Surveillance of HIV Knowledge, Attitudes, Beliefs, and Behaviors in the General Population

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SYNOPSIS

THIS ARTICLE DISCUSSES METHODS AND ELEMENTS of three major national health survey systems, particularly as they relate to HIV infection and AIDS. The National Health Interview Survey and the Behavioral Risk Factor Surveillance System provide information about health-related knowledge, attitudes, beliefs, and behaviors of adults in the United States. The Youth Risk Behavior Surveillance System measures health-related behaviors of American youth.

Questions and survey designs differ among the three surveys, but all three surveys utilize probability sampling. The National Health Interview Survey's AIDS Knowledge and Attitudes Supplement is administered to a subsample of approximately 20,000 people annually. The Behavioral Risk Factor Surveillance System consists of telephone surveys providing data for all 50 states and the District of Columbia, with an average annual sample size of approximately 2,000 per state. The Youth Risk Behavior Surveillance System samples approximately 12,000 youth for its national school-based survey, 2,000 (average) for each of its state and local school-based surveys, 10,000 for its national household-based survey, and 6,000 (projected) for its national college-based survey.

This article is meant to assist researchers, students, health educators, public health officials and others in utilizing survey data bases to address policy, program, research, and evaluation needs. All three surveys can help guide prevention efforts by providing information about the general population and by identifying national, local, or state-wide trends. More detailed studies and targeted studies of specific high-risk populations are also needed in light of the complexity of the determinants of HIV risk behavior.

HIV prevention programs need data on the general population, as well as on specific high-risk populations *(1, 2)*. The Centers for Disease Control and Prevention (CDC) provides HIV-related information on general population groups through three major multi-purpose national survey systems with sections dedicated to HIV-AIDS knowledge, attitudes, beliefs, and behaviors. These three survey systems are the National Health Interview Survey (NHIS), the Behavioral Risk Factor Surveillance System

Table 1. Comparison of HIV/AIDS components of CDC's general health-related surveillance systems that have specific sections dedicated to HIV/AIDS*

	NHIS	BRFSS	YRBSS
Cooperating field agency	Census Bureau	state health departments	state and local education agencies
Survey venue	home	home	school and home
Survey method	face-to-face interview (sometimes telephone is used instead)	telephone interview	self-administered written questionnaire or audiocassette with a written answer sheet
Confidentiality	yes	yes	yes
Anonymity	no	only phone # is known to interviewer	yes (school-based); and no (home-based)
Age range	> 18 years	18-65 years	9th-12th grade, 12-24 years
Questions	emphasize knowledge, attitudes, beliefs, and HIV testing	emphasize knowledge, attitudes, beliefs, and HIV testing	emphasize HIV-specific risky behavior
Approximate sample size	20,000	average of 2,000 per state	12,000 for national school-based survey; average of 2,000 per state and local school-based survey; 10,000 for national household-based survey; 6,000 for national college-based survey

NHIS=National Health Interview Survey
BRFSS=Behavioral Risk Factor Surveillance System
YRBSS=Youth Risk Behavior Surveillance System

*Note: Characteristics shown in this table apply only to the HIV-AIDS component of the data base listed, not necessarily to the entire data base.

(BRFSS), and the Youth Risk Behavior Surveillance System (YRBSS).

NHIS, BRFSS, and YRBSS differ from most other data collection systems in that they are ongoing (either continuous or repeated at regular intervals) and are designed using rigorous probability-based sample survey methods to obtain representative samples of the U.S. population. As probability-based general surveys, these systems provide data not available from other sources for evaluating and targeting HIV prevention programs. In addition, since they provide data over time, NHIS, BRFSS, and YRBSS can be used to determine national, state-wide, and local trends, as well as other emerging patterns.

The objective of this article is to provide a user-friendly overview of the methods and elements of these three systems for questionnaire designers, students, educators, policy makers, public health and prevention planners, and others who might want to use the data in these surveys.

