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 not 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

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

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

3. **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

Chronic Hepatitis C Diagnoses by Year of Diagnosis and Age - Louisiana, 2006, 2010, 2014, and 2018
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

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

<table>
<thead>
<tr>
<th>Prior to May 2019</th>
<th>As of May 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic HCV was only mandated for Laboratory reporting</td>
<td>Chronic HCV now listed as a Class C Provider reportable condition</td>
</tr>
<tr>
<td>Only positive HCV laboratory test results were reportable</td>
<td>All HIV, HCV, and syphilis laboratory tests results are mandated to report electronically, regardless of result (includes all positives and negatives)</td>
</tr>
</tbody>
</table>
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
First de-duplicated with Link King

Sent to Lexis Nexis for a batch match

Removed over 2,000 duplicates
Medicaid Data

Monthly files include:

1. Enrollment/Demographic file that includes persons who have had a medical service with an ICD10 diagnostic code for HCV

2. 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

- **Identify**
  - 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

![Graph showing reported cases per 100,000 population by year and age group. The graph demonstrates an increase in reported cases from 2002 to 2017.](source: CDC, National Notifiable Diseases Surveillance System.)

*Background*
Challenge: Complexity

- Typically, chronic infection with long-term effects
- Impacts highly stigmatized populations
- Curable
Success: Ongoing Surveillance in Massachusetts

Age distribution of HCV in Massachusetts, 2007
N=8,241 (875 missing age or gender excluded)

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

- 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
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

New York State Electronic Clinical Laboratory Reporting System (ECLRS)

- Laboratories
  - NYC area hospital and commercial
  - Paper or electronic laboratory orders and results

- Ordering facilities and health care facilities (including EHRs)

- NYC Department of Health and Mental Hygiene

- Electronic Disease Reporting Infrastructure (eDRI)
  - Data transformation and linkage (patient, provider and facility)
  - Disease reporting standardization application

- Reporting Central mandated provider reporting

- TB Maven
- STD Maven
- BCD Maven
- Hepatitis C
- VPD Maven
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

### Reportable

- Positive antibody
- Positive and negative RNA results, genotype
- ALTs if reported on the same accession as a reportable lab

### Not Reportable

- Negative antibody tests
- Positive rapid antibody tests
- ALTs not performed on the same specimen as a hepatitis test
- Bilirubin
## Demographic Information from Laboratory Reports

<table>
<thead>
<tr>
<th>Reportable</th>
<th>Not Reportable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Race/ethnicity</td>
</tr>
<tr>
<td>Sex</td>
<td>Gender identity</td>
</tr>
<tr>
<td>Date of birth</td>
<td>Risk factors</td>
</tr>
<tr>
<td>Social security number</td>
<td>Country of birth</td>
</tr>
<tr>
<td>Address</td>
<td>Treatment information</td>
</tr>
<tr>
<td>Phone number</td>
<td>Liver health</td>
</tr>
<tr>
<td></td>
<td>HIV status</td>
</tr>
<tr>
<td></td>
<td>Pregnancy status</td>
</tr>
</tbody>
</table>
Hepatitis C Surveillance Activities

- **Enhanced surveillance investigations**
  - 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

- **Data matching**
  - HIV
  - NYS Cancer Registry
  - NYC Vital Statistics (births and deaths)
Surveillance-based HCV Prevalence Estimate, 2015

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)
<table>
<thead>
<tr>
<th>Strengths</th>
<th>Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Measures both diagnosed and undiagnosed infections</td>
<td></td>
</tr>
<tr>
<td>• Methods consistent across states, allowing direct comparisons</td>
<td></td>
</tr>
<tr>
<td>• Does not require a robust, long-standing surveillance system</td>
<td></td>
</tr>
<tr>
<td>• NHANES sampling not representative for people most likely infected with HCV</td>
<td></td>
</tr>
<tr>
<td>• Sheltered homeless, unstably housed, etc.</td>
<td></td>
</tr>
<tr>
<td>• Adjustments for unrepresented groups (unsheltered homeless, incarcerated) based on sparse data, requiring strong assumptions</td>
<td></td>
</tr>
<tr>
<td>• Assumptions needed to apportion estimated cases across states</td>
<td></td>
</tr>
<tr>
<td>• Data sources have indirect relationship to prevalence</td>
<td></td>
</tr>
<tr>
<td>• Relationship might not hold for all states</td>
<td></td>
</tr>
</tbody>
</table>
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

HepVu.org | info@HepVu.org | @HepVu
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

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

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

% HIV patients co-infected with hepatitis C

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

Hepatitis A, B, and C Annual Report

Hep Free NYC

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

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

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 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 EpiQuery page.

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

✉️ info@hepvu.org
Facebook
HepVu
Twitter
@HepVu

Subscribe to newsletter and updates at HepVu.org!