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The Florida Cohort Study: Methodology, initial findings and lessons learned from a multisite cohort of people living with HIV in Florida

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Abstract

In 2013, Florida had the highest rate of new HIV infections and only 56% of persons living with HIV (PLWH) were virally suppressed. In response, we initiated a new HIV cohort in Florida to better understand issues affecting HIV health outcomes including viral suppression. The objectives of this paper are to describe the study procedures for the Florida Cohort; summarize information regarding enrollment, follow-up, and findings to date; and discuss challenges and lessons learned regarding the establishment of a new, multisite cohort of PLWH. Florida Cohort participants were enrolled from clinics and community-based organizations in eight geographically diverse counties across Florida. Data were obtained from participant questionnaires, medical records, and state surveillance data that are updated annually. From 2014 to 2018, 932 PLWH (mean age 46.7±11.2 years, 64% male, 55% black, 20% Latinx) were enrolled; 61% (n=569) completed follow-up questionnaires ≥6 months after enrollment. At baseline, 83% were retained in care and 75% had HIV viral suppression. Research findings to date have focused on outcomes such as HIV viral

suppression, antiretroviral therapy adherence, HIV-related comorbidities, alcohol and drug use, and interest in mHealth interventions. Strengths of the study include the diversity of the sample and the linkage of participant surveys with existing surveillance data. However, the research data are affected by several challenges and decisions made during study planning and follow-up, including issues related to sampling strategy and recruitment location. The lessons learned from this study can be helpful when initiating a new longitudinal cohort study.

In 2013, Florida ranked first in new HIV infections in the United States. Currently, Florida ranks second nationally in new HIV diagnoses (22.1 cases in 100,000 persons) and third for persons currently living with HIV or AIDS (612.3 cases per 100,000 persons) (CDC, 2019; CDC, 2017). The Miami-Fort Lauderdale-Palm Beach metropolitan statistical area (MSA) continues to rank number one in the country for new HIV diagnoses (34.4 per 100,000 persons) (CDC, 2019). At end-of-year 2017, Florida accounted for approximately 11.0% of all adolescents and adults living with HIV in the U.S. (CDC, 2019). Compared to the general U.S. population of people living with HIV (PLWH), Florida has a greater proportion of women, African Americans, and persons older than 50 represented in the incident HIV population (CDC, 2019; FDOH, 2018).

Florida faces significant gaps in the HIV care continuum for those who are diagnosed. The HIV care continuum includes HIV testing, linkage to care, retention in care, and ultimately HIV viral load suppression (CDC, 2011; Colasanti et al., 2015; Gardner et al., 2011). Although definitions for the steps in the HIV care continuum continue to evolve, linkage to care refers to an individual visiting a medical provider within a certain time period (e.g., 1 - 6 months) after diagnosis. An individual is considered retained in care if they have had 2 or more medical visits at least 90 days apart in the last year. Viral suppression is established when the amount of the virus in the blood is less than the detectable amount of the diagnostic test assay (200 copies/mL at the time the study was initiated) (FDOH, 2018). In Florida, at the time the study was initiated, 64.4% were retained in care, and 56.3% virally suppressed (FDOH, 2017). Given the sheer number of HIV cases, the diversity of PLWH, and the gaps in HIV care, further HIV studies focusing on PLWH in Florida are warranted.

Prior to this study's initiation, there had been no large cohort studies focusing on PLWH in Florida. Cohort studies allow researchers to understand what happens to persons over time, and to identify strategies to improve health outcomes. The Florida Cohort research team, comprised of investigators and clinicians from several Florida universities and the Florida Department of Health (FDOH), sought to create a cohort that would span the entire state of Florida and reflect the unique demographic characteristics of PLWH. The Florida Cohort recruited primarily from public health settings, in order to engage a population which typically has less access to healthcare. Employing a socio-ecological conceptual model, the research team hypothesized that variables affecting the HIV care continuum would reflect the individual (e.g., attitudes, substance use, mental health), society (e.g., social support, stigma), and healthcare system (e.g. insurance, access to care, types of provider). Alcohol consumption was a focus of the cohort, because it is common in PLWH and correlates with HIV care (Vagenas et al., 2015).

Establishing the Florida Cohort offered the promise of a vital rich database which could help inform policies or interventions to improve HIV viral suppression and reduce new HIV infections. Researchers also sought to create a participant registry to facilitate recruitment into future research studies and to create a de-identified database for future analyses. In the present study, the aims are to (1) describe the methodology utilized in the development of the Florida Cohort, (2) present baseline characteristics and summary of findings to date, and (3) discuss the challenges and lessons learned in initiating a diverse cohort of PLWH at multiple sites.

METHODS

Study Design

The cohort employed a targeted, convenience sampling methodology, and data were collected via questionnaire assessments, medical records abstraction, and linkage to existing state HIV surveillance data from the FDOH. Researchers assessed participants at baseline with plans to conduct follow-up surveys between 6 -18 months later, while following participants indefinitely via the state surveillance system. The institutional review boards (IRB) at the University of Florida, Florida International University, and the FDOH each approved the research procedures.

