SPECIAL SECTION: THE SENTINEL HIV SEROPREVALENCE SURVEYS

The Family of HIV Seroprevalence Surveys: Objectives, Methods, and Uses of Sentinel Surveillance for HIV in the United States

MARGUERITE PAPPAIOANOU, DVM, PhD TIMOTHY J. DONDERO, Jr., MD, MPH LYLE R. PETERSEN, MD IDA M. ONORATO, MD CAROLYN D. SANCHEZ JAMES W. CURRAN, MD, MPH

The authors are with the Division of HIV/AIDS, Center for Infectious Diseases, Centers for Disease Control (CDC); four of them are with the HIV Seroepidemiology Branch (HSB). Dr. Pappaioanou is Assistant Chief for Science, HSB; Dr. Dondero is Chief, HSB; Dr. Petersen is Chief, Population Studies Section, HSB; and Dr. Onorato is Chief, Clinic and Special Surveys Section, HSB. Ms. Sanchez is Chief, Microcomputing Section, Statistics and Data Management Branch. Dr. Curran is Director of the Division.

Tearsheet requests to Technical Information Activity, Division of HIV/AIDS, Center for Infectious Diseases, CDC, Atlanta, GA 30333.

Synopsis

During 1987-89, the Centers for Disease Control (CDC), in collaboration with State and local health departments, other Federal agencies, blood collection agencies, and medical research institutions, implemented a national sentinel surveillance system for human immunodeficiency virus (HIV) infection. This ongoing surveillance system, known as the CDC family of HIV seroprevalence surveys, uses standardized survey and HIV serologic testing procedures in a group of sentinel populations from geographically diverse metropolitan areas, States, and Territories of the United States. As of September 1989, sentinel surveillance for HIV infection was being conducted in 41 States, Puerto Rico, and 39 metropolitan areas, including the District of Columbia. Information from this system complements AIDS surveillance data to assist health officials to direct resources and develop strategies for HIV prevention and health-care programs.

The series of papers in this issue of Public Health Reports describes the objectives and methods of seven of the surveys as well as the interpretation and uses of the data. This first paper provides an overview of the national sentinel surveillance system for HIV.

As OF SEPTEMBER 30, 1989, 105,990 persons with acquired immunodeficiency syndrome (AIDS) had been reported to the Centers for Disease Control (CDC) by the 50 States, the District of Columbia, and U.S. Territories (1). Since recognition of the syndrome in 1981, a national surveillance system, which uses a uniform case definition and case report form, has provided information for monitoring the human immunodeficiency virus (HIV) epidemic, identifying characteristics of persons at risk and modes of transmission, projecting the number of AIDS cases, and targeting resources for prevention and treatment efforts (2).

Reported AIDS cases, however, do not accurately reflect current levels of HIV infection in the U.S. population. Most infected persons have not developed AIDS; the median time from infection to a diagnosis of AIDS in adults is approximately 10 years (3, 4) and may lengthen as effective therapeutic interventions for HIVinfected persons become more widely used (5). Reported AIDS cases more likely represent the transmission pattern several years earlier.

Need for Information on Levels, Trends of HIV

In 1987, CDC extensively reviewed available published and unpublished information of the levels of HIV infection in the United States (6). Since the surveys and studies had been conducted using various survey methods and laboratory procedures, the similarities or differences in HIV prevalence rates among the different surveyed groups across different areas and over time were difficult to interpret. Standardized information by demographic subgroup and geographic area over time was urgently needed (7).

Sentinel Surveillance

AIDS surveillance and available HIV seroprevalence information (6, 7) indicate that the HIV epidemic consists of multiple subepidemics in different population groups and in different geographic areas. Access to different population groups for conducting HIV seroprevalence surveys is frequently limited to health-care settings where blood is drawn routinely for other purposes. Thus, a sentinel system, involving the systematic collection of data over time from different and accessible subgroups, was developed for HIV surveillance.

