Building an Enhanced Hepatitis C Surveillance System: the Philadelphia Department of Public Health Methodology

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Philadelphia Department of Public Health
OUTLINE

• Background
• Methodology
• Results
• Lessons Learned
• Future Directions
• Discussion
BACKGROUND
Hepatitis C (HCV) is the most common chronic bloodborne infection—and leading cause for liver transplantation—in the United States

- 3.2 million people in the US have chronic hepatitis C
- 50-75% of these individuals are unaware of their infection*
- National trends indicate increasing new HCV infections in young adults**

** CDC. Viral Hepatitis Surveillance United States, 2010
Hepatitis C Surveillance

• HCV is a reportable condition in Philadelphia
• Historically, limited funding for HCV surveillance
• Local epi characterization previously limited to:
  • Incidence: ~5,000 new confirmed cases/yr
  • Age
  • Gender
  \}
  obtained from laboratory reports
• Local data is mirroring emerging national trend of increasing new HCV infections in young adults
  • 2011 $\rightarrow$ a 23% (n=557) increase from 2010 in confirmed cases in persons born after 1982*

*PDPH. Annual Report; Hepatitis C, 26. 2011
Boktor, S. et al. Increasing Rates of Hepatitis C Infection Past or Present Reports Among Adolescents and Young Adults in Pennsylvania. ICEID Conference_2012
ENHANCED HEPATITIS C SURVEILLANCE

• CDC ELC award to PDPH & 5 other state HDs

• Characterize epi of HCV in young adults
  • Particular focus on recreational substance use

Allowed PDPH to:

- hire a 0.6 FTE Surveillance Coordinator (x7mo)
- launch an Enhanced Hepatitis C Surveillance System on January 1st, 2012
METHODOLOGY
1. Inclusion Criteria:
   - *Philadelphia resident*
   - *Event date*: January 1-June 30, 2012
   - <31 years old
   - *never previously reported*
     - cross-check of local communicable disease registry

2. Investigation Approach two-pronged
   - Case phone interview attempts (x3)
   - Ordering Provider mailed interview (x2)

* *Event date* = symptom onset date > laboratory test date > report date
CASE INVESTIGATION FORM

• Self-Perceived Risks

• Scope of Risk Factor Ascertainment
  • Travel; Medical; Sexual; Recreational Habits
    • Ever vs. Past 6mo
  • Patterns of Street Drug Use
  • Age of First; Route; Freq; Lifetime Years
  • Social Networks

• Unmet Needs

• 5 pg form (25-45min process)
Creation of customized investigation tools to detail demographic, clinical, and risk factor information

<table>
<thead>
<tr>
<th>PERSON-TO-PERSON EXPOSURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Incarcerated for <strong>over 24 hours?</strong></td>
</tr>
<tr>
<td>□ Jail □ Prison □ Juvenile Facility</td>
</tr>
<tr>
<td>□ □ Close contact of a confirmed or presumptive case</td>
</tr>
<tr>
<td>Describe type of contact:</td>
</tr>
<tr>
<td>□ Household □ Needle-use □ Maternal-Infant</td>
</tr>
<tr>
<td>□ Other _______________</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>EXPOSURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Sexually transmitted disease (STD)</td>
</tr>
<tr>
<td>□ □ Gonorrhea</td>
</tr>
<tr>
<td>□ □ Chlamydia</td>
</tr>
<tr>
<td>□ □ Genital warts</td>
</tr>
<tr>
<td>□ □ Herpes simplex virus (HSV)</td>
</tr>
<tr>
<td>□ □ HIV</td>
</tr>
<tr>
<td>□ □ Hepatitis B</td>
</tr>
<tr>
<td>□ □ Hepatitis C</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SEXUAL/PERINATAL TRANSMISSION (for persons &gt; 13 years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Sexual contact</td>
</tr>
<tr>
<td>with: □ men □ women □ both □ Unknown</td>
</tr>
<tr>
<td>that is: receptive □ vaginal □ anal □ oral</td>
</tr>
<tr>
<td>insertive □ vaginal □ anal □ oral □ Unknown</td>
</tr>
<tr>
<td>□ □ with a partner at the time/since diagnosed with Hepatitis C?</td>
</tr>
<tr>
<td>□ □ Birth mother has history of viral hepatitis (for persons &lt; 13 years)</td>
</tr>
<tr>
<td>If yes, specify _______________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>BODILY FLUID/TISSUE/ORGAN EXPOSURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Patient received or donated blood products, organs or tissues (including ova or semen) before June 1992</td>
</tr>
<tr>
<td>□ □ Patient received clotting factor concentrates prior to 1987</td>
</tr>
<tr>
<td>□ □ Patient ever on long-term hemodialysis?</td>
</tr>
<tr>
<td>□ □ Patient received frequent blood sugar tests and/or uses a glucometer?</td>
</tr>
<tr>
<td>□ □ Patient self-injects (ed) prescribed medication (steroids, etc)</td>
</tr>
<tr>
<td>□ □ Patient employed in medical or dental field involved with direct contact to human blood</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>RECREATIONAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Has the patient ever received a tattoo or body piercing?</td>
</tr>
<tr>
<td>□ □ Has the patient ever used injection drugs that were <strong>not</strong> prescribed by a doctor?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>COUNSELING</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □ Has the patient been counseled about avoiding transmission of Hepatitis C?</td>
</tr>
<tr>
<td>□ □ Has the patient been counseled about a concerning level of alcohol intake?</td>
</tr>
</tbody>
</table>
Methodology: Hepatitis C Data Flow

