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**The Promise of Integrated Representative Surveys About Sexually Transmitted Diseases and Behavior**

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# The Promise of Integrated Representative Surveys About Sexually Transmitted Diseases and Behavior

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***Background:*** **It has been difficult to conduct representative surveys measuring both sexually transmitted disease prevalence and behavioral data. This article reviews the literature, describes a recent pretest of the feasibility of integrated surveys, and discusses the potential implications.**

***Methods:*** **Several national surveys are reviewed, including the National Health and Nutrition Examination Surveys, National Health and Social Life Survey, and National Survey of Adolescent Males. The 1994 pretest of the National Survey of Adolescent Males collected urine specimens of male respondents, which were tested for *Chlamydia trachomatis* using ligase and polymerase chain reaction tests.**

***Results:*** **There have not been any prior national surveys that collect clinical measures of STD infection and detailed behavioral data. In the pretest, 85% of the eligible interview respondents provided a urine specimen. Of those tested, 6% were positive for *C. trachomatis*.**

***Conclusions:*** **Combining behavioral surveys with collection of urine specimens for STD testing in representative samples is feasible. However, STD testing adds new operational and ethical challenges to the conduct of household surveys.**

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A LONGSTANDING GAP in the study of sexually transmitted diseases (STDs) is the lack of survey data that are generalizable to broader populations, providing both meaningful clinical and behavioral data. Despite recommendations for surveys like this from the National Academy of Sciences and a National Institute of Allergy and Infectious Diseases study group, there has been little progress.[1,2] Most research in this area has come from either (1) medical-epidemiologic studies, which include clinical STD testing but are not representative of broader populations and often have little demographic or behavioral data, or (2) demographic or behavioral surveys that were drawn to be statistically representative of a population but lack meaningful clinical disease measures.

The purposes of this article are to (1) review the scientific literature in this area and compare the two approaches and (2) briefly present findings from a recent feasibility study that linked representative sample surveys with STD testing, using ligase chain reaction (LCR) and polymerase chain reaction (PCR) tests. Finally, the study concludes with a discussion of the implications of representative sample surveys that include both clinical and behavioral data for improving our understanding of STDs.

## Literature Review

### *Sexually Transmitted Disease Prevalence Surveys*

From a public health perspective, it is disappointing that the United States lacks statistically representative data on the prevalence of certain STDs, including *Chlamydia trachomatis, Neisseria gonorrhoeae*, or human immunodeficiency virus (HIV). These gaps make it difficult to identify the extent of infections and progress in prevention and treatment over time. Instead, there are a cluster of alternative data sources, including the communicable disease reporting system, routine screening of special populations, and special research studies of clinic patients or other limited populations, such as college stu-

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dents, prisoners, or detainees, and so on. Although each of these data sources is valuable, they still are not generalizable to broader populations because of inherent limits of how samples were constructed.

The most commonly cited statistics about STD prevalence or incidence come from the joint federal–state communicable disease reporting system that is a fundamental component of the public health system for tracking infectious diseases. However, since reports of infection are primarily based on patient-initiated visits to medical providers, they underreport asymptomatic STDs and may also underrepresent persons who have limited access to medical care. A common metaphor is that reported cases may represent the tip of the iceberg. In addition, comparisons across areas or over time may be biased, owing to variations in the public health systems or reporting requirements.[3] For example, a state with an extensive network of public STD clinics might appear to have a higher level of STDs than a state dependent on reporting from private physicians, but these might be artifacts of the reporting systems. From a research perspective, a limitation of the communicable disease reporting system is that it lacks detailed information about the persons infected: only minimal demographic traits are available, with no behavioral data at all.

Routine STD screening of certain groups (e.g., Job Corps recruits[4] or family planning clinic patients[5]) can provide stronger prevalence data because they do not rely on self-initiated referral for medical care; thus, asymptomatic cases are included and there is less bias, owing to differential access to medical care. Screening data still have limited generalizability: Job Corps recruits or family planning patients are not random members of the broader population. Like communicable disease reports, screening data often have limited research use because there are few behavioral or demographic data about those tested.