National Surveillance for HIV

In late 1987, CDC, in collaboration with State and local health departments, other Federal agencies, blood collection agencies, and medical research institutions, developed and began implementation of a national sentinel surveillance system for HIV infection based on standardized survey and serologic testing procedures across geographically diverse areas of the United States (8). This system, also known as the family of HIV seroprevalence surveys, comprises surveys and studies in selected subgroups and includes the systematic collection of information from ongoing HIV screening programs of population groups monitored for HIV since 1985 (for example, blood donors and civilian applicants to the military) (6-8). These complementary surveys provide State and local health departments with standardized, consistent information on the local level, patterns, and trends of HIV infection by demographic subgroup. National public health officials are provided with information on HIV prevalence by metropolitan, State, regional, and national areas.

As of September 1989, sentinel surveillance for HIV infection was ongoing in 41 States, Puerto Rico, and 39 metropolitan areas, including the District of Columbia (table 1). The series of papers in this issue of *Public Health Reports* describes the objectives and survey methods of seven of the surveys (9-16) and discusses several important considerations in interpreting and using the data (9-17).

Selection of Sentinel Populations

There is a need to monitor the levels of HIV infection across geographically diverse areas in accessible population groups that are potentially at increased risk of exposure, are otherwise of public health importance, or attend facilities where, if indicated, routine, voluntary counseling and testing could be made available on a priority basis. Sentinel populations were selected by expected levels of risk for HIV exposure, special public health significance, and accessibility (table 1).

Persons seeking services at clinics for sexually transmitted diseases (9) or drug treatment centers (10) were chosen to monitor infection in people at increased risk of HIV exposure. The subgroup of women of reproductive age seeking family planning services, abortion services, or prenatal care (at varied risk of exposure) was selected to provide information on HIV prevalence that could identify areas with people in greatest need of HIV counseling and testing (11). The population of patients seeking care at tuberculosis (TB) clinics was selected to provide data on HIV prevalence in local patient populations to aid in evaluating counseling and testing services (12). The population of TB patients often has an increased HIV prevalence and needs routine counseling and testing since HIV-related immunodeficiency activates latent TB (18).

Patients admitted to sentinel hospitals with diagnoses not likely to be associated with HIV infection or its major risk factors were selected as a sentinel group to monitor the prevalence of infection in the communities served (13). Similarly, primary care outpatients who visited a sentinel physician network, or who had blood specimens sent to a large, national diagnostic laboratory for a complete blood count (not specifically associated with HIV-related illness), are monitored for levels and trends of HIV infection (14).

Several other populations were selected to monitor HIV prevalence in groups where the majority of people are believed to be at low risk of exposure. For example, women giving birth are accessible for HIV serosurveys through the blood specimens routinely collected from their newborn infants. The survey in childbearing women directly measures HIV prevalence in women at the time of delivery (15). Additionally, results from this survey can be used to estimate the prevalence of HIV infection in sexually active women and indirectly measure the incidence of infection in newborns (19).

CDC also routinely receives seroprevalence data on blood donors from the American Red Cross and other agencies (16) and on civilian applicants for military service from the Department of Defense (20). CDC also obtains seroprevalence data on Job Corps entrants from the Department of Labor (6–8), which permits monitoring infection in this group of disadvantaged urban and rural youths 16–21 years of age. Other sentinel populations include students seeking health care at university health clinics, American Indian and Alaskan Natives seeking health care at Indian Health Service clinics, incarcerated persons in selected correctional facilities, migrant farm workers, and selected groups of homeless persons.

Selection of Metropolitan Areas

At the start of the program, health departments in 30 metropolitan areas were invited to participate in the implementation of serosurveillance surveys among patients seeking care at sexually transmitted disease and tuberculosis clinics; women attending family planning, prenatal care, and abortion clinics; intravenous drug users beginning drug treatment programs; and patients

| | Table 1 | . Sentinel | populations i | in the | family of HI | / seroprevalence su | rveys |
|--|---------|------------|---------------|--------|--------------|---------------------|-------|
|--|---------|------------|---------------|--------|--------------|---------------------|-------|

