

Developing a Chronic Hepatitis Surveillance System: The New York State Experience

NASTAD Technical Assistance Meeting
September 30, 2008

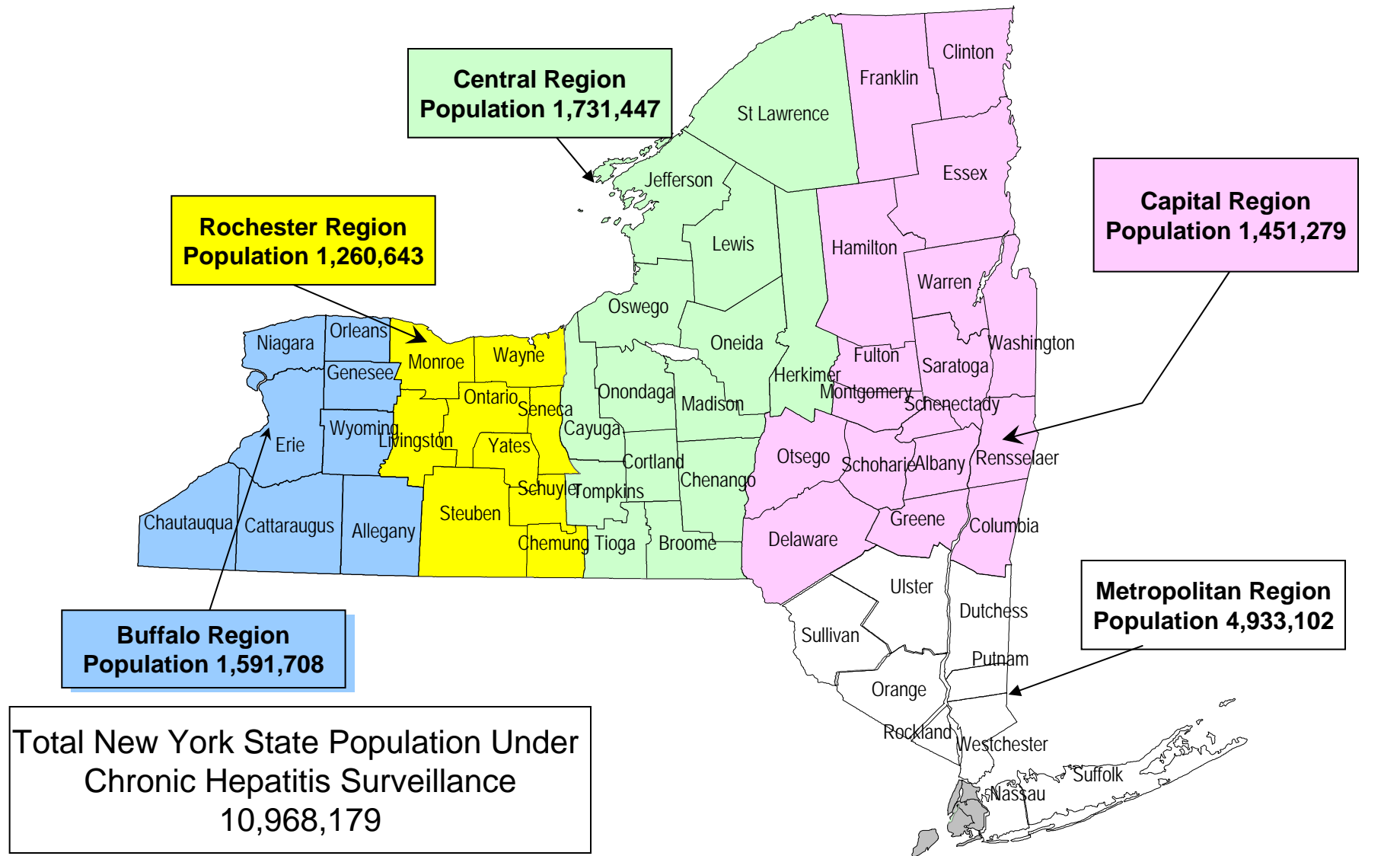
Elena M. Rocchio, MA
Viral Hepatitis Surveillance Coordinator
New York State Department of Health

