Improving Data Collection & Health Equity

NASTAD
February 2023
Harm Reduction Section
Agenda

- Getting started
- Quality Assurance
- Next steps
Hepatitis C Surveillance in Wisconsin

Laboratories → Wisconsin Electronic Disease Surveillance System (WEDSS) → Reported to CDC to assess national trends

Providers

Local Health Department
DPH Chart

Division of Public Health (DPH)

Operations and Policy Focus

Bureau of Communicable Diseases (BCD)

Bureau of Operations (BOO)

Office of Health Informatics (OHI)

Office of Preparedness and Emergency Health Care (OPEHC)

Harm Reduction Unit

WEDSS
WEDSS Support

- **WEDSS Support Team**
  - 4 system administrators
  - Provide updates
  - TA and meet needs of disease-specific reporting
  - Implementation of automation
- **2 WEDSS trainers**
  - WEDSS training to Local and Tribal Health Departments (LTHDs) and other WEDSS operators
- **Informaticists**
  - Data system connections
  - Reporting to CDC
  - System maintenance
- **Electronic Case Reporting (eCR) implementation – 2023**
  - Additional staff positioned at Wisconsin State Lab of Hygiene (WSLH) coordinating ELR
  - WEDSS staff at WSLH communicate with lab partners across the state to increase quality of reporting and provide TA
Our Program
Wisconsin Medicaid HCV Treatment has...

- No sobriety restrictions.
- No provider restrictions.
- No disease severity restrictions.
- No prior authorization needed.
- Retreatment considered.
Organizational Chart
Hepatitis C Program Chart

Funding mechanisms:
- CDC PS21-2103
- CDC Health Equity Grant (HEG)
- STI Supplemental Grant
- Opioid Settlement
Data Quality
## Chronic Hepatitis C Case Reports

<table>
<thead>
<tr>
<th>Demographic category</th>
<th>Number of case reports with complete information (total counts)</th>
<th>Percentage of case reports with complete information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>1501</td>
<td>99</td>
</tr>
<tr>
<td>Gender</td>
<td>1514</td>
<td>100</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>1507</td>
<td>99</td>
</tr>
<tr>
<td>County of residence</td>
<td>1513</td>
<td>100</td>
</tr>
</tbody>
</table>

## Acute Hepatitis C Case Reports

<table>
<thead>
<tr>
<th>Demographic category</th>
<th>Number of case reports with complete information</th>
<th>Percentage of case reports with complete information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>77</td>
<td>92</td>
</tr>
<tr>
<td>Gender</td>
<td>84</td>
<td>100</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td>84</td>
<td>100</td>
</tr>
<tr>
<td>County of residence</td>
<td>84</td>
<td>100</td>
</tr>
</tbody>
</table>
Pivots

- Digestible products
- Assessing terminology
- Auto-importing
- Electronic reporting
- Quickly implement case definition changes
Statewide Partnerships

- Wisconsin State Lab of Hygiene
- Local and Tribal Health Departments
- Department of Corrections: 9% - 11% of HCV cases
- Local Healthcare Systems
- Syringe Service Programs
- Healthcare Providers/Infection Preventionist
- Plasma and Blood Donation Centers
- HIV Tribal Coordinators
- GLITEC
- University of Wisconsin – Madison
- Statewide Action Planning Group
Recap: Improving Data Quality and Completeness

1. Good relationship with surveillance and IT teams/robust surveillance system
   1. Getting providers set-up in WEDSS
2. Building laboratory coordination to ensure quality of reporting and case classification data elements
   1. 2023 Lab Survey – inclusion of data elements like bilirubin, pregnancy status, ALT, AST, etc.
   2. 2023 eCR
   3. Automating race, ethnicity, other demographic data collection
   4. Tracking – negative RNA reportable
3. Collaborate internally!
4. Data Equity and language matters!
5. Community feedback and external collaborations!

FOUNDATIONAL!
First step in equity is improving the data we have available
Demographic Data Resource!

