The DC Cohort: A Population-based Study to Monitor and Improve Care and Clinical Outcomes among PWH in DC

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January 31, 2023

Agenda

- DC Cohort study overview
- Highlight available data and data sources
- Outline processes for working with Cohort data for CFAR Pilot awards

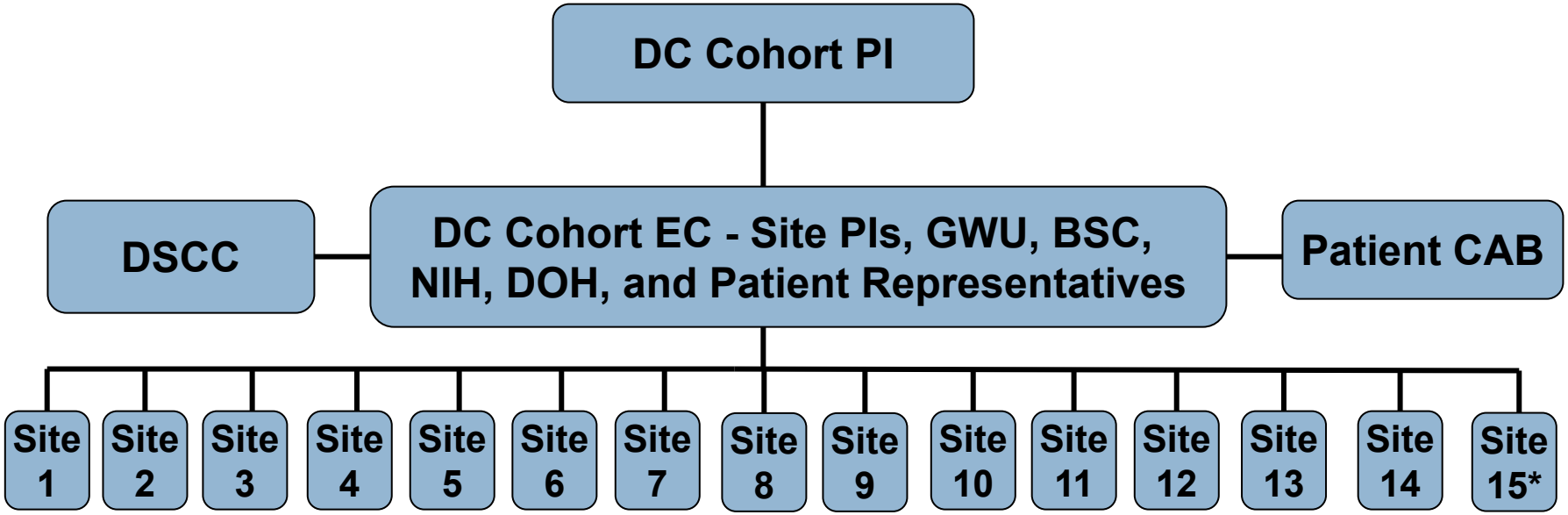
What is the DC Cohort?

- NIH funded: CTU (2009-2020), R24 (2020-2025)
- Longitudinal database of consenting PWH receiving outpatient care at 14 clinics in DC that contains information on:
  - Risk factors, diagnoses, lab results, treatments and procedures
  - Baseline data extraction followed by monthly EHR extractions into a centralized database
- City-wide initiative with academic, community and government clinics
- One of the largest HIV cohorts to date (>12,000 participants)
- Close collaboration with DOH to improve the completeness of information through periodic data linkages

DC Cohort Clinics by EMR and Clinic Type

Clinic	EMR and Year of Implementation	Clinic Type
DC Veterans Affairs Medical Center	Vista-CPRS, 1994	Federal Hospital
Georgetown University	Cerner, 2016	Academic Hospital
Whitman-Walker Health	eClinical Works, 2008	Community Based/FQHC
GWU Medical Faculty Associates	Epic, 2021	Academic Hospital
Family and Medical Counseling Service	eClinical Works, 2008	Community Based/FQHC
Washington Hospital Center	Cerner, 2016	Hospital
Children's National Health System Pediatric Clinic	Cerner, 2016	Academic Hospital
Howard Univ. Hosp. Pediatric Clinic	Touchworks, 2009	Academic Hospital
Howard Univ. Hosp. Adult Clinic	Touchworks, 2009	Academic Hospital
La Clinica del Pueblo	eClinical Works, 2008	Community Based/FQHC
Metro Health	eClinical Works, 2012	Community Based
Unity Health Care	eClinical Works, 2009	Community Based/FQHC
Washington Health Institute	eClinical Works, 2013	Hospital
Kaiser Permanente	Epic, 2004	Non-profit

