

Improving Hepatitis C Surveillance and Data Usage Within the RWHAP





None of today's presenters have relevant financial or non-financial interests to disclose.

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At the conclusion of this activity, participants will be able to:

- 1. Describe the importance of hepatitis C surveillance data for building a HCV cascade of care.
- 2. Describe how collaboration between hepatitis C and HIV surveillance systems can facilitate people with HIV and HCV and in need of HCV treatment to be identified, linked, and retained in care.
- 3. Understand where to locate additional resources related to hepatitis C surveillance data improvements.

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Strategically Addressing Viral Hepatitis 2020 National Ryan White Conference on HIV Care & Treatment



Carol Jimenez, Deputy Director for Strategic Initiatives Office of Infectious Disease and HIV/AIDS Policy (OIDP) @HHS ViralHep

Meet the OIDP Team

Carol Jimenez, JD Deputy Director for Strategic Initiatives



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Office of Infectious Disease and HIV/AIDS Policy (OIDP)

- Provides strategic leadership and management, while encouraging collaboration, coordination, and innovation among federal agencies and stakeholders to reduce the burden of infectious diseases.
- Health policy and program issues related to:
 - HIV/AIDS;
 - Viral hepatitis;
 - Vaccines;
 - Sexually transmitted infections (STIs);
 - Other infectious diseases of public health significance; and
 - Blood and tissue safety and availability in the U.S.



National Strategies Coordinated by OIDP

- HIV National Strategic Plan (HIV Plan)
 - Current National HIV/AIDS Strategy expires 2020
- Viral Hepatitis National Strategic Plan (Hepatitis Plan)
 - Current National Viral Hepatitis Action Plan expires 2020
- Sexually Transmitted Infections National Strategic Plan (STI Plan)
 - First ever federal STI Plan
- National Vaccine Plan (Vaccine Plan)
- Releases planned for 2020



National Strategic Plans – Coordinating Across Four Areas

OIDP is using a consensus approach to developing strategic plan documents

- Federal Steering Committees comprised of leadership throughout HHS and other federal departments
- Integrated approach across plans to address the syndemic
- Stakeholder input: Requests for Information (Federal Register), listening sessions, advisory committees consultation
- Aligned with Ending the HIV Epidemic, Healthy People 2030, and other initiatives
- Five-year plans (2021-2025) with annual targets through 2030
- Federal implementation plans to be developed following each strategic plan release





Impact of COVID-19 on Viral Hepatitis Programs

We recognize that the response to COVID-19 has been a top priority for many people across the United States. **Thank you** for your unwavering commitment to supporting this vital response.

- Many HIV, hepatitis, and STI health department staff are being detailed to state and local COVID-19 efforts, putting an additional strain on already lean programs.
- CDC posted What to Know About Liver Disease and COVID-19
- Opportunities presented by the pandemic include: integrated infectious disease testing, innovations in delivering SSP services, expanded telehealth, scope of practice, and access to substance use disorder treatment.

Together, we can work to provide our families, friends, and communities with information and resources needed to stay healthy and protect ourselves from COVID-19 and viral hepatitis.



Hepatitis C Medicaid Affinity Group



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Federal Partners Engaged in Hepatitis C Medicaid Affinity Group

- Office of Infectious Disease and HIV/AIDS Policy (OIDP)
- Centers for Disease Control and Prevention (CDC)
- Centers for Medicare & Medicaid Services (CMS)
- Health Resources and Services Administration (HRSA)
 - HIV/AIDS Bureau (HAB)
 - Bureau of Primary Health Care (BPHC)
- Substance Abuse and Mental Health Services Administration (SAMHSA)

Overview and Purpose of The Hepatitis C Medicaid Affinity Group

Foster state collaboration and the sharing of promising practices Support states in developing and implementing innovative HCV-related policies and programs

Increase the number and percentage of individuals screened and treated for HCV

State Participants



Examples - State Action Plans and Strategies



Example - State Action Plans and Strategies Building Provider Capacity

- Providers don't always feel capable of managing HCV treatment
- State strategies:
 - Indiana: Implement Project ECHO model to train primary care providers
 - Tennessee: Create a provider survey to assess training needs
 - Michigan and Wisconsin: Identify counties with high HCV prevalence and few DAA prescribers