Richer data come from medical studies that explicitly seek to collect both clinical measures and behavioral data from convenience samples, such as persons attending certain clinics[6,7] and youth in juvenile detention centers.[8] Although these studies may use sampling methods to select respondents from the defined population (e.g., select a random sample of patients attending the clinic during the 2- month data collection period), these findings customarily cannot be generalized beyond that particular setting. In some cases, convenience samples are the only feasible method to study certain population groups. Some high-risk subpopulations, such as homosexual men, runaways, prostitutes, or drug addicts, are essentially impossible to identify in sufficiently large numbers through representative sampling methods, and convenience samples become more important.

Nationally representative surveys of the prevalence of STD infection have been rare because of the expense and logistical complexities. Historically, clinical testing required medical staff and a medical setting for specimen collection and initial storage or processing. The only nationally representative estimates of STD prevalence have been based on the National Health and Nutrition Examination Survey series (NHANES), which is a very complex and relatively costly survey effort. Table 1 summarizes three of the reports available from the 1976 to 1980 and 1988 to 1994 surveys.[9–11] In addition, the 1960 to 1962 National Health Examination Survey (NHES) included syphilis serology.[12] The 1988 to 1994 NHANES includes serologic tests for HIV and herpes simplex viruses 1 and 2 (HSV-1 and HSV-2); preliminary results from the HIV tests have been published, but the HSV data have not been published yet.

National Health and Nutrition Examination Survey series is a large, multiyear population survey that collects a broad battery of medical data, including information on cardiovascular and pulmonary function and nutritional status.[13] To collect these data, NHANES used mobile examination centers that were driven around the country, typically staffed by 16 medical professionals, plus additional interviewers and administrative staff. Because the survey was designed to draw blood, the additional cost of collecting sera for STD or HIV testing and testing the specimens was modest. On the other hand, the comprehensive nature of the data collection meant that it took years to complete the survey, process the specimens, and release the findings. Given the broad topics covered, relatively scant relevant behavioral or demographic data are collected. The 1976 to 1980 survey did not include questions about sexual behavior. The 1988 to 1994 interview contained a very limited number of questions about sexual experience and asked whether a doctor had ever diagnosed herpes but did not ask about condom use or STD symptoms. To fully ensure that the HIV data were confidential, these samples were collected anonymously and were not linked with the behavioral or other laboratory data.

National Health and Nutrition Examination Survey series data collection requires an unusually high level of respondent cooperation. Respondents, recruited and initially interviewed at home, must then come to the mobile examination site and participate in 3½ hours of physical examination, including drawing blood. Nonetheless, the researchers have attained admirable response rates. In the 1988 to 1991 component of NHANES, 83% of those selected to participate responded to the interview (weighted) and 74% had at least some form of the medical examination. There was a small, additional drop-off for blood donation, which had a weighted response rate of 67% for those older than 1 year of age.[14]

TABLE 1. Prior Nationally Representative Prevalence Surveys of STDs

| Data Source and Citation | Key Prevalence Estimates | Comments |
|---|---|---|
| 1976–1980 NHANES<br>Johnson et al[10] | 16.4 % of adults ages 15–74 tested positive to herpes simplex virus-2 antibodies. Prevalence was higher among women, blacks, southerners, city dwellers, lower-income groups and divorced or widowed persons.<br>Positive test results indicate infection, although the infection may not be clinically symptomatic. Asymptomatic shedding of the virus occurs in a small proportion of people. | Serology was tested for a subsample of the total NHANES population. Serum samples were available only for 51% of adults selected, and only 34% of the serum samples were tested (N = 3,416). |
| 1976–80 NHANES<br>Hahn et al[9] | 0.8% of persons, 12 years of age or older tested positive to syphilis antibodies. Prevalence was higher among blacks, older persons, lower-income groups, city dwellers, and divorced or widowed persons.<br>Positive test results indicate either current or past (treated) infection. | Serology was tested for a subsample of those selected for the general interview (N = 12,989). |
| 1988–94 NHANES<br>McQuillan et al[11] | 0.39% of persons 18 to 59 years of age tested from 1988 to 1991 were HIV positive. Prevalence was higher among men and blacks.<br>Positive test results indicate that the virus is present. | To ensure confidentiality, specimens for HIV testing were blinded for all data, except age group, race/ethnicity, and county of residence. Of 5,430 unweighted people tested, 29 were HIV positive. A more sophisticated statistical analysis is in preparation. |

HSV-2 = herpes simplex virus type 2; HIV = human immunodeficiency virus; NHANES = National Health and Nutrition Examination Survey.

