

John E. Anderson, PhD

Dr. Anderson is a sociologist with the Division of Adolescent and School Health, National Center for Chronic Disease Prevention and Health Promotion, at the Centers for Disease Control and Prevention.

CDC Data Systems Collecting Behavioral Data on HIV Counseling and Testing

SYNOPSIS

THIS PAPER DESCRIBES TWO SYSTEMS, the HIV Counseling and Testing Data System and the National Health Interview Survey, AIDS Knowledge and Attitudes Supplement, that collect behavioral information on HIV counseling and testing in the United States. Together these data sources provide valuable information for planning and evaluating counseling and testing programs. While these two systems are not designed primarily for behavioral research, they both collect behavioral data, including the behavioral risk category of persons being tested.

HIV counseling and testing (CT) is one of the largest HIV prevention programs conducted by the Centers for Disease Control and Prevention (CDC) (1, 2). CT is provided to let persons know their serostatus, to allow those being tested to receive prevention messages and help in changing behavior, to help tested individuals obtain needed medical care and other services, and to provide services and referrals for sex and needle-sharing partners of HIV-infected persons (3). The HIV Counseling and Testing Data System (CTS) and the National Health Interview Survey, AIDS Knowledge and Attitudes Supplement, (NHIS) are two data systems supported by CDC that collect information about persons being tested for HIV.

The Counseling and Testing Surveillance System

To evaluate and manage the CT program, CDC maintains a data system of all tests taking place in CDC-funded public testing sites throughout the United States (4, 5). The objectives of the CTS are to determine the quantity of testing services provided by CDC-funded programs; to describe the characteristics of persons being tested, and testing positive, including behavioral risk factors for HIV transmission; and to measure the number of persons being tested and receiving counseling services. A high percentage of all publicly funded tests in the United States are funded by CDC and therefore included in the CTS; the percentage of public tests that are not funded by CDC is not known, but is known to be higher in some types of sites, such as prenatal care sites. Tests supported by state funds or Medicaid may not always be included in

Requests for tear sheets should be addressed to Dr. John E. Anderson, Division of Adolescent and School Health, NCCDPHP, Centers for Disease Control and Prevention, Mail Stop K-32, 1600 Clifton Road, NE, Atlanta, GA 30333.

the CTS. The CTS contains information on more than 2 million tests conducted in 1992, including characteristics of test recipients—age, sex, race/ethnic group, test result, behavioral risk category—and whether the client returned and received posttest counseling. The tests included in this system are provided in a variety of settings including stand-alone HIV testing sites, sexually transmitted disease (STD) clinics, family planning clinics, prenatal and obstetrical clinics, drug treatment centers, and jails and correctional institutions.

Key Features of the CTS

- CTS is national in scope, and is intended to include all CDC-funded tests.
- CTS provides data on tests, not persons being tested; data from the system indicate that 38 percent of clients have been tested previously at some time in their lives, but duplicate tests cannot be eliminated.
- Behavioral data reported on the CTS are limited.
- CTS can provide information for states and smaller areas, which is useful for HIV community planning and other program evaluation activities.
- CTS provides information only on persons seeking tests; it is not representative of population groups and cannot be used to calculate rates of testing or seroprevalence.

CTS data are collected on all CDC-funded tests in the United States from 65 reporting areas—50 states, the District of Columbia, 6 cities, and 8 territories. Test data are reported in two different formats: (1) aggregated numbers of tests in specific categories (27 reporting areas), and (2) a client record system (one record for each test, in 38 reporting areas). More detailed analysis is possible with the client record reporting areas, but these data do not produce complete national estimates. Estimates for the total United States are based on the aggregated data.

Key Features of the NHIS AIDS Supplement

- Data on testing are self-reported.
- No information on test results is obtained.
- Data are collected for persons receiving tests from all sources, including publicly funded tests and tests obtained from private doctors and hospitals.
- Information is collected on persons receiving all types of tests, including blood donations and tests that are required (for example, for military induction or insurance).
- Information on specific behavioral risk factors is not obtained.
- Rates of testing can be calculated for the nation and population subgroups.
- Results are representative of the national population.

In 1992, 2.7 million tests were performed (table 1). Relatively few tests were reported for persons in the major HIV transmission risk groups, homosexual and bisexual males and injecting drug users (6.9 and 6.0 percent). In more than half of the tests, clients were assigned to the "Other" and "Unknown" risk categories. Note that for those reporting areas that collect client record data, more detailed risk categories can be reported (table 1), and a higher percentage of tests are among persons reporting specific risk factors. More than 60 percent of tests in this system occurred in HIV CT centers and STD clinics (table 2).