| Sentinel population and reference number | Access for seroprevalence survey | Overall level of risk of exposure | |
|---|---|--|--|
| Persons with sexually transmitted diseases (STD)(9) | State and local health department STD clinics | Increased | |
| IV drug users entering drug treatment pro- grams (10) | Drug treatment centers | Increased | |
| Women seeking family planning services, prenatal care, abortion services (11) | Family planning clinics, prenatal care clinics, abortion clinics | All levels | |
| Persons treated for tuberculosis (12) | State and local health department tuber- culosis clinics | 1 Increased | |
| Selected hospital patients at admission for non-HIV related diagnoses (13) | Hospitals | All levels | |
| Primary care outpatients (14) | Clinical laboratory | All levels | |
| Primary care outpatients (14) | Physician network | All levels | |
| Childbearing women (15) | Neonatal screening programs | All levels | |
| Blood donors (16) | Blood collection agencies | Deferral of persons at increased risk | |
| Civilian applicants to military service (20) | Department of Defense HIV Screening Pro- gram | Deferral of persons at increased risk | |
| American and Alaskan Natives (6) | Indian Health Service health clinics | All levels | |
| Job Corps entrants (6) | Department of Labor HIV Screening Program | All levels | |
| University students (6) | University health clinic | All levels | |
| Prisoners (6) | Prisons and jails | All levels | |
| Homeless persons (6) | Health clinics | All levels | |

1 HIV-related immunodeficiency activates latent tuberculosis, leading to an increased prevalence of HIV infection among TB patients.

in sentinel hospitals (table 2). Selection of areas was based on AIDS cumulative incidence rates, syphilis and gonorrhea rates, feasibility of timely implementation of the surveys, and geographic diversity. In addition, the corresponding 22 States, the District of Columbia, and Puerto Rico were invited to participate in statewide surveys among childbearing women (table 2). In 1989 the system was expanded to include nine additional metropolitan areas and additional States (table 2, figure).

Survey Design

To provide estimates of HIV prevalence unbiased by self-selection (6-8), blinded, unlinked surveys are conducted in sentinel clinic, hospital, and primary care outpatient populations and among women delivering live children. In blinded surveys, there is no interaction or intervention with eligible people for the purpose of the survey, and HIV serologic test results cannot be linked to identifiable persons. Thus, blood specimens collected for other purposes are tested for HIV antibody after all identifiers have been removed. Likewise, only demographic and behavioral information already collected for other purposes is used in the survey. Because there is neither interaction with nor risk to persons, informed consent is not required (21), avoiding any impact of self-selection bias (22). In high prevalence areas, nonblinded surveys complement the blinded surveys in the same sentinel clinic populations (9-12) to evaluate risk behaviors associated with HIV seropositivity. In nonblinded surveys, clinic clients who are receiving HIV counseling and testing provide detailed information on risk behaviors by consenting to a standardized interview.

Laboratory Procedures

Specimens for the surveys are tested for HIV-1 antibody, using standardized protocols and procedures. Serum and plasma specimens that are repeatedly reactive by an HIV enzyme immunoassay (EIA) licensed by the Food and Drug Administration (FDA) are confirmed by an FDA-licensed Western blot assay (9-13, 16) (or as in the clinical laboratory specimen survey, a test shown to be equivalent to an FDA-licensed Western blot assay). Eluates from dried blood spots in the survey of childbearing women are tested by an EIA licensed for use with serum or plasma and shown suitable for use with dried blood spot specimens. Repeatedly reactive eluates are then confirmed by immunoblot (15). Laboratories participating in the family of HIV seroprevalence surveys take part in the CDC Model Performance Evaluation Program for HIV-1 Antibody Testing (23), or the CDC Quality Assurance Program

| Table 2. Participating States, me | etropolitan areas, clinics, | , and hospitals in the family of | f HIV seroprevalence surv | eys as of September 1989 |
|-----------------------------------|-----------------------------|----------------------------------|---------------------------|--------------------------|
| | | | | |