Instruments and Methodology

NHIS, BRFSS, and YRBSS are coordinated by the CDC, although BRFSS and some components of YRBSS are administered by state or local authorities. While the three systems have similarities, they differ methodologically and in the questions they ask. The HIV and AIDS components of the adult surveillance systems, NHIS and BRFSS, focus mainly on knowledge, attitudes, and beliefs pertaining to HIV and AIDS, as well as HIV testing. The youth surveillance system, YRBSS, focuses on behavior.

Probability-based surveys, such as these three, use statistically validated methods of sample selection so that the probability of selection of each respondent is known. This enables estimates to be extended beyond the persons interviewed to the entire target population, and the sampling errors of such estimates to be calculated. In contrast, many studies related to HIV infection and AIDS have been conducted with persons or groups that do not represent larger populations, making it impossible to draw conclusions beyond the group that was interviewed.

While these systems all share the common characteristics of probability samples, they still miss some people, for example, the homeless, the institutionalized, and, for phone surveys, those without phones. Differences between those with and without phones can be estimated from the household-based survey. However, populations such as the homeless that are missed by the standard general population probability studies must be studied through special surveys targeted at these populations.

Table 1 compares the characteristics of the HIV-AIDS components of NHIS, BRFSS, and YRBSS.

The National Health Interview Survey (NHIS). NHIS is a general purpose health survey with a multistage probability design that permits continuous sampling of persons in the

United States *(3, 4)*. The sample size is about 50,000 households each year. Sampling and field operations are conducted by the U.S. Bureau of the Census under specifications established by CDC's National Center for Health Statistics (NCHS).

The NHIS is generally not viewed as a traditional surveillance system. However, many of the variables collected can be used for surveillance since they have been collected annually since 1957, with some modifications to the basic health questions occurring every 10-15 years. Data are collected from one person in the household regarding illness and injuries, disabilities, and use of health services among all family members. Information on special health topics, including AIDS, is obtained through personal interviews with a randomly selected subsample of adults. The response rate for the basic health component of the survey is about 96 percent, and for the supplements, about 85 percent.

The content of the AIDS Knowledge and Attitude Supplement was developed by NCHS and an Interagency Task Force created by the Public Health Service Health Data Policy Committee. Questions have been added, expanded, or deleted as data requirements have changed since the first supplement in 1987. For example, several questions were asked in 1991 and 1992 about attitudes towards home collection kits for HIV testing to help guide the development of policies regarding this new technology. The same question set that was used in 1994 will be repeated in 1995. There will be no HIV-AIDS supplement in 1996 or 1997. Many of the questions in this set have been in use, with minor word changes, since 1987.

The Behavioral Risk Factor Surveillance System (BRFSS). BRFSS is comprised of state-administered telephone surveys that provide data for all 50 states and the District of Columbia. The surveys are performed by the state health departments or their contractors using random-digit dialing. In each state, approximately 100 to 400 state residents are interviewed each month and asked about recent activities, behaviors, knowledge, beliefs, and attitudes which may affect their health *(5)*.

In every state, the survey uses probability-based sampling methodology, the most common being the Waksberg Cluster design. Households are selected according to each state's sampling design and then an individual is randomly selected from among the eligible persons in the household who are 18 or more years of age. The HIV and AIDS questions are only asked of respondents 18-65 years of age. Response rates vary by state. For example, the range of response rates was between 51 percent and 91 percent in 1993. In 44 states and the District of Columbia, computer-assisted telephone interviewing is now utilized. In these states, the BRFSS survey questionnaire is programmed into the interviewer's computer. Then, as the individual respondent answers each question, the caller types the answer into the computer.

Lead CDC Offices for NHIS, BRFSS, and YRBSS

There is a designated division or office at CDC with lead responsibility for coordinating each of the three survey systems discussed in this paper. For **NHIS,** the lead office is the Division of Health Interview Statistics, National Center for Health Statistics, CDC, 6525 Belcrest Road, Hyattsville, MD 20782. For **BRFSS,** the lead office is the Division of Adult and Community Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, 1600 Clifton Road, NE, Atlanta, GA 30333. For **YRBSS,** the lead office is the Division of Adolescent and School Health, National Center for Chronic Disease Prevention and Health Promotion, CDC, 1600 Clifton Road, NE, Atlanta, GA 30333.