Sample size was sometimes further reduced because there was not enough sera for some laboratory analyses.

The data from the 1976 to 1980 NHANES are the key source for the often-cited statistic that one sixth (16.4%) of adults are infected with HSV-2.[9] The survey also found that syphilis was much rarer (0.8% prevalence in those 12 years of age or older), although it was much more common among some subpopulations.[8] Partial data from the early (1988–1991) portion of the 1988 to 1994 survey indicate that 0.39% of the adult population is infected with HIV, a level substantially lower than estimates provided by earlier, indirect calculations.[10] However, the authors note that the data do not include certain high-risk groups, such as the homeless or those in institutions such as prisons or hospitals.

### *National Behavioral and Demographic Surveys Related to Sexually Transmitted Diseases*

In the past decade, there has been an increase in the number of nationally representative surveys of adults and youth, focusing on acquired immune deficiency syndrome (AIDS) and STD-related behaviors, especially sexual activity and condom use. The interviews typically focus on sexual and condom use behaviors, related attitudes, and other key demographic variables. These are important because sexual activity and condom nonuse are the proximate causes of STDs, whereas social, psychological, and demographic traits are risk factors for sexual and condom use behaviors. There are also many behavioral and demographic studies of convenience samples (e.g., college students, patients at family planning clinics) that are not discussed in this article. A pitfall of these surveys is that they do not include data about actual STD status (although some ask about self-reported history of diagnosed STDs). Thus, they do not have clinically meaningful outcome measures of disease status. A further problem is that the self-reported data about sensitive sexual behaviors are sometimes viewed as untrustworthy because of intentional or unintentional misreporting of behaviors.

*Survey Methods.* In Table 2, the target populations, survey modes, and response rates for six of the recent nationally representative surveys of sexual behavior in the United States are described, including the National Health and Social Life Survey (NHSLS),[15,16] National AIDS Behavioral Surveys (NABS),[17,18] National Survey of Men (NSM),[19–22] National Surveys of Family Growth (NSFG),[23–27] Youth Risk Behavior Surveys (YRBS),[28–30] and National Surveys of Adolescent Males (NSAM).[31–34] Some of these surveys have multiple components or waves so that there are more than six actual data collection efforts represented. All the surveys are nationally representative in scope, although only two (NHSLS and

TABLE 2. Target Populations and Methods Used in Nationally Representative Demographic and Behavioral Surveys

| Data Source and Citations | Target Populations and Sample Size | Survey Mode and Response Rate |
|---|---|---|
| 1992 National Health and Social Life Survey (NHSLS)<br>Laumann et al.[15]<br>Michael et al[16] | Adults 18–59 years of age.<br>N = 3,432.<br>Analyses that do not include race or ethnicity were based on core sample of 3,159 adults. Oversampled blacks and Hispanics. | Face-to-face interviewing at household level.<br>Four short self-administered questionnaires for sensitive subjects.<br>Response rate = 79%. |
| 1990–1991 National AIDS Behavioral Surveys (NABS)<br>Catania et al[17]<br>Dolcini et al[18]<br>(Conducted again in 1995.) | Adults 18–75 years of age.<br>Nationally representative sample, N = 2,673.<br>Sample in 8 high-risk cities, N = 8,263.<br>High-risk cities selected on basis of high AIDS prevalence or high minority population. | RDD telephone surveys.<br>National sample response rate = 70%.<br>High-risk city response rate = 65% |
| 1991 National Survey of Men (NSM)<br>Billy et al[20]<br>Tanfer et al.[21]<br>Tanfer[22] | Males 20–39 years of age.<br>N = 3,321.<br>Oversampled black population. | Face-to-face interviews at household level for sexual behavior questions.<br>Response rate = 70%. |
| 1988 National Survey of Family Growth (NSFG)<br>Mosher[23]<br>Mosher et al[24]<br>Aral et al[25]<br>Seidman et al[26]<br>Kost and Forrest[27] | Women 15–44 years of age.<br>N = 8,450.<br>(Also conducted in 1982 and 1995. Follow-up to 1988 survey conducted in 1991. Version before 1982 were restricted to married women.) | Face-to-face interviews for sexual behavior questions. Paper and pencil self-administered questionnaire for other data elements.<br>Response rate = 82.5%. |
| 1991 and 1992 Youth Risk Behavior Surveys (YRBS)<br>Kolbe, Kann, and Collins[28]<br>CDC[29]<br>Adams et al[30] | National school-based sample: students in 9th, 12th grades. 1991 survey, N = 12,272 School-based survey conducted periodically since 1989.<br>1992 supplement to National Health Interview Survey (NHIS): subjects 12–21 years of age, N = 10,645. | School sample: brief paper and pencil self-administered questionnaire.<br>NHIS supplement: household survey. Questions heard through headphones from a portable cassette recorder; answers written on answer sheet. Response rate = 74%. |
| 1988 National Survey of Adolescent Males (NSAM)<br>Sonenstein, Pleck, and Ku[31]<br>Ku, Sonenstein, and Pleck,[32,33]<br>Pleck, Sonenstein, and Ku | Never-married men 15–19 years of age in 1988.<br>N = 1,880 in 1988. Follow-up in 1990–1991 when they were 17–22 years of age N = 1,676. Oversampled minorities.<br>Follow-up of old cohort and start of new cohort in 1995. | Face-to-face interviews at household level.<br>Sensitive questions asked in paper and pencil self-administered questionnaire.<br>Response rate = 74% in 1988.<br>Follow-up rate = 89% in 1990–1991. |

