### Thank you for joining our webinar on

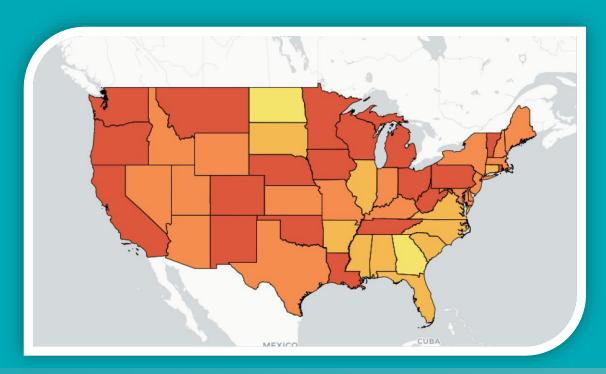
# Best Practices & Challenges in Hepatitis C Surveillance

The webinar will begin at 12:30 PM EST / 9:30 AM PST



- Join the call via phone or computer by clicking the phone button
- We will <u>not</u> be using webcams for this presentation, please turn off your webcam with the camera button
- To submit questions, click the chat icon and type your question before hitting the "enter" key





# HepVu Webinar: Best Practices & Challenges in Hepatitis C Surveillance

January 28, 2020



#### **Overview**

#### I. Introduction: HepVu & the Importance of Hepatitis C Surveillance

Heather Bradley, PhD, Assistant Professor of Epidemiology, Georgia State University, and HepVu Project Director

Eli Rosenberg, PhD, Associate Professor of Epidemiology and Biostatistics, University at Albany

# II. Louisiana's Big Bet: Eliminating Hepatitis C as a Public Health Problem – Ramping Up HCV Surveillance

Jessica Fridge, MSPH, STD/HIV/Viral Hepatitis Surveillance Manager, Louisiana Department of Health, Office of Public Health

#### III. Successes & Challenges in Hepatitis C Surveillance in Massachusetts

Anthony Osinski, MPH, Viral Hepatitis Surveillance Coordinator, Massachusetts Department of Public Health

#### IV. Hepatitis C Surveillance in New York City

Angelica Bocour, MPH, Director of Viral Hepatitis Surveillance, Bureau of Communicable Disease, New York City Department of Health and Mental Hygiene

Miranda Moore, MPH, Senior Data Analyst, Bureau of Communicable Disease, New York City Department of Health and Mental Hygiene

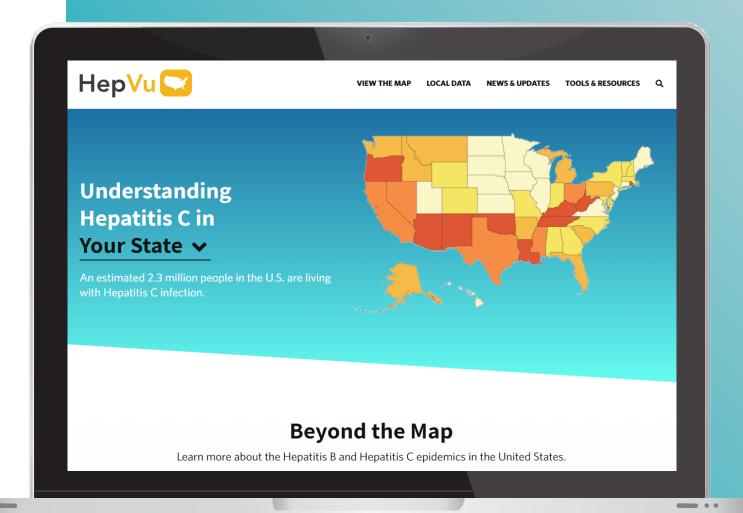
# Introduction: HepVu & the Importance of Hepatitis C Surveillance

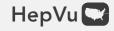
Heather Bradley, PhD, Assistant Professor of Epidemiology, Georgia State University, and HepVu Project Director

Eli Rosenberg, PhD, Associate Professor of Epidemiology and Biostatistics, University at Albany

# HepVu Overview

- HepVu.org is an online platform that visualizes data and disseminates insights on the Hepatitis C epidemic across the United States
- Established in 2017 to present the first standardized state-level estimates of people living with Hepatitis C
- HepVu is presented by Emory
   University's Rollins School of Public
   Health in partnership with Gilead
   Sciences, Inc.





