html.
7. [Accessed January 22, 2015] State HIV Laws. 2014. http://www.cdc.gov/hiv/policies/law/states/.
8. Glynn MK, Ling Q, Phelps R, Li J, Lee LM. Accurate monitoring of the HIV epidemic in the United States: case duplication in the national HIV/AIDS surveillance system. J Acquir Immune Defic Syndr. 2008 Mar 1; 47(3):391–396. [PubMed: 18176325]
9. Hall HI, Frazier EL, Rhodes P, et al. Differences in human immunodeficiency virus care and treatment among subpopulations in the United States. JAMA internal medicine. 2013 Jul 22; 173(14):1337–1344. [PubMed: 23780395]
10. 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 Aug; 26(8):471–478. [PubMed: 22731500]
11. Gray KM, Cohen SM, Hu X, Li J, Mermin J, Hall HI. Jurisdiction Level Differences in HIV Diagnosis, Retention in Care, and Viral Suppression in the United States. J Acquir Immune Defic Syndr. 2014 Feb 1; 65(2):129–132. [PubMed: 24121761]
12. Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living with HIV in 13 U.S. areas. J Acquir Immune Defic Syndr. 2012 May 1; 60(1):77–82. [PubMed: 22267016]
13. Valdiserri RO, Forsyth AD, Yakovchenko V, Koh HK. Measuring what matters: development of standard HIV core indicators across the U.S. Department of Health and Human Services. Public health reports. 2013 Sep-Oct;128(5):354–359. [PubMed: 23997280]
14. Frankel MR, McNaghten A, Shapiro MF, et al. A probability sample for monitoring the HIV-infected population in care in the U.S. and in selected states. The open AIDS journal. 2012; 6:67–76. [PubMed: 23049655]
15. Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents. Department of Health and Human Services. 2013
16. Nash D, Andreopoulos E, Horowitz D, Sohler N, Vlahov D. Differences among U.S. states in estimating the number of people living with HIV/AIDS: impact on allocation of federal Ryan White funding. Public health reports. 2007 Sep-Oct;122(5):644–656. [PubMed: 17877312]
17. Centers for Disease Control and Prevention. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data -- United States and 6 dependent areas -- 2011. HIV Surveillance Supplemental Report. 2013 Oct.18(5) 2013.
18. Hallett TB, Ghys P, Barnighausen T, Yan P, Garnett GP. Errors in 'BED'-derived estimates of HIV incidence will vary by place, time and age. PLoS One. 2009; 4(5):e5720. [PubMed: 19479050]