AIDS = acquired immunodeficiency syndrome; RDD = random digit dial.

NABS) encompass adults of both genders. The others have more specialized target populations: adult women (NSFG), adult men (NSM), adolescents (YRBS), and young men (NSAM). Some of the surveys oversampled certain groups, such as minorities or persons living in areas with high AIDS prevalence. Oversampling was performed to ensure adequate sample sizes for subpopulations of interest; sample weights compensate for this in analysis. It is worth noting that only two of the surveys (NSFG and YRBS) were directly administered by the federal government. The rest were all investigator-initiated survey projects, although the federal government was the primary grant-funding source for all except one of the surveys (NHSLS).

The most common survey approach has been face-to-face household interviews with randomly selected respondents conducted on a household basis, with the most confidential topics covered in brief self-administered questionnaires. The response rates (percent of eligible respondents who are interviewed) ranged from 70% to 83%. Computer-assisted telephone interviewing was used in NABS, and the school-based component of YRBS uses self-administered questionnaires completed by students at school. Although they are much less expensive, telephone surveys typically must be shorter (and thus cover fewer topics), usually have lower response rates than household surveys, and exclude some groups (those without phones). It is not possible to add a urine collection component to a phone survey, and it would be very difficult to add such a component to a school-based survey.

*Survey Results.* Key findings regarding heterosexual behaviors and condom use are provided in Table 3. The

TABLE 3. Summary of Results About Heterosexual Behaviors in Demographic and Behavioral Surveys

