



# Establishing a Chronic Hepatitis B Registry

San Francisco's experience

# Overview

- Potential uses of a chronic hepatitis B registry
- Local context for the development of SF's chronic hepatitis B surveillance and registry
- Enhancing chronic hepatitis B surveillance data
- Surveillance interviews
- Uses of SF's chronic hepatitis B registry
- Current resources
- Lessons learned

# Potential Uses of a Chronic Hepatitis B Registry

# Potential Uses of a Chronic Hepatitis B Registry

- Person-level data
  - allows case follow-up, education
  - contact tracing, education
  - increased finding of pregnant women who are chronically infected with hepatitis B
- Identify a pool of providers likely to care for persons chronically infected with hepatitis B for outreach

# Potential Uses of a Chronic Hepatitis B Registry, cont'd

- Provide local, state, and national estimates of the proportions of persons chronically infected with hepatitis B – very difficult with chronic infection
- Guide prevention, education, and vaccination guidelines – can be done with periodic surveys

# Local Context

## San Francisco's Chronic Hepatitis B Registry

# SF Demographics



**812,241 residents**

Male	51%
White	44%
Black	8%
<b>Asian</b>	<b>31%</b>
Native Am	0.3%
Hispanic	14%
Multi	2%

**37% foreign-born**

Region of Birth	# (% total SF pop)
Europe	40,612 (5%)
<b>Asia</b>	<b>178,693 (22%)</b>
Africa	3,249 (0.4%)
Oceania	3,249 (0.4%)
Latin Am	64,979 (8%)

# SF Chronic Hepatitis Registry History

1984 - Hepatitis database established

- HBsAg on persons w/ no evidence of acute hepatitis
  - Only 1<sup>st</sup> test entered
- 1984-2005 ~25,000 HBsAg test results on unique individuals

# Data Elements Reported by Laboratories

Positive laboratory results for  
hepatitis B:

- Name, gender, address, phone, age or date of birth of patient
- Name, address, phone of ordering provider
- Laboratory findings and date of positive findings

# Gaps in SF Chronic Hepatitis B Surveillance

- Other markers for Hepatitis B
  - HBV DNA
  - HBeAg
- County of residence
- Contact information for the patient
- Contact information for the physician
- Deduplicated, longitudinal data

# Improved Chronic Hepatitis B Surveillance and Registry

- January 2006 standardized protocol for data entry, enter (+) test results for HBV including repeat tests
- True registry of individuals with longitudinal data
- Database Elements
  - Patient Information
    - Name, gender, race, ethnicity,
    - DOB, born in US, SSN, date of death
    - Address, phone #
  - Laboratory information
    - Facility
    - Date and type of lab test
    - Test result
    - Date of report
  - Ordering Provider Information

# Improved Chronic Hepatitis B Surveillance and Registry, cont'd

- **Electronic reporting** – 3 large laboratories
  - More complete reporting
    - Positive HBV DNA and HBeAg tests
    - Ordering provider information
    - Patient contact information
    - Race, ethnicity (infrequently)
- Advisory panel

# Positive HBV Reports

## Jan 1, 2006 thru Dec 31, 2007

Report Year	Number of Positive HBV Tests	Number of Individuals	Number and % of Newly Reported Individuals
2006	3,862	2,964	1,226 (41%)
2007	4,811	3,289	1,299 (39%)

# Enhancing Chronic Hepatitis B Surveillance

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- Provider fax-back
  - Race, Ethnicity
  - Primary language
  - Pregnancy status
- Surveillance Interview

# Chronic Hepatitis B Surveillance Interview Goals

- To better characterize the population of San Francisco residents with chronic HBV
- To characterize the population(s) at risk for contracting HBV from identified cases
- To describe prevention practices adopted by cases
- To provide public health follow-up to prevent the spread of HBV

# Chronic Hepatitis B Surveillance

## Interview Methods

- Case selection
  - Confirmed and probable chronic HBV
  - 25% of all cases reported, ~1000 cases/year
  - Women of child-bearing age, ~1000 cases/year
  - Children 18 years and under, ~30 cases/year
- Fax back form used to notify physician and obtain case's contact information, primary language, race/ethnicity and pregnancy status
- Structured telephone interviews
- Cantonese speaking interviewers and Language Line used to conduct interviews and leave messages
- Educational materials and community resources for testing and vaccination are offered and sent to contacted cases in the desired language(s)
- Protocols for children and for unaware cases

# Chronic Hepatitis B Surveillance

## Interview Content

- Demographics
  - Race, ethnicity, language, current address, country of birth, pregnancy status
- Knowledge of HBV diagnosis
- Disease status
- HBV risk factors
- Adoption of prevention behaviors
- Testing and vaccination status of contacts

# Case follow-up activities

- Inform of diagnosis
- Educate on preventing transmission to contacts
- Give info to relay to contacts about testing & vaccination
- Educate on recommended medical f/u
- Assist with medical referrals if not in care
- Collect and distribute information on pregnant women to perinatal program

# What we're finding/learning

- >70% response rate
- >60% of interviews performed in Cantonese
- 5% of interviewed were not aware they had hepatitis B
- Privacy Concerns
  - Concerned about privacy and confidentiality
  - Stigma associated with having HBV
- Gaps in Knowledge
  - Refrain from sharing food, drinks, plates, utensils, cups, etc. to prevent spreading HBV.
  - State they are healthy and feel fine and do not understand why SFDPH is calling.
  - State that they are a carrier but not infected.
  - Think that because they have hepatitis B they can't get hepatitis A

# Uses of SF's Chronic Hepatitis B Registry

- MMWR 2007; 56(18):446-448. Characteristics of Persons with Chronic Hepatitis B - San Francisco, California, 2006.
- Annual surveillance report
- Develop culturally appropriate educational materials targeted to specific issues
- Provider outreach
  - Provide educational materials & tools
- Possible Contact follow-up
  - Find and notify, educate and advise

# Current Resources

Surveillance Level	Activities	Resources
Core	Registry development & maintenance, PH surveillance reporting	2 epidemiologists 1 data entry/admin
Core	IT –as needed	In-house developer Contractor, as needed
Enhanced	Fax backs, Case interviews, counseling, mailings	1 project coordinator 3 research assistants
Enhanced	Phone interpretation, translation of materials	Contract costs
Enhanced	Health education materials, clinician outreach	0.20 physician + printing & postage

# Lessons Learned

- Communication with labs
  - Lab survey
- Electronic reporting
- Establish connection with providers
  - Advisory panel
  - Mailings, honor roll
- Keep forms and surveys simple

# Lessons Learned cont'd.

- Case follow-up via telephone interviews on a small number of cases by trained, culturally sensitive interviewers
- Provide culturally sensitive educational materials in appropriate languages
- High levels of follow-up require lots of resources

# Thank You

## CERTIFICATE OF APPRECIATION

for the Completion of Hepatitis B Forms in 2007

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San Francisco Chronic Viral Hepatitis Registry