# HepVu Advisors

- Co-Chair: Patrick Sullivan, PhD, DVM, Professor, Department of Epidemiology, Emory University, Rollins School of Public Health, and Principal Scientist, AIDSVu and HepVu
- Co-Chair: Ron Valdiserri, MD, MPH, Professor, Department of Epidemiology, Rollins School of Public Health, Emory University, Former Deputy Assistant Secretary for Health, Infectious Diseases, U.S. Department of Health and Human Services
- Project Director: Heather Bradley, PhD, Assistant Professor of Epidemiology, Georgia State University
- HepVu Working Group Advisors:
  - amfAR
  - CDC
  - Hepatitis B Foundation
  - Howard University Hospital
  - Kaiser Family Foundation
  - Massachusetts Department of Health
  - MedStar Health Research Institute

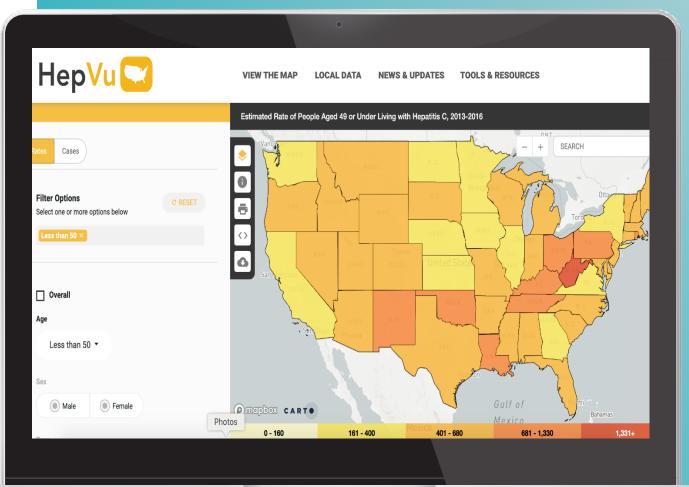
- NASTAD
- National Viral Hepatitis Roundtable
- NIDA
- Philadelphia Health Department
- UAB Emergency Medicine Department
- UCSD

# New Data Launched This Month

State-level Hepatitis C prevalence estimates (2013-2016) stratified by:

- Sex
- Age
- Race







---

# **Today's Objectives**

Spark discussion about best practices and challenges in conducting Hepatitis C surveillance and estimating the burden of Hepatitis C locally

Highlight local success stories and challenges in Hepatitis C surveillance and burden of disease estimation

Foster dialogue about resources HepVu could provide to encourage ongoing conversation about improving Hepatitis C surveillance in state and local jurisdictions

# Hepatitis C Surveillance Challenges

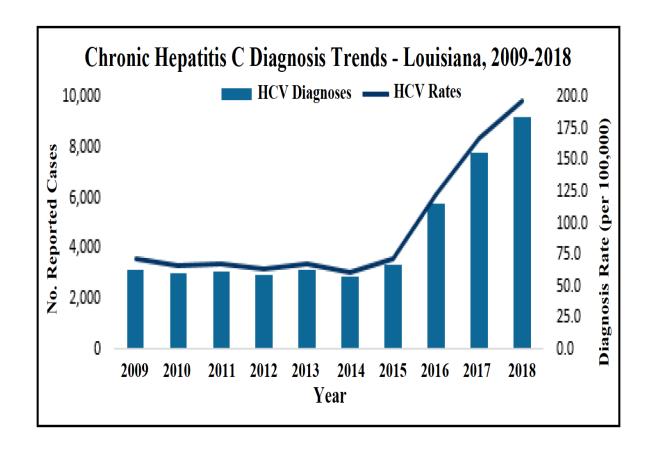
- Many states have their own unique methods for quantifying the number of Hepatitis C infections in their state
- Methods based on locally available surveillance data may generate different results
- As a result of the variability in approaches and data sources among individual states, it is difficult to compare results across jurisdictions
- Today, we will highlight three jurisdictions and discuss how they estimate Hepatitis C burden of disease