Table 2. Topics covered in HIV-AIDS sections of adult surveillance systems, 1994[1]

Knowledge, Attitudes, and Beliefs Regarding HIV Transmission and Contraceptive Use
- NHIS–questions 4-6, 35, 36
- BRFSS–questions 66, 75

Attitudes and Beliefs Related to Exclusion of HIV-Infected Persons From School, Work, and Medical Care
- NHIS–question 3
- BRFSS–questions 63, 64

Knowledge, Attitudes, Beliefs, and Experience Regarding AIDS Awareness and Education
- NHIS–questions 1, 2, 7-11
- BRFSS–questions 65, 76

Knowledge, Attitudes, Beliefs, Behavior, and Experience Regarding HIV Testing and Counseling
- NHIS–questions 15-29
- BRFSS–questions 69-74

Blood Donation History
- NHIS–questions 13, 14
- BRFSS–question 70

Self-Perceived HIV Risk
- NHIS–question 30
- BRFSS–questions 67, 68

Personal HIV Risk Behavior
- NHIS–question 31
- BRFSS–not included in core questionnaire, but some states add their own questions to cover this topic

Knowledge, Attitudes, and Beliefs Regarding Tuberculosis
- NHIS–questions 32-34
- BRFSS–not included in HIV-AIDS section

[1]Denotes a comparison between the 1994 BRFSS "AIDS Knowledge and Testing" Section and the 1994 NHIS "AIDS Knowledge and Attitudes Supplement." Question numbers for questions relating to each topic are listed by surveillance system beneath the topic. Lists of the actual survey questions may be obtained through the lead CDC offices (see box).

The core questions used for the BRFSS survey are set by a working group that includes public health representatives from the states and CDC. For the HIV-AIDS section, extensive state input is additionally sought through regional meetings. For BRFSS, the same basic core questions, with some minor changes, have been asked since 1989. Additional changes will be made as needed.

Table 3. HIV-AIDS questions that are similar in both adult surveillance systems—NHIS AND BRFSS, 1994[1]

- At what age AIDS education should begin
- The subject's perceived risk of contracting the AIDS virus
- Whether the subject has been tested for the AIDS virus
- Whether the subject has donated blood since March 1985
- When the subject last donated blood
- The date of the subject's last blood test
- The main reason for the subject's last blood test
- Whether the subject received the test results and counseling
- How effective the subject perceives condoms are
- Whether the subject has ever known anyone with AIDS or AIDS virus

[1]Denotes a comparison between the 1994 NHIS "AIDS Knowledge and Attitudes Supplement" and the 1994 BRFSS "AIDS Knowledge and Testing" section.

Individual states usually add some of their own questions to the BRFSS. In 1994, six states (Hawaii, Colorado, Michigan, North Dakota, Ohio, and Tennessee) added their own questions about HIV and AIDS in addition to the standard national BRFSS questionnaire.

The Youth Risk Behavior Surveillance System (YRBSS). This survey has evolved through the collaborative efforts of several federal agencies interested in youth health issues, as well as state and local authorities, and has been in use since 1990 *(6)*. It is now administered every odd year. YRBSS has four components: (a) national school-based surveys, (b) state and local school-based surveys, (c) national household-based surveys, and (d) the newly established national college-based surveys.

The national school-based survey is administered to a national probability sample of approximately 12,000 high school students. The state and local school-based surveys use probability samples of varying sizes, with the average size being somewhere around 2,000. A multistage sample design is used to select schools and students within schools to gain appropriate probability samples. CDC provides technical assistance to the states and localities that administer the survey and has developed special software to aid in the drawing of samples.

In 1991, the national school-based survey had a school response rate of 75 percent and a student response rate of 90 percent *(7)*. That same year, state and local surveys reported school response rates ranging from 48 percent to 100 percent and student response rates ranging from 44 percent to 96 percent *(7)*.

Currently, the YRBSS core questions, used for national and state and local school-based surveys, are revised every 2 years. The 1993 core questions remain the same through 1995. A major redesign of the NHIS questionnaire will go into the field in 1996.