Data from Five State Medicaid Programs*

HCV Screening and Treatment within Select State Medicaid Programs

	Average (%)	Minimum (%)	Maximum (%)
1. HCV Screening	7.4	1.0	19.1
1a. Baby boomers	9.5	2.1	22.6
1b. PWID	30.5	2.8	61.3
2. Confirmation of Diagnosis	67.1	43.9	92.3
3. Chronic HCV Prevalence	1.3	0.9	2.6
4a. Treatment of Chronic HCV (1 claim)	21.0	9.4	39.2
4b. Treatment of Chronic HCV (2 claims)	16.4	7.2	29.4
5. Post-Treatment Care	42.9	3.7	64.2

* Data collected as part of Medicaid Affinity Group activities. Based on Medicaid claims data submitted by five participating states.

New HHS Affinity Group Website Content!

 HHS Medicaid Affinity Group website: <u>https://www.hhs.gov/hepatitis/action-plan/federal-</u> response/hepatitis-c-medicaid-affinity-group/index.html

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A Growing Number of States, Regions, and Organizations Are Committing to Viral Hepatitis Elimination

- In March 2019, OIDP invited states, local jurisdictions and organizations to share their work toward viral hepatitis elimination.
- Mapping Hepatitis Elimination in Action goals:
 - help stakeholders find others who think it is feasible to eliminate the public health threat of viral hepatitis;
 - provide the opportunity to learn from and contact others who are pursuing similar goals;
 - expand support for elimination efforts by identifying existing efforts that stakeholders can join; and
 - raise awareness of the growing number of states, local jurisdictions and non-governmental
 organizations that are setting their sights on achieving the elimination of viral hepatitis among the
 people they serve.
- <u>https://www.hhs.gov/hepatitis/get-involved/hepatitis-elimination/</u>





To be added to the Map, contact <u>Carol.Jimenez@hhs.gov</u>

Elimination Projects Overview:

- 3 clinics/health systems
- 23 state/regional
- 5 national/multiple locations (not shown on map)

Focus: HBV: 7 plans HCV: 21 plans HBV & HCV: 5 plans HIV/HCV: 2 plans HIV/HBV/HCV: 1





Office of Infectious Disease and HIV/AIDS Policy Office of the Assistant Secretary for Health Department of Health and Human Services WWW.HHS.GOV/ASH WWW.HHS.GOV/HEPATITIS

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Improving Hepatitis C Surveillance and Data Usage within the Ryan White HIV/ AIDS Program

Neil Gupta, MD, MPH Chief, Epidemiology & Surveillance Branch Division of Viral Hepatitis Centers for Disease Control and Prevention

2020 National Ryan White Conference August 13, 2020



Overview

- Hepatitis C Update
 - Epidemiology
 - Updated Testing Recommendations
- HIV and Hepatitis C
- Hepatitis C Continuum of Care



Hepatitis C Update

Hepatitis C Virus (HCV) Epidemiology

- Ongoing hepatitis C epidemic in the United States
 - 2.4 million adults (1.0% of U.S. adults) living with hepatitis C during 2013–2016*
 - Leading cause of death from liver disease (15,713 deaths in 2018)
- Historically, highest prevalence of chronic hepatitis C among those born 1945–1965 ("Baby Boomers")
- Acute hepatitis C rates increased four-fold from 2009–2018⁺
 - New cases occurring among young adults, concurrent with opioid crisis
- In 2015, 0.38% of live births delivered by mothers with HCV infection[§]
 - Perinatal transmission occurs in 5.8% of infants born to HCV-infected mothers[¶], and 10.8% of infants born to HCV/HIV co-infected mothers



*Hofmeister M, et al. Hepatology 2019; ⁺2018 CDC surveillance data; [§]Schillie S, et al. Am J Prev Med 2018; [¶]Benova L, et al. CID 2014

Acute Hepatitis C Infections Continue to Soar





Source: CDC, National Notifiable Diseases Surveillance System

Acute Hepatitis C Infections Highest Among 20–39 Year Olds

Rate of reported acute hepatitis C cases by year and age group — NNDSS, 2009–2018





Source: CDC, National Notifiable Diseases Surveillance System

Newly Reported Chronic Hepatitis C Affecting Adults Across Generations

Number of newly reported chronic hepatitis C cases by sex and age — NNDSS, 2018





Source: CDC, National Notifiable Diseases Surveillance System

Awareness of Infection Low Among People Living with Hepatitis C

Proportion of HCV RNA+ adults aware of their infection status, NHANES, 2015–2018





Progression of National Hepatitis C Testing Recommendations

- Until now, CDC has focused testing efforts on:
 - Those with identified risk factors
 - Born 1945–1965 (Baby Boomers)