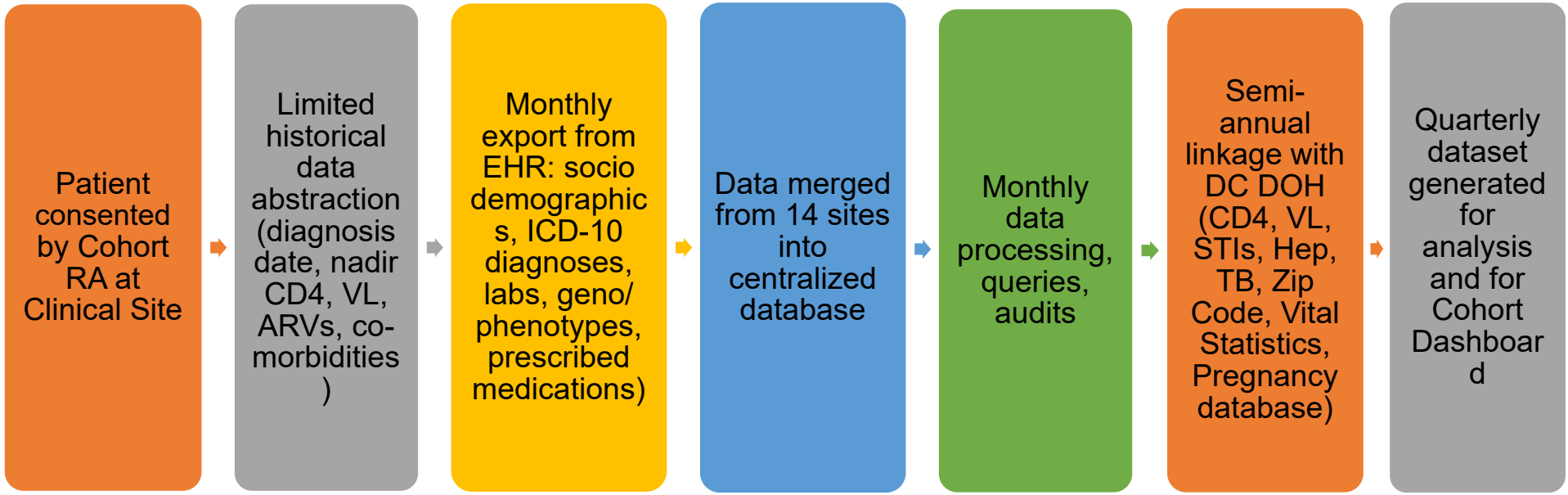
DC Cohort Organizational Structure



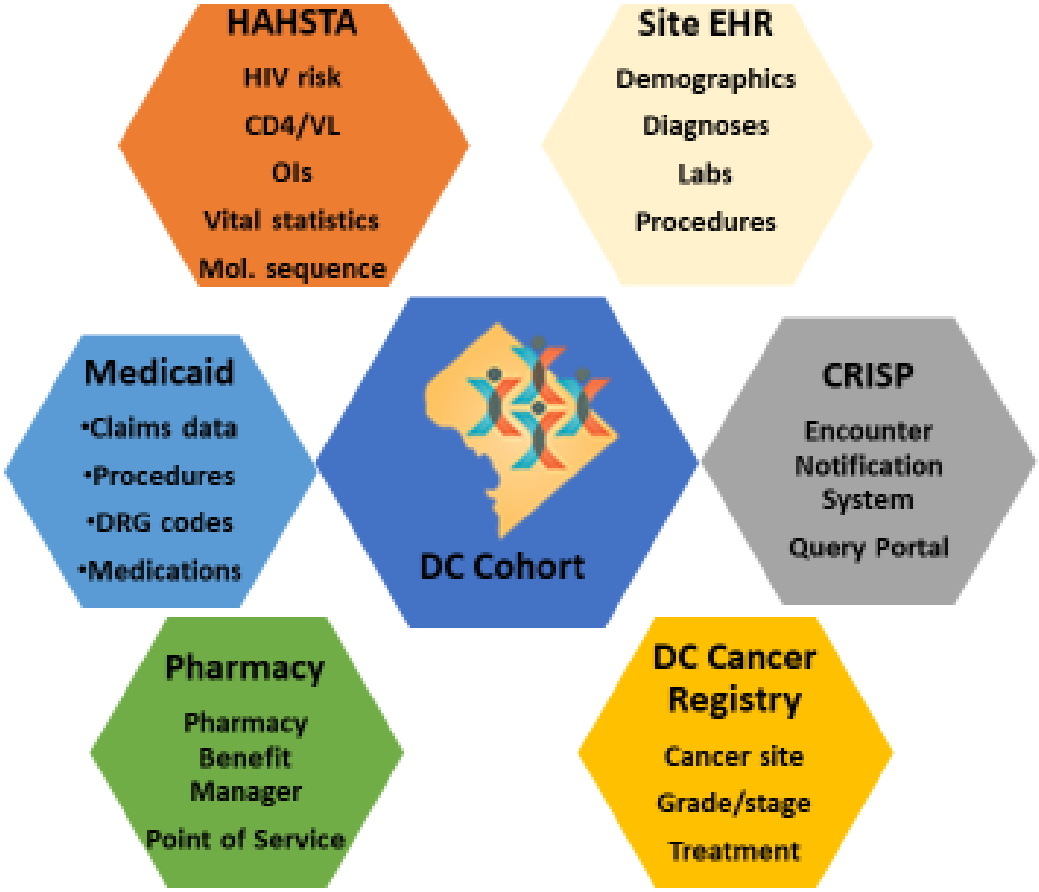
CNH Adolescent Clinic- closed in 2020

PFAP: Partnership for AIDS Progress
EC: Executive Committee
DSCC: Data and Statistics Coordinating Center
CAB: Community Advisory Board

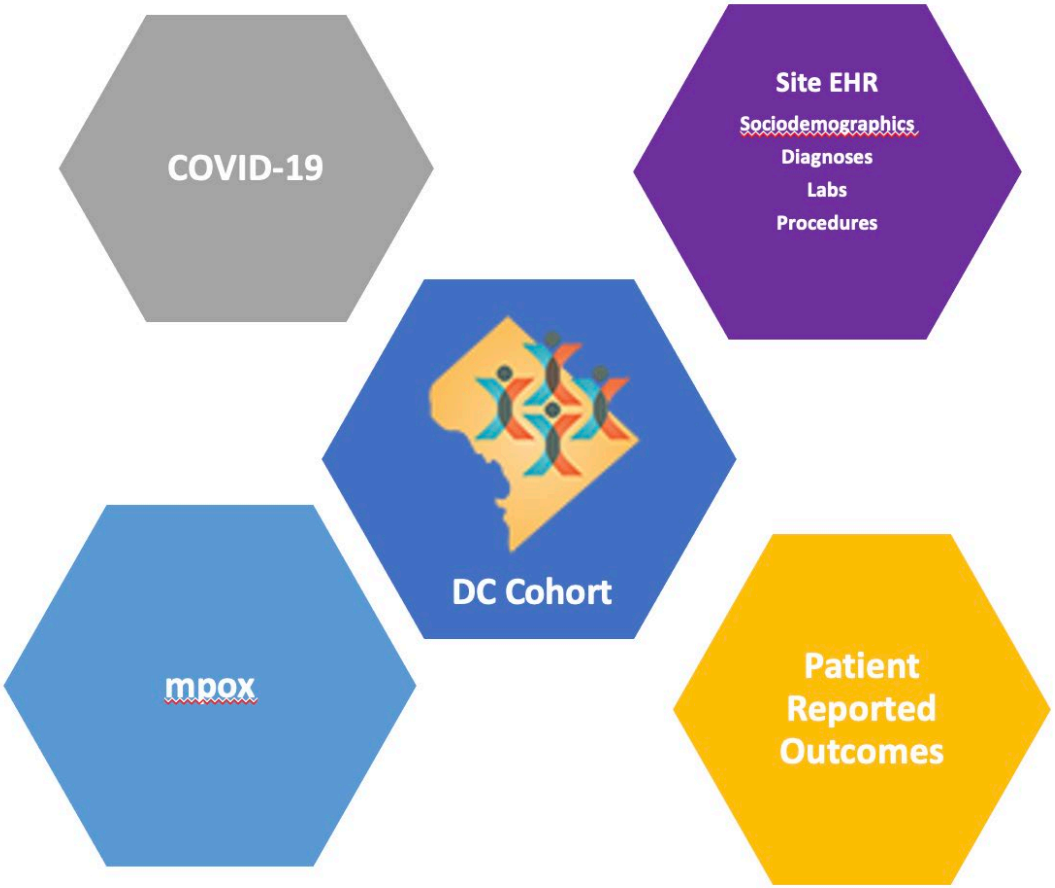
DC Cohort Consent and Data Flow



DC Cohort Data Linkages (in Progress)



DC Cohort Existing Data Linkages



DC Cohort as a Platform for Substudies (1)

- **Molecular Epidemiology** data collection completed 11/2020
  - Characterize phylogenetics, transmission patterns and behavioral risks for transmission among PWH (N=218)
- **Patient Reported Outcomes** (PI: Monroe)
  - Gathering patient reported data to complement EHR abstraction with a focus on mental health and substance use (all participants annually)
- **Positive Links R01** (PI: Castel, Ingersoll (UVA))
  - Cluster randomized trial of an mHealth app to improve retention in care and viral suppression (N=560)