Recruitment Settings

Participants were recruited from a collaborative network of county health departments and community-based clinics/organizations throughout Florida in both rural and urban areas, and in north, central and south Florida. Recruitment sites were Lake City, Gainesville, Tampa, Orlando, Wildwood, Sanford, Ft. Lauderdale, and Miami. The sites were selected based on the geographic location of the investigators and the willingness and interest of specific public health clinics and community organizations to participate in the Florida Cohort. While nearly all recruitment settings were clinics, the clinic sites could recruit and enroll participants from the surrounding community as well. We also included one non-clinical recruitment site (a food bank in Broward County).

Study Population

Researchers enrolled as many participants as funding would allow, up to 1000 PLWH. Participants were deemed eligible for the study if they had confirmed HIV infection, were aged 18 or older, planned to remain in Florida for at least 6 months, and communicated in English (all sites) or Spanish (Miami and Sanford sites). HIV status was confirmed via lab results or medical prescriptions, and by linkage to medical records and the state surveillance system (described below).

Recruitment and Informed Consent

Recruitment for the cohort took place between October 2014 and June 2018, most participants were enrolled between 2015 - 2017. At each site, research staff presented information about the study to clinical and administrative staff and placed brochures in clinic settings. Potential participants were referred by clinic staff providing, or by the participants directly contacting the team themselves. Towards the end of recruitment, we introduced a

pre-screening system to increase the proportion of participants who were Latino, or who were older than age 60, in order to better match the overall demographics of HIV infection in Florida. Identified participants met with a study research assistant who obtained informed consent and confirmed eligibility. When not recruited directly from a medical HIV clinic, participants were required in order to meet enrollment criteria to bring documentation of their HIV status.

Data Collection

Study Questionnaire.—After providing consent, participants completed the study questionnaire. Participants could take the questionnaire on paper or on a computer; alternatively, participants could have the research assistant read the questions aloud to them. The assessment was designed to take approximately 30–45 minutes to complete, and participants received a \$25 gift card for their time.

The questionnaires asked about factors pertaining to the individual: demographic characteristics, health status, history of HIV, HIV-related health behavior (e.g. medication adherence), alcohol and drug use, and mental health symptoms. The survey also assessed interpersonal factors such as social support, HIV disclosure, and experienced HIV stigma. Finally, the survey assessed factors relating to the healthcare system such as healthcare utilization, insurance, and transportation. Specific alcohol-related questions assessed alcohol use (Bush et al., 1998), frequency of binge drinking (CDC, 2012), the greatest number of drinks consumed in the past month (CDC, 2012), the number of alcohol-related consequences (Miller et al., 1995), and any prior experience with alcohol treatment. A summary of the specific measures used in the cohort are listed in Table 1, and the actual study questionnaires are available online at <http://sharc-research.org/research/florida-cohort/>.

Participants also provided contact information on a separate form in order to maximize study follow-up rates, and link questionnaire data to their medical records and surveillance data. During the consent process, participants were also asked if their contact information could be included in a participant registry of persons willing to hear about other research studies in the future, which resulted in a high acceptance rate (93%).

Medical Records Abstraction.—For each participant, the research team completed a medical chart abstraction or obtained a HIPAA form requesting medical records from the participant's clinic. Information obtained consisted of a list of current medical diagnoses (with ICD9, ICD10 code), current medications, and recent laboratory results (e.g., HIV viral load, CD4 count, etc.).

Linkage to HIV Surveillance Data.—The research team established a Data Use Agreement with the FDOH HIV Surveillance Division, which maintains the Enhanced HIV/AIDS Reporting System (eHARS) database in collaboration with the Centers for Disease Control and Prevention (CDC). A single data analyst involved in the study provided participant contact information and study identification number to the FDOH, who then returned eHARS data with the participant identification number but none of the other specific identifying information. The eHARS database included HIV viral load, CD4 count test results, and other related information (e.g., HIV risk category, gender, race/ethnicity).

Updated eHARS data continues to be obtained for study participants every 6 months, allowing for ongoing follow-up with cohort participants. The surveillance information was able to be matched and linked for 98% of all study participants.

Follow-Up Assessment.—The research team attempted to contact participants between 6 – 18 months after baseline for a follow up questionnaire. The follow up was conducted by telephone or by face-to-face contact during a scheduled clinical follow-up visit. The follow up questionnaire included most of the core measures found in the baseline assessment, and participants received an additional incentive payment.

Quality Assurance.—All recruitment staff underwent extensive training at the beginning of the study. Regular weekly phone calls between the research coordinator, principal investigator, and a representative of each recruitment site took place to keep the research team up to date. Additionally, a central project coordinator conducted regular site visits approximately 1-2 times a year per site for quality assurance. To date, there have been no serious adverse events (e.g., deaths, hospitalizations), episodes of participant disclosure, or formal complaints about the study.