Data Flow for Hepatitis C Reports Received by PDPH

- Electronic Lab Reporters (ELR)
- Health Care Provider Direct Data Entry
- Laboratory Direct Data Entry
- PDPH Epi Unit Staff
- Data Extracts (.csv)
- PA-NEDSS Cognos Server
- PDPH Youth HCV Surveillance Staff
  - Manual Entry
    - PA-NEDSS
    - Direct Paper Reports
  - ELR Processing
- PDPH Communicable Disease Management System (CDMS)
**BUILDING A DATA MANAGEMENT SYSTEM**

- MAVEN Platform for:
  - Data Entry/Receipt
  - Investigation Flow
  - Communication Across Team Members
## Limitations

- **Reporting Sources**

<table>
<thead>
<tr>
<th>Patient Information</th>
<th>Reporting Agency</th>
<th>PA--NEDSS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient ID</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Last Name</td>
<td>First Name</td>
<td>Middle Name</td>
</tr>
<tr>
<td>Address</td>
<td>City</td>
<td>State</td>
</tr>
<tr>
<td>Phone Number</td>
<td>DOB</td>
<td>Age</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Ordering Facility Information</th>
<th>Ordering Physician Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility</td>
<td>Physician</td>
</tr>
<tr>
<td>Address</td>
<td>Address</td>
</tr>
<tr>
<td>City</td>
<td>State</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Laboratory Information</th>
<th>Laboratory:</th>
<th>Organization:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specimen Type</td>
<td>Quantitative</td>
<td>Qualitative</td>
</tr>
<tr>
<td>ID</td>
<td>Type</td>
<td>Source</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>HepBlabs</th>
</tr>
</thead>
<tbody>
<tr>
<td>ID</td>
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<tr>
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</table>
Data Needed for Case Classification

Hepatitis C, Acute

2012 Case Definition
CSTE Position Statement Number: 11-ID-05

Clinical Description
An acute illness with a discrete onset of any sign or symptom* consistent with acute viral hepatitis (e.g., fever, headache, malaise, anorexia, nausea, vomiting, diarrhea, and abdominal pain), and either a) jaundice, or b) elevated serum alanine aminotransferase (ALT) levels >400IU/L.

*A documented negative HCV antibody laboratory test result followed within 6 months by a positive test (as described in the laboratory criteria for diagnosis) result does not require an acute clinical presentation to meet the surveillance case definition.

Laboratory Criteria for Diagnosis
One or more of the following three criteria:

- Antibodies to hepatitis C virus (anti-HCV) screening-test-positive with a signal to cut-off ratio predictive of a true positive as determined for the particular assay as defined by CDC. (URL for the signal to cut-off ratios: http://www.cdc.gov/hepatitis/HCV/LabTesting.htm), OR
- Hepatitis C Virus Recombinant Immunoblot Assay (HCV RIBA) positive, OR
- Nucleic Acid Test (NAT) for HCV RNA positive (including qualitative, quantitative or genotype testing)

AND, if done meets the following two criteria:

- Absence of IgM antibody to hepatitis A virus (if done) (IgM anti-HAV), AND
- Absence of IgM antibody to hepatitis B core antigen (if done) (IgM anti-HBc)

Case Classification
Confirmed
A case that meets the clinical case definition, is laboratory confirmed, and is not known to have chronic hepatitis C.
METHODOLOGY RE-EXAMINED