DC Cohort as a Platform for Substudies (2)

- **Impact of COVID-19 on PWH** (NIH COVID-19 Supplement)
  - Cross-sectional survey via REDCap to assess incidence and impact of COVID-19 among PLWH (goal N=4,000)
  - **mpox survey** questions added in August 2022
- **HIV and aging** (PI: Monroe, CFAR supplement)
  - Funding to support research on polypharmacy/potentially inappropriate prescribing among older PWH
- **Implementation of Brain Health Screening** (PI: Gondre-Lewis, DC CFAR Supplement)
  - Funding to support research on brain health screening and referral among PWH across select Cohort sites

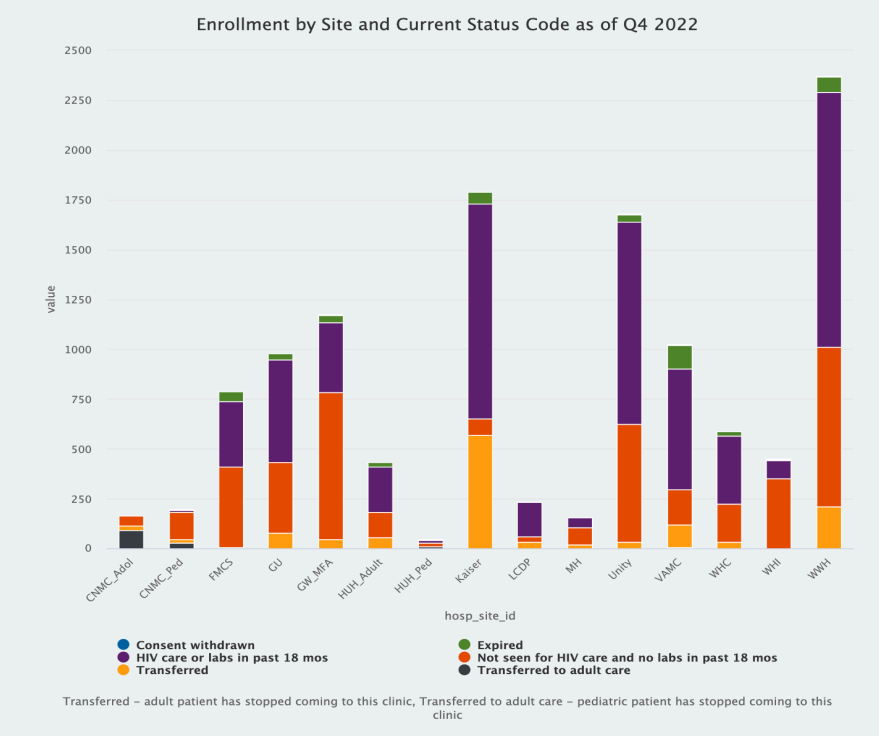
Enrollment Progress as of November 30, 2022

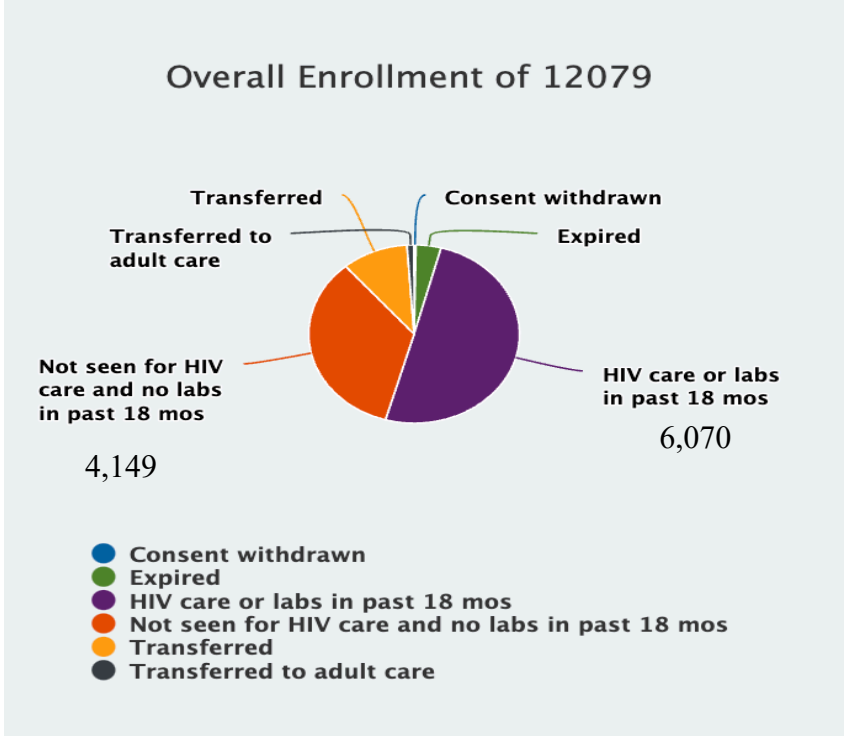
Cumulative Enrollment in the DC Cohort as of November 30th, 2022				
Site	Total Estimated Patients	Consented	Refused/ Withdrawn*	Undecided
Veterans Affairs Medical Center	1,300	1,016	131	105
Georgetown University	1,233	976	111	93
Whitman-Walker Health	3,795	2,368	416	239
George Washington Medical Faculty Associates	1,800	1,170	368	170
Washington Hospital Center	1,012	604	190	84
Family and Medical Counseling Service	880	766	79	18
Children's National Hospital Adolescent Clinic*	200	169	22	2
Children's National Hospital Pediatric Clinic	270	202	42	29
Howard University Hospital Pediatric Clinic	45	45	0	0
Howard University Hospital Adult Clinic	600	432	93	87
MetroHealth	280	152	44	56
La Clinica del Pueblo	577	242	28	26
Unity Health Care	2,500	1,688	358	210
Washington Health Institute (formerly Providence Hospital)	810	434	51	67
Kaiser Permanente Mid-Atlantic	1,790	1,790	0	N/A
TOTAL	17,092	12,054	1,933	1,186