Table 1. Number of HIV antibody tests, by risk exposure category—1992 CDC CTS

HIV risk category	Total tests	Percent	Positive tests	Percent
<i>Aggregate data</i>				
Homosexual/bisexual male IDU	13,988	0.5	2,146	3.9
Homosexual/bisexual male	182,715	6.9	16,769	30.7
Heterosexual IDU	159,331	6.0	10,292	18.8
Hemophilia	665	0.0	21	0.0
Blood recipient	32,440	1.2	402	0.7
Heterosexual at risk	844,513	31.8	10,974	20.1
Other	961,728	36.3	9,248	16.9
Unknown	456,303	17.2	4,812	8.8
Total	2,651,683	100.0	54,664	100.0
<i>Client record data</i>				
Men who have sex with men (MSM)	153,699	8.2	13,763	34.4
MSM/injecting drug user	12,351	0.7	1,884	4.7
Heterosexual IDU	134,351	7.1	7,533	18.8
Sex partner at risk	360,611	19.2	5,362	13.4
Child of HIV+ woman	2,050	0.1	218	0.5
STD diagnosis	169,776	9.0	2,087	5.2
Sex for drugs/money	28,131	1.5	701	1.8
Sex and using drugs	97,374	5.2	687	1.7
Hemophilia/blood recipient	22,463	1.2	274	0.7
Victim of sexual assault	14,843	0.8	70	0.2
Health care exposure	30,823	1.6	100	0.3
No acknowledged risk	210,862	11.2	1,554	3.9
Other	583,486	31.0	4,363	10.9
Not specified	59,223	3.2	1,380	3.5
Total	1,880,043	100.0	39,976	100.0

NOTE: Aggregate data are for all areas; client record data are from 38 of 65 reporting areas only.

Table 2. Number of HIV antibody tests, by sources of test—1992 CDC CTS

Source of HIV test	Total tests	Percent	Positive tests	Percent
HIV CT center	932,686	34.7	19,658	35.7
STD clinic	715,962	26.6	14,532	26.4
Drug treatment facility	117,940	4.4	3,978	7.2
Family planning clinic	301,252	11.2	1,321	2.4
Prenatal/OB clinic	131,479	4.9	784	1.4
TB clinic	16,805	0.6	285	0.5
Other health dept.	134,532	5.0	4,377	8.0
Prison	88,635	3.3	3,896	7.1
College	4,079	0.2	52	0.1
Private MD/clinic	94,039	3.5	1,725	3.1
Other	121,523	4.5	3,090	5.6
Unknown	30,124	1.1	1,326	2.4
Total	2,689,056	100.0	55,024	100.0

The National Health Interview Survey, AIDS Knowledge and Attitudes Supplement

The National Health Interview Survey is an annual survey of a representative household-based sample of the United States population ages 18 and older (6, 7). Since 1987, an AIDS supplement has been administered to a

sample of 18,000 to 40,000 respondents each year. The purpose of this supplement is to provide population-based data on a number of topics including attitudes and knowledge about AIDS and HIV, sources of information about AIDS, and HIV testing experience, types of tests, and sources of HIV testing. No information is collected on results of HIV tests, but it is possible to calculate rates of testing for the U.S. population and major subgroups. The NHIS collects extensive behavioral data related to health care, but does not ask about specific HIV risk behaviors. Rather, respondents are asked whether they are members of one or more risk categories without having to name which one. The categories are men who have had sex with men, injecting drug users, persons receiving hemophilia clotting factors, persons exchanging sex for money or drugs, and sex partners of persons in one of the other categories.

Information on HIV testing from the NHIS is self-reported, and may be subject to reporting errors. However, the NHIS data includes tests from all sources, such as private sources not covered by the CTS.

The NHIS data indicate that 32.4 percent of the adult population had been tested by 1992 (table 3), representing about 60 million people. These tests include blood donations (the largest category) as well as required tests, and voluntary tests, which form the basis of HIV CT programs. Persons with increased risk were more likely to be tested, and in particular to have had voluntary tests—33 percent had been voluntarily tested compared with 9 percent of the general population.