| | Year of Participating clinics 1 | | | Sentinel | | | |
|---------------------------------------|---------------------------------|-----|-------|----------|-------|-----------|---------------------------------------|
| Geographic division-metropolitan area | enrollment - | STD | DTC | WHC | ТВ | hospitals | State survey among childbearing women |
| Northeast | | | | | | 10 | ••• |
| Boston | 1987 | 4 | 3 | 3 | 1 | | Massachusetts |
| New Haven | 1987 | 1 | 1 | 3 | | | Connecticut |
| Providence | 1989 | 1 | 2 | 1 | | | Rhode Island |
| New York | 1987 | 8 | 5 | 8 | 8 | | New York |
| Rochester | 1987 | 1 | 1 | 3 | | | New York |
| Newark | 1987 | 2 | 2 | 6 | 1 | | New Jersev |
| Philadelphia | 1989 | 1 | 5 | 4 | | | Pennsylvania |
| Aidwest | | | - | | | 10 | |
| Chicago | 1987 | 8 | 1 | 6 | 8 | | Illinois |
| Cleveland | 1987 | 2 | 2 | 3 | 1 | | Ohio |
| Detroit | 1987 | 6 | 2 | 6 | 2 | | Michigan |
| Minneapolis | 1987 | ž | | 4 | 1 | | Minnesota |
| Milwaukee | 1989 | 2 | 2 | 1 | 1 | | Wisconsin |
| Indianapolis | 1989 | 1 | 1 | 3 | | ••• | Indiana |
| Kansas City | 1987 | 2 | 3 | 2 | | ••• | Missouri |
| Saint Louis | 1987 | 2 | 1 | 4 | 2 | | Missouri |
| South | 1907 | 2 | | 4 | 2 | | |
| | 1987 | | 4 | 6 | 1 | - | Mondond |
| Baltimore District of Columbia | | 3 | 4 | - | | ••• | Maryland |
| | 1987 | 3 | • | 6 | • • • | • • • | Delement |
| Wilmington | 1989 | 2 | 1 | 1 | ••• | ••• | Delaware |
| Richmond | 1987 | 1 | 1 | 4 | 1 | • • • | Virginia |
| Atlanta | 1987 | 3 | 3 | 3 | ••• | • • • | Georgia |
| Miami | 1987 | 2 | • • • | 2 | 1 | • • • | Florida |
| Jacksonville | 1987 | 1 | 1 | 3 | 1 | • • • | Florida |
| Memphis | 1987 | 1 | 2 | 1 | 1 | • • • | Tennessee |
| Little Rock | 1989 | 1 | | 2 | 1 | | Arkansas |
| Birmingham | 1989 | 1 | 2 | 4 | 2 | • • • | Alabama |
| New Orleans | 1987 | 2 | 2 | 3 | 3 | • • • | Louisiana |
| Oklahoma City | 1989 | 2 | 1 | | | | Oklahoma |
| Dallas | 1987 | 1 | 1 | 6 | 1 | | Texas |
| Houston | 1987 | 3 | 3 | 9 | | | Texas |
| Vest | | | | | | 12 | |
| Denver | 1987 | 2 | 4 | 3 | 1 | | Colorado |
| Albuquerque | 1987 | 1 | 1 | 3 | 1 | | New Mexico |
| Phoenix | 1987 | 1 | 2 | 1 | 1 | | Arizona |
| Salt Lake City | 1987 | 2 | 1 | 1 | 2 | | Utah |
| Seattle | 1987 | 3 | 5 | 3 | 1 | | Washington |
| Portland | 1989 | 4 | 2 | 3 | | | Oregon |
| San Francisco | 1987 | 9 | 9 | 14 | 2 | | California |
| Los Angeles | 1987 | š | ő | 6 | 6 | | California |
| Honolulu | 1987 | 1 | 1 | 2 | 1 | ••• | Hawaii |
| Dther | 1307 | • | | - | | ••• | i iawan |
| San Juan | 1987 | 1 | 1 | 2 | 1 | ••• | Puerto Rico |
| Total | | 101 | 85 | 145 | 54 | 41 | |

1 Clinics with blinded surveys. NOTE: STD = sexually transmitted diseases; DTC = drug treatment center; WHC = women's health clinic; TB = tuberculosis.