CDC Hepatitis C Screening Recommendations





Updated Hepatitis C Testing Recommendations (April 10, 2020)

- Rapid increases in acute infections among young adults, including reproductive-aged persons, have put multiple generations at risk for chronic hepatitis C
- Concurrent Release of New Screening Recommendation

CDC Recommendations for Hepatitis C Screening Among Adults — United States, 2020

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Updated Hepatitis C Testing Recommendations

- At least once in a lifetime for all adults aged 18 years and older, except in settings where the prevalence of HCV infection is less than 0.1%
- All pregnant women during each pregnancy, except in settings where the prevalence of HCV infection is less than 0.1%

Note: Testing continues to be recommended for all individuals with risk (once and periodically as risk persists).



Call to Action

Get tested. Get cured.





HIV and Hepatitis C

Overlap of Overdose and Vulnerability for Rapid Dissemination of HIV/HCV Among PWID



Source: CDC, NCHS/NVSS, 2018; CDC NCHHSTP, 2018

Coinfection with HIV/ HCV is Common in Outbreaks among PWID: Outbreak of HIV among PWID — Cabell County, WV, 2018–2019



- Largest relative HIV increase in the U.S. since outbreak in Scott County, IN
 - More than 20-fold increase above prior annual average (2 PWID diagnoses)
- 72 (88%) had lab evidence of current or past HCV infection
- Lasting public health impacts
 - Sparked investments in surveillance
 - Improved capacity to detect and respond to future clusters and outbreaks
 - Service delivery improvements for PWID

Sources: (1) Atkins A, McClung RP, Kilkenny M, et al.. MMWR Weekly. 2020 Apr 24; 69(16);499–500; (2) McClung RP, CROI 2020
Coinfection with HIV/HCV is Associated with Morbidity and Mortality

Organ systems	Selected complications
Immune	HIV disease progression, cryoglobulinemia
Liver	Fibrosis, cirrhosis, ESLD, HCC
Metabolic	Insulin resistance, diabetes
Cardiovascular	Cardiovascular disease, acute MI
Hematologic	Thrombocytopenia
Kidney	Proteinuria, MPGN, renal failure
Nervous system	Neurocognitive, peripheral neuropathy
Bone	Osteoporosis, osteonecrosis

HIV and Hepatitis C Coinfection Analysis using Surveillance Data

Jurisdiction	Among persons living with HIV		Among cumulative HCV cases	
	Living with HIV	% HIV/HCV	Cumulative HCV	% HIV/HCV
Arizona	16,664	7.9	108,608	2.1
Connecticut	10,478	9.3	30,325	4.9
Florida	110,145	4.6	137,172	4.4
Iowa	2,496	0	1,118	0.2
Louisiana	20,231	2.1	17,634	3.2
Maryland	35,000	9.8	51,305	8.5
Massachusetts	21,243	7.4	67,767	2.8
Michigan	15,257	5.6	81,289	1.7
Minnesota	8,140	6.6	41,198	2.7
North Dakota	353	7.4	7,669	0.7
South Carolina	18,238	7.4	40,374	5.1
Texas	79,733	7.7	211,117	3.8
Virginia	24,631	4.8	54,307	3.1
Washington	12,805	8.1	78,988	2.2
Wisconsin	6,677	8.7	42,846	2.2
New York City	108,723	7.3	101,980	10.9
San Francisco	13,584	11.3	19,353	13.3
Total	504,398	6.7	1,093,050	4.3

Coinfection with HIV and Hepatitis C varies by jurisdiction

- 6.7% of people with HIV coinfected with HCV
- 4.3% of persons ever reported with HCV were coinfected with HIV

Among HIV/ HCV coinfected persons:

- 42.3% were black/ African American
- Injection drug use was more commonly reported than those with HIV monoinfection
- HIV preceded HCV diagnosis in 83% of cases
- Surveillance is critical to guide public health interventions

Hepatitis C Continuum of Care

Without surveillance, we miss opportunities to:

- Identify impending public health emergencies
- Clarify and monitor the epidemiology of health problems
- Document the impact of an intervention or track progress towards specified goals
- Utilize data to set priorities and inform public health policy and strategies



Establishing Comprehensive Viral Hepatitis Surveillance

CDC DVH Strategic Planning for 2025

- Establish comprehensive national viral hepatitis surveillance for public health action

Objectives

- Strengthen capacity of all jurisdictions to report and describe their true burden of disease
- Provide framework to develop jurisdictional HCV continuums of care
- Ensure data is collected, analyzed, and reported in a manner than informs prevention and control
- Build capacity in all jurisdictions to detect and respond to VH outbreaks

Hepatitis C Continuum of Care (CoC)

Percentages for 715 hepatitis C virus (HCV) antibody-positive patients, showing cascade of care, Cherokee Nation Health Services, October 2012–July 2015



Mera J, Vellozzi C, Hariri S, et al. Identification and Clinical Management of Persons with Chronic Hepatitis C Virus Infection — Cherokee Nation, 2012–2015. MMWR Morb Mortal Wkly Rep 2016;65:461–466.

Chronic Hepatitis C Cascade of Care, New York City

(among those with positive hepatitis C test report, 7/1/14-6/30-18)



Hepatitis A, B, and C in New York City: 2018 Annual Report

Developing a Hepatitis C CoC Based on Lab Results Only



Development and Utility of a Lab Result- Based Hepatitis C CoC Among People Living with HIV



Summary

- Hepatitis C is a public health priority
 - Prevalence is high for a curable disease
 - Incidence is increasing
- Universal HCV screening is recommended for:
 - All adults, once
 - Pregnant women, every pregnancy
 - Anyone with risk, and periodically as risk persists
- Substantial overlaps exists between HIV and HCV
- Public health surveillance provide an opportunity to monitor the HCV CoC and achieve HCV micro-elimination among people living with HIV

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Improving Hepatitis C Surveillance and Data Usage Within the RWHAP: ConnQuER Hep C Project (Connecticut Quantification, <u>E</u>valuation, & <u>R</u>esponse: <u>HIV/HCV Elimination in Persons of Color</u>)

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Director of HIV/AIDS Program and Associate Professor of Medicine Yale University School of Medicine

HIV/HCV Co-infection Epidemiology



25% have HIV/HCV co-infection



WHO Hepatitis Elimination Goals

TOWARDS ELIMINATION OF VIRAL HEPATITIS BY 2030



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CT HIV Cascade of Care



HIV Continuum of Care, Connecticut, 2018



Based on persons receiving HIV care in 2018 among persons ≥13 years old at diagnosis, resided in Connecticut (based on most recent residence) and diagnosed with HIV infection through 2017 and living with HIV on 12/31/2018. A visit is defined as a CD4, viral load, or genotype test result during the evaluation period. The overall HIV population may be overestimated because cases are only followed up for 11 months. Source: HIV surveillance data through December 2019. Based on the number of persons ≥13 years old, diagnosed with HIV in 2018, who resided in Connecticut (based on residence of HIV diagnosis) and were linked to care within 1,3,6,12 months after HIV diagnosis. Numbers may be underestimated for persons linked to care within 12 months. CDC suggests 15 months delay for analysis. Source: HIV surveillance data through December 2019.

CT HIV Cascade of Care





Based on persons receiving HIV care in 2018 among persons ≥13 years old at diagnosis, resided in Connecticut (based on most recent residence) and diagnosed with HIV infection through 2017 and living with HIV on 12/31/2018. A visit is defined as a CD4, viral load, or genotype test result during the evaluation period. The overall HIV population may be overestimated because cases are only followed up for 11 months. Source: HIV surveillance data through December 2019. Based on the number of persons ≥13 years old, diagnosed with HIV in 2018, who resided in Connecticut (based on residence of HIV diagnosis) and were linked to care within 1,3,6,12 months after HIV diagnosis. Numbers may be underestimated for persons linked to care within 12 months. CDC suggests 15 months delay for analysis. Source: HIV surveillance data through December 2019.