| Survey and Target Population | % Ever Had Heterosexual Intercourse | No. of Heterosexual Partners | Condom Use |
|---|---|---|---|
| 1992 National Health and Social Life Survey (NHSLS)<br>Adults 18–59 years of age | 95% of men and 97% of women had sexual intercourse.<br>88% of men 18–24 years of age were sexually experienced. | Median number of heterosexual and homosexual partners since 18 years of age = 3.<br>Median number of heterosexual and homosexual partners for respondents 18–24 years of age = 2. | 16.3% used a condom at last vaginal sexual intercourse.<br>N = 2,313 (includes men and women). |
| 1990–1991 National AIDS Behavioral Surveys (NABS)<br>Adults 18–75 years of age | Asked, but data not reported. | % with 2 or more partners in last 12 months = 9% in national sample, 12% in high-risk cities.[4] | Among heterosexuals with 2 or more partners in last 12 months:<br>% using condoms all the time during vaginal intercourse = 11% in national sample, 17% in high-risk cities.<br>% never using condoms = 38% in high-risk cities.[4] |
| 1991 National Survey of Men (NSM)<br>Men 20–29 years of age | 95% of men were sexually experienced. | Since January 1990 (about 18 months), the mean no. of vaginal partners = 1.8. (N = 2,815) and median = 1.1 partners (N = 3,169). | In last 4 weeks, 26.5% of sexually active men report using a condom at least once. |
| 1988 National Survey of Family Growth (NSFG)<br>Women 15–44 years of age | 89% of women had sexual intercourse in last 3 months. | 1988: In last 3 months, 11% of women had no intercourse, 85% had sex with 1 partner, 4% with 2 men, 1% with 3 or more men. | 1988: 10% of sexually experienced women were using condoms as primary method of contraception. 19.7% use condoms, including other reasons. |
| 1991 and 1992 Youth Risk Behavior Surveys (YRBS)<br>High school students in school-based survey<br>In National Health Interview Survey (NHIS), youth 12–21 years of age | 1991 school-based survey: 57% of men ever had sex, 51% of women.<br>1992 NHIS supplement for never-married youth 14–21 years of age: 62.7% of men ever had sex, 58.7% of women. | 1991 school-based survey: % with 4 or more partners in lifetime: men, 14%; women 23%.<br>(YRBS does not ask about gender of partners, but most are heterosexual.) | 1991 school-based survey: % using condom at last intercourse: men, 54%; women, 38%. |
| 1988 and 1991 National Survey of Adolescent Men<br>Men 15–19 years in 1988, 17–22 years in 1991 | 1988, men 15–19 years of age ever had sex = 60%.<br>1991, men 17–22 years of age ever had sex = 83.6%. | 1988: mean number of female partners in last 12 months = 2.1 (among men who report had sex in last 12 months).<br>1991: mean number of female partners in last 12 months = 2.5 | 1988: % using condom at last intercourse with women = 57%. Average % condom use in last 12 months = 55.6%<br>1991: % using condom at last intercourse with women = 44.2%<br>Average % common use in last 12 months = 45.6%. |

four surveys that concentrate on adults (NHSLS, NABS, NSM, and NSFG) typically show that the great majority of adults are sexually experienced but that the number of sexual partners is fairly conservative (e.g., NHSLS reports for adults a median of 3 partners since 18 years of age, and NABS reports that 9% had more than 1 partner in the last 12 months). A small, but nontrivial proportion of adults used condoms (e.g., in NHSLS, 16% used a condom during last intercourse; in NSFG, 20% of women reported using condoms). The NSFG is the only survey that can be used to examine changes in adults' condom use since the early 1980s and indicates that there have been substantial increases in condom use since 1982. Because the great majority of sexual experience was with steady partners (e.g., spouses), the low proportion of condom use was not surprising. However, NABS specifically examined condom use among those with more than one partner in the last 12 months and reported that only 11% of the national sample used condoms all the time and 38% never used them.

The behavior of adolescents and young men is different. A slight majority of 15- to 19-year-old American adolescents are sexually active. The NSAM reports that an average sexually active male teenager had two female partners in the last year, reflecting the lower stability of relationships among the young. However, young people tend to have relatively higher levels of condom use. In both

the 1991 YRBS and 1988 NSAM, more than 50% of youth reported they used a condom the last time they had sex.

Each of the six surveys has a number of questions about heterosexual behavior and condom use, but they vary greatly in the level of data about other factors relevant to STDs. In Table 4, an assessment of the relative depth of data about sexual and prophylactic behaviors in each survey is provided, and those behaviors with specific data about same-gender sex and self-reported STD status are illustrated. The NSFG and YRBS have other areas of interest–women's general fertility experience and the gamut of youth risk behaviors–and have relatively less information about sexual behavior. The other four surveys, which were researcher-initiated surveys, have been more focused on sexual and related risk behaviors relevant to STD or HIV risk.

Neither NSFG or YRBS include questions about homosexual intercourse. The other surveys have asked about same-gender sex, although the findings have been somewhat discrepant. The NHSLS appears to be the best source of data about same-gender sex and reports that 4.9% of men and 4.1% of women have had same-gender sex at least once while they were adults. The NSM reported much lower percentages of homosexual behavior, but this is probably an underestimate because questions about homosexual behavior were asked in a face-to-face interview and not in a self-administered questionnaire.