Data Management

The Florida Cohort database is maintained on secure servers at the University of Florida. Participant Contact Registry, enrollment/visit logs, and assessments were entered at each site into REDCap (Research Electronic Data Capture), a secure web-based data system. All other data collected using paper forms were de-identified and mailed to study staff at the University of Florida. Double data entry was performed to minimize data entry errors. After initial data cleaning and recoding by the data team, a completely de-identified dataset was created to allow researchers to analyze the data. To encourage others to use the data, we created a formal concept system that researchers could use to request a de-identified dataset (available on www.sharc-research.org), and approved researchers completed individual Data Use Agreements.

Outcomes of interest.—Alcohol use patterns and HIV continuum outcomes were two of the primary outcomes of interest for the cohort study. Alcohol use was categorized as current, heavy, binge, and hazardous drinking. Current drinking was defined as ‘any drink in the past 12 months’; heavy drinking was defined as having 7 or more drinks per week for women, or 14 or more drinks per week for men. Binge drinking was defined as 4 or more drinks at least once a month for women in the past 12 months, or 5 or more drinks at least once a month for men in the past 12 months. Hazardous drinking was defined as either heavy drinking or binge drinking. Drug use was assessed from a list of several types of drugs, with current drug use defined as any use (injection or non-injection) of drugs within the past 12 months, except for marijuana which was defined by any use in the past 3 months.

The HIV care continuum outcomes among PLWH included retention in care, medication adherence, and HIV viral suppression. Retention in care was defined as 2 visits at least 90 days apart in the past 12 months among people diagnosed with HIV for at least 1 year. Medication adherence was defined as the proportion of the previous 30 days in which

persons took all their HIV medications (e.g., $\geq 90\%$ or $\geq 95\%$; 14). HIV viral load suppression was defined as most recent HIV viral load < 200 copies/ml (which was the lower limit of detection at some settings when we began the study in 2014), or durable HIV viral load suppression (suppression at every assessment in the 12 months prior to survey completion).

RESULTS

The Florida Cohort study enrolled 932 PLWH. Of these, we obtained medical record abstraction for 90%, linked 98% to eHARS data, and 93% agreed to participate in a future study contact registry. Of those enrolled, 569 (61.1%) completed a follow-up survey 6-18 months after enrollment.

In table 2, we list the characteristics of our sample with the characteristics of Florida overall. The mean age of study participants was 46.7 ± 11.2 years, 64% were male, and the racial/ethnic distribution was 55% black, 20% Latinx, and 21% white. While we did not conduct formal statistical comparisons of demographic characteristics between our sample and among PLWH in Florida in 2015 overall, in general a higher proportion of our sample reported retention in care (83% vs. 64%), being on ART (90% vs. 67%), and viral suppression (75% vs. 58%).

Table 3 describes additional background variables, mental health, and, alcohol/substance use. Approximately one-third (34%) had less than a high-school education, most reported currently drinking (71%) and almost a third reporting hazardous drinking (35%); however, only 9% reported heavy drinking. Over a third of participants reported marijuana use in the past 3 months (37%). In the past 12 months, 14% reported smoking crack/cocaine, 11% reported recreational use of pain medication, and 11% reported recreational use of sedatives.

As of early 2020, eleven peer-reviewed papers have been published using Florida Cohort data, at least 20 manuscripts currently in development. To date, the papers have focused on various outcomes among PLWH, including chronic disease (e.g. hypertension, cancer screening) (Xu et al., 2019; Wijayabahu et al. 2019), substance use (e.g. alcohol-related problems, drug use) (Mannes et al., 2019; Mannes et al., 2018; Sharpe et al., 2018), mobile app use and potential interest in mHealth interventions (Sharpe et al., 2018; Lucero et al., 2017), healthcare utilization (e.g. emergency room visits, hospitalizations) (Mannes et al., 2019a), HIV-related stigma (Algarin et al., 2019), PrEP awareness (Algarin et al., 2020), HIV medication adherence (Dunne et al., 2019; Mannes et al., 2018a), and HIV viral suppression (Cook et al., 2017). The findings have demonstrated clustering of risk factors and poor health outcomes, identified subgroups of the population who may be most vulnerable, and showed interest among PLWH in future mHealth intervention strategies. For example, one study found that heavy drinking was a risk factor for suboptimal anti-retroviral adherence and poor viral suppression (Cook et al., 2017). Another study found that those with moderate to severe generalized anxiety disorder had greater odds of missing their HIV care appointments and visiting an emergency room, making them vulnerable to poorer health outcomes (Mannes et al., 2019a). Additionally, our findings suggest that mental health, impulsivity, and recreational marijuana use are related to sub-optimal HIV care. Our

data also shows that stigma is a nuanced construct among people living with HIV, and that the intersectionality of stigma with variables such as age, race, and ethnicity are important to consider in accessing HIV care. The Florida Cohort registry has also been successful in helping to recruit participants for future research studies.