NHIS data also indicate that about one-third of tests were reported from the public sources covered by the CTS (table 4). Among persons who were at increased risk for HIV infection, however, a higher percentage (47.7 percent) reported a public sector source of testing. Relatively few NHIS respondents named HIV counseling and testing centers and STD clinics as a source for their tests, whereas CTS data (table 2) indicated that these are the two largest sources of testing in that system, accounting for more than 60 percent of CDC-funded tests. It may be that NHIS respondents report these tests under more generic categories such as community health center, public clinic, and other clinic. These findings suggest that the CTS may be a better source for measuring the importance of specific sources of HIV testing.

Table 3. Persons in the United States reporting ever being tested for HIV, by type of test—1992 NHIS AIDS Supplement

	Percent of population			
	All respondents		Increased risk group	
	Percent	95% C.I.	Percent	95% C.I.
Ever tested, incl. blood donor	32.4	31.6-33.3	58.6	54.7-62.4
Donated blood since 1985	18.9	18.1-19.6	24.4	20.8-28.1
Ever tested, excl. blood donor	18.1	17.4-18.7	46.9	43.0-50.8
Ever had a voluntary test	9.0	8.6-9.5	33.0	29.1-36.9
Ever had a required test	8.9	8.5-9.4	14.3	11.6-17.0
	Estimated number tested			
	All respondents		Increased risk group	
	Estimated number (1000s)	95% C.I.	Estimated number (1000s)	95% C.I.
Ever tested, incl. blood donor	59,994	58,370-61,618	4,057	3,789-4,325
Donated blood since 1985	34,895	33,514-36,275	1,691	1,438-1,943
Ever tested, excl. blood donor	33,404	32,173-34,635	3,248	2,979-3,517
Ever had a voluntary test	16,684	15,864-17,504	2,286	2,019-2,553
Ever had a required test	16,526	15,638-17,414	990	803-1,177
No. of observations	20,974		872	

Table 4. Source of last HIV test—1992 NHIS AIDS Supplement

Last test voluntary	All respondents		Increased risk group	
	Percent	95% C.I.	Percent	95% C.I.
Public source	35.4	33.3 - 37.4	47.7	41.8 - 53.5
AIDS CT center	2.0	1.4 - 2.5	4.3	2.2 - 6.5
Community health center	12.1	10.2 - 14.0	16.4	11.7 - 21.0
Family planning clinic	2.2	1.4 - 2.9	3.1	0.6 - 5.5
Military site	0.8	0.4 - 1.3	0.9	-0.2 - 1.9
Prenatal clinic	0.7	0.2 - 1.2	1.2	-1.2 - .6
Drug treatment facility	0.3	0.0 - 0.6	0.6	-0.6 - 1.7
STD clinic	0.3	0.1 - 0.5	0.6	-0.3 - 1.4
TB clinic	0.0	0.0 - 0.1	0.0	0.0 - 0.0
Public clinic	6.5	5.1 - 7.9	8.1	5.1 - 11.2
Other clinic	3.5	2.6 - 4.3	4.0	1.5 - 6.5
Other site	7.0	5.8 - 8.2	8.5	5.5 - 11.6
Private source	64.0	61.9 - 66.1	51.1	45.2 - 6.9
Physician/HMO	39.7	37.7 - 42.1	30.0	24.8 - 35.2
Hospital/ER	22.4	20.4 - 24.4	19.3	14.5 - 24.1
Employer clinic	1.5	0.8 - 2.1	1.1	-0.4 - 2.6
At home with nurse	0.4	0.1 - 0.8	0.7	-0.6 - 2.0
Refused/unknown/don't know	0.6	0.2 - 1.1	1.3	-0.2 - 2.8
Number of observations	2,126		313	

Conclusions

The CTS and NHIS differ in the data collected, how representative they are of the national population, and how completely they cover HIV tests taking place in the United States. Looking at data from both systems can lead to a more complete picture of HIV counseling and testing for

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the country and groups of interest. For example, the CTS data indicate the importance of AIDS counseling and testing centers and STD clinics as sources of HIV counseling and testing, particularly for persons at increased risk for infection. The NHIS data, on the other hand, reveal the importance of private sources of testing which are not covered in the CTS.

Behavioral data collected in these systems is limited largely to information on HIV risk categories. The data on risk category indicates that while many individuals who are tested are not at high risk for HIV infection, those in higher risk behavioral categories are much more likely to be tested, and to use public counseling and testing programs that are funded as a major part of CDC's HIV prevention programs.

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