*Total of 38 withdrawals as of November 30th, 2022

*Children's National Hospital Adolescent Clinic is no longer open for enrollment

DC Cohort Clinical Dashboard





Dashboard data as of Q4 2022

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DC Cohort Demographic Characteristics through June 30, 2022 (N=6,273 active participants)

Characteristic	n	%
Age (median, IQR)		56 (45, 63) years
Race (NH Black)	4,737	75.5
Gender (Male)	4,473	71.3
HIV Transmission Risk Factor		
MSM	2,507	40.0
HRH	2,079	33.1
IDU	333	5.3
Perinatal	56	0.9
ARV experienced at baseline	5,786	92.2
Baseline co-morbidities		
Hypertension	1,955	31.2
Mood disorder	1,611	25.7
Hepatitis C	910	14.5
Diabetes	730	11.6
Hepatitis B	241	3.8
Characteristic	**median**	**IQR**
Length of HIV diagnosis in years at enrollment	9.2	(4.2, 16.0)
CD4 cells/µl (most recent)	662	(452, 893)
VL copies/ml (most recent)	20	(20, 40)

Uses of DC Cohort Data

- Longitudinal data available on >6K active participants from 14 sites
- Approximately 64,980 person-years of data
- 42 publications to date
  - 7 manuscripts currently under review/revise and resubmit
  - >20 additional projects in progress
- Cohort data used for 4 doctoral dissertations (2 pending), and numerous MPH students

Using the DC Cohort to Describe Care Among PWH in DC

JMIR PUBLIC HEALTH AND SURVEILLANCE Castel et al

Original Paper

Defining Care Patterns and Outcomes Among Persons Living with HIV in Washington, DC: Linkage of Clinical Cohort and Surveillance Data

Amanda D Castel[1], MPH, MD; Arpi Terzian[1], MPH, PhD; Jenevieve Opoku[2], MPH; Lindsey Powers Happ[1], MPH; Naji Younes[1], PhD; Michael Kharfen[2], BA; Alan Greenberg[1], MPH, MD; DC Cohort Executive Committee[1]

AIDS CARE, 2016
http://dx.doi.org/10.1080/09540121.2016.1189496

Routledge Taylor & Francis Group

Disparities in achieving and sustaining viral suppression among a large cohort of HIV-infected persons in care – Washington, DC*

Amanda D. Castel[a], Mariah M. Kalmin[a], Rachel L. D. Hart[b], Heather A. Young[a], Harlen Hays[b], Debra Benator[c], Princy Kumar[d], Richard Elion[e], David Parenti[f], Maria Elena Ruiz[g], Angela Wood[h], Lawrence D'Angelo[i], Natella Rakhmanina[j], Sohail Rana[k], Maya Bryant[l], Annick Hebou[m], Ricardo Fernández[n], Stephen Abbott[o], James Peterson[a], Kathy Wood[p], Thilakavathy Subramanian[b], Jeffrey Binkley[q], Lindsey Powers Happ[a], Michael Kharfen[r], Henry Masur[s] and Alan E. Greenberg[a]

Clinic-Level Factors Associated With Time to Antiretroviral Initiation and Viral Suppression in a Large, Urban Cohort