DISCUSSION

We were able to successfully initiate The Florida Cohort study, which is, to our knowledge, the first HIV research cohort that specifically sought to span and focus upon an entire state. The Florida Cohort Study had several strengths. One of the main strengths of the study was the use of a multi-recruitment site approach that spanned an entire state, which included four of the counties with the highest rate of HIV incidence (FDOH, 2018). Recruitment from multiple locations offers a more generalizable sample of the state and could offer important insights on disparities by location such as urban and rural areas. By recruiting from public health department clinics, federally qualified health centers, and a food bank, we attempted to capture people who may have increased challenges to be engaged in HIV care. Another unique strength of the Florida Cohort is our ongoing collaboration with the FDOH and the ability to link participant data to HIV surveillance data such as eHARS. Linking our data with the Florida's eHARS system allowed for the study to gain objective clinical health outcomes and to obtain follow up surveillance data on participants even after primary data collection is complete. The specific process to merge our data and the eHARS data securely from FDOH was worked out during several face-to-face discussions, required approvals by multiple IRBs, and involves a Data Sharing Agreement for this specific study to help ensure the protection of participant identity. Linkage to surveillance data will allow the research team to continue to monitor HIV viral load, CD4 counts, engagement in care, and survival for at least 5 years after enrollment. We also successfully linked questionnaire data to medical records for most participants; however, this required much additional labor to abstract the information, and medical records were harder to obtain in some settings than others.

Despite its strengths, the design and implementation of the Florida Cohort study presented several challenges and lessons learned, including issues related to sampling, data collection and management, and fiscal and regulatory processes. We sought a sample that was reasonably representative of the state of Florida, yet the available resources would require us to enroll from a limited number of locations. We sought to include participants from both urban and rural areas, but recruitment would be much more challenging in rural settings (e.g. Wildwood, Lake City) because the HIV clinic services were limited. In order to ensure sufficient numbers of persons from rural areas were included, we occasionally limited the pace of recruitment in larger clinics but not in the rural settings.

We considered the pros and cons of a cohort recruited from clinics and an interval cohort recruited from the general community (Lau et al., 2007). Recruitment from clinics would provide convenience and improved access to medical records but would include fewer individuals considered to be out of care, and HIV care engagement was of interest. Most of the clinical care for PLWH in Florida is provided throughout a network of HIV clinics based in the FDOH's county health departments. Therefore, we chose to recruit most participants

from county health department clinics but also included one recruitment setting that was not associated with a clinic (e.g. a community food bank for PLWH), and a community health center. It was more difficult to obtain medical record information from persons recruited outside of clinics.

During the design of the study questionnaire, the research team was also challenged to choose between measuring a wide range of domains related to the socio-ecological model, vs. the ability to have detailed measures of specific topics. We elected to use briefer, screening measures for most domains, rather than more extensive measures. The follow-up questionnaire maintained several “core” measures, but we also replaced some of the baseline measures with new measures.

Our goal was to try to enroll a sample that had a similar age, gender, and racial/ethnic distribution as the state of Florida overall. The surveys and questionnaires were translated to Spanish. Overall, the baseline demographic characteristics of the Florida Cohort appear to be similar to those of all PLWH in Florida in the same time period (FDOH, 2018). However, statistical testing to compare proportions between the Cohort data and the state-wide data was not possible. This is a limitation of the study. The Cohort did not enroll persons aged younger than 18 and included a lower proportion of older persons (aged >60 years). Yet, 583 (62%) participants reported that they had been in jail or prison at least once in their lifetime. We need to better understand how HIV care engagement and outcomes are affected as persons go into and out of the criminal justice system. Also, some groups of persons relevant to the HIV epidemic in Florida are underrepresented, including people who speak Haitian Creole, people under age 18, and people who are transgender. We intend to address these limitations in the next wave of the Florida Cohort study starting in 2020.

The follow-up rate for questionnaires was somewhat lower than desired (61%), with better follow-up rates at those clinics with the most consistent staffing over time. Although alcohol was to be a major focus of the cohort, only about 9% of participants met criteria for “heavy drinking” (>14 drinks per week for men and >7 drinks per week for women) (Cook et al., 2017), which was lower than expected based on prevalence of heavy drinking in other HIV cohorts (Conigliaro et al., 2006). The relatively low proportion of heavy drinkers limits our ability to understand potential mechanisms by which heavy drinking affects HIV-related health outcomes. It could be that heavy drinking among PLWH truly is lower overall, compared to the previous decades or other study populations, or it could be that the heaviest drinkers tended to avoid this research study or under-reported their true level of drinking. In the future, we plan to actively enroll a higher proportion of heavy drinkers, use more extensive alcohol assessments, include biomarkers of alcohol consumption, and/or use transdermal alcohol biosensors (Wang et al., 2018).

In summary, the Florida Cohort is a new HIV cohort that enrolled 932 PLWH from 2014 to 2018, with ongoing follow-up via HIV surveillance data. Data from the cohort has resulted in numerous publications and presentations that have helped to identify factors associated with the HIV care continuum in Florida. Our experience has provided lessons learned regarding the relative advantages and disadvantages of different recruitment settings and the importance of consistent staffing during follow-up. In 2018, additional research funding was

obtained from NIAAA and NIDA to continue to follow a subset of the original cohort, while also including new enrollment that will include at least 200 PLWH with heavy drinking, over 300 PWLH who currently use marijuana, and up to 150 persons who are transgender. Collectively, the data from the Florida Cohort will continue to be used for research that seeks to improve the HIV care continuum and reduce HIV-related comorbidities.

