

Linking Surveillance to Prevention through Data

2002 Perinatal Prevention Grantees Meeting

February 12-14, 2002

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Invited Speakers: Linda DiMasi and Daniel Lauricelli, New Jersey Dept of Health

HIV/AIDS Surveillance 101

Session Outline

- I. Introduction
- II. Framework for integrated HIV/AIDS surveillance
- III. Critical concepts: confidentiality, dissemination, and evaluation
- IV. Technical assistance
- V. Relevant resources
- VI. Pediatric/perinatal surveillance

HIV/AIDS Surveillance

Definition

The systematic collection, analysis, interpretation, dissemination, and evaluation of population-based information about persons with diagnosed HIV and AIDS.

Public Health Surveillance

- Ongoing, systematic **collection, analysis, and interpretation of data** essential to the **planning, implementation, and evaluation of public health practice**
- Closely integrated with the timely **dissemination** to those responsible for **prevention and control**

Public Health Surveillance

Goals

1. To recognize cases or clusters to trigger interventions;
2. To assess the public health impact of a health event or determinant and measure trends;
3. To demonstrate the need for public health intervention programs and resources, and allocate resources;

Public Health Surveillance

Goals (continued)

4. To monitor effectiveness of prevention and control measures and intervention strategies
5. To identify high-risk population groups or geographic areas to target interventions and guide analytic studies
6. To develop hypotheses leading to analytic studies about risk factors for disease causation, propagation, or progression