GOING BACK TO THE SOURCE

• Laboratories
• Providers

Signal-to-Cut-Off Ratios
Case/Provider Contact Information

Developing database of provider POCs
to fill reporting gaps

LOOKING IN NEW DIRECTIONS

• Identifying Addition Data Sources
  • Commercial
  • Departmental Searching Capabilities
Lexis Nexis

- Source: public records
  - bills, property, parking tickets

- Pros
  - Search Criteria
    - by address/telephone #
  - Robust results
    - all previous → current “owners” for the record

- Cons
  - Minors may not share parent (record holder) name
  - If no “exact match” → reams of names
STD database

Dates to: late 90s

• Source: records from clinics, providers, HSs
  • SDP is the nation’s 7th largest public school system
  • Since 2003 High School STD screening program available to > 55,000 students annually in grades 9-12

• Pros
  • Prevalence of STD testing

• Cons
  • Sensitive data; our access limited to demographics
  • Dated records/parent’s address
Data Sources: Immunization

Immunization registry (KIDS)

- Dates to 2005
- **Electronic tracking system for health care providers to retrieve and store patients’ immunization records**
- All birth records incorporated

- **Pros**
  - Scope of provider-data entry opportunities

- **Cons**
  - Majority of cases beyond vaccine-receiving age
**DATA SOURCES: Incarcerated Cases**

- **Public Sources**
  - Inmate Locator

**Challenges:**
- Identifying Eligible Cases
- OOJ
- Reporting errors
- Establishing Contact
DATA SOURCES: Prison

• **Lock ‘N’ Track**
  • PP #
  • Current Location within the System
  • Last Known Address & ER Contact

• **Pros**
  • Identifying true residency status
  • Identifying alias use → ID of prior record
  • Family contact → interview scheduled for post-discharge date

• **Cons**
  • Limited access & requires 3 day training
  • Record only active while case is incarcerated
    -reporting lag
  • Inmate transfers/court appearances listed as discharged
RESULTS
**RESULTS: RESPONSE RATES**

Figure 1 Enhanced HCV Surveillance Investigation Outcomes

All Reports
N (%)  
700 (100)

Non-Eligible
441 (63)

Investigation Initiated
259 (37)

Previously Reported
409 (93)

OOJ
32 (7)

All Responders [Case or Provider]
243(94)

* Previously Reported = found in local (CDR) or state (PA-NEDSS) historical data search

** Varying levels of completion
RESPONSE RATES: BY INVESTIGATION ARM

All Responders [Case or Provider] 243 (94)

Provider-Interview Responders 182 (75)
Provider-Only Responders 95 (40)

Case-Interview Responders 148 (61)
Case-Only Responders 61 (25)

Case & Provider Responders 87 (36% of All Responders)
### RESULTS: FROM Data Source Providers

- CDMS not initially designed to quantify need or success
  - analysis reflects currently populated info
- Flexibility in our data management system has been key
  - as of March 2013:
    - back-populated during case closure review

<table>
<thead>
<tr>
<th></th>
<th>Need? N (%)</th>
<th>Obtained? N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signal to Cut-Off Ratio</td>
<td>77 (69)</td>
<td>68 (99)</td>
</tr>
<tr>
<td>Contact Information</td>
<td>70 (78)</td>
<td>61% Case RR</td>
</tr>
</tbody>
</table>
**RESULTS: DEMOGRAPHICS**

Table 1 Demographic Comparison of all Received HCV Reports vs. Enhanced Surveillance Case Responders

<table>
<thead>
<tr>
<th>Age Group</th>
<th>All HCV Reports* (N=700)</th>
<th>Case Responders (N=148)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n ( %)</td>
<td>n ( %)</td>
</tr>
<tr>
<td>0 to 12</td>
<td>26 (4)</td>
<td>6 (4)</td>
</tr>
<tr>
<td>13 to 18</td>
<td>16 (2)</td>
<td>10 (7)</td>
</tr>
<tr>
<td>19 to 25</td>
<td>231 (33)</td>
<td>58 (39)</td>
</tr>
<tr>
<td>26 to 30</td>
<td>427 (61)</td>
<td>74 (50)</td>
</tr>
</tbody>
</table>

- Limited Utility of Immunization database explained by Age Distribution
- Transient Residency status among this demographic
Hepatitis C Risk Factors Among Youth & Young Adults—Philadelphia, PA 2012
Shadia Bel Hamdounia, Ami Patel PhD MPH
1Philadelphia Department of Public Health (PDPH) 2Centers For Disease Control and Prevention (CDC)

BACKGROUND
Hepatitis C (HCV) is the most common chronic bloodborne infection and leading cause for liver transplants in the United States. 12 million people in the US have chronic hepatitis C. 4000 new diagnoses are made annually among Philadelphia residents. National trends show increasing new HCV infections in 20-30 year olds.