Anne K Monroe ✉, Lindsey P Happ, Nabil Rayeed, Yan Ma, Maria J Jaurretche, Arpi S Terzian, Kevin Trac, Michael A Horberg, Alan E Greenberg, Amanda D Castel for the District of Columbia (DC) Cohort Executive Committee

Clinical Infectious Diseases, ciz1098, https://doi.org/10.1093/cid/ciz1098
Published: 08 November 2019 **Article history** ▾

AIDS and Behavior
https://doi.org/10.1007/s10461-018-2103-8

ORIGINAL PAPER

CrossMark

Identifying Spatial Variation Along the HIV Care Continuum: The Role of Distance to Care on Retention and Viral Suppression

A. S. Terzian[1] · N. Younes[1] · A. E. Greenberg[1] · J. Opoku[2] · J. Hubbard[1] · L. P. Happ[1] · P. Kumar[3] · R. R. Jones[4] · A. D. Castel[1] on behalf of the DC Cohort Executive Committee

PLOS ONE

RESEARCH ARTICLE

Use of national standards to monitor HIV care and treatment in a high prevalence city—Washington, DC

Amanda D. Castel[1]*, Arpi Terzian[1], Rachel Hart[2], Nabil Rayeed[2], Mariah M. Kalmin[1], Heather Young[1], Alan E. Greenberg[1], for the DC Cohort Executive Committee[¶]

JMIR Publications

Comparing clinical outcomes of persons living with HIV by enrollment status in a large longitudinal HIV cohort study, Washington, DC

Jenevieve Opoku; Rupali K. Doshi; Amanda D. Castel; Ian Sorensen; Michael Horberg; Adam Allston; Michael Kharfen; Alan E. Greenberg;

WASHINGTON, DC

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Using the DC Cohort to Describe Clinical Outcomes Among PWH in DC

Rakhmanina N et al. *Journal of the International AIDS Society* 2016, **19**:20936
http://www.jiasociety.org/index.php/jias/article/view/20936 | http://dx.doi.org/10.7448/IAS.19.1.20936

JIAS Journal of the International AIDS Society

Research article

Interruptions of antiretroviral therapy in children and adolescents with HIV infection in clinical practice: a retrospective cohort study in the USA

Natella Rakhmanina[§,1,2,3], Kam S Lam[4], Jaclyn Hern[5], Heather A Young[6], Alex Walters[7] and Amanda D Castel[6]

HIV MEDICINE
British HIV Association BHIVA
Explore this journal >

Original Research

High burden of metabolic comorbidities in a citywide cohort of HIV outpatients: evolving health care needs of people aging with HIV in Washington, DC

ME Levy ✉, AE Greenberg, R Hart, L Powers Happ, C Hadigan, A Castel,

ORIGINAL ARTICLE

Sexually transmitted infections in persons living with HIV infection and estimated HIV transmission risk: trends over time from the DC Cohort

Alessandra Anna Secco [1,2] Hana Akselrod,[1] Jonathan Czeresnia,[3] Matthew Levy,[4] Morgan Byrne,[4] Anne Monroe [4] Jose Lucar,[5] Michael Horberg,[6] Amanda Derryck Castel,[4] Rupali Doshi,[4,7] Heather Rivasplata,[2] Leah Squires,[2,8] David Parenti,[1] Debra Benator,[1,2] on behalf of the DC Cohort Executive Committee

Open Forum Infectious Diseases
MAJOR ARTICLE
IDSA Infectious Diseases Society of America hivma hiv medicine association OXFORD

Sexually Transmitted Infections Among HIV-Infected Individuals in the District of Columbia and Estimated HIV Transmission Risk: Data From the DC Cohort

Jose Lucar,[1,2,6] Rachel Hart,[3] Nabil Rayeed,[3] Arpi Terzian,[4] Amy Weintrob,[1,2] Marc Siegel,[1] David M. Parenti,[1] Leah E. Squires,[2,5] Rush Williams,[2,7] Amanda D. Castel,[4] and Debra A. Benator[1,2]; for the DC Cohort Executive Committee

AIDS PATIENT CARE and STDs
Volume 32, Number 2, 2018
© Mary Ann Liebert, Inc.
DOI: 10.1089/apc.2017.0304

Evaluation of Statin Eligibility, Prescribing Practices, and Therapeutic Responses Using ATP III, ACC/AHA, and NLA Dyslipidemia Treatment Guidelines in a Large Urban Cohort of HIV-Infected Outpatients

Matthew E. Levy, BS, Alan E. Greenberg, MD, MPH, Manya Magnus, PhD, MPH, Naji Younes, PhD, and Amanda Castel, MD, MPH, on behalf of the DC Cohort Executive Committee*

WASHINGTON, DC

CLINICAL SCIENCE

Pharmacologic Treatment of Psychiatric Disorders and Time With Unsuppressed HIV Viral Load in a Clinical HIV Cohort

