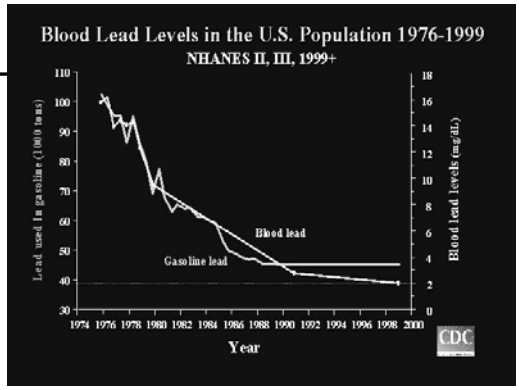


Cigarettes and Lung Cancer

Source: American Cancer Society CPEDFF 2002

Surveillance—1

- **Definition**
  - **"the ongoing systematic collection, analysis, and interpretation of outcome-specific health data, closely integrated with the timely dissemination of these data to those responsible for preventing and controlling disease or injury"**
    - ***Thacker and Berkelman 1992***
- **Modern surveillance began with diseases such as malaria and smallpox**
  - **Alexander Langmuir at the CDC in the 1940s**

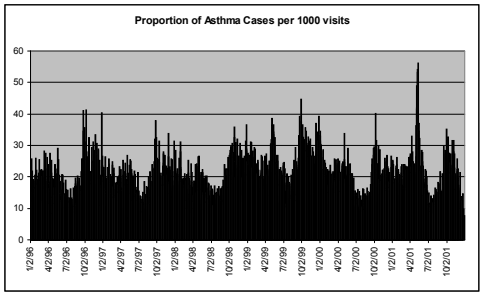
Surveillance—2

- **Goals**
  - **Historically**
    - » **Isolate infected individual to minimize disease transmission**
  - **Current**
    - » **Assess disease status**
    - » **Develop disease prevention and control programs**
- **Implications**
  - » **Without action, surveillance is bad resource allocation (i.e., it is actuarial)**
  - » **This link of research to policy (action) is the difference between public health work and biomedical research**

Types of surveillance

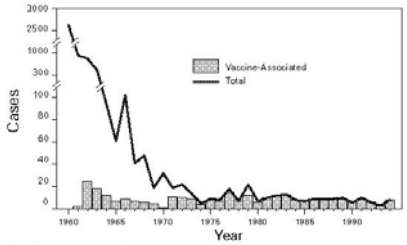
- **Active**
  - **Relies on periodic solicitation of data**
    - » **Expensive; rarely done**
- **Passive**
  - **Relies on reporting by healthcare provider**
    - » **e.g., births, deaths, cancer registries**
- **Sentinel**
  - **Relies on reporting of unusual diseases**
    - » **E.g., polio, mesothelioma**

Asthma Visits Adjusted for Total Visits



Sentinel Reporting of Polio

FIGURE 1. Total number of reported paralytic poliomyelitis cases* and number of reported vaccine-associated cases — United States, 1960–1994



*Excluding imported cases.

Defining "Disease Cluster"

- "two or more cases occurring close together"
- "5 cases representing at least a 5-fold increase in risk…seen by a single physician over a short period of time"
- "occurrence of a greater than expected number of cases within a small geographic area and/or within a short period of time (i.e., 3-5 years)"

A Typical Cluster Report

- A few to several dozen reported cases
- Cases aggregated, e.g., in space, time…
- No known exposures
- No population at risk delineation
- Limited demographic information
- No residence history information
- No surveillance data available

Cases DO Cluster!

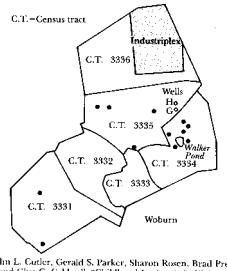
- Common demographics (age, race, genetic)
  - genetic examples emerging (breast cancer)
- Common interpersonal contact (biological)
  - several validated examples (Legionella, HIV)
- Common exposures (chemical)
  - workplace: several examples (VC, DBCP)
  - pharmaceuticals: few examples (DES, thalidomide)\
  - environment: controversial
- Common behavior (e.g., smoking, drinking)

Some Reported Clusters

- Childhood Leukemia (several dozen studies since the 1950s)
- Minimata Disease (1950s)
- Thalidomide and phocomelia (1960s)
- DES and vaginal cancer (1971)
- Lymphoma (1970s)
- BSME and lung cancer (1973)
- Vinyl chloride monomer and liver cancer (1974)
- Legionnaires Disease and pneumonia (1976)
- DBCP and male infertility (1977)
- Kepone and neurotoxicity, infertility (1978)
- HIV/AIDS (1981)
- Leukemia on Meadow St., CT (emfs--1980s)
- Leukemia near Seascale Nuclear Facility (1980s)
- Cancer in NY Giants football players (1987)

Case Map: Woburn, MA
"A Civil Action"

Map 3. Twelve Leukemia Cases, 1969–1979, Identified by Massachusetts Department of Public Health



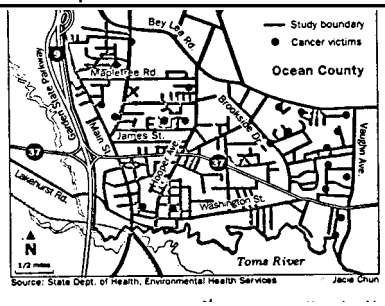
SOURCE: John L. Cutler, Gerald S. Parker, Sharon Rosen, Brad Prenney, Richard Healy, and Glyn G. Caldwell, "Childhood Leukemia in Woburn, Massachusetts," *Public Health Reports*, 1986, 101:204.

Example: Childhood Leukemia in Woburn, Ma.

- State Study (Kotelchuck and Parker 1979)
  - » Overall cancer mortality (1969-1979) higher in Woburn than six adjacent communities and whole state
- State Study (Parker and Rosen 1981)
  - » 12 childhood cancers observed, 5.3 expected, p=0.008
- State/Federal Study (Cutler et al. 1986)
  - » "This investigation confirmed an increase in incidence…Six of the persons with leukemia were located close to each other in one census tract, 7.5 times the expected number."
  - » "There were no significant differences between the leukemia victims and persons in the control group"
- Harvard study positive (1984)—controversial
  - » 12 childhood leukemia cases where 5.3 expected
- New cases found after wells closed
  - » MADPH study finds *prenatal water exposure* a risk (1996)

Another Example: Toms River, NJ

Case Map: Toms River, NJ



- 14 cases mapped of 21 observed

Initial Toms River Data

Toms River, NJ

- Letter from NJDOH to USEPA/ATSDR
  August 31, 1995
  - …moderately elevated SIR for all cancers
  - Brain and CNS cancer was more than three times higher than expected for children under 20.
  - For Toms River children under five, brain and CNS cancer incidence was significantly elevated and over seven times higher than expected.
  - *Because of the small number of cases included in this analysis, it is not possible to conduct studies to determine possible causes at the municipality or even county level.*

Toms River Chronology

- Fall 1995
  - Childhood cancer excess by nurse at CHOP to USEPA
- February 1996
  - Network TV coverage of possible cluster
- March 1996
  - NJDHSS reports childhood cancer excess, 1977-1995
  - Governor and Health Commissioner at Toms River Town Mtg
- July 1997
  - State and Federal scientists begin $10 million study
- December 2001
  - 69 families settle with Ciba-Geigy, Union Carbide, United Water $13.2 million
  - State/Federal draft report associates *prenatal exposure* contaminated water and air from Ciba-Geigy with leukemia cases
  - No single risk factor responsible

Scientists' Anti-Cluster Views

- **"The reality is that they're an absolute, total, and complete waste of taxpayer dollars"**
  - **Alan Bender, Chief of the Section of Chronic Disease and Environmental Epidemiology, Minnesota Department of Health**
- **"With few exceptions, there is little scientific or public health reason to investigate individual clusters at all"**
  - **Ken Rothman, author of *Modern Epidemiology* and founding editor of the journal *Epidemiology***
- **BUT**
  - **Etiology: Searching under the lamp post problem**
  - **Community Concerns**

Why study clusters?

- **Public concern—***A Local Disease Excess*
  - **Clarify of misconceptions—Allay unfounded concerns**
  - **Initiate study when concerns are well founded**
- **Encourage Remediation—***Disease Prevention*
  - **Determine if situation is a sentinel of a larger problem**
  - **Identify unknown exposure situations**
- **Facilitate Scientific Discovery--***Etiology*
  - **Identify new exposure-disease link**
  - **Identify new carcinogens**

Statistical Significance

- **False Positives**
  - **consider every neighborhood and every cancer**
  - **adjust for multiple comparisons**
- **False Negatives**
  - **small sample size**
  - **methods have low power**
  - **persistence and a priori hypotheses**

New Approach: Surveillance

- **Frequent evaluation of a large database**
  - **evaluate locally**
  - **look for changes in space, time, space-time**
  - **assess persistence of pattern over time**
- **Combine data with other information**
  - **confounders, behaviors**
- **Requires new methods**
  - **» Kulldorff (1995)**
  - **» Rogerson (1997)**

Why Surveillance?

- **Addresses both WHEN and WHERE**
- **Responsive to community concerns**
  - **monitor status of variations**
  - **can respond meaningfully to inquiries**
- **Can prioritize situations based on data**
- **Can investigation most usual occurrences**
  - **highest rates, most persistent, known exposure**

What Can DIMACS Offer?

- **Methods for SMALL data sets**
- **Methods for repeated or *post hoc* looks at:**
  - **The same data set**
    - **» Texas sharpshooter vs. sentinel surveillance**
  - **Routinely updated time series**
    - **» Clusters, bioterriorism,...**
- **Methods to integrate other types of data**
  - **Birth outcomes, genetics, risk factor information**
- **Methods for non-coincident boundaries**
  - **Data collected for different purposes (exposure, disease)**