In several of the surveys, the respondents also were asked whether they had ever had or had ever been told that they had an STD. The level of self-reported STDs will underestimate disease prevalence because of undiagnosed infection, poor respondent recall (e.g., inability to remember disease names), and hesitancy to report having a stigmatized disease. The results are divergent: for example, the NSFG estimated that 26% of women ever had gonorrhea, chlamydia, or herpes, whereas 10% of men in NSM reported ever having an STD. It is plausible that much of the male–female difference is because of the fact that women have periodic reproductive health examinations, whereas men do not. Women might also have better recall of their medical histories or be more willing to report STDs than men. The very low prevalence of self-reported STDs in male adolescents in the 1988 NSAM (1.9%) is well below estimated prevalence levels in adolescents and is probably largely because of undiagnosed STDs.

*Criticisms of the Survey Data.* The most important methodological criticisms of the demographic and behavioral surveys concern the validity and reliability of self-reported sexual, contraceptive, or other risk behaviors (e.g., intravenous drug use).[3,35,36] Many are skeptical about the honesty or accuracy of self-reports about these sensitive and personal behaviors. Respondents may have "social desirability bias"; that is, they may be inclined to provide answers that they believe are more socially acceptable to the interviewer. Thus, respondents may

TABLE 4. Data About Riskier Behaviors and Self-Reported STDs in Demographic and Behavioral Surveys

| Survey and Target Population | Amount of Data about Sexual Behavior | Same Gender Sex | Self-Reported STDs |
|---|---|---|---|
| 1992 National Health and Social Life Survey (NHSLS)<br>Adults 18–59 years of age | High content. | 4.9% of men had same gender sex since age 18.<br>4.1% of women reported female partners since age 18. | Diagnosed with an STD in past 12 months is 1.6% |
| 1990–1991 National AIDS Behavioral Survey (NABS)<br>Adults 18–75 years of age | High content. | Ask about sex with person of same gender. Data not reported. | Ask about HIV test results. Data not reported. |
| 1988 National Survey of Family Growth (NSFG)<br>Women 15–44 years of age | Moderate content. | Not asked. | 1988: 25.7% of women reported they ever had gonorrhea, chlamydia, or herpes.<br>10.8% of women ever had PID. |
| 1991 National Survey of Men (NSM)<br>Men 20–39 years of age | High content. | 2.3% of men had same gender sex in 10 years preceding survey. | 9.7% of men reported ever having an STD.<br>Since January 1990 (about 18 months) 0.9% of men reported having an STD. |
| 1991 and 1992 Youth Risk Behavior Surveys (YRBS)<br>High school students in school-based survey | Moderate content. | Not asked. | Not asked. |
| 1988 and 1991 National Survey of Adolescent Males (NSAM)<br>Men 15–19 years of age in 1988, 17–22 years of age in 1991 | High content. | 1988: 1.4% of men had homosexual intercourse.<br>1991: 1.0 of men ever had oral or anal intercourse with another man. | 1988: 1.9% said they ever had gonorrhea, syphilis, herpes, or venereal warts.<br>1991: STD status asked but not reported. |

STD = sexually transmitted diseases; HIV, human immunodeficiency virus; PID, pelvic inflammatory disease.

underreport stigmatized behaviors, such as homosexual activity or drug injection, or overreport socially favored behaviors, such as condom use.

Methodological studies of self-reported sexual behaviors have yielded mixed results. For example, Upchurch et al[37] found that there was a high degree of concordance in reports of sexual behaviors by both members of a couple. On the other hand, Zenilman et al[38] found that self-reports on condom use were essentially uncorrelated with measured STD incidence, and many people who reported using condoms all the time still acquired an STD. It is likely that the validity of self-reported sexual or other risk behaviors is heterogeneous: most people are relatively honest and answer to the best of their ability, but a significant minority intentionally or unintentionally misreport their behaviors.