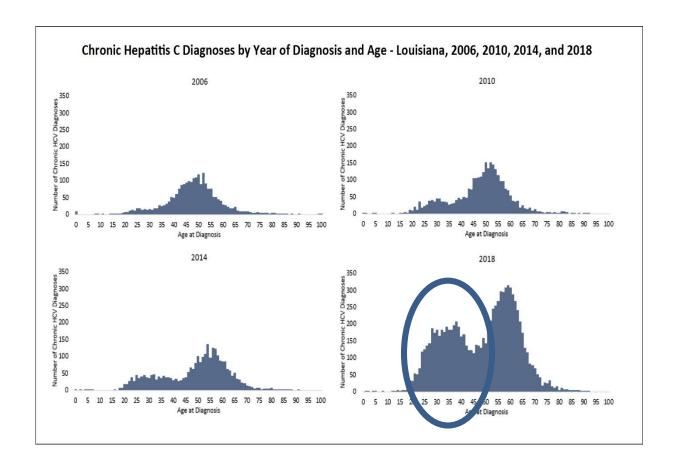
# Louisiana's Big Bet: Eliminating Hepatitis C as a Public Health Problem – Ramping Up HCV Surveillance

Jessica Fridge, MSPH, STD/HIV/Viral Hepatitis Surveillance Manager, Louisiana Department of Health, Office of Public Health

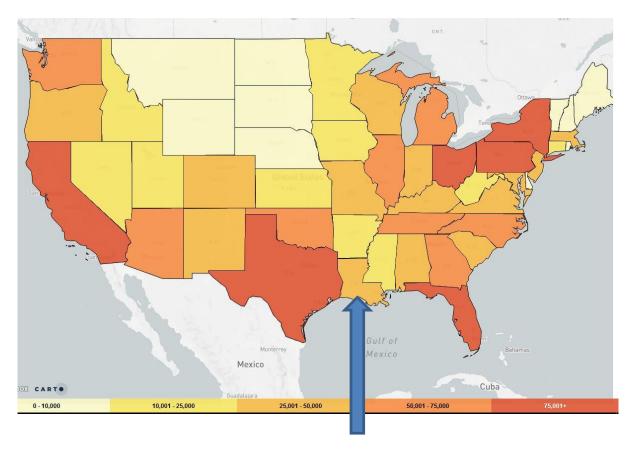
# Chronic Hepatitis C: Louisiana



# Chronic Hepatitis C: Louisiana



# Hepatitis C in Louisiana



HepVu estimates that **50,000 people** are living with HCV in Louisiana (2013-2016)

## Louisiana's Hepatitis C Elimination Program

- Establish a modified Hepatitis C medication subscription model for Medicaid and corrections
- Educate public on availability of cure and mobilize priority populations for screenings
- Expand HCV screening and expedited linkage to HCV cure
- Strengthen HCV surveillance to link persons previously diagnosed to treatment
- Expand provider capacity to treat Hepatitis C
- Implement harm reduction and complementary treatment strategies
- Extend elimination efforts to all populations within the state

# **History of HCV Surveillance**

Prior to Surveillance Focus	Current Modifications
Reduced reporting in the Louisiana Sanitary Code	Enhanced reporting in the Louisiana Sanitary Code
All reporting and laboratory processing in NBS	Migration from NBS to a homegrown HCV Surveillance system (HepCat)
No follow-up unless a case was presumed to be Acute HCV	Chart abstractions on chronic HCV diagnoses
Limited matching with external data sources	Robust matching with external sources
Large Access database of all HCV diagnoses, limited data cleaning	Access database archived

# **Modifications to the Louisiana Sanitary Code**

Prior to May 2019	As of May 2019
Chronic HCV was only mandated for Laboratory reporting	Chronic HCV now listed as a Class C Provider reportable condition
Only positive HCV laboratory test results were reportable	All HIV, HCV, and syphilis laboratory tests results are mandated to report electronically, regardless of result (includes all positives and negatives)