Estimating HIV/HCV Coinfection in CT



- Incomplete epidemiologic profile:
 - True prevalence
 - Extent of screening, staging, referral, linkage, treatment, SVR are not known
- Prevalence of co-infected persons in CT: 1500-2200
 - 70% (1060-1540) are persons of color
- Likely underestimated
- Highest prevalence in urban areas: Bridgeport, Hartford, New Haven

Treatment Cascade Model for Monoinfected HCV: US 2014





Yehia et. al PLoS One 2014; 9(7): e101554

HCV Cascade in PWH following HCV Diagnosis, UCSD Owen Clinic: 1/2008-12/31/2012 (IFN-era)



Total number of patients with access to HIV care with HCV antibody positive (n=748)

Chronic active HCV infection with access to HIV care 100% (n=562)

Referred for HCV treatment 54% (n=303)

Attended at least 1 clinic visit for HCV treatment evaluation 50% (n=283)

Final decision made regarding HCV therapy initiation **44% (n=250)**

Initiated HCV treatment 16% (n=88)

> HCV cure **7% (n=41)**



Cachay, et al. PLoS One 2014.; 9 (7): e102883

HCV Cascade in HIV/HCV: New Haven, CT Clinic (Nathan Smith Clinic) DAA Era



Figure 2 The figure depicts the diagnosis-based hepatitis C virus (HCV) cascade of care among human immunodeficiency virus/HCV-coinfected patients at the Nathan Smith Clinic In New Haven, Connecticut between January 2014 and August 2018. The starting point is for the total number patients with diagnosed coinfection. DAA, directacting antiMirals; SVR12, SVR at 12 weeks posttreatment or cure.

Rizk et al. Open Forum Infectious Disease 2019 Aug 14

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HCV Cascade in HIV/HCV: Amsterdam Data







Boerekamps et al. Clin Infect Dis 2018; 66:1352-59

Challenges to Creating HCV Cascade for HIV/HCV Co-infected Persons



- Incomplete HCV surveillance data
 - Lack of funding
 - Lack of dedicated staff
 - Lack of automated data entry
- Lack of standardized matching algorithms
- Inaccurate determinations of HCV care status

Project ConnQuER HEP C



• What is it?

- Project ConnQuER HEP C <u>Connecticut Quantification</u> <u>Evaluation and Response:</u> <u>HIV/HCV Elimination in</u> <u>Persons of Color</u>
- Funded by HRSA SPNS (-047) to address racial disparities in access to HIV/HCV treatment for co-infected individuals





*Project ConnQuER is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$2,300,000 with no percentage financed with nongovernmental sources. The contents presented above are those of the author and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

Project Partners

Overall Project Goals



- 1. Cure Hepatitis C (HCV) in persons with HIV (PWH) in CT, particularly persons of color through improvements in the HCV cascade of care
- 2. Improve partnerships with key stakeholders
- **3.** Improve surveillance mechanisms statewide for HIV/HCV coinfection

Data Flow Model







DPH HIV/HCV Data Matching Flowchart



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HCV-HIV Matching Flowchart

Use SAS 9.4 (SAS Institute, Inc., Cary, North Carolina, USA). SAS extracts from CTEDSS and eHARS. Match using a CDC developed hierarchical deterministic matching SAS program. Method validated by 6 jurisdictions (findings published in American Journal of Epidemiology, kwy161,

*We created a Master List from all CTEDSS cases (HCV surveillance since 1994) matched to eHARS patients active from 2009-2018. This yielded an estimated 5185 patients Connecticut statewide **potentially co-infected** since 1994.



Using Surveillance Data to Determine HCV Outcomes (Rules for Determining if a Patient has SVR, Self-Cleared, or a False Positive)



HCV Antibody	HCV PCR	Interpretation
Positive	None reported	Incomplete evaluation
	Negative on same date/specimen	Spontaneous clearance
	Positive on same date/specimen <i>followed by</i> 2 or more positive PCRs	Chronically infected, untreated
	Positive on same date/specimen <u>followed by</u> negative PCR >4 weeks but <20 weeks later	Chronically infected, undergoing treatment
	Positive on same date/specimen <u>followed by</u> two or more negative PCRs with different collection dates	Chronically infected, SVR
	Positive on same date/specimen <u>followed by</u> negative PCR >20 weeks later	Chronically infected, SVR
	Positive on same date/specimen <u>followed by</u> negative PCR >20 weeks later <u>followed</u> by positive PCR with same or different genotype	Chronically infected, reinfection after SVR
Negative or Positive	Quantitative negative <u>with</u> qualitative positive on same date/specimen	Error or false positive
Negative	N/A	Reporting error