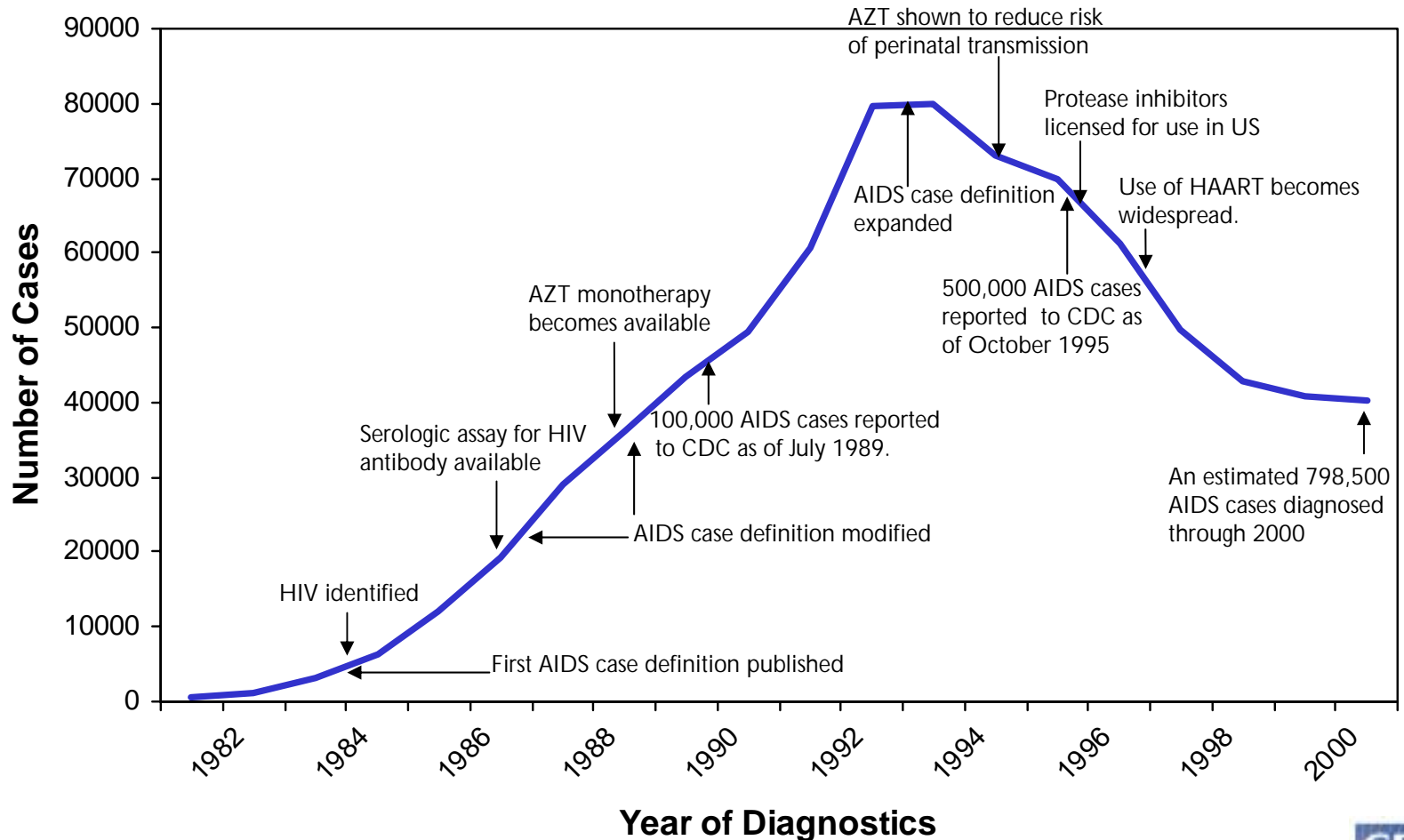
HIV/AIDS Surveillance

How Data are Used

- Monitor incidence and prevalence of diagnosed HIV infection and AIDS
- Track HIV-related morbidity and mortality
- Detect trends in HIV transmission
- Follow the characteristics of those affected
- Identify populations at risk
- Estimate incidence and prevalence of HIV infection
- Target prevention activities and evaluate their effectiveness
- Allocate funds for health care and social services

Evolution of an Epidemic

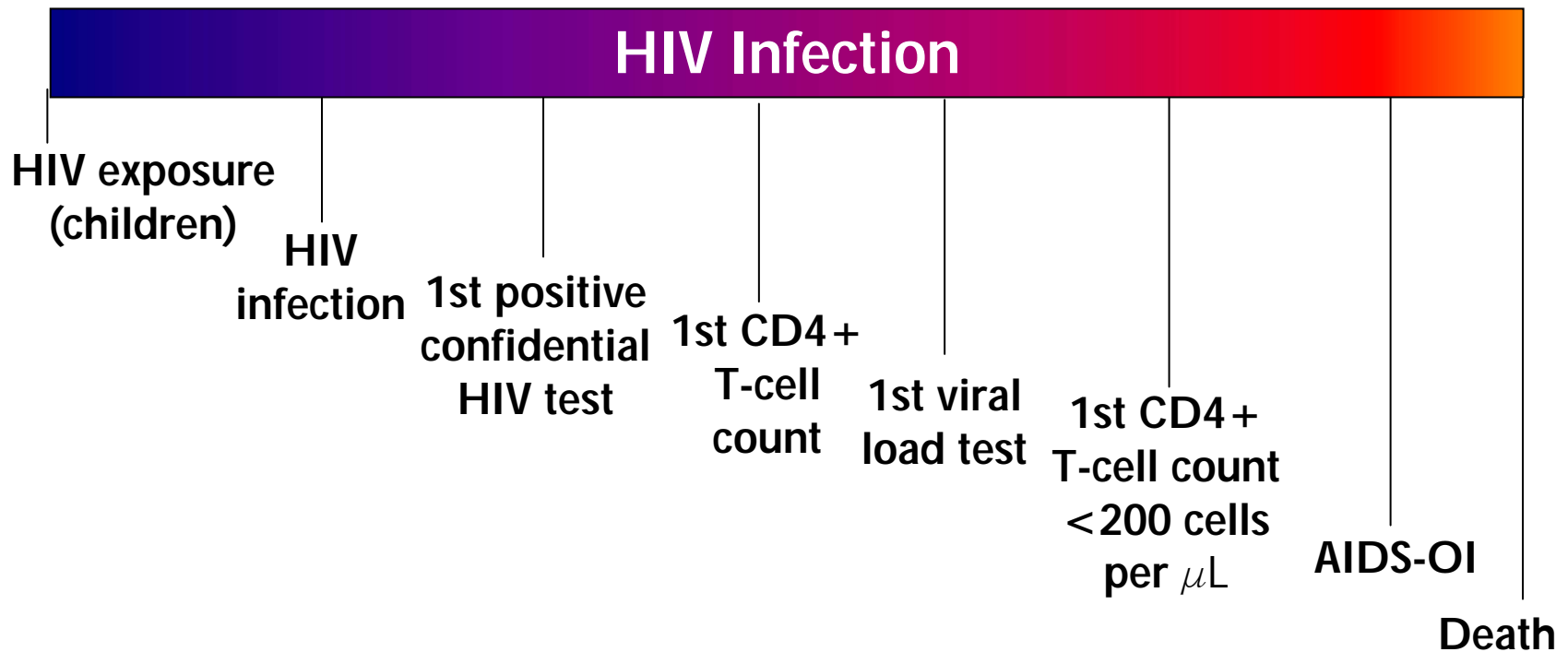
Estimated AIDS incidence* through 2000, United States