#### **Additional Data Sources**

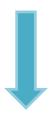
- Batch matches with Lexis Nexis
- Monthly Medicaid matches
  - Louisiana Department of Health has a data sharing agreement with Medicaid
- Chart abstractions
- Facility treatment lists
  - Patient level lists of persons previously treated at the facility

### **Lexis Nexis**

First de-duplicated with Link King



Sent to Lexis Nexis for a batch match



Removed over 2,000 duplicates

#### **Medicaid Data**

#### **Monthly files include:**

- Enrollment/Demographic file that includes persons who have had a medical service with an ICD10 diagnostic code for HCV
- Outpatient encounter file for persons included in enrollment file
- 3. DAA pharmacy claims
- 4. Lab claims for HCV antibody, HCV RNA Qualitative, HCV RNA Quantitative, and HCV Genotypes

#### **Chart Abstractions**

- Received ASTHO grant to fund chart abstraction project
- Hired and trained 6 RNS

- Abstracted over 3,300 chronic HCV cases
- **2020:** HIV chart abstractors to also abstract for HCV. Hire one full-time HCV chart abstractor.

## **HepCat**

#### **Match**

Automatically match lab results to generate a unique profile for each case as Acute, Chronic, or Perinatal

#### <u>Identify</u>

Flag cases
requiring
follow up.
Acute cases
requiring
investigation,
reinfection,
lab quality
issues,
perinatal
cases, etc.

#### **Combine**

Merge
automated
lab test
results with
additional
data from
chart
abstractions
and data
matches

#### **Capture**

Gather multiple names, addresses, and treatment indicators for each unique person diagnosed

#### **HCV Prevalence: Louisiana**

# 73,107 confirmed or probable chronic HCV cases have been reported to us:

- 8,481 moved
- 13,507 died
- 1,664 cleared Negative RNA after positive Antibody
- 766 laboratory evidence of completed treatment
- 3,659 Medicaid claims evidence of completed treatment

#### **Current prevalence estimate of known HCV diagnoses:**

- 47,369 persons are living with untreated HCV in Louisiana

# Thank you!

Jessica Fridge, MSPH STD/HIV/Hepatitis Surveillance Manager Louisiana Office of Public Health Jessica.Fridge@la.gov

Thanks to:

Kristina Larson

Hepatitis Surveillance Supervisor
Louisiana Office of Public Health

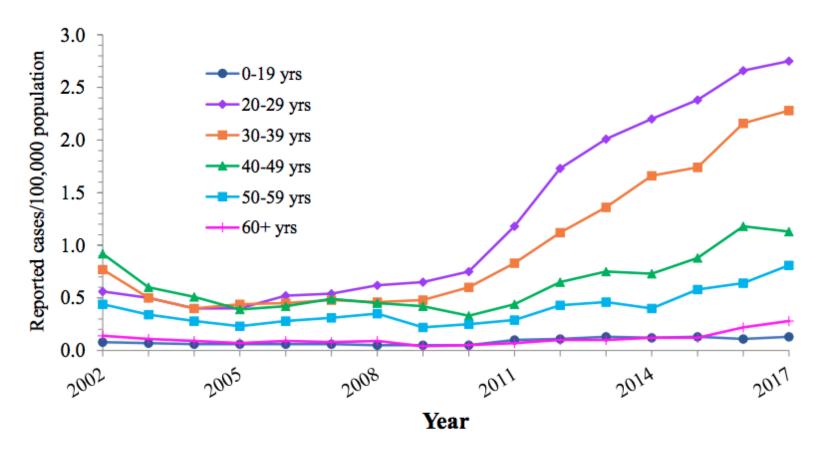
Kristina.Larson@La.gov



# Successes & Challenges in Hepatitis C Surveillance in Massachusetts

Anthony Osinski, MPH, Viral Hepatitis Surveillance Coordinator, Massachusetts Department of Public Health

# **Background**



Source: CDC, National Notifiable Diseases Surveillance System.