Risk Factors
- Injection drug use (IDU)
- Sex risk (female-economic status, casual sex)
- Blood products prior to 1992
- Transfusion
- Transplant

Surveillance
- Hepatitis C is a reportable condition in Philadelphia
- Historically, limited funding for HCV surveillance and investigation
- Local epidemiology characterized previously limited to age and gender obtained from laboratory reports

OBJECTIVES
1. Launch an enhanced HCV surveillance program in Philadelphia
2. Establish baseline understanding of local burden in residents 40+ years old
3. Characterize local epidemiology with respect to:
   - Demographic
   - Clinical characteristics
4. Use this data to design and implement interventions

METHODS
Enhanced surveillance launched January 1, 2012

- Inclusion Criteria:
  - Philadelphia resident
  - Event date: January 1, 2012–June 30, 2012
  - IDU or Never previously reported to PDPH
  - Cross checking both statewide and local communicable disease registries

RESULTS
Table 1: Demographic Comparison of All Reassessed HCV Cases

Table 2: Clinical Course and Access to Care of Investigated HCV Cases

Table 3: IDU Epidemiology of Time of First Use Among Investigated HCV Cases

Table 4: Injecting Behaviors at the Time of Diagnosis Among Investigated HCV Cases

Table 5: Underlying Medical Conditions Among Investigated HCV Cases

Table 6: Clinical Characteristics

RESULTS: RESPONSE RATES

CONCLUSIONS
The newly established PDPH enhanced hepatitis C surveillance system has identified a baseline local characterization of HCV in the under 31 population.

- Respondents were 54% female and slightly younger than nonrespondents (median age 29.5 vs 31.7 years old and 74% Caucasian, 26% Hispanic)
- Male predominant in clinical history were STD history and current pregnancy status
- A gap between self-reported and surveillance identified risk factors was fewer respondents with previous contact with sexual partners
- Greatest behavioral risk factors are history of injecting drugs, particularly heroin, and incarceration

LIMITATIONS
- Reporting bias
- Data: Age of first illicit use of recreational drugs

LESSONS LEARNED
- Researcher able to increase screening test availability for the detection of new cases, and for those infected, ensuring linkage to care

ACKNOWLEDGEMENTS
- Philadelphia Department of Public Health
- Julie Tolson
- CDC-Viral Hepatitis

Funded by the Centers for Disease Control and Prevention and Laboratory Capacity for Infectious Disease Cooperative Agreement

Contact: Shadia.belhamdounia@phila.gov
To Address Unmet Needs

• Immunizations
  Recommended: Hep A & B Vaccine for all HCV + persons

Step 1: Determining Need
  • Provider form Results

→ Intervention Launched August 2012

2: Verification of Need
  • KIDS Registry
    → Letter-based patient request for records

3: Addressing Need
  • Coordinating/offering vaccine opportunities

RESULTS: CROSS DEPARTMENTAL COLLABORATION
PDPH Intervention:
HCV Educational Outreach

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Drug Use and Harm Reduction 13
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Hep C Information & Resources 18
Local Youth Services 20

Uptake = 64%

www.phila.gov/health
LESSONS LEARNED
LESSONS LEARNED

• PDPH Capacity Requirements to Sustain System
  o Estimated Effort Per Report Processing
  o Estimated Effort Per Case Investigation

• Key role played by
  o Existing staff
  o Interns
LESSONS LEARNED

• Flexibility of Data Management System is Key
  o CDMS Customization
    o Workflows
    o Enhancing Data Captured
Ongoing efforts:

- 1yr Grant Extension Awarded

Continuing to look in new directions

- ELR and Historical Data Migration
  - Will minimize time spent identifying “new reports”

- Surveillance System Evaluation
  - Development of Transition Plan for Scaled-Back Efforts
• An effective hepatitis C surveillance system can be established on a limited budget

• Maximizing resources involves
  • Creativity
  • Cooperation

• PDPH has identified a baseline local characterization of HCV in Philadelphia residents under 31 and is sharing & integrating the data into interventions for this population.

The Public Health Approach

Conclusions

Problem
Risk Factor Identification: What is the cause?
Surveillance What is the problem?
Communicable Disease Reporting

Intervention Evaluation: What works?
ACKNOWLEDGMENTS

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• Anil Suryaprasad

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DISCUSSION