The national household-based survey component of YRBSS was initially conducted in 1992 as a follow-back supplement to the NHIS. The questionnaire that is used in the YRBSS national school-based survey was administered to a sample of about 10,000 adolescents and youth ages 12-21 from the households in the 1992 NHIS. Interviews were conducted in person using an audio cassette with head phones and a coded answer sheet to ensure privacy. The sexual behavior questions were not asked of 12-and 13-year-olds. The total response rate for this national household-based survey was 74 percent. A time frame for repeated administrations of this component of YRBSS has not yet been announced.

The YRBSS national college-based survey will begin in 1995. It will use a modified YRBSS questionnaire developed specifically for college students.

Survey Content

The adult surveys, NHIS and BRFSS, contain HIV and AIDS questions that focus predominantly on knowledge, attitudes, and beliefs (table 2). Tables 3 and 4 provide a summary of how questions in the 1994 HIV and AIDS sections of NHIS and BRFSS compare with one another. In contrast to the surveys for adults, which have few or no behavioral questions in their HIV and AIDS sections, YRBSS devotes all of its HIV and AIDS questions to behavior (table 5).

In YRBSS, most questions related to HIV and AIDS are not grouped together in a discrete section of the questionnaire. In NHIS and BRFSS, most HIV-related information is located in discrete sections designed to focus on HIV and AIDS. Still, some HIV-relevant information may be found outside of those sections. For example, in BRFSS, questions on health status, health care access, demographics, socioeconomic status, and reproductive health are located outside of the HIV-AIDS section. In NHIS, questions on worksite prevention programs, family discussions, and health practitioner-patient discussions are found outside of the HIV-AIDS section.

Increasingly, researchers are using focus groups and "think-aloud" interviews with subjects to help in the development of survey questions. Testing of proposed new questions has shown that respondents sometimes answer a question that is different from the one asked and the one that the researcher thought was a very clearly worded question. For example, respondents have their own definitions of sex, sexual intercourse, or sex partner, and even when there is an effort to define these terms in the actual question asked, respondents often still apply their own definitions when responding.

The NCHS Questionnaire Development and Research Laboratory has tested many of the questions used in the NHIS AIDS supplement as well as on the BRFSS and the YRBSS. Focus groups were used to assess the acceptability of the audio cassette methodology that was employed in the household component of YRBSS. The NCHS questionnaire development activities include, in addition to focus groups, the use of cognitive methodologies to better understand how people interpret and respond to knowledge and attitude

Table 4. HIV/AIDS questions found in only one of the two adult surveillance systems—BRFSS OR NHIS—but not in both, 1994[1]

Questions found only in NHIS	Questions found only in BRFSS
Likelihood of contracting AIDS by working near someone with AIDS	Whether respondent would work next to or near someone with AIDS virus
Likelihood of contracting AIDS by attending the same school as some one with AIDS	Whether respondent would allow his or her child to attend class with child with the AIDS virus
Likelihood of contracting AIDS virus by being coughed on or by sharing toilets, showers, plates, utensils, or needles	Whether respondent would encourage his or her sexually active teenager to use condom
Whether respondent's children have had AIDS education in school or through respondent	
AIDS education at respondent's church, school, social or civic club, clinic, hospital, or another place	
Respondent's knowledge of AIDS and its contagion and presentation	
Sources of AIDS knowledge	
Whether respondent has at least one risk factor from a given list of risk factors	
Number of times respondent tested for AIDS virus in past year	
How long it took to receive results of last AIDS test	
How, and with what information, above results were given, and whether respondent asked questions	
Whether practitioners should be allowed to refuse health care to AIDS patients	

[1]Denotes a comparison between the 1994 NHIS "AIDS Knowledge and Attitudes Supplement" and the 1994 BRFSS "AIDS Knowledge and Testing" section.

questions as well as to sensitive behavioral questions. Laboratory subjects are asked to explain their answers in much greater detail than in an actual interview. They are asked how they define certain terms in the question and how they arrived at the responses. They may be asked additional questions related to the question being tested. These interviews are usually audio recorded and sometimes video recorded so laboratory staff can discuss respondents' responses and reactions to questions and better understand what respondents were thinking when they answered the questions.

Copies of the actual questions used in NHIS, BRFSS and YRBSS can be obtained through the appropriate coordinating offices at CDC.