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REFERENCES

- Algarin AB, Zhou Z, Cook CL, Cook RL, & Ibañez GE (2019). Age, Sex, Race, Ethnicity, Sexual Orientation: Intersectionality of Marginalized-Group Identities and Enacted HIV-Related Stigma Among People Living with HIV in Florida. *AIDS and Behavior*, 23(11), 2992–3001. [PubMed: 31392442]
- Algarin AB, Zhou Z, Canidate S, Gebru NM, Krieger JL, Neil JM, Cook RL & Ibañez GE (2020). PrEP awareness among people living with HIV in Florida: Florida Cohort study. *AIDS care*, 1–6.
- Amtmann D, Cook KF, Jensen MP, Chen WH, Choi S, Revicki D, Cella D, Rothrock N, Keefe F, Callahan L & Lai JS (2010). Development of a PROMIS item bank to measure pain interference. *Pain*, 150(1), 173–182. [PubMed: 20554116]
- Bush K, Kivlahan DR, McDonell MB, Fihn SD, & Bradley KA (1998). The AUDIT alcohol consumption questions (AUDIT-C): an effective brief screening test for problem drinking. *Archives of internal medicine*, 158(16), 1789–1795. [PubMed: 9738608]
- Buysse DJ, Yu L, Moul DE, Germain A, Stover A, Dodds NE, Johnston KL, Shablesky-Cade MA & Pilkonis PA (2010). Development and validation of patient-reported outcome measures for sleep disturbance and sleep-related impairments. *Sleep*, 33(6), 781–792. [PubMed: 20550019]
- Centers for Disease Control and Prevention (CDC). (2019). HIV Surveillance Report, 2018. 30. Available at: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-2018-vol-30.pdf> . Accessed January 21, 2020.
- Centers for Disease Control and Prevention (CDC). (2017). HIV in the United States by Geographic Distribution. Available at: <https://www.cdc.gov/hiv/statistics/overview/geographicdistribution.html>. Accessed March 11, 2018.
- Centers for Disease Control and Prevention (CDC). (2011). Vital signs: HIV prevention through care and treatment--United States. *MMWR. Morbidity and mortality weekly report*, 60(47), 1618. [PubMed: 22129997]
- Cleeland CS, & Ryan KM (1994). Pain assessment: global use of the Brief Pain Inventory. *Annals, Academy of Medicine, Singapore*.
- Colasanti J, Kelly J, Pennisi E, Hu YJ, Root C, Hughes D, del Rio C & Armstrong WS (2016). Continuous retention and viral suppression provide further insights into the HIV care continuum compared to the cross-sectional HIV care cascade. *Clinical Infectious Diseases*, 62(5), 648–654. [PubMed: 26567263]
- Conigliaro J, Justice AC, Gordon AJ, & Bryant K (2006). Role of alcohol in determining human immunodeficiency virus (HIV)-relevant outcomes: A conceptual model to guide the implementation of evidence-based interventions into practice.