Although it may be difficult to validate individuals' responses, external data help verify broad trends. For example, increases in self-reported condom use among young men from 1979 and 1988 appeared consistent with reports of increasing condom sales in the late 1980s,[30] and the lack of growth in condom use from 1988 to 1991 also corresponded with sales data.[32]

Although there is no clear consensus on the extent of error in self-reports of sexual behavior, it is reasonable to conclude that (1) more sensitive topics are more prone to misreporting than less-sensitive topics, and (2) the most sensitive topics, such as same-gender sex or illegal drug use, should be asked confidentially by self-administered questionnaires that the interviewer is not permitted to view.[39] A new method of data collection, the Audio Computer-Assisted Self-Interview (ACASI), which permits respondents to either hear questions read to them through headphones or read them on a laptop computer screen and select responses on the computer in a private fashion, has shown promising results as a method of asking about sensitive behaviors.[40]

Representative surveys may also underrepresent or exclude certain high-risk groups. Some socially marginalized populations, such as the homeless, prostitutes, intravenous drug users, and undocumented aliens, are probably undercounted in most surveys. These marginalized groups may also be more prone to social desirability bias and want to report safer behaviors to appear more "normal." Because most household surveys exclude people in institutions, they may miss prisoners, people in residential treatment programs, or hospitalized patients. These high-risk groups may represent a significant share of infected persons, particularly those seen in public clinics.

## The Feasibility of Sexually Transmitted Disease Testing in a Representative Household Survey

The primary logistical barrier, until recently, in adding STD testing to nationally representative household surveys has been that the specimens required for clinical tests generally required blood or urethral swabs. This meant that a data collector had to be a medical professional, such as a nurse or phlebotomist. Although NHANES included a number of medical staff, this is not the norm for most household surveys. In addition, many respondents are hesitant to provide blood or a urethral swab; therefore, participation rates might be low anyway, jeopardizing the validity of the data. The recent advent of PCR and LCR tests for *C. trachomatis* and *N. gonorrhoeae* have made it feasible to conduct STD tests that have high sensitivity and specificity using first-catch urine specimens.[41,42] The simplicity of the new specimen collection means that (1) regular survey interviewers (who are not medically trained) can administer the specimen collection in the field and (2) most respondents should be willing to donate specimens. The new tests have much better performance (i.e., better sensitivity) than prior nonculture tests, such as enzyme immunoassay or leukocyte esterase tests, greatly reducing the risks of misclassification of infected and uninfected persons. That is, the new tests are not only easier to administer, they also yield more valid results.

Aware of the new diagnostic tests, in 1994 researchers from the Urban Institute, Research Triangle Institute, and the Centers for Disease Control and Prevention (CDC) decided to test the feasibility of adding an STD testing component to the 1995 NSAM, which was planned as a behavioral and demographic household interview survey.[43] Interviewers would collect the urine samples from the interview respondents and ship them to the CDC for laboratory analyses of *C. trachomatis* (with eventual plans for testing *N. gonorrhoeae*). If the pretest proved successful (as it did), we would add this component to our full-scale national survey.

The purposes of the pretest were to determine whether collection of urine specimens was feasible in household surveys and to assess alternative strategies for data collection protocols. Because this was a pretest, with limited resources and time, the sample size was relatively small, and we knew that comparisons of alternative data collection protocols would not be statistically significant at a 95% confidence level. As such, most of the findings reported here should be viewed as tentative.

### *Methodology*

*Sampling and Participant Selection.* The NSAM pretest was focused in three counties in Maryland in the late summer of 1994. Emulating procedures from a full-scale survey, sampled addresses were statistically generated from Census data, and trained interviewers screened households to identify eligible male participants 15 to 25 years of age. Although the original goal was to get 200 respondents, higher-than-expected field costs meant that we could interview only 124 persons, of whom 82 were

eligible to be asked for urine specimens. (The remainder were not asked because they were too young [younger than 18 years of age] or in an experimental group not asked to provide urine at all.)

Urine collection was limited to those 18 years of age or older. As a matter of policy, NSAM has always required written parental consent for interviews of minors (those younger than 18 years of age). If we added STD testing for minors, we expected that written parental consent would be needed for the STD tests, and test results possibly would have to be given to parents, which could potentially reduce participation rates and embarrass or harm some minors; therefore, we chose to not ask for urine specimens from the minors. In addition, we advised those providing urine specimens that they would be used only for STD tests and would not be used for drug testing. Respondents were offered $10.00 to $20.00 to complete the interview and an additional $10.00 to $20.00 to provide a urine specimen. To examine alternative approaches for obtaining consent, we randomly allocated eligibles into experimental treatments (described in the Results section below).