*Estimated from data reported to CDC through June 2001, adjusted for reporting delays.

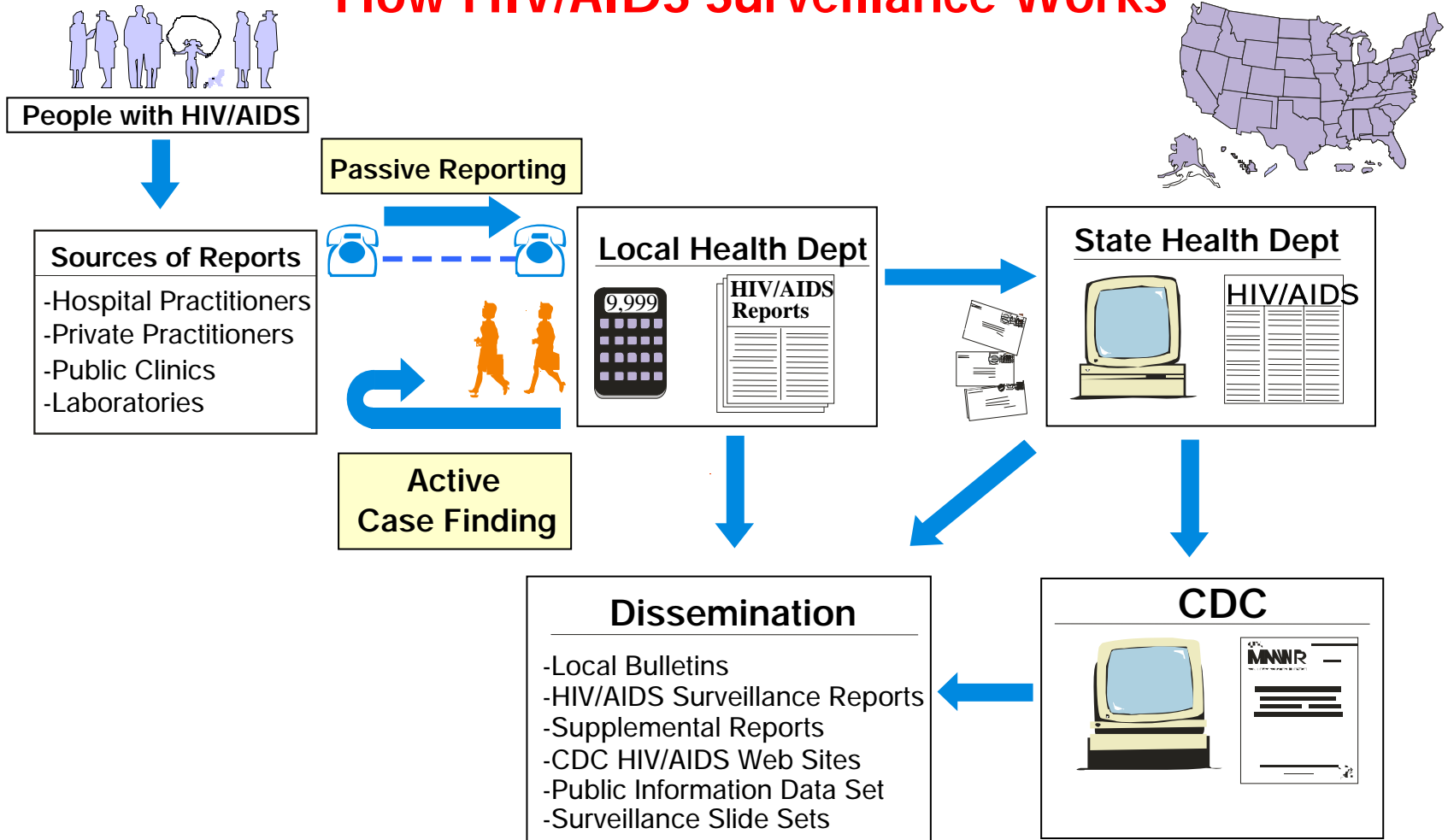
HIV/AIDS Surveillance

Monitoring the Spectrum of Infection



HIV/AIDS Surveillance

How HIV/AIDS Surveillance Works



HIV/AIDS Surveillance

How Data are Collected

- **Passive reporting**