- Cook RL, Zhou Z, Kelso-Chichetto NE, Janelle J, Morano JP, Somboonwit C, Carter W, Ibanez GE, Ennis N, Cook CL & Cohen RA (2017). Alcohol consumption patterns and HIV viral suppression among persons receiving HIV care in Florida: an observational study. *Addiction science & clinical practice*, 12(1), 22. [PubMed: 28950912]
- Derouesne CDJM, Dealberto MJ, Boyer P, Lubin S, Sauron B, Piette F, Kohler F & Alperovitch A (1993). Empirical evaluation of the 'Cognitive Difficulties Scale' for assessment of memory complaints in general practice: A study of 1628 cognitively normal subjects aged 45–75 years. *International Journal of Geriatric Psychiatry*, 8(7), 599–607.
- Dunne EM, Cook RL, & Ennis N (2019). Non-planning Impulsivity But Not Behavioral Impulsivity is Associated with HIV Medication Non-adherence. *AIDS and Behavior*, 23(5), 1297–1305. [PubMed: 30264205]
- Florida Department of Health (FDOH). (2018). Epidemiological Profile, Florida: Continuum of HIV Care by County, 2017. Available at: http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/epi-profiles/Epi_Profile_Tables_Florida_2018_Locked.xlsx. Accessed March 12, 2018.
- Florida Department of Health (FDOH). (2017). Epidemiological Profile, Florida: Continuum of HIV Care by County, 2016. Available at: http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/epi-profiles/Epi_Profile_Tables_Florida_2017_Locked.xlsx. Accessed March 12, 2018.
- Gardner EM, McLees MP, Steiner JF, del Rio C, & Burman WJ (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical infectious diseases*, 52(6), 793–800. [PubMed: 21367734]
- Gershon RC, Lai JS, Bode R, Choi S, Moy C, Bleck T, Miller D, Peterman A & Cella D (2012). Neuro-QOL: quality of life item banks for adults with neurological disorders: item development and calibrations based upon clinical and general population testing. *Quality of Life Research*, 21(3), 475–486. [PubMed: 21874314]
- Herek GM, Saha S, & Burack J (2013). Stigma and psychological distress in people with HIV/AIDS. *Basic and Applied Social Psychology*, 35(1), 41–54.
- Justice AC, Dombrowski E, Conigliaro J, Fultz SL, Gibson D, Madenwald T, Goulet J, Simberkoff M, Butt AA, Rimland D & Rodriguez-Barradas MC (2006). Veterans aging cohort study (VACS): overview and description. *Medical care*, 44(8 Suppl 2), S13. [PubMed: 16849964]
- Kiluk BD, Dreiffuss JA, Weiss RD, Morgenstern J, & Carroll KM (2013). The Short Inventory of Problems–Revised (SIP-R): Psychometric properties within a large, diverse sample of substance use disorder treatment seekers. *Psychology of Addictive Behaviors*, 27(1), 307. [PubMed: 22642856]
- Kimerling R, Trafton JA, & Nguyen B (2006). Validation of a brief screen for post-traumatic stress disorder with substance use disorder patients. *Addictive behaviors*, 31(11), 2074–2079. [PubMed: 16574331]
- Kroenke K, Spitzer RL, & Williams JB (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of general internal medicine*, 16(9), 606–613. [PubMed: 11556941]
- Lahiri K, Rettig-Ewen V, Böhm M, & Laufs U (2007). Perceived psychosocial stress and cardiovascular risk factors in obese and non-obese patients. *Clinical research in cardiology*, 96(6), 365. [PubMed: 17453138]
- Lau B, Gange SJ, & Moore RD (2007). Interval and clinical cohort studies: epidemiological issues. *AIDS research and human retroviruses*, 23(6), 769–776. [PubMed: 17604539]
- Lucero RJ, Frimpong JA, Fehlberg EA, Bjarnadottir RI, Weaver MT, Cook C, Modave F, Rathore MH, Morano JP, Ibanez G & Cook RL (2017). The relationship between individual characteristics and interest in using a mobile phone app for HIV self-management: observational cohort study of people living with HIV. *JMIR mHealth and uHealth*, 5(7), e100. [PubMed: 28751298]
- Maddox L & Poschman K (2015) The continuum of HIV Care Florida, 2014. Available at: http://www.floridahealth.gov/diseases-and-conditions/aids/surveillance/_documents/hiv-aids-slide-sets/2014/florida-continuumofhivcare-2014b.pdf. Accessed March 3, 2018.