Matthew E. Levy, PhD,[a] Anne K. Monroe, MD, MSPH,[a] Michael A. Horberg, MD, MAS,[b] Debra A. Benator, MD,[c,d] Sherry Molock, PhD, MDiv,[e] Rupali K. Doshi, MD, MS,[a] Lindsey Powers Happ, MPH,[a] and Amanda D. Castel, MD, MPH,[a] on behalf of the DC Cohort Executive Committee

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Molecular Epidemiology Studies

frontiers in Microbiology | Virology

SCIENTIFIC REPORTS
nature research

ORIGINAL RESEARCH ARTICLE
Front. Microbiol., 08 March 2019 | https://doi.org/10.3389/fmicb.2019.00369

A 28-Year History of HIV-1 Drug Resistance and Transmission in Washington, DC

Keylie M. Gibson[1*], Margaret C. Steiner[1], Seble Kassaye[2], Frank Maldarelli[3], Zehava Grossman[3,4], Marcos Pérez-Losada[1,5,6] and Keith A. Crandall[1,6]

A cross-sectional study to characterize local HIV-1 dynamics in Washington, DC using next-generation sequencing

Keylie M. Gibson[1*], Kamwing Jair[2], Amanda D. Castel[2], Matthew L. Bendall[1], Brittany Wilbourn[2], Jeanne A. Jordan[2], Keith A. Crandall[1,3], Marcos Pérez-Losada[1,3,4] & the DC Cohort Executive Committee[†]

PLOS ONE

RESEARCH ARTICLE

Characterization of HIV diversity, phylodynamics and drug resistance in Washington, DC

Marcos Pérez-Losada[1,2,3]*, Amanda D. Castel[3], Brittany Lewis[3], Michael Kharfen[4], Charles P. Cartwright[5], Bruce Huang[1], Taylor Maxwell[1], Alan E. Greenberg[3], Keith A. Crandall[1], on behalf of the DC Cohort Executive Committee[¶]

1 Computational Biology Institute, Milken Institute School of Public Health, The George Washington University, Ashburn, VA, United States of America, **2** CIBIO-InBIO, Universidade do Porto, Campus Agrário de Vairão, Vairão, Portugal, **3** Milken Institute School of Public Health, Department of Epidemiology and Biostatistics, The George Washington University, Washington, DC, United States of America, **4** District of Columbia Department of Health, Washington, DC, United States of America, **5** Laboratory Corporation of America, Burlington, NC, United States of America

RESEARCH ARTICLE

Validation of publicly-available software used in analyzing NGS data for HIV-1 drug resistance mutations and transmission networks in a Washington, DC, Cohort

Kamwing Jair[1☯], Chase D. McCann[2☯], Harrison Reed[3], Amanda D. Castel[1], Marcos Pérez-Losada[1,4], Brittany Wilbourn[1], Alan E. Greenberg[1], Jeanne A. Jordan[1]*, the DC Cohort Executive Committee[¶]

1 Department of Epidemiology and Biostatistics, Milken Institute School of Public Health, The George Washington University, Washington, DC, United States of America, **2** Department of Immunology and Microbial Pathogenesis, Weill Cornell Graduate School of Medical Sciences, New York, NY, United States of America, **3** Department of Forensic Sciences, Public Health Laboratory, District of Columbia, Washington, DC, United States of America, **4** GWU Computational Biology Institute and CIBIO-InBIO, Centro de Investigação em Biodiversidade e Recursos Genéticos, Universidade do Porto, Campus Agrário de Vairão, Vairão, Portugal

COVID and mpox Studies

- COVID
  - Risk of Severe COVID-19 and Service Utilization (*AIDS & Behav*, 2022)
  - Impact of COVID on the HIV Care Continuum (CROI, 2022)
  - COVID-19 Incidence (IAPAC Adherence 2022)
  - Vaccine Hesitancy and Uptake (under review)
  - Long COVID
- Mpox
  - Knowledge, Behavior Change, and Vaccine Uptake (CROI, 2023)

Potential Future Scientific Focus Areas

- Cancer diagnoses
- STIs and public health interventions focused on reducing HIV risk
- Health disparities among DC Cohort participants
- Interventions to improve metabolic disease outcomes
- Contraceptives and reproductive health in women
- Opportunistic Infections
- CNS HIV Complications (neurocognitive dysfunction, cerebrovascular complications)
- Medication adherence/persistence
- Cost effectiveness of different HIV care delivery models
- Pediatric/Adolescent: care trajectories (historically high rates of mortality after transfer to adult care); adolescent care continuum; mental health and substance use among adolescents