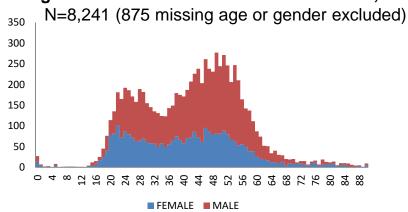
# **Challenge: Complexity**

- Typically, chronic infection with long-term effects
- Impacts highly stigmatized populations
- Curable

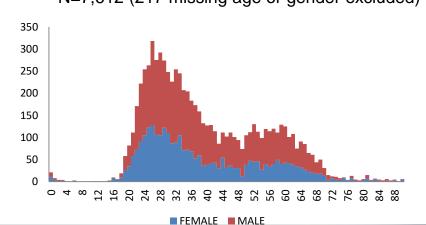
ELIMINATING
THE PUBLIC HEALTH PROBLEM
OF HEPATITIS B AND C
IN THE UNITED STATES

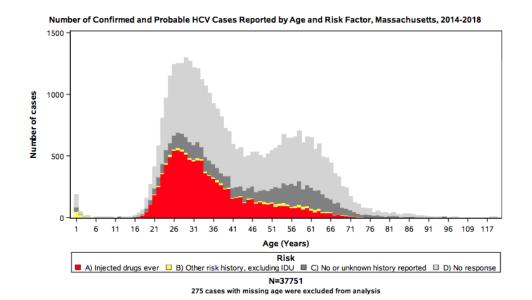
### Success: Ongoing Surveillance in Massachusetts

#### Age distribution of HCV in Massachusetts, 2007



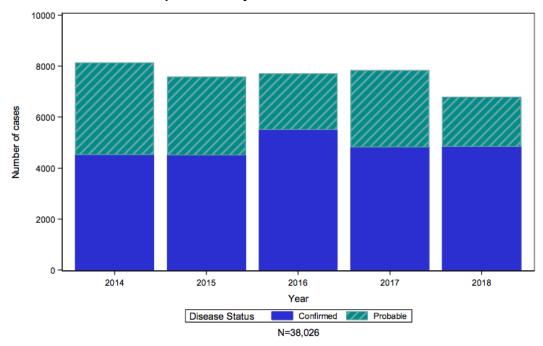
#### Age distribution of HCV in Massachusetts, 2016 N=7,612 (217 missing age or gender excluded)





## **Challenge: Volume**

#### Number of Confirmed and Probable HCV Cases Reported by Year, MA, 2014-2018



Data are current as of March 25, 2019 and are subject to change

- Prioritization of follow-up
- Provider requests
- Response rates
- Case review

## **Challenge: Resource Limitations**

- CDC funding makes a positive impact, but there are still unmet needs
- Delays in data entry and maturity of datasets
  - Timeliness
- Creative collaborations
  - HIV
  - Cancer registry
  - Vital statistics

## **Challenge: Estimating Prevalence**

222,000 - 252,000

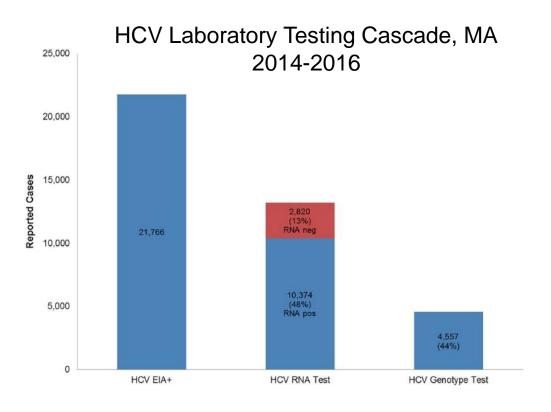
MDPH Estimate of People Living with Chronic HCV Infection

- Reported cases
- Assumptions about clearance, treatment, death

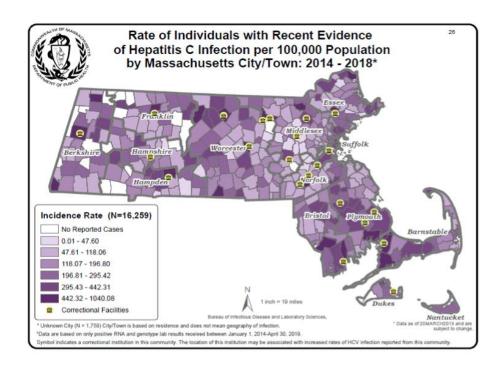
38,100

HepVu Estimate

## Where We Are Going



Vo, Quynh, et al. "The Massachusetts Hepatitis C Testing Cascade, 2014-2016." Microbiology Insights, vol. 12, 21 June 2019, pp. 1-6.