- Mannes ZL, Bryant VE, Burrell LE, Lu H, Ferguson EG, Zhou Z, Cook RL & Ennis N (2019). The prevalence and patterns of substance use by birth cohort among HIV-positive adults in Florida. *Aging & mental health*, 23(4), 515–523. [PubMed: 29436844]
- Mannes ZL, Burrell LE II, F. EG, Zhou Z, Lu H, Somboonwit C, Cook RL & Ennis N (2018a). The association of therapeutic versus recreational marijuana use and antiretroviral adherence among adults living with HIV in Florida. *Patient preference and adherence*, 12, 1363. [PubMed: 30100713]
- Mannes ZL, Hearn LE, Zhou Z, Janelle JW, Cook RL, & Ennis N (2019a). The association between symptoms of generalized anxiety disorder and appointment adherence, overnight hospitalization, and emergency department/urgent care visits among adults living with HIV enrolled in care. *Journal of behavioral medicine*, 42(2), 330–341. [PubMed: 30387009]
- Mannes ZL, Ferguson EG, Burrell LE, Cook RL, & Ennis N (2018). Brief report: the association between recreational versus therapeutic marijuana use on hazardous alcohol consumption and alcohol-associated behavioral consequences among adults living with HIV in Florida. *Harm reduction journal*, 15(1), 61. [PubMed: 30526597]
- Miller WR (1995). *The Drinker Inventory of Consequences (DrInC): An instrument for assessing adverse consequences of alcohol abuse: Test manual (No. 95)*. US Department of Health and Human Services, Public Health Service, National Institutes of Health, National Institute on Alcohol Abuse and Alcoholism.
- Pilkonis PA, Choi SW, Reise SP, Stover AM, Riley WT, Cella D, & PROMIS Cooperative Group. (2011). Item banks for measuring emotional distress from the Patient-Reported Outcomes Measurement Information System (PROMIS®): depression, anxiety, and anger. *Assessment*, 18(3), 263–283. [PubMed: 21697139]
- Pilkonis PA, Yu L, Colditz J, Dodds N, Johnston KL, Maihoefer C, Stover AM, Daley DC and McCarty D (2013). Item banks for alcohol use from the Patient-Reported Outcomes Measurement Information System (PROMIS®): Use, consequences, and expectancies. *Drug and alcohol dependence*, 130(1-3), 167–177. [PubMed: 23206377]
- Russell DW (1996). UCLA Loneliness Scale (Version 3): Reliability, validity, and factor structure. *Journal of personality assessment*, 66(1), 20–40. [PubMed: 8576833]
- Sharpe JD, Zhou Z, Escobar-Viera CG, Morano JP, Lucero RJ, Ibañez GE, Hart M, Cook CL & Cook RL (2018). Interest in using mobile technology to help self-manage alcohol use among persons living with the human immunodeficiency virus: A Florida Cohort cross-sectional study. *Substance abuse*, 39(1), 77–82. [PubMed: 28723300]
- Sherbourne CD, & Stewart AL (1991). The MOS social support survey. *Social science & medicine*, 32(6), 705–714. [PubMed: 2035047]
- Spitzer RL, Kroenke K, Williams JB, & Löwe B (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine*, 166(10), 1092–1097. [PubMed: 16717171]
- Steinberg L, Sharp C, Stanford MS, & Tharp AT (2013). New tricks for an old measure: The development of the Barratt Impulsiveness Scale–Brief (BIS–Brief). *Psychological assessment*, 25(1), 216. [PubMed: 23148649]
- Vagenas P, Azar MM, Copenhaver MM, Springer SA, Molina PE, & Altice FL (2015). The impact of alcohol use and related disorders on the HIV continuum of care: a systematic review. *Current HIV/AIDS Reports*, 12(4), 421–436. [PubMed: 26412084]
- Wang Y, Fridberg DJ, Leeman RF, Cook RL, & Porges EC (2019). Wrist-worn alcohol biosensors: strengths, limitations, and future directions. *Alcohol*, 81, 83–92. [PubMed: 30179709]
- Ware JE, Kosinski M, Dewey JS, & Gandek B (2001). How to score and interpret single-item health status measures: a manual for users of the SF-8 health survey.
- Wijayabahu AT, Zhou Z, Cook RL, Brumback B, Ennis N, & Yaghjian L (2019). Healthy behavioral choices and cancer screening in persons living with HIV/AIDS are different by sex and years since HIV diagnosis. *Cancer Causes & Control*, 30(3), 281–290. [PubMed: 30739240]
- Wilson IB, Fowler FJ, Cosenza CA, Michaud J, Bentkover J, Rana A, Kogelman L & Rogers WH (2014). Cognitive and field testing of a new set of medication adherence self-report items for HIV care. *AIDS and Behavior*, 18(12), 2349–2358. [PubMed: 24077970]

Xu Y, Chen X, Zhou Z, Morano J, & Cook RL (2019). The interaction between detectable plasma viral load and increased body mass index on hypertension among persons living with HIV. *AIDS care*, 1–6.

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Table 1.

Description of the Measures used in the Florida Cohort Assessments

Key Variables	Baseline	Follow up	Source
1. Socio-Demographics	X		
2. General Health			
Quality of Life	X	X	Short Form (SF)-8 Health Survey (Ware et al., 2001)
Physical Activity		X	
3. Social Support			
Social Support (1)	X		Medical Outcomes Study - Social Support Survey (MOS-SSS) – Emotional / Informational Support and Tangible Support (Shelbourne & Stewart, 1991)
Social Support (2)		X	Patient Reported Outcomes Measurement Information System (PROMIS) / SF Emotional Support 6a (Pilkonis et al., 2011)
Stigma and Discrimination	X		Enacted Stigma Scale (Herek et al., 2013)
4. Health Care Utilization			
Stay at hospital, emergency room, mental health provider, dental care provider, taken care of by friends or family	X	X	
5. HIV Care and Treatment			
HIV duration, testing facility, linkage to care, barriers to care, HIV care services	X		
HIV Antiviral Medication Adherence	X	X	Ira Wilson ART adherence measure (Wilson et al., 2014)
HIV care satisfaction		X	
Current ART	X	X	
6. Mental Health			
Depression	X		Patient Health Questionnaire (PHQ)-8 (Kroenke et al., 2001)
Anxiety(1)	X		Generalized Anxiety Disorder (GAD)-7 (Spitzer et al., 2006)
Anxiety(2)		X	PROMIS SF Anxiety 7a (Pilkonis et al., 2011)
PTSD	X		Primary Care PTSD Screen (PC-PTSD) (Kimerling et al., 2006)
Life Stress	X		INTERHEART Study (Lahiri et al., 2007)
Use of antidepressant medication, mental health services	X		
Loneliness		X	UCLA Loneliness Scale (Russell, 1996)
7. Cognitive Function			