Unique DC Cohort Features

- Automated electronic data capture
- Population-based longitudinal sample
- Inclusion of PWH from pediatrics to geriatrics
- Diversity of academic, hospital-based and community-based clinics
- Unique Cohort-DOH database linkage
- Quality of Care Clinical Dashboard
- Public health and research resource

DC Cohort and Related Data Sources

Patient reported outcomes (PROs)

	Instrument
MH screening questionnaires	
Depressive symptoms	PHQ-8
Post-traumatic stress disorder	PTSD screen primary care
Anxiety	GAD-7
Self-reported substance use	
Unhealthy alcohol use	AUDIT
Substance use (substances assessed: cannabis, cocaine, amphetamines, inhalants, sedatives, hallucinogens, opioids)	ASSIST
Antiretroviral medication adherence	
Adherence assessment	ACTU-4
Quality of Life	
QOL questionnaire	EuroQoL 5 Dimensions 3 Levels (EQ-5D-3L)
Social determinants of health (SDOH)	
	Accountable Health Communities screening
Symptoms	
	The Memorial Symptom Assessment Scale-Short Form (MSAS-SF)
Stigma	
	4-item internalized HIV stigma scale

PROs Data collection

- 869 participants have been enrolled from May 2021 through December 31, 2022
- Annual PROs survey rollout began May 2022
  - 118 annual surveys have been completed thus far

COVID survey domains

- Healthcare access
- Pre-existing medical conditions
- Household contacts
- COVID-19 symptoms and testing
- Impact of COVID-19
- Risk perceptions related to COVID-19
- Mental health symptoms
- Tobacco product use
- Sexual risk behaviors
- COVID-19 stigma
- ART adherence
- Telehealth

COVID survey data collection

- COVID
  - 1,912 participants have been enrolled since December 31, 2022
    - Will continue data collection through May 2023
  - 30 out of 122 (25%) long COVID surveys have been completed

Mpox survey domains

- Mpox awareness and information sources
- Vaccination status
- Exposure, infection, and treatment
- Worry about mpox and behavioral modifications
- Negative impact of mpox outbreak

Mpox survey data collection

- Mpox questions added in August 2022 on awareness, information sources, vaccine uptake, behavior change, and negative impacts
- 229 participants have completed the mpox survey questions as of January 15, 2023

DC Cohort Pilot Study Collaboration Process

General Guidelines for Concept Sheet and Data Request Submissions

- Data dictionaries available upon request
- Data request and concept sheets available on DC Cohort website
- Data use agreements are required for investigators
- DSCC analytic staff and DC CFAR biostatisticians are available to work with investigators/analysts
- All Cohort-wide concepts are reviewed, approved, and prioritized by the DC Cohort Executive Committee
- DC Cohort website: http://go.gwu.edu/dccohort

Pilot Award Process and Dates

Contact Drs Castel/Monroe via email with written concept (2/6)

Arrange a meeting to discuss concept (meetings 2/6-2/15)

DC Cohort will assess feasibility of concept within 1 week of receipt (2/6-2/17)

If feasible, DC Cohort PI/PD will circulate concept sheet to EC for review and approval (2/6-2/17)

DC Cohort PI/PD will assist in identifying potential collaborating sites if project involves clinics; identify DC Cohort analyst to work on the project (2/6-2/17)

DC Cohort PI/PD will facilitate letters of support from Cohort and from participating sites for submission (2/6-4/12)

DC Cohort PI/PD will review draft proposal/provide feedback prior to submission (draft due 4/3; reviews 4/3-4/12)

Acknowledgements

- **DC Cohort Study Team**
  - Alan Greenberg
  - Anne Monroe
  - Ella Temprosa
  - James Peterson
  - Bianca Stewart
  - Morgan Bryne
  - Paige Kulie
  - Shannon Barth
  - Elisabeth Andersen
  - Mark Storey
  - Shannon Hammerlund
  - DC Cohort Executive Committee
- **Molecular Epidemiology Study Team**
  - Brittany Lewis
  - Jeanne Jordan
  - Kamwing Jair
  - Keith Crandall
  - Seble Kassaye
- **DC DOH HAHSTA**
  - Clover Barnes
  - Michael Kharfen
  - Rupali Doshi
  - Kerri Dorsey
  - Garret Lum
  - Adam Allston
  - Brittani Saafir-Calloway
  - GWU student RAs
- **DC CFAR**
- **NIH funders and collaborators**
  - Carl Dieffenbach
  - Henry Masur
  - NIAID: WIHS 5U01AI034994; 3U01 A1 069503_03 03S2; DC CFAR 5P30AI087714;1R24AI152598-01
  - NIMH: R01MH122375

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QUESTIONS

DC Cohort website: http://go.gwu.edu/dccohort

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