Creating a Statewide HCV Treatment Cascade for HIV/HCV Using Surveillance Data

- Data sources: eHARS and CTEDSS
- Flow
 - 1. CTEDSS updated with paper lab backlog
 - 2. DPH creates Coinfected list
 - 3. Yale Epidemiologist evaluates HCV labs location on cascade & inclusion/exclusion
- Two timeframes
 - 1. Cumulative (CTEDSS all time-1/1/1994-1/1/2020)
 - 2. Report Card Snapshot: CTEDSS labs from 1/1/2016 to 1/1/2020
 - Active in eHARS from 1/1/2015 to 10/1/2019; query as of 10/1/2019





Creating a Statewide HCV Treatment Cascade for HIV/HCV Using Surveillance Data: CUMULATIVE





Coinfected Treatment Cascade Inclusion/Exclusion: Cumulative N=3,689







Statewide Treatment Cascade: Report Card Snapshot 1/1/16-1/1/20





Coinfected Treatment Cascade Inclusion/Exclusion: CTEDSS 1/1/2016-1/1/2020 N=912





Coinfected Lab Dispositions for those Included: CTEDSS All Time N=665



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Coinfected Treatment Cascade: CTEDSS Labs from 1/1/2016 to 1/1/2020 N=665

Y

Statewide Treatment Cascade Findings

Lab dates from the beginning of surveillance time

- SVR rate is low at 36.5%
- The proportion of those with antibody only results is high at 29% (after exclusions)
- The amount excluded is high at 48%

1 Jan. 1994 – 1 Jan. 2020: CUMULATIVE

1 Jan. 2016 -1 Jan. 2020: SNAPSHOT REPORT CARD

Lab dates between 1/1/2016 and 1/1/2020

- SVR rate is fairly high at 68.6%
- The proportion of those with antibody only results is low at 3% (after exclusions)
- The amount excluded is lower at 37%

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Limitations on Use of Surveillance Data

- Data entry errors
- Reporting lags
- Assumptions made on lab results may be incorrect as detailed treatment history not obtained

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Multi-Site Clinics Project



- APPROACH: Obtain detailed HCV treatment status by direct communication with clinics
- Eligibility: All patients receiving HIV medical care in 11 HIV clinics in CT in timeframe
- Data sources: Clinic patient rosters (CAREWare, EMRs), eHARS, CTEDSS
- Timeframe: 9 years (1/2009-9/2018)
- Data Flow: Clinic patient rosters matched by CT DPH to eHARS and CTEDSS using validated algorithm



- Regular refinement cycles (5 cycles to Feb 2020)
 - Clinics update based on their data
 - Additional sources: Vital records, DIS OOC (LEP3), Tx init & SVR, Care Transfer (eHARS)

Multi-Site Clinics Project (2 of 2)











- It is feasible to create statewide treatment cascades for HIV/HCV co-infected individuals based on surveillance data
- SVR rates depend on starting point for denominator: cumulative vs snapshot
 - SVR improved from 36.5% to 68.6% with use of a more recently updated HCV surveillance database.
- Contributing factors:
 - 2016 HCV case definition change (with increased HCV PCR testing);
 - Increased electronic lab interface with CTEDSS being able to record negative PCRs in 2018
 - Enhanced DAA availability with decreased barriers to implementation (no fibrosis, sobriety or provider restrictions)
- SVR rates as determined by representative multi-site clinic data (with clinical input) corroborates SVR trends but labor intensive
 - Also depends on periodic clean-up of rosters based on various data sources
- CT cascade is close to micro-elimination target of 80% proposed by WHO

Timing of HCV Elimination in US

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Overall Year of Elimination in the US

- The US is projected to achieve HCV elimination by 2037, with the target for diagnosis being achieved by 2027, incidence by 2037, treatment by 2033, and HCV mortality by 2020
- Only three states (6% Connecticut, South Carolina, and Washington) are on track to achieve elimination by 2030



*The estimation may be less accurate owing to the small number of patients with HCV in the area.