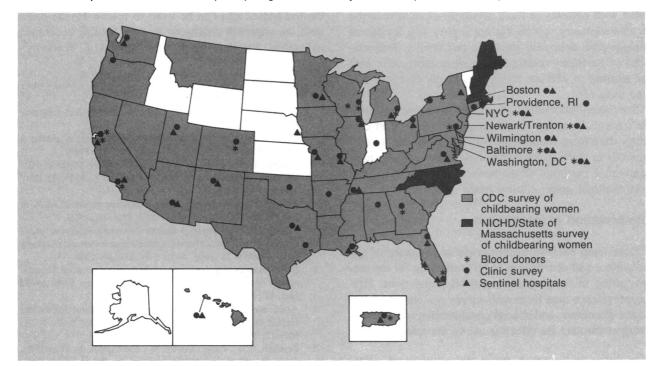
for Human Immunodeficiency Virus seropositivity screening of dried blood spots (24), or both.

Data Management

Clinic surveys and childbearing women survey. CDC has developed microcomputer software for data management and analysis. This software is used for the collection and transfer of data from the HIV sentinel surveillance populations to State and local health departments and to CDC (25). This system can be used

independently of or in conjunction with local data systems already in place. The software is used for the blinded and nonblinded clinic surveys (9-12) and for the surveys in childbearing women in some States (15), although several States use their own neonatal screening program software.

Scannable mark sense forms, constructed of detachable sections—one for demographic, geographic, and risk behavior information and "local use" variables, and one for HIV serologic test results—are provided for data collection in the blinded clinic surveys (9-12). The



local use section of the form is used for other data of interest to the local or State health department, or both. For nonblinded clinic surveys, CDC also provides standardized risk assessment instruments and laboratory report forms for HIV test results.

The scannable forms and risk assessment questionnaires (filled out at sentinel sites) are sent to the respective local or State health department for entry into a computerized data base using the survey software. Similarly, HIV serologic test results from participating laboratories are sent to the health department and merged with the demographic and risk information. Data are analyzed and used by local or State health departments and transferred to CDC, which serves as the repository of the national HIV seroprevalence database.

Other sentinel populations. Sentinel hospitals send demographic information and corresponding EIA test results to CDC on computer diskette or by hardcopy. Similarly, data from the physician network and clinical laboratory primary care outpatient surveys also are sent to CDC on diskette. Data tapes with HIV serologic test results and corresponding demographic characteristics for Job Corps entrants from the Department of Labor and civilian applicants for military service from the Department of Defense are sent to CDC quarterly. Data from routine blood donor screening are collated and analyzed at the American National Red Cross Headquarters, which then shares summary results with CDC. Trained personnel in 20 blood centers, using a standardized data collection instrument, interview seropositive blood donors for information on risk behaviors and motivation for blood donation. Completed questionnaires are sent directly to CDC and entered into a computer database. Personal identifiers are not communicated to CDC.

Analysis of Data, Reporting of Results

In an effective surveillance system, the resulting information is disseminated in a timely fashion to those who need to know. Public health officials and policymakers can then use the information to plan, direct, and evaluate the most effective strategies for disease prevention and control.

Data from the clinic surveys are first analyzed, and reports are generated by State and local health departments so that the results can be rapidly disseminated in the local health community. Nationally, CDC will provide periodic summary tabulations of results from the family of HIV seroprevalence surveys by demographic and behavioral subgroup and metropolitan area.

Protection of anonymity. To ensure that HIV test results cannot be linked to identifiable persons, data are first collected in aggregated categories (for example,

age-group, month or quarter of year). In addition, staff at participating laboratories and clinics (who have interacted with patients or have access to clinical records) receive summary reports but not line-by-line listings of demographic data with serologic test results. Presentations of summary results do not show table cells with the number of persons tested in a single category less than three (26).

Special considerations are needed to choose appropriate statistical methods for analysis and to interpret correctly data from sentinel surveillance systems. Useful methods in the analysis of these data may include nonparametric methods or methods used to analyze data from multiple center clinical trials.