Other Sources of Information

Other surveys also provide pertinent information about HIV-AIDS knowledge, attitudes, beliefs, and behaviors. The National Survey of Family Growth *(8)*, for example, provides data particularly relevant to the HIV epidemic, as does the Substance Abuse and Mental Health Services Administration's annual National Household Survey on Drug Abuse *(9)*. There are currently plans to add a special module of HIV risk questions involving sexual behavior to the latter survey in 1996. The University of Chicago's National Opinion Research Center has included a short self-administered questionnaire on selected HIV-related risk behaviors on its annual omnibus General Social Survey since 1988 *(10)*.

Several large national surveys have focused on sexual behavior, including the National AIDS Behavioral Surveys *(11)*, the National Survey of Men *(12)*, and the University of Chicago's much publicized National Health and Social Life Survey *(13, 14)*.

One example of an unexpected source of HIV-related information is CDC's 1993 Teenage Attitudes and Practices Survey, which was primarily focused on smoking attitudes and behavior. This survey included questions on general risk-taking behavior, parental supervision, and time spent with friends. An additional question asked respondents over age 12 if they had "ever had a steady (boyfriend/girlfriend)...".

Additional information regarding available literature and research pertinent to HIV infection and AIDS can be obtained by calling the CDC National AIDS Clearinghouse at (800) 458-5231. More general information regarding HIV infection and AIDS is available 24 hours a day from the CDC National AIDS Hotline at (800) 342-AIDS. State and local health departments, state HIV-AIDS

Table 5. Comparison of HIV-related behavioral questions in CDC's general purpose adult and youth surveillance systems, 1993-1994.

Questions only in adult surveys (NHIS and/or BRFSS)[1]	Questions only in youth surveys (just YRBSS)[1]
NHIS asks parents whether they have ever discussed AIDS with any of their children, ages 10-17.	YRBSS asks youth if they have ever talked about AIDS-HIV with parents or other adults in the family.
NHIS asks adults whether there has been AIDS education in the respondent's church, school, social or civic club, clinic, hospital, or any other place.	YRBSS asks if there has been AIDS-HIV education in the school.
NHIS asks adults whether they have at least one HIV risk factor from a given list.	YRBSS asks youths whether they have participated in specific risk behaviors. Individual questions inquire about sexual intercourse, use of alcohol and other drugs, use of condoms, number of sex partners, history of sexually transmitted diseases, and pregnancy.

[1]Denotes a comparison between CDC's adult surveillance systems of HIV-related knowledge, attitudes, beliefs, and behaviors (the 1994 BRFSS "AIDS Knowledge and Testing" section and the 1994 NHIS "AIDS Knowledge and Attitudes Supplement") and CDC's youth surveillance system, the Youth Risk Behavior Surveillance System (YRBSS), which focuses on behavior.

hotlines, and, occasionally, local clinics may also be sources of information for locally relevant data.

Using the Data

Probability-based population surveys, such as NHIS, BRFSS, and YRBSS, are a valuable resource for understanding the public's response to HIV-AIDS and for helping to guide HIV prevention programs. For example, CDC's earlier America Responds to AIDS campaign helped target its messages by using information from NHIS on where people got their HIV-AIDS information and what their levels of knowledge were. In addition, NHIS, BRFSS, and YRBSS have been used to assess progress toward the Healthy People 2000 Objectives *(15)*. Clinicians, public health officials, researchers, and students should find these systems useful in developing HIV-related prevention programs, and in supporting related research and evaluation activities.

While NHIS, BRFSS, and YRBSS can be used to make total population estimates regarding a broad range of health topics, including HIV, they do not provide the kind of in-depth information that can be obtained through more targeted studies. This is particularly important with respect to HIV in light of the complexity and sensitivity of the information that is needed to better understand risk behaviors. Thus, special research projects and targeted studies of high-risk populations remain a crucial complement to general population-based surveillance.

The monitoring of knowledge, attitudes, and behaviors related to HIV transmission and prevention has been recognized as an important part of the nation's HIV prevention effort *(2)*. We must continue to examine our current public health surveillance strategies to make the best use of them today, and improve them for tomorrow.

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