#### **Other Successes**

- Secondary data sources
  - ICD-10 codes
  - Integrated testing and linkage to care sites
  - Electronic medical records

- Reporting of negative HCV lab results
- Reflex RNA testing at the State Laboratory
- Expansion of syringe service programs

## **Acknowledgments**

#### **Anthony Osinski, MPH**

Viral Hepatitis Surveillance Coordinator Massachusetts Department of Public Health anthony.osinski@state.ma.us

HepVu
CDC Division of Viral Hepatitis
MDPH Viral Hepatitis Project Team
MDPH Surveillance and Informatics Office
MDPH Office of Health Care Planning



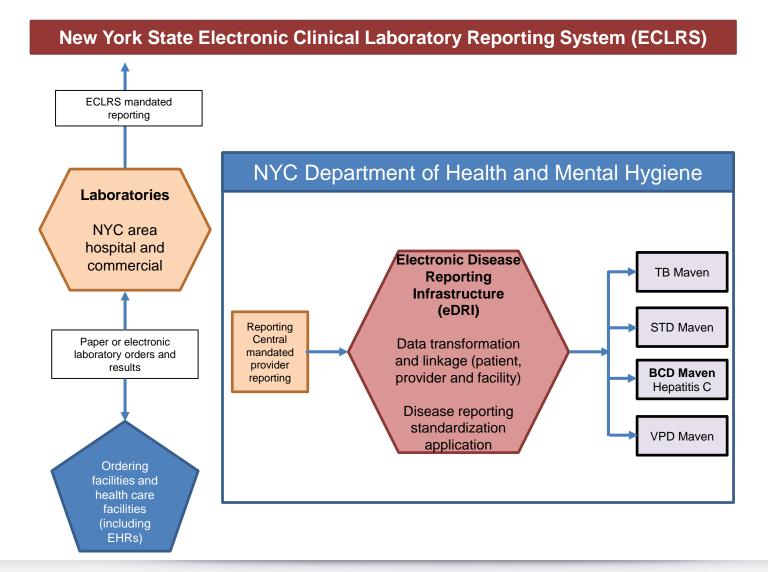
# Hepatitis C Surveillance in New York City

Angelica Bocour, MPH, Director of Viral Hepatitis Surveillance, Bureau of Communicable Disease, New York City Department of Health and Mental Hygiene

Miranda Moore, MPH, Senior Data Analyst, Bureau of Communicable Disease, New York City Department of Health and Mental Hygiene

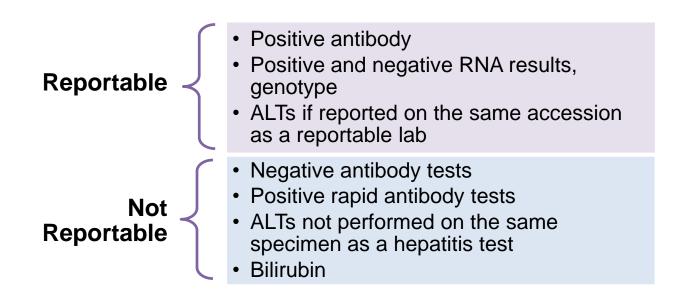
### New York City Hepatitis C Surveillance Registry

- Maven
  - Electronic workflows
  - Automated deduplication system
  - Manual review of partial matches
  - Person-based with testing history



## **Reportable HCV Tests**

- >90% of HCV test results are sent electronically from laboratories
- High volume of reports
  - >200,000 HCV tests reported in 2019
- Acute hepatitis C reporting
  - Not reliably reported by providers
  - Without negative antibody test results, cannot identify seroconversions