Interpretation of Information

Data from each survey provide an estimate of the prevalence and distribution of HIV infection for the survey period in the respective sentinel populations. HIV seroprevalence data from each survey are biased in particular directions, and special consideration is needed to interpret the data for effective use of the information.

Prevention and control. Sentinel surveillance for HIV should be an important component of HIV prevention and control programs (16, 27, 28). Several States have already used early results from sentinel serosurveillance activities to guide prevention policy (29, 30). In this series of papers, Onorato and coauthors (27) describe how sentinel seroprevalence data can be used to manage public health programs. Some important uses of data from the HIV surveys include (a) monitoring levels and trends of HIV infection in the sentinel populations, (b) detecting deviations from expected transmission patterns, (c) determining risk factors for infection, (d) defining and targeting immediate or longer range public health actions for prevention and control of HIV, (e) setting priorities for interventions, (f) assessing the proportion of infected persons seeking care in clinical settings who have received counseling, (g) indirectly estimating the incidence of HIV from results of serial cross-sectional surveys, (h) projecting future numbers of persons with AIDS, and (i) planning for adequate resources for public health actions and health care.

National estimates of prevalence and trends of HIV.

Other important uses of these sentinel surveillance data will be to assist in making interval estimates (upper and lower bounds) of the number of persons in the United States infected with HIV and to compare these results with national estimates made from the use of other, independent methods (for example, back-calculation models). Results from the sentinel surveys can, when considered together with their respective biases, yield an overall picture of the level of HIV infection in the United States and can be used to follow trends over time, an approach analogous to "the leading economic indicators" that describe the state of the U.S. economy.

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HIV Seroprevalence Surveys in Sexually Transmitted Disease Clinics

IDA M. ONORATO, MD EUGENE MC CRAY, MD MARGUERITE PAPPAIOANOU, DVM, PhD ROBERT JOHNSON, MD SEVGI ARAL, PhD ANN M. HARDY, DrPH TIMOTHY J. DONDERO, Jr., MD, MPH

The authors are with the Centers for Disease Control, Public Health Service. Dr. Onorato, Dr. McCray, Dr. Pappaioanou, and Dr. Dondero are with the Division of HIV/AIDS, Center for Infectious Diseases. Dr. Johnson and Dr. Aral are with the Division of STD/ HIV Prevention, Center for Prevention Services. Dr. Hardy is with the National Center for Health Statistics.

Tearsheet requests to CDC, Technical Information Activity, Mail Stop G29, Atlanta, GA 30333.

Synopsis

The Centers for Disease Control, in cooperation with State and local health departments, is conducting human immunodeficiency virus, type 1 (HIV), seroprevalence surveys, using standard protocols, in sexually transmitted disease (STD) clinics in selected metropolitan areas throughout the United States. The surveys are blinded (serologic test results not identified with a person) as well as nonblinded (clients voluntarily agreeing to participate).

STD clinics are important sentinel sites for the surveillance of HIV infection because they serve persons who are at increased risk as a result of certain behaviors, such as unprotected sex, homosexual exposure, or intravenous drug use. HIV seroprevalence rates will be obtained in the sentinel clinics each year so that trends in infection can be assessed over an extended period of time. Behaviors that place clients at risk for infection, or protect against infection, are being evaluated in voluntary, nonblinded surveys to define groups for appropriate interventions and to detect changes in response to education and prevention programs.

Although inferences drawn from the surveys are limited by the scope of the clinics and clients surveyed, HIV trends in STD clinic client populations should provide a sensitive monitor of the course of the acquired immunodeficiency syndrome (AIDS) epidemic among persons engaging in high-risk sexual behaviors.

HUMAN immunodeficiency virus, type 1 (HIV), the causative agent of acquired immunodeficiency syndrome (AIDS), is transmitted by sexual contact between homosexual and bisexual men as well as through het-

erosexual activity by bisexual or heterosexual men and women. The present extent of HIV transmission among sexually active persons, and changes now taking place in that transmission, are unknown.