I. Disaggregating data → improved health equity

II. Law permits the collection of demographic data
   I. HIPAA allows for public health data collection
   II. Main barriers in reporting: patient hesitancy, provider non-reporting, and technological issues
   III. Explore whether to explicitly mandate or adopt penalty structure for non-reporting
Hepatitis C Rapid Tests - 2022

2,031 total tests

- Age: 12 unknown (0.6%)
- Gender: 62 unknown (3.1%)
- Ethnicity: 47 unknown (2.3%)
- Race: 47 unknown (2.3%)

182 persons had confirmatory tests (~9%) reported before rapid

282 Reactive (14%)

Rapid tests only visible to state employees in WEDSS
Data Improvements from Rapid Tests – 2022

- **Ethnicity**
  - 114 additions to Hispanic/Latino
  - 543 additions to Not Hispanic/Latino

- **Race**
  - 18 additions to Native (AI/AN)
  - 13 additions to Asian
  - 88 additions to Black or African American
  - 101 additions to Multiple Races
  - 313 additions to White

- **Gender**
  - 133 additions to Female
  - 300 additions to Male
  - 3 additions to Transgender, Female to Male
  - 1 addition to Transgender, Male to Female

2,031 Total Tests
Hepatitis C Rapid Tests – Exposure

Among the 1,749 Non-Reactive Rapids:
- Ever injected drugs: 61%, 39%
- Ever shared snorting equipment: 53%, 47%
- Injection drugs in past 6 months: 68%, 32%

Among the 282 Reactive Rapids:
- Ever injected drugs: 4%, 96%
- Ever shared snorting equipment: 16%, 84%
- Injection drugs in past 6 months: 9%, 91%

For Discussion
<table>
<thead>
<tr>
<th>2013 Cleaning Codes</th>
<th>2023 Cleaning Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duplicates</td>
<td>Look for HCV labs in non-HCV incidents</td>
</tr>
<tr>
<td>Missing race or ethnicity</td>
<td>Look for possible acutes</td>
</tr>
<tr>
<td>Out of state</td>
<td>Looks for perinatal cases</td>
</tr>
<tr>
<td>Check resolution status</td>
<td>Find possible test conversion</td>
</tr>
<tr>
<td></td>
<td>Numbers in name</td>
</tr>
<tr>
<td></td>
<td>Check labs and confirm resolution status</td>
</tr>
<tr>
<td></td>
<td>Duplicates and separating incidents</td>
</tr>
<tr>
<td></td>
<td>Confirming address</td>
</tr>
<tr>
<td></td>
<td>DOC cases</td>
</tr>
<tr>
<td></td>
<td>Suspected reinfection</td>
</tr>
<tr>
<td></td>
<td>Missing race or ethnicity</td>
</tr>
<tr>
<td></td>
<td>Missing sex</td>
</tr>
</tbody>
</table>
Data Completion

Abstract all missing/unknown Race/Eth/Sex

Quarterly SAS Code

117 unknown Race/Eth cases

Match against other Disease Incidents

Provide unique DIs to WEDSS → WEDSS conducts matching

Corrected 45/117 cases = 72 unknown cases

Log into and search across two databases

Wisconsin Circuit Court Access (CCAP)
Wisconsin Statewide Health Information Network (WISHIN)

Corrected 30/72 cases = 42 unknown cases remaining
Next Steps
Goals

• Biannual meetings with top 5 health systems in WI
• Lab reporting clinical information – bilirubin, AST, ALT, etc.
• Disaggregation of racial and ethnic groups
• Native demographic data linkage to the Great Lakes Inter-Tribal Epidemiology Center (GLITEC)
Goals in Motion

HCV DIS
- Risk factor information
- Improve data completeness through client interviews

WEDSS
- Improvements to data reporting/eCR
- Gender identity and sexual orientation

LHDs
- Trainings
- Advancing data collection practices

Reporting
- Data integration to elevate lived experience and expose injustice
- Data visualizations → data equity!!
Increases in rates of HCV have occurred among all racial and ethnic groups in Wisconsin.
But the rates of HCV increases have been highest among Native people.

Rate people aged 15–29 newly reported with positive hepatitis C test results by year of report, Wisconsin.
“It is important to consider differences in trends in hepatitis C by race and ethnicity to understand which communities are being impacted and where attention is needed to improve health equity. Race or ethnicity does not make a person more or less likely to acquire hepatitis C. Other factors such as structural racism, stigma, and poverty, as well as unequal access to health care, education, and housing affect communities of color disproportionately and can put individuals at greater risk for acquiring hepatitis C.”
Contact information

Kelsa Lowe – Hepatitis C Epidemiologist
kelsa.lowe@dhs.wisconsin.gov

Kailynn Mitchell – Viral Hepatitis Prevention Coordinator
kailynn.mitchell@dhs.wisconsin.gov

Caroline Mohr – Hepatitis C Surveillance Specialist
caroline.mohr@dhs.wisconsin.gov

Emily Hacker – Disease Intervention Specialist (DIS)
emily.hacker@dhs.wisconsin.gov

Wisconsin Hepatitis C Program