 - Health care practitioners, hospitals, clinics, and laboratories report cases of HIV/AIDS to state and local health departments
- **Active reporting**
 - Health department surveillance staff find cases by contacting health care practitioners and reviewing medical records in hospitals and clinics

HIV/AIDS Surveillance

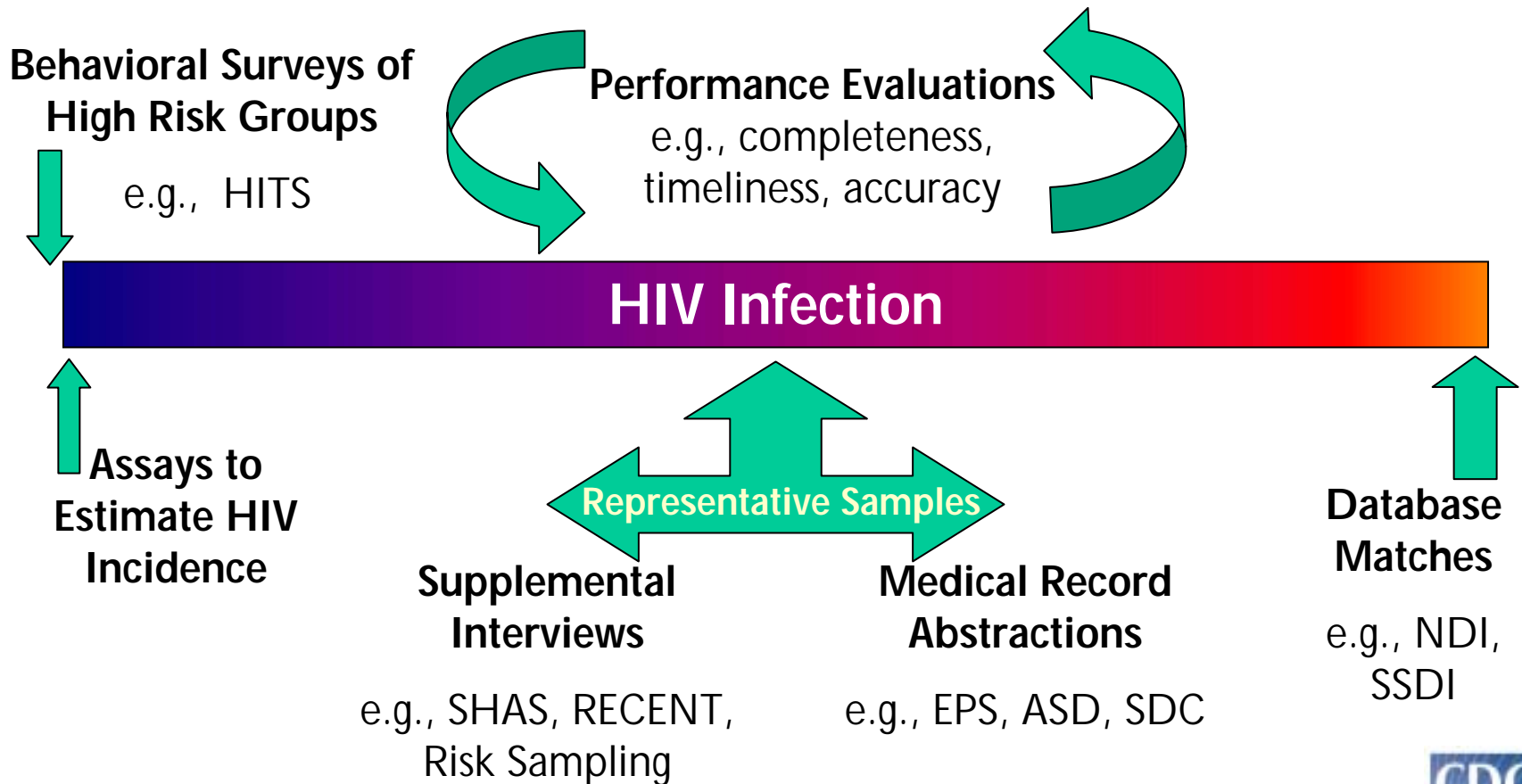
What Data are Collected?