Overview



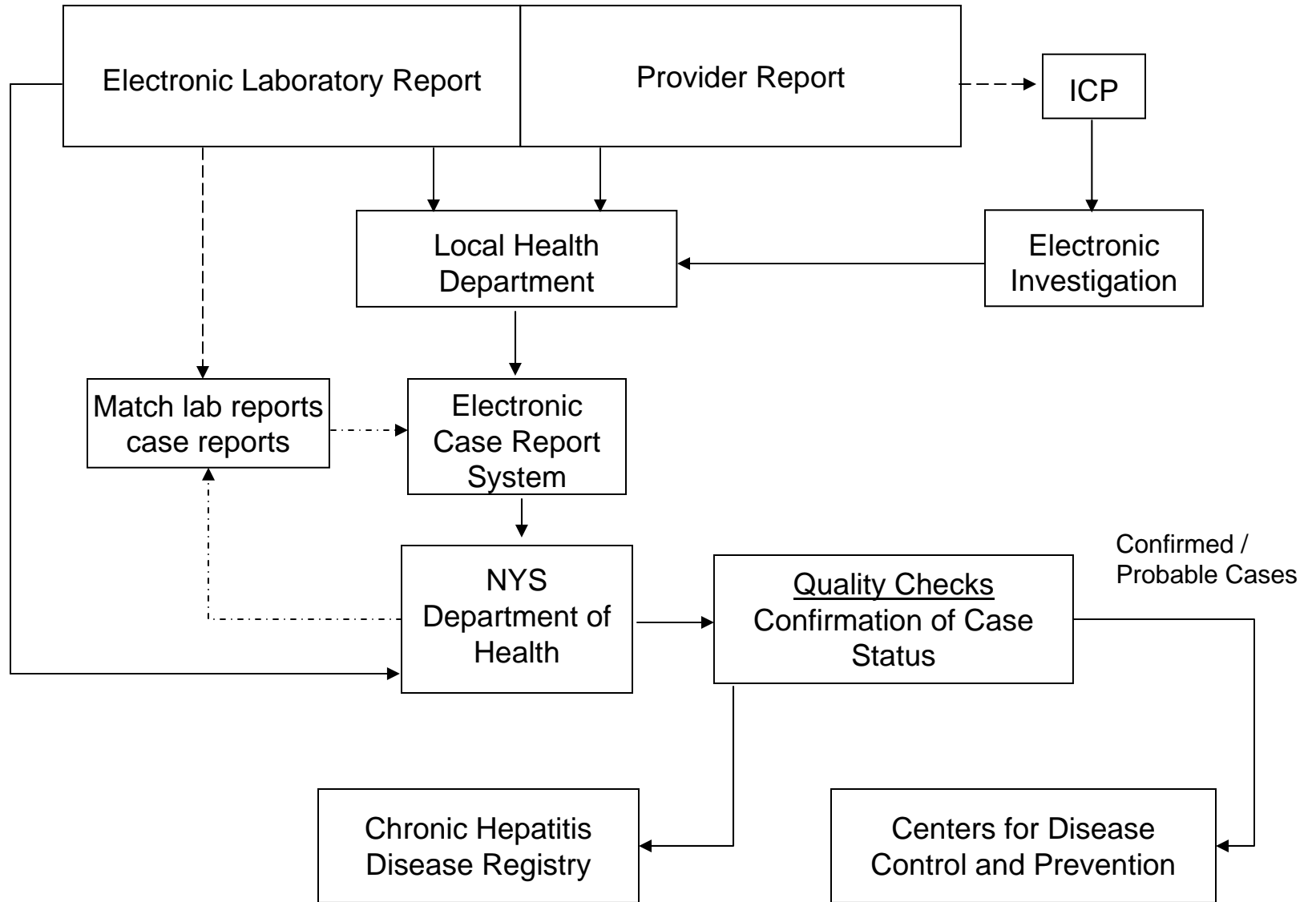
- NYSDOH hepatitis surveillance system
- System development
- Data uses and limitations
- The surveillance domino effect
- What works / what doesn't
- Plans for further improvement

NYS Chronic Hepatitis Surveillance Population



*Based on 2000 U.S. Census Data

NYSDOH Viral Hepatitis Surveillance System



Surveillance Resources



- No state monies
- CDC Funding
 - 3 Regional Surveillance Officers
 - Enhanced acute hepatitis project
 - Assist local health departments
 - 1 Central Office Surveillance Officer
 - Cover acute/chronic surveillance >60% of total population
 - 1 Viral Hepatitis Surveillance Coordinator
 - Overall program coordination
 - Outbreak investigations
 - 1 Project Aide
 - 6 month enhanced HBV project
 - 1 Data Manager (currently vacant, no funds to rehire)

System Development



- 2001
 - NYSDOH funded by CDC to develop a chronic hepatitis disease registry
- 2002
 - Chronic surveillance coordinator hired
 - Local health department (LHD) survey of chronic surveillance activities and existing laboratory and case report data

System Development (cont.)



- 2003
 - Chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) Nationally Notifiable Diseases January 2003
 - Developed case definitions
 - Developed case report forms
 - Lots of data entry!
 - Initiated LHD reporting



System Development (cont.)

- 2004
 - Pilot tested and revised “Dear Doctor Letter”
 - Developed surveillance guidelines
 - Trained local health department staff
 - Developed data quality control measures
 - CDC funded enhanced surveillance project (select NYS regions)
 - Hired three regional surveillance officers
 - Acute cases – completed reports, sera collection
 - Increased chronic case reporting
 - Revised laboratory reporting guidelines

System Development (cont.)



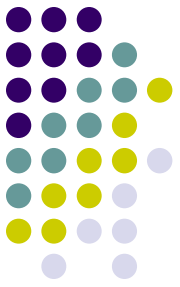
- 2005
 - Hired central office surveillance officer
 - Developed patient-centric chronic disease registry
- 2006
 - Launched patient-centric reporting system
 - Enhanced patient risk factor data collection
 - Updated surveillance guidelines
 - Trained local health department staff

System Development (cont.)



- 2007
 - Continued development of quality control measures
 - Collaborated with other state agencies to improve reporting
- 2008
 - Expanded patient risk factor data collection
 - Enhanced chronic hepatitis B project

Surveillance System: Basic Elements



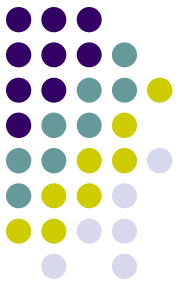
- Authority
 - Public health laws and regulations
- Case definitions
- Laboratory Reporting
 - Electronic system allows standardization
 - Report hepatitis panel results (positive and negative markers)
 - LFTs
- Chronic Hepatitis Case Reporting
 - Patient-centric, dynamic, allows patient tracking
 - Confidential

Surveillance System: Basic Elements (cont.)



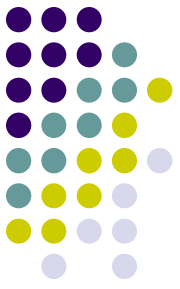
- Data Management
 - Confidentiality
 - Monitoring
 - Dissemination
- Staff Training
 - Guidelines for both acute and chronic surveillance
 - Assist with acute case finding and public health response
 - Prioritize case follow-up

Step One: Take an Inventory



- Public Health Reporting Laws
- Guidelines
 - Local, State, National
- CSTE case definitions
- Laboratory reporting
- Case report forms
- Existing case report data
- Communicable disease reporting systems
- Data Management Software
- Staff Knowledge/Skills

Step Two: Assess Inventory



- Public Health Laws & Regs
 - Is hepatitis reportable?
 - Labs -- Positive HBsAg, IgM anti-HBc and HCV PCR
 - Providers -- Emphasis on acute cases
- Case definitions
 - CSTE acute HBV, HCV, HAV, chronic/resolved HCV, chronic HBV
- Case Report Forms
 - CDC Viral Hepatitis Case Report (VHCR) – Feb 2002
 - NYSDOH Acute HBV/HCV, Chronic HCV, HAV

Assess Inventory (cont.)

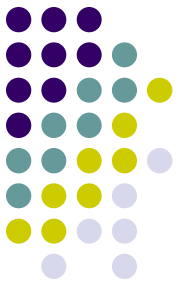


- Available Data
 - LHD Case Report Data
 - Electronic databases, paper lab reports, various data elements collected
 - Electronic laboratory reports since 2001
 - Many missing patient demographics
 - Unconfirmed anti-HCV positive results



Assess Inventory (cont.)

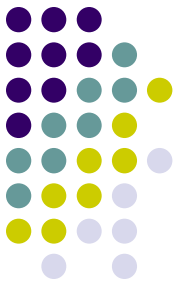
- Existing Reporting Systems
 - Case-centric Confidential Case (“Conf Case”) Report System
 - Electronic format
 - Secure, internet based system
 - No disease code for chronic HBV
 - No supplemental report form for chronic HBV
 - Used for other “chronic” infections (i.e., Lyme Disease)
- Data Management
 - MS Office, SAS, Sybase
 - Secure local area network (LAN)



Assess Inventory (cont.)

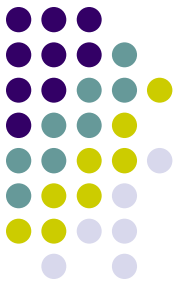
- Staff Knowledge/Skills
 - CDC Guidelines for Viral Hepatitis Surveillance and Case Management (2001, revised 2005)
 - Case ascertainment
 - Databases of chronically infected persons
 - Case reporting
 - Monitoring data quality
 - Data analysis and dissemination
 - Training needed
 - Epidemiology
 - Laboratory tests and interpretation

Step Three: Developing the System



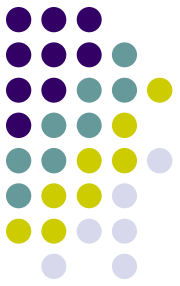
- Add hepatitis to reportable disease list
- Case definitions
 - Used CSTE approved acute case definitions
 - CSTE (proposed) chronic case definitions
 - Developed local case “status” (i.e., suspect and unknown)
- Revised laboratory reporting guidelines to include:
 - Anti-HCV with confirmatory signal-to-cutoff ratio
 - Positive and negative hepatitis test results when at least one reportable marker is positive
 - ALT/AST results with positive, reportable hepatitis marker

Developing the System (cont.)



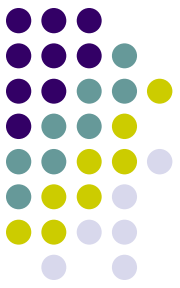
- Case report forms
 - Developed supplemental chronic HBV based on CDC forms and guidelines
 - Revised existing acute A, B and C forms and chronic C form based on CDC supplemental forms
 - Pilot tested “Dear Doctor Letter” for follow-up of positive lab reports

Developing the System (cont.)



- Existing data
 - Collected electronic and paper laboratory and case reports from LHDs
 - Matched and updated cases entered to electronic lab reports
- Existing Reporting System
 - Created unique disease code for chronic HBV
 - Data entered existing data collected
 - CSTE definitions and NYS specific case status definitions
 - Eliminated need for repeat follow-up of existing cases
 - Chronic cases not “closed” at reporting year end
 - Patient tracking - add test results, upgrade case status
 - Encouraged LHDs to begin reporting chronic cases

Developing the System (cont.)



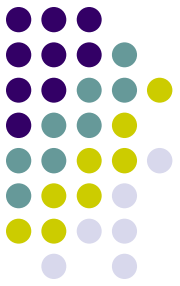
- Developed Viral Hepatitis Surveillance Guidelines for LHDs (A,B,C)
 - Basic Epi information (statistics, risk factors, PEP, vaccine, hepatitis serology and interpretation)
 - Incorporated CDC Guidelines (case definitions, case ascertainment, minimum data collection elements)
 - Prioritizing reports for follow-up
 - Case Ascertainment - Dear Doctor Letters
 - Case Report forms
 - Conf Case system, data entry and query instructions
 - Resources

Developing the System (cont.)



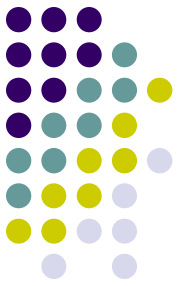
- Data Management
 - Weekly “edit” checks (SAS jobs, Access databases)
 - De-duplicate case reports
 - Ensure cases meet case definition/case status definition
 - Monitor electronic lab reports with no corresponding case report within 60 days

Developing the System (cont.)



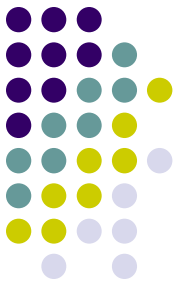
- Lab report monitoring – prioritize new/acute infections
 - IgM anti-HAV, IgM anti-HBc
 - Elevated LFT
 - Positive HCV laboratory reports for persons <30 years old
 - Pregnant female – HBV positive
 - HCV < 2 years old
- Distribute to Surveillance Officers for corrections/follow-up

Developing the System (cont.)



- Staff Training
 - 15 workshops conducted statewide (2003)
 - Introduction of Viral Hepatitis Surveillance Guidelines
 - Epidemiology 101 (A,B,C)
 - Serology 101
 - Case Investigation and Reporting
 - Case Studies
 - On-going training as needed

Step Four: Ongoing Improvement



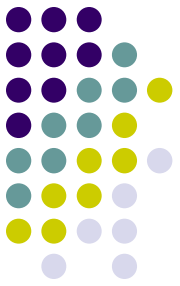
- Evaluation of the system (2005)
 - According to CDC Guidelines (MMWR, 2001)
 - Recommendations
 - Create simplified reporting forms
 - Develop more efficient reporting methods
 - Create a patient-centric reporting system
- Decrease burden on LHDs
 - Assist with reporting in non-EIP regions
 - Automated Dear Doctor Letters

Ongoing Improvement (cont.)



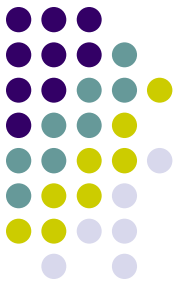
- Patient-centric reporting system (2006)
 - Electronic transfer of lab reports to case report system
 - Concept of investigation report introduced
 - Reduce duplicate case reporting
 - Electronic case report transfer between LHDs
 - Create chronic case from acute case report
 - Update case demographics
- Revise forms, tools, guidelines
- Re-train LHD staff

Ongoing Improvement (cont.)

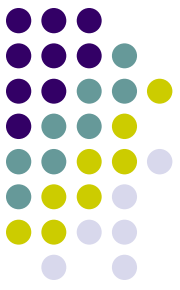


- Educational packets for confirmed chronic cases (2006)
 - ~19,900 sent to date
 - Criteria:
 - >18 years old
 - Not incarcerated
 - Confirmed
 - Case reported > 60 days prior

Ongoing Improvement (cont.)



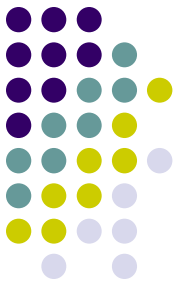
- Educational packets (cont.)
 - Contents:
 - Cover letter – key information
 - Disease Fact Sheet, brochure
 - Risk factor survey, self-addressed stamped envelope (2007)
 - ~7% return rate
- Expanded distribution criteria (2008)
 - Regardless if education provided by physician
 - Translated HBV packet into Cantonese



Ongoing Improvement (cont.)

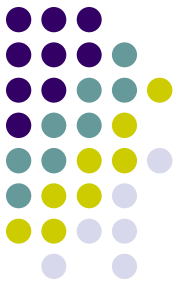
- Laboratory survey (2006, 2007)
 - Responses used to identify areas for improvement
- Mandate electronic lab reporting (2008)
- Chronic HBV Project (EIP Regions - 2008)
 - Sample patients for telephone interview
 - Collect demographic and risk factor information
 - If successful, continue and expand to chronic HCV patients

Ongoing Improvement (cont.)

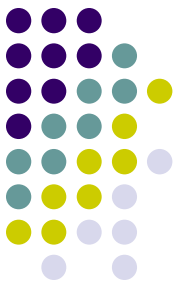


- Partner with other state agencies
- Department of Correctional Services
 - Provided staff training
 - Developed one-page reporting form
 - Quarterly workgroup meeting
- Office of Alcoholism and Substance Abuse Services
 - Partnered to developed mechanism to allow treatment centers to report while maintaining patient confidentiality under Federal Regulations
 - Joint letter to all licensed treatment facilities

Data Uses

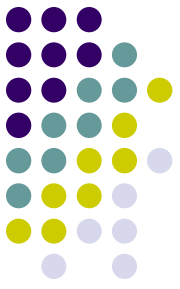


- Cluster detection
 - Geographic Information System mapping
 - Demographic distribution
 - Erie County, NY Cluster (MMWR, 2008)
- Healthcare related transmission investigations
 - Identify additional epi linked cases
 - Potential source patients
 - Monitor for related cases
- Dissemination of data to internal partners, public
 - Annual Chronic Hepatitis Surveillance Summary
 - Annual Acute A, B and C Surveillance Reports
 - Data requests



Data Limitations

- Cannot be used to determine prevalence / true incidence
 - Registry too “young”
 - Registry does not include NYC residents
 - Currently not feasible to de-duplicate
 - Vital statistics and current residence unknown
 - Underreporting & diagnosing (~25-50%)
 - Surveillance activities not standardized statewide
 - Negative test results not reportable – cannot determine new infections of HCV



Data Limitations (cont.)

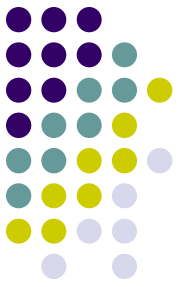
- Cannot be used to determine prevalence / true incidence (cont.)
 - HCV case definition includes chronic and resolved infections
 - Date of initial chronic diagnosis often unknown
 - No laboratory marker for new/acute HCV
- Risk factor information incomplete
 - ~75% missing
 - Cannot accurately describe risk & inform prevention

The Domino Effect



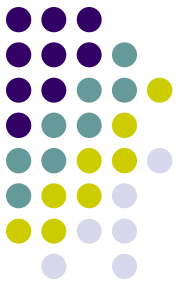
- Enhanced surveillance activities
 - Stretch resources to the limit
 - Possible healthcare related transmission investigations
- Increase chronic cases identified, reported and educated
 - Data maintenance
- Broadened education
 - Increase in patient inquiries

Improve the System: Future Plans



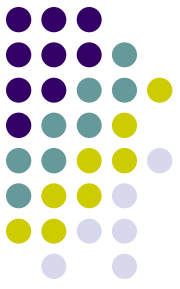
- Routine GIS mapping
 - Outbreak detection
 - Inform prevention programs
- Collaborate with internal DOH Programs
 - HIV/AIDS Epi Registry Matching Project
 - Perinatal Hepatitis Program (Immunization Program)
 - Routine Vital Statistics Death Registry Match

Improve the System: Future Plans (cont.)

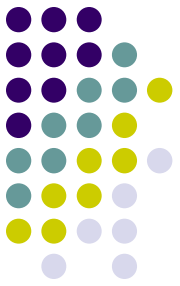


- Data analysis
 - Acute/Chronic case vs. new infections (i.e., documented seroconversions)
 - Chronic vs. resolved infections
- Enhance chronic surveillance
 - Surveillance Officers in all regions
 - Develop new methods to collect risk factors
- De-duplicate with NYC registry

Summary



- Start with an inventory
- Determine what you can use & adapt
- Determine what needs to be developed & use existing guidelines
- Standardize wherever possible
- Prioritize report follow-up
- Evaluate data collection tools and electronic reporting systems periodically
- Monitor and disseminate data
- Ongoing improvements

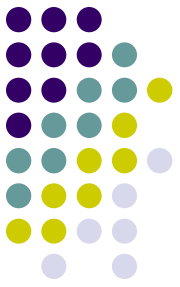


Summary: What works?

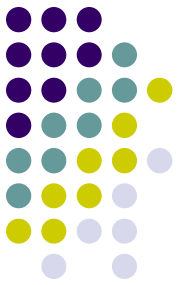
- Laboratory based surveillance (electronic!)
- “Dear Doctor” letter for case ascertainment
- Patient outreach
- Surveillance Officers
- Centralized data monitoring
- LHD training (offered continually)
- Prioritizing case ascertainment
- Cross-trained staff for all hepatitis surveillance

Summary:

What doesn't work?



- Provider-based surveillance alone
- Mailed patient surveys (low response rate)
- “Dear Doctor” letters for risk factor collection
- Separating surveillance
 - Acute vs. chronic infection
 - Hepatitis A vs. B vs. C



Resources

- www.nyhealth.gov/diseases/communicable/hepatitis/surveillance.htm
 - NYSDOH Local Health Department Viral Hepatitis Surveillance Guidelines (2006)
 - Communicable Disease Reporting Guidelines
 - Laboratory Reporting Guidelines
 - Signal-to-cutoff ratios for specific anti-HCV assays
- www.cdc.gov/hepatitis
 - CDC Viral Hepatitis Surveillance Guidelines (2005)
 - Surveillance Forms
 - Statistics
 - MMWR February 2003