Key Variables	Baseline	Follow up	Source
Memory experiences	X		Abbreviated cognitive difficulties scale (Derouesne et al., 1993)
Impulsivity		X	Barratt Impulsivity Scale-Brief (BIS-Brief) (Steinberg et al., 2013)
Planning		X	Neuro-QOL Cognition Function Short Form (Gershon et al., 2012)
8. Behavioral Risk Factors			
Alcohol use, cigarette smoking, and drug use	X	X	
Alcohol use consequences (1)	X		Short Inventory of Problems (SIP-2R) (Kiluk et al., 2013)
Alcohol use consequences (2)		X	PROMIS Alcohol Positive & Negative Consequences 7a (Pilkonis et al., 2013)
Sexual Behaviors	X	X	VACS Cohort sexual risk measures (Justice et al., 2006)
Relationships		X	
9. Other Health Conditions			
Pain Scale	X	X	Brief Pain Inventory (BPI) short form (Cleeland et al., 1994)
Pain Interference		X	PROMIS SF Pain Interference 4a (Ammann et al., 2010)
Sleep		X	PROMIS SF Sleep Disturbance 6a (Buysse et al., 2010)
Screening: Hepatitis C, TB, pap smear, hysterectomy, History of STDs	X		
Pregnancy	X	X	
Testing for cancer		X	
10. Others			
Use of digital technology (phone, apps, etc)	X		
PrEP		X	
Medical conditions and medications		X	
11. Medical Record Abstraction			
Current conditions and medications	X		
Weight, Height, BMI	X		
HIV viral load, CD4 count, HCV antibody and viral, complete blood panel, completed metabolic panel	X	X	
HIV viral resistance		X	
12. eHARS	X	X	
HIV viral load, CD4 count	X	X	
Years of HIV diagnosis	X		

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	Source	Follow up	Baseline	
		X	X	Retention in Care

Table 2.

Sample Characteristics and HIV care continuum described for both the cohort and the state overall, The Florida Cohort 2014-2018 ***

		Florida Cohort Baseline (N=932)	Florida *(N=116,944) (FDOH, 2018) **(N=109,969) (Maddox & Poschman, 2015)
Age	13-19 ^a	2 (<1%)	556 (>1%) [*]
	20-29	88 (9%)	9,903 (8%) [*]
	30-39	148 (16%)	18,803 (16%) [*]
	40-49	276 (30%)	26,632 (23%) [*]
	50-59	321 (34%)	37,758 (32%) [*]
	60+	96 (10%)	23,130 (20%) [*]
Gender	Male	594 (64%)	84,826 (73%) [*]
	Female	310 (33%)	32,118 (27%) [*]
	Transgender	28 (3%)	-- ^d
Race/Ethnicity	White	194 (21%)	33,964 (29%) [*]
	Black	514 (55%)	53,333(46%) [*]
	Latino	189 (20%)	27,250 (23%) [*]
	Other	35 (4%)	2,397 (2%) [*]
Mode of Transmission	MSM	382 (42%)	58,756 (50%) [*]
	MSM+IDU	81 (9%)	4,344 (3%) [*]
	Hetero	309 (34%)	42,990 (37%) [*]
	IDU only	119 (13%)	9,044 (8%) [*]
	Other	22 (2%)	1,811 (2%) [*]
Ever in care		910 (98%)	99,516 (90%) ^{**}
Retention in care ^b		701 (83%)	70,287 (64%) ^{**}
On ART		832 (90%)	74,218 (67%) ^{**}
Viral Suppression ^c		669 (75%)	64,230 (58%) ^{**}

^a Florida cohort data is only for participants aged 18-19 years old

^b Data includes only those participants who have been diagnosed for at least 1 year

^c Participants who did not have eHARS data were excluded since their viral load was unavailable.

^d Transgender identification was not available from Florida State data

* Florida State Data 2017

** Florida State Data 2014

Note: The Florida State Data was obtained from their website; therefore, statistical testing was not possible. Comparisons are only descriptive.

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Table 3.

Select background variables, substance use patterns and mental health variables among Florida Cohort participants at baseline (N=932), The Florida Cohort 2014-2018

Variables	N (%)
Education	
Less than high school	319 (34%)
High school diploma/GED	275 (30%)
Some College	196 (21%)
College or trade school graduate	102 (11%)
Graduate degree	37 (4%)
Recruitment Year	
2014	194 (21%)
2015	371 (40%)
2016	319 (24%)
2017	45 (5%)
2018	3 (<1%)
Alcohol use	
Current drinkers	649 (71%)
Heavy drinkers	79 (9%)
Binge drinkers	303 (34%)
Hazardous drinkers	312 (35%)
Ever in Alcohol Treatment	238 (26%)
Injection Drug use	
Injection heroin use past 12 months	16 (2%)
Injection cocaine use past 12 months	19 (2%)
Injection Stimulant use past 12 months	33 (4%)
Non-Injection drug use	
Marijuana use past 3 months	305 (37%)
Snorted Cocaine use past 12 months	88 (10%)
Smoked crack/cocaine use past 12 months	126 (14%)
Snorted or smoked heroin past 12 months	12 (1%)
Stimulants or "uppers" (like amphetamines, speed, "crank") past 12 months	44 (5%)
Pain medication use past 12 months	95 (11%)
Sedatives or "downers" past 12 months	97 (11%)
Ecstasy or Molly use past 12 months	42 (5%)
Mental health	
Current depression symptoms	305 (34%)
Current anxiety symptoms	282 (31%)
Post-traumatic stress disorder symptoms	260 (29%)