- Demographic characteristics
 - Sex, race/ethnicity, age, residence
- Risk information
 - Potential modes of exposure to HIV
- Laboratory and clinical information
 - Virologic and immunologic status
 - Opportunistic illnesses diagnosed
- Supplemental information
 - Prescription of antiretroviral and prophylactic therapies
 - Use of medical and substance abuse treatment services
 - Health insurance coverage

HIV/AIDS Surveillance

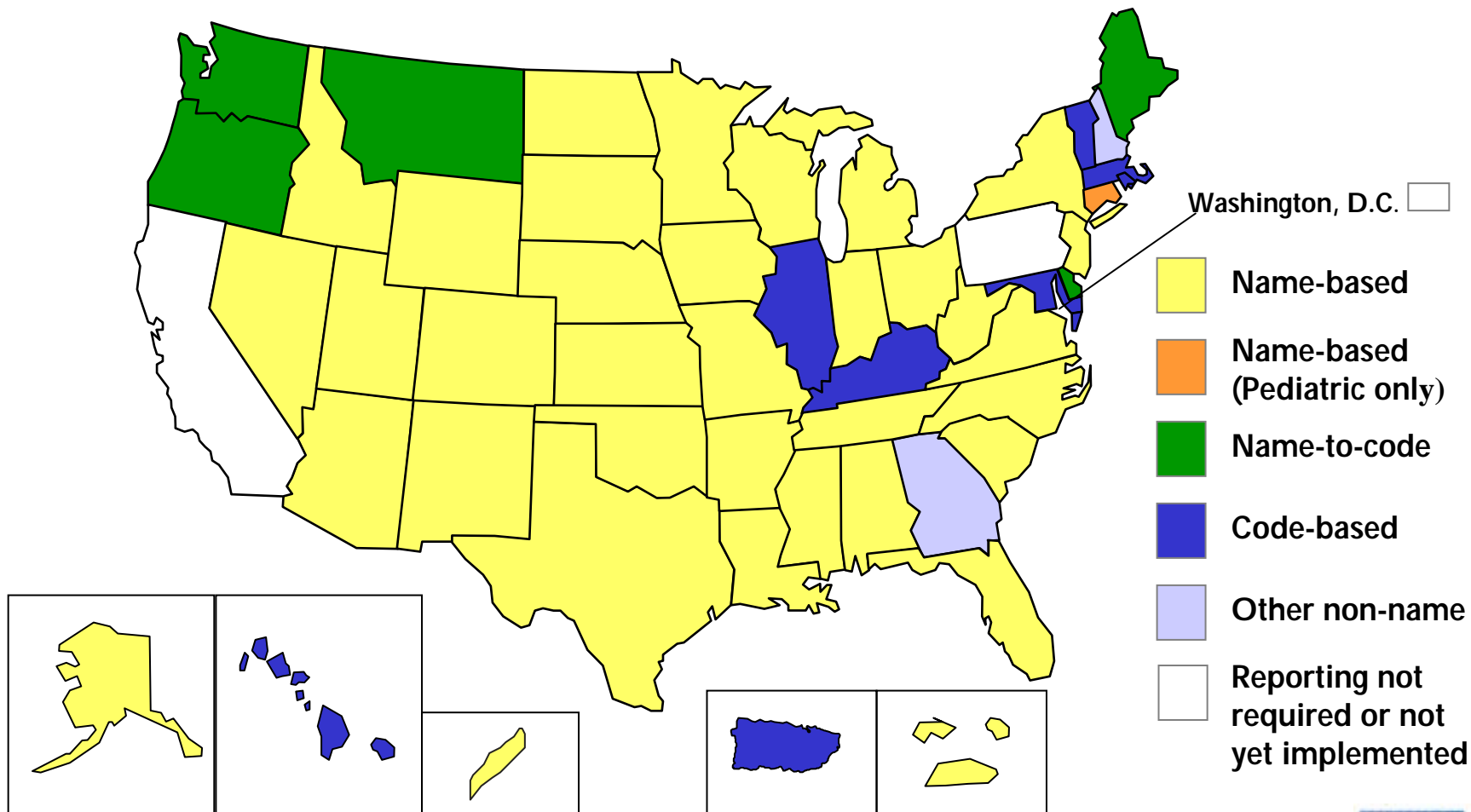
Building a Better System

Methods Research and Supplemental Data Collection



Progress Toward a National Integrated HIV/AIDS Surveillance System

Status of HIV Infection Reporting as of December 2001



HIV/AIDS Surveillance

Confidentiality of Data

- State and territorial laws for protection of public health data apply to HIV/AIDS data
- CDC requires that
 - HIV/AIDS case data be maintained in physically secure environments with limited access by authorized personnel
 - State surveillance programs certify that
 - Program requirements have been met
 - Overall Responsible Party (ORP) has been identified
 - Confidentiality policies have been written
- Patient's and physician's names and other personal identifiers are not sent to CDC

Public Health Surveillance

Provides Information for Action

- **Planning**
- Implementation
- Evaluation

HIV/AIDS Surveillance

- **HIV/AIDS surveillance programs** are responsive to data needs for planning **prevention** and **care**.

HIV/AIDS Surveillance Data

Data Requests

HIV Prevention