An additional informed consent issue concerned reporting the names of infected persons to state or local health departments. It was plausible that this might reduce willingness to participate, particularly among high-risk persons. One of our experimental variations compared persons who were told that persons infected would be reported, and another group promised complete confidentiality. This was possible because the pretest site did not mandate *C. trachomatis* reporting at that time, although most states require it. (Interested readers may contact the senior author or their state health departments for more discussion of STD reporting requirements in research studies.)

All of those tested could call a toll-free telephone number and, after providing identification, learn the status of his or her STD test results. In addition, we called anyone who had a positive test result, discussed the implications of chlamydial infection, and urged them to see a physician for further testing and treatment. Where appropriate, we provided referrals to local clinics that offered free or discount STD treatment services.

*Laboratory Methods.* After collection, data collectors labeled the urine specimens with a respondent identification code, the date of collection, and the time between specimen donation and last urination. Specimens were then packed in ice chests, frozen in home freezers, packed on wet ice, and mailed with overnight delivery to the CDC in Atlanta for laboratory analyses.

Urine specimens were tested for the presence of *C. trachomatis* using commercial PCR assays (Amplicor, Roche Diagnostic Systems, Branchburg, NJ) and LCR assays (Abbott Laboratories, Abbott Park, IL). Specimens were processed and tested according to the manufacturer's instructions as described previously,[44,45] except for the modification of freezing specimens before testing by PCR. After arrival in the laboratory, specimens were kept at 4°C for no more than 48 hours before processing by sedimentation and replacement of supernatant with the appropriate urine resuspension buffer provided in the PCR and LCR kits. Processed specimens were tested by PCR and LCR immediately or frozen at -70°C until tested, up to 10 days later. For the purposes of the pretest study, subjects from whom a specimen tested positive by either PCR or LCR were considered to be infected.

## Results

Of the 82 persons who consented to be interviewed, 85% provided a urine specimen (95% confidence interval, 77% to 93%). The majority of those who were willing to be interviewed would donate a urine specimen. The relatively low nondonation rate reduces the risk of serious nonresponse bias.

We included small, randomized, experimental variations in the informed consent procedures that examined the impact of (1) a one- versus two-stage consent (asking for the interview and urine specimen all at the same time versus asking for the interview, and only requesting the urine specimen after the interview is completed) and (2) reporting STD versus not reporting STD to state or local health departments. Because of the small sample size, it was not possible to detect significant differences in the groups, but data suggested that a two-stage consent without reporting STD yielded the best combination of interview response rates and urine specimen donation rates.

To assess nonresponse bias, we examined interview responses of those who provided urine specimen and those who did not. Again, small samples precluded statistically significant findings, but data suggested that those who provided urine specimens were not substantially different from those who did not. If anything, those who did not provide urine specimens were at lower risk. For example, those who donated urine specimens appeared more likely to be sexually experienced. This is consistent with prior research that indicated that survey nonrespondents sometimes have less sexual experience than respondents.[46]

Of those tested, 6% were positive for *C. trachomatis*. Because of the small and localized sample, this should not be extrapolated to a national level. However, this rate is consistent with other recent surveys.

## Conclusions

The primary source of national estimates of STD infection has been the communicable disease-reporting

system, which can lead to biased estimates because of the lack of scientific sampling. Although it has been technically possible to collect nationally representative serological data for syphilis since the 1960s, logistical problems and expense rendered this infeasible unless the data collection was just one part of a large battery of medical data collection, as in the NHANES surveys. The new DNA-based PCR and LCR tests of urine specimens help open a new door for scientific research regarding STDs. In addition to the PCR and LCR tests for *C. trachomatis* and *N. gonorrhoeae,* similar DNA amplification tests exist (for research use) for HIV and other STDs.

The convenience of data collection, stability of specimens, and high sensitivity and specificity make it is possible for nonmedical data collectors to obtain urine specimens in the field without great difficulty. In our pretest, 85% of the young men who were willing to answer an interview were also willing to provide a urine specimen for STD testing. Based on this pretest, we added an STD testing component to the 1995 National Survey of Adolescent Males, and results should be forthcoming within the next year or so. Although pretest results suggested that there was relatively low nondonation of urine specimens, it will be important to more rigorously examine whether those who do not provide specimens differ from those who do.

Adding urine specimen collection and PCR/LCR testing to a survey