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- Community Healthcare Van
- GBAPP
- ACT

SUDs

- Recovery Network of Programs, Inc.
- APT Foundation
- Wheeler Clinic

Multisite Clinics

- YNHH Nathan Smith Clinic
- YNHH Haelen Center
- Cornell Scott Hill Health Center
- Waterbury Hospital ID Clinic
- StayWell Health Center
- Circle Care Center
- Optimus Health Care
- Southwest CHC
- Norwalk CHC
- Lawrence & Memorial (NEMG)
- Anchor Health Initiative



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Yale Team











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Challenges of Using Client Data in the HIV/HCV Care Cascade

Courtney Gidengil, MD MPH Senior Physician Policy Researcher RAND Corporation

Introduction



- RAND is the evaluator for the Jurisdictional Approach to Curing Hep C Among HIV/HCV Coinfected People of Color and Curing Hep C Among HIV/HCV Coinfected People of Color projects
- These projects focused on disparities in the treatment for people with HIV/HCV coinfection
- In the evaluation, RAND developed steps corresponding to, and assessed progress along, the path to cure
- The result was the flow of people with HIV through the HCV care cascade

Proposed HCV Care Cascade for People with HIV/HCV



Data are for demonstration purposes only and do not reflect actual data



Project HCV Care Cascade for People with HIV/HCV



Data are for demonstration purposes only and do not reflect actual data



Challenges with Client-Level Data



- Sites were not able to collect data in a consistent manner
 - Not all data were captured in data systems
 - Pre-existing data were not defined or captured in the same way across sites
- Not all sites were able share data due to external constraints
 - Restrictions on sharing surveillance data (e.g., legal restrictions by states)
 - Issues with reporting from partner clinics
 - Changes in electronic health records (EHRs) during the project period
 - Challenges working with data vendors to produce the data tables
- Timeframe of study was relatively short
 - Longer period is needed to follow clients through the care cascade implementation was ongoing throughout the evaluation period
 - COVID-19 impacted Curing Hep C Among HIV/HCV Coinfected People of Color project clinics' ability to see and screen clients

Care Cascade – Available Data May Not Reflect Screening Efforts or Care Delivery





Client Screening— Difficulty Differentiating Between Ab and RNA Screening



The flow of client care is not always linear; using data in aggregate categories does not present the whole story

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DATA ARE NOT FINAL

Client Care Across Cascade – Lack of Data Makes Evaluation Difficult

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- Refine to reflect those sites able to contribute across entire cascade
- Compare across client characteristics
 - Where on the cascade are people of color differentially impacted?
 - Does the care cascade differ for those who are virally suppressed vs those who are not?
- Apply the cascade to a national population so that jurisdictions can compare their own performance on the care cascade
 - Develop benchmarks for performance comparison

Evaluation: Lessons Learned



- HIV/HCV coinfection is a growing area for research and evaluation
 - HIV/HCV care cascade and the data to populate it not yet well established
 - Restrictions on sharing protected data should be explicitly considered when planning research in people with HIV
- Populating the HCV care cascade with data is complex
 - Data sources for HCV are not as comprehensive compared to HIV
 - Testing for HCV is complex
 - Two different tests to confirm diagnosis, potential for spontaneous clearance, and possibility of reinfection after cure mean that data must be detailed and collected over a sufficiently long period of time
 - Proxies can be useful pending development of more refined measures, but do not help to populate individual steps on the care cascade
- HIV data systems function well to collect data and track HIV
 - Co-infection/mental health/substance use service data is lacking or inconsistently tracked
 - Could leverage HIV resources to expand to intersecting client needs

RECOMMENDATION



Develop and publish HCV care cascade measures for people with HIV

- Operationalization of standard measures to lead the development of data standards for vendors
- Support health departments/RWHAP recipients on processes for the collection of new measures
 - Promote ability of subrecipients and others to set up EHRs to facilitate data collection
 - HCV Ab and RNA PCR lab test dates and results
 - SVR12 (marker of cure)

RECOMMENDATION





Build on existing relationships to address co-infection in other vulnerable populations and support dissemination of findings

- National organizations
 - SAMHSA
 - CDC
 - American Association for the Study of Liver Diseases (AASLD)
 - Other groups working on opioid epidemic
- Local partners
 - SUD Treatment
 - AETC / Training

RECOMMENDATION



Develop validated tools for data collection

- Validate patient knowledge assessment tool to fill in gaps in care cascade (patient-centered approach)
- Continue to develop quality measures related to HCV (and HIV/HCV coinfection)
- Leverage tools, such as dynamic microsimulation models, to help support jurisdictions, states, and other decisionmakers

Questions?



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- Vivian Towe (formerly at RAND)

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