19. Karita E, Price M, Hunter E, et al. Investigating the utility of the HIV-1 BED capture enzyme immunoassay using cross-sectional and longitudinal seroconverter specimens from Africa. AIDS. 2007 Feb 19; 21(4):403–408. [PubMed: 17301558]
20. Hargrove JW, Humphrey JH, Mutasa K, et al. Improved HIV-1 incidence estimates using the BED capture enzyme immunoassay. AIDS. 2008 Feb 19; 22(4):511–518. [PubMed: 18301064]
21. Hall HI, Song R, Gerstle JE 3rd, Lee LM. Group HARSE. Assessing the completeness of reporting of human immunodeficiency virus diagnoses in 2002–2003: capture-recapture methods. American Journal of Epidemiology. 2006; 164(4):391–397. [PubMed: 16772373]
22. 2012 HIV/STD Surveillance Report: Addendum. North Carolina Division of Public Health; 2012.
23. Molloy R, Smith CL, Wozniak A. Internal Migration in the United States. J Econ Perspect. 2011 Sum;25(3):173–196.
24. Buskin SE, Kent JB, Dombrowski JC, Golden MR. Migration Distorts Surveillance Estimates of Engagement in Care: Results of Public Health Investigations of Persons Who Appear to be Out of HIV Care. Sex Transm Dis. 2014 Jan; 41(1):35–40. [PubMed: 24326579]
25. Lau B, Cole SR, Gange SJ. Competing risk regression models for epidemiologic data. Am J Epidemiol. 2009 Jul 15; 170(2):244–256. [PubMed: 19494242]
26. Dombrowski JC, Kent JB, Buskin SE, Stekler JD, Golden MR. Population-based metrics for the timing of HIV diagnosis, engagement in HIV care, and virologic suppression. AIDS. 2012 Jan 2; 26(1):77–86. [PubMed: 22008656]
27. Tripathi A, Gardner LI, Ogbuanu I, et al. Predictors of time to enter medical care after a new HIV diagnosis: a statewide population-based study. AIDS Care. 2011; 23(11):1366–1373. [PubMed: 22022847]
28. Rhodes, A.; Gilmore, K.; Yerkes, LE., et al. There's corn in my wheat: Data sources for evaluating the HIV continuum of care and the issue of silos. Paper presented at: CSTE Annual Conference; June 25, 2014; Nashville, TN, USA. 2014.
29. North Carolina Epidemiologic Profile for HIV/STD Prevention & Care Planning. North Carolina Division of Public Health; 2011 Dec. 2011.
30. Chaiwarith R, Praparattanapan J, Nuntachit N, Kotarathititthum W, Sirisanthana T, Supparatpinyo K. Impact of the frequency of plasma HIV-1 RNA monitoring on the outcome of antiretroviral therapy. Current HIV research. 2011 Mar; 9(2):82–87. [PubMed: 21361862]
31. Buscher A, Mugavero M, Westfall AO, et al. The association of clinical follow-up intervals in HIV-infected persons with viral suppression on subsequent viral suppression. AIDS Patient Care STDS. 2013 Aug; 27(8):459–466. [PubMed: 23886048]
32. Ford, MA.; Spicer, CM. Institute of Medicine (U.S.). Monitoring HIV care in the United States : indicators and data systems. Washington, DC: National Academies Press; 2012. Committee to Review Data Systems for Monitoring HIV Care.
33. Hernan MA, Hernandez-Diaz S, Robins JM. A structural approach to selection bias. Epidemiology. 2004 Sep; 15(5):615–625. [PubMed: 15308962]
34. Westreich D. Berkson's bias, selection bias, and missing data. Epidemiology. 2012 Jan; 23(1):159–164. [PubMed: 22081062]
35. Robins JM, Finkelstein DM. Correcting for noncompliance and dependent censoring in an AIDS Clinical Trial with inverse probability of censoring weighted (IPCW) log-rank tests. Biometrics. 2000 Sep; 56(3):779–788. [PubMed: 10985216]
36. Hallett TB, Eaton JW. A side door into care cascade for HIV-infected patients? J Acquir Immune Defic Syndr. 2013 Jul; 63(Suppl 2):S228–S232. [PubMed: 23764640]
37. Powers KA, Miller WC. Building on the HIV cascade: a complementary "HIV States and Transitions" framework for describing HIV diagnosis, care, and treatment at the population level. J Acquir Immune Defic Syndr. 2015 Mar 27.
38. McNairy, ML.; Lamb, M.; Elul, B.; Abrams, E.; El-Sadr, WM. Conference on Retroviruses and Opportunistic Infections. Boston, MA: 2014. A new paradigm for evaluating the HIV care cascade.
39. Nosyk B, Montaner JS, Colley G, et al. The cascade of HIV care in British Columbia, Canada, 1996–2011: a population-based retrospective cohort study. The Lancet infectious diseases. 2014 Jan; 14(1):40–49. [PubMed: 24076277]

40. Lee PK, Kieffer TL, Siliciano RF, Nettles RE. HIV-1 viral load blips are of limited clinical significance. The Journal of antimicrobial chemotherapy. 2006 May; 57(5):803–805. [PubMed: 16533823]

41. Miller WC, Siripong N. Estimates of sexually transmitted infection prevalence and incidence in the United States: time to embrace uncertainty. Sex Transm Dis. 2013 Mar; 40(3):194–196. [PubMed: 23403599]

Table 1

Brief description of databases relevant for HIV care continuum estimation in NC and in other jurisdictions

Database	Description[a]
ADAP	AIDS Drug Assistance Program; database includes all HIV-positive persons who have applied for ADAP funding, including data on HIV medication utilization for persons having drugs paid for by ADAP.
CAREWare	Database includes all HIV positive persons who received services paid for by Ryan White Part B funds, including the dates and types of services provided.
eHARS	Enhanced HIV/AIDS Reporting System; database includes all persons diagnosed with HIV or AIDS or living with HIV/AIDS in NC who have been reported to the NC Division of Public Health.
MMP	Medical Monitoring Project; database include clinical and interview data on a representative sample of all HIV positive persons who are in medical care in NC.

[a] More detailed descriptions of these, and all databases relevant for HIV surveillance and care continuum estimation are available in the appendix of the NC Epi Profile: http://epi.publichealth.nc.gov/cd/stds/figures.html#profile