# Demographic Information from Laboratory Reports

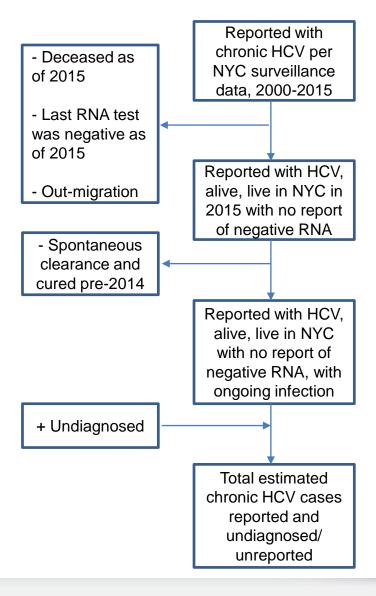
Reportable	Not Reportable				
Name	Race/ethnicity				
Sex	Gender identity				
Date of birth	Risk factors				
Social security number	Country of birth				
Address	Treatment information				
Phone number	Liver health				
	HIV status				
	Pregnancy status				

### **Hepatitis C Surveillance Activities**

- Enhanced surveillance investigationsData matching
  - Patient and provider interviews with people newly reported aged <35 years to identify demographics, risk factors, acute infection
  - Surveillance-based treatment and cure definition validation
  - Recurrent events after cure to identify re-infection

- HIV
- NYS Cancer Registry
- NYC Vital Statistics (births and deaths)

### **Surveillance-based HCV Prevalence Estimate, 2015**



116,000

New Yorkers with hepatitis C

Bocour A, Greene SK, Laraque F, Winters A. Estimating the prevalence of chronic hepatitis C virus infection in New York City, 2015. Epidemiol Infect. 2018; 146(12):1537-1542

## Comparison of Surveillance-based & NHANES HCV Prevalence Estimates

#### NYC surveillance-based

- 116,000 persons with HCV infection in 2015
- NYC residents
  - Total population: 8.6 million

#### State level NHANES-based

- 116,000 persons with HCV infection, 2013-2016
- NYS residents (NYC + rest of state)
  - Total population: 15.5 million (adult only)

## NHANES-based Prevalence Estimate Strengths & Weaknesses

### **Strengths**

- Measures both diagnosed and undiagnosed infections
- Methods consistent across states, allowing direct comparisons
- Does not require a robust, long-standing surveillance system

### Weaknesses

- NHANES sampling not representative for people most likely infected with HCV
  - Sheltered homeless, unstably housed, etc.
- Adjustments for unrepresented groups (unsheltered homeless, incarcerated) based on sparse data, requiring strong assumptions
- Assumptions needed to apportion estimated cases across states
  - Data sources have indirect relationship to prevalence
  - Relationship might not hold for all states

# Surveillance-based Prevalence Estimate Strengths & Weaknesses

### **Strengths**

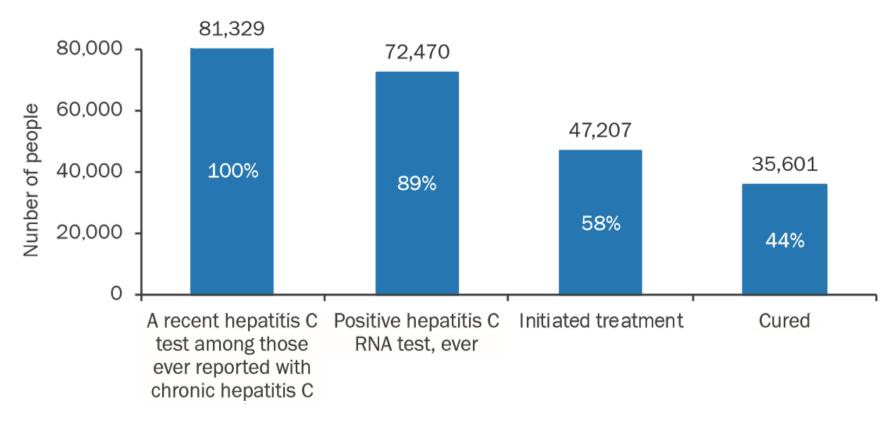
- Based on case reports of people living in NYC
  - Does not require broad assumptions that may not be applicable to NYC
- Directly determine number currently infected because of negative RNA reporting
- Able to update readily for monitoring efforts

### Weaknesses

- Requires robust reporting infrastructure
  - Data processing and maintenance errors
- Doesn't account for deaths outside of NYC
- Assumptions needed about outmigration
- Must estimate the number of undiagnosed infections

### Surveillance-based HCV Care Cascade

Care cascade for people in NYC with chronic hepatitis C recently reported (from July 1, 2014 to June 30, 2018) with a positive hepatitis C test, regardless of year of first report

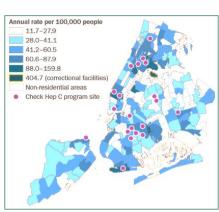


Moore MS, Bocour A, Jordan L, et al. Development and validation of surveillance-based algorithms to estimate hepatitis C treatment and cure in New York City. J Public Health Manag Pract. 2018; 24(6):562-532

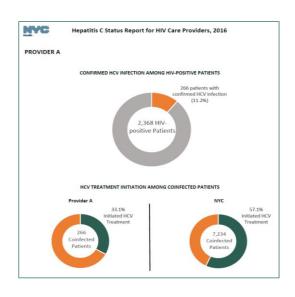
## Surveillance Implementation: Data to Care, Hep C Dashboards, & Patient Lists

#### **Data to Care**

- Identifying areas with high rates of HCV
- Health care facility dashboards
- Patient lists to facilities to review care for their own patients



### **Dashboards**



% HIV patients co-infected with hepatitis C

% co-infected patients at facility who initiated treatment vs. treatment initiation rates across NYC

#### **Patient Lists**

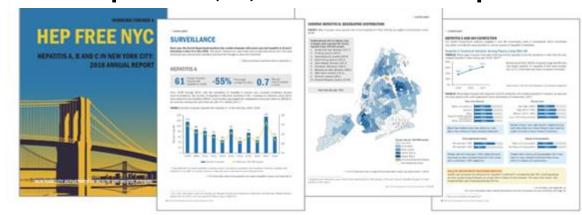
Health Department-generated, facility-specific lists of HIV and Hepatitis C RNA positive patients

#### Facilities were asked to:

- Review list
- Promote hepatitis C treatment
- Return list to the Health Department with patient disposition

### **Resources & Community Engagement**

### **Hepatitis A, B, and C Annual Report**



### **Hep Free NYC**



Photo: Hepatitis Awareness Month event on the steps of City Hall, May 2017

Sort results
Alphabetically

Communicable	Disease	Surveillance	Data
--------------	---------	--------------	------

Reported cases for recent years are shown below, click a data point to explore a disease.

	2012	2013	2014	2015	2016	2017
Hepatitis A	48	94	47	75	49	135
Hepatitis B, acute	64	69	57	48	61	45
Hepatitis B, chronic	7,363	7,092	7,412	7,652	8,416	7,204
Hepatitis C, chronic	7,273	6,704	7,470	6,972	6,133	5,308

Data from the most recent year are not final and are subject to change.

Minor variations in data presented here and elsewhere (including other publications of the NYC Department of Health and Mental Hygien)

Minor variations in data presented here and elsewhere (including other publications of the NYC Department of Health and Mental Hygiene) may be due to several factors, including reporting delays, census data availability, corrections, and data processing refinements (for example, the removal of duplicate reports). See additional information on definitions and methodology on the notes page.

EpiQuery (https://a816-health.nyc.gov/hdi/epiquery/)

### **Questions?**



To submit questions, click the chat icon and type your question before hitting the "enter" key

### HepVu: Resources & Awareness Dates

- Continuing focus on viral hepatitis surveillance
- May: Hepatitis Awareness Month and Testing Day
  - National Hispanic Hepatitis Awareness Day
- July: World Hepatitis Day
  - National African American Hepatitis C Action Day
- Ongoing blog series with experts and infographics

How can HepVu better support your organization and contribute to Hepatitis C elimination efforts?

## **Engage With HepVu**

- Share data and news with your networks
- Follow us on social media: @HepVu
- Sign up for our newsletter: www.hepvu.org
- Let us know how you use HepVu: info@hepvu.org

Visit HepVu.org's News & Updates to download today's presentation and watch the recording

## Learn more at HepVu.org







Subscribe to newsletter and updates at HepVu.org!