Community Planning Groups

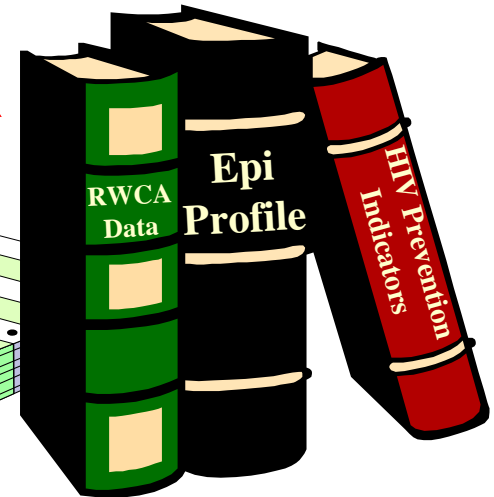
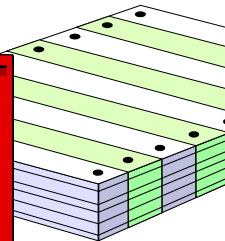
RWCA Title I
Planning Councils

RWCA Title II
Planning Consortia

Program Staff, Media,
Legislators, Ad Hoc Requests



**Surveillance
Staff**



HIV/AIDS Surveillance

Dissemination of Data

- Surveillance Reports
- Epi Profiles
- Ryan White CARE Act Applications
- Grant Applications
- Responses to:
 - *Ad hoc* Requests
 - Media Requests
 - Congressional/Political Inquiries

HIV/AIDS Surveillance

National Data Dissemination



- *HIV/AIDS Surveillance Reports*

www.cdc.gov/hiv/surveillance.htm

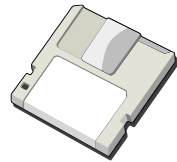
- *MMWRs* www.cdc.gov/hiv/pubs/mmwr.htm



- Slide sets www.cdc.gov/hiv/graphics.htm

- Prevention and treatment guidelines

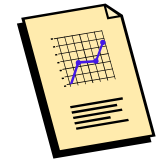
www.cdc.gov/hiv/pubs/guidelines.htm



- Public information data set (PIDS)

www.cdc.gov/software/apids.htm

- CDC fact sheets www.cdc.gov/nchstp/od/nchstp.html



- Presentations at meetings and conferences

- Peer-reviewed journal articles



- AIDS hotline 1-800-342-AIDS www.ashastd.org/nah.org



HIV/AIDS Surveillance

Evaluation of System Performance

- HIV/AIDS surveillance systems evaluated for:
 - Accuracy
 - Completeness of case reporting
 - Timeliness of reporting (time between diagnosis and report)
 - Completeness and accuracy of data collected
- Evaluation provides information needed to:
 - Improve the system
 - Interpret analyses of data collected
 - Promote the best use of public health resources

HIV/AIDS Surveillance

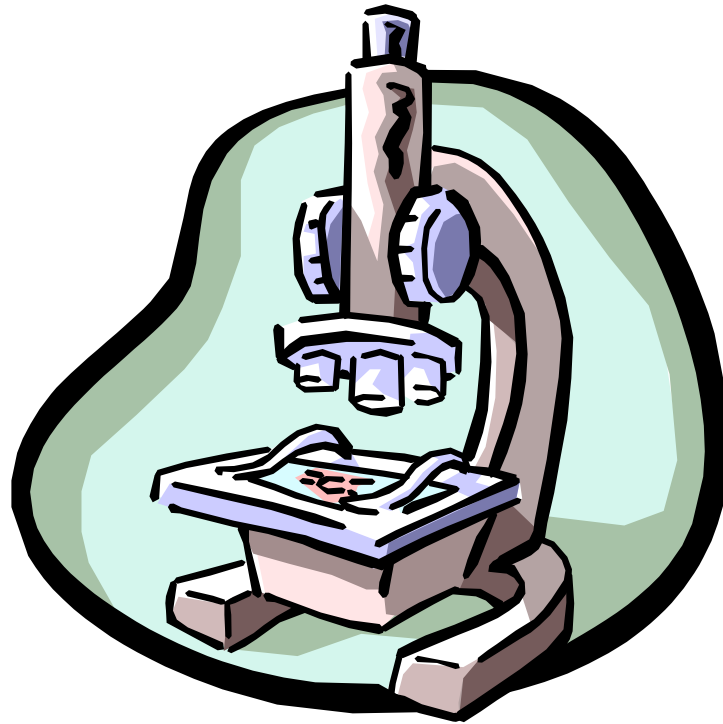
Evaluation of System Performance (*cont'd*)

Minimum Performance Standards

- **Timeliness**
66% reported in 6 months
- **Completeness**
≥85%
- **Accuracy**
≤5% duplication and ≤5% incorrect matching
- **Completeness of risk ascertainment**
>85%

As outlined in: Centers for Disease Control and Prevention. CDC guidelines for national HIV case surveillance, including monitoring for HIV infection and AIDS. MMWR 1999;48 (No. RR-13).

Focus on pediatric/perinatal surveillance



Perinatal Exposure/Infection Surveillance

- Routine perinatal surveillance
 - **Population-based**
 - **Active case ascertainment**
 - **Follow-up of exposed infants every 6 months to obtain HIV infection status, AIDS and death**
 - **Match to death registry**

Pediatric/Perinatal Surveillance

- **A subset of HIV/AIDS Surveillance**
- **Identify HIV infected women who are pregnant**
 - **Identify children born exposed to HIV**
 - **Not all children born to HIV-infected mothers will be infected**
- **Additional information collected on mothers and children**
- **Enhanced surveillance methods (EPS) used in 25 sites**

Pediatric/Perinatal Methods

- AIDS Surveillance data – all states
- HIV reporting in 37 States and Territories
 - Conduct active case finding and monitor perinatally exposed children for HIV status, receipt of ARV, maternal HIV testing, PNC
- Enhanced Perinatal surveillance
 - STEP
 - EPS

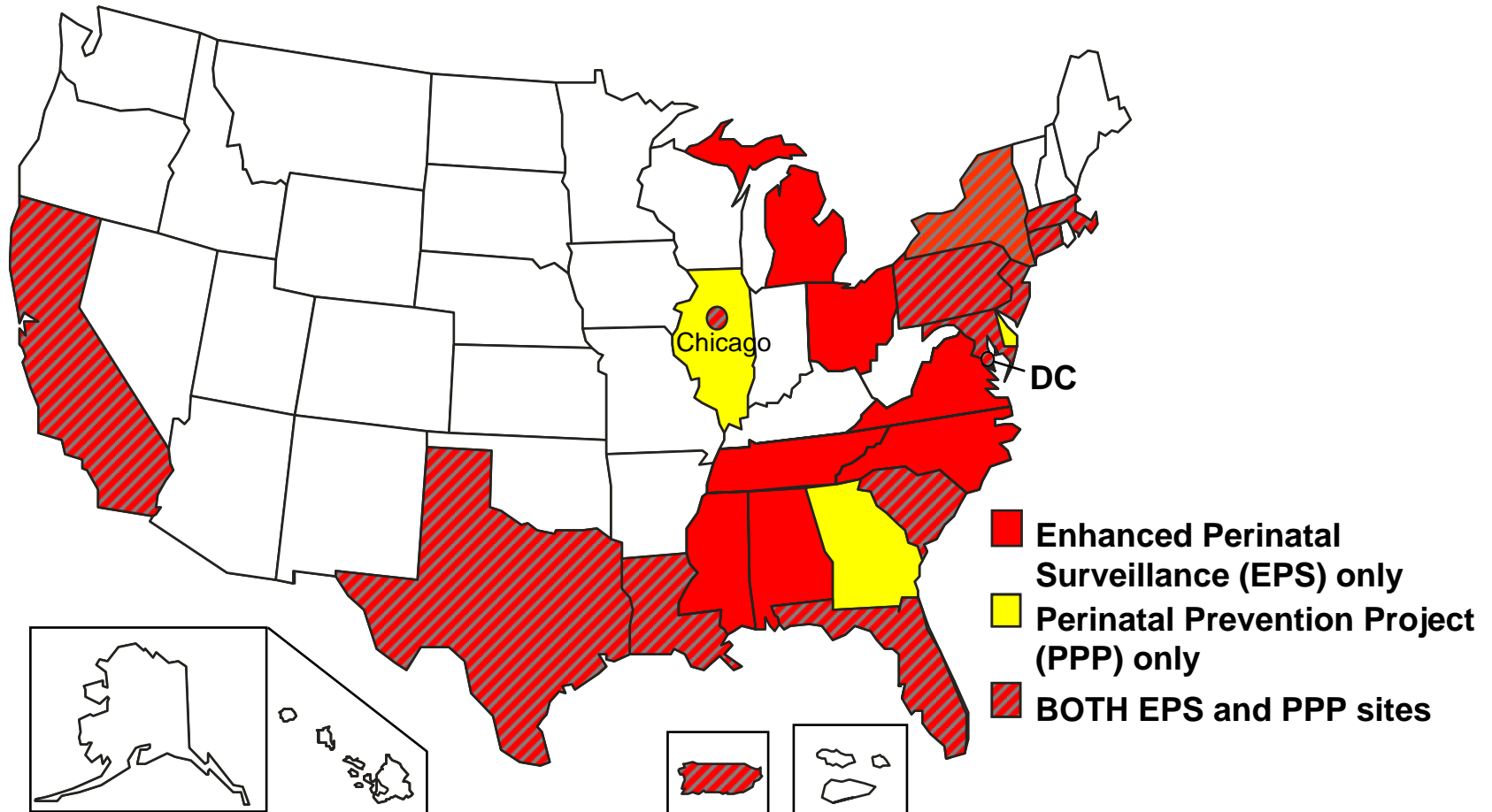
Enhanced Perinatal HIV Surveillance

- STEP
 - 7 states previously funded
 - to collect data on mother-child pairs for 1993, 1995, 1996 and 1997
 - Pilot project that expanded to EPS

EPS Methods

- 25 sites currently funded
- Match HIV/AIDS and birth registries for birth years 1999, 2000, 2001
- Review maternal HIV, prenatal, labor/delivery, newborn and pediatric records
- Includes states with named HIV reporting and states with non-named reporting, using facility based, IRB-approved protocols

Project Sites: Enhanced Perinatal HIV Surveillance and Perinatal HIV Prevention



Puerto Rico

HIV/AIDS Surveillance

Know Thy Data

Additional resources

- Recent *HIV/AIDS Surveillance Reports and Supplemental Reports*
www.cdc.gov/hiv/surveillance.htm
- Recent HIV/AIDS-related *MMWRs*
www.cdc.gov/hiv/pubs/mmwr.htm
- Fleming PL, Wortley PM, Karon JM, De Cock KM, Janssen RS.
Tracking the HIV epidemic: current issues, future challenges. *Am J Pub Health* 2000;90:1037-41.
- Karon JM, Fleming PL, Steketee RW, De Cock KM. **HIV in the United States at the turn of the century: an epidemic in transition.** *Am J Pub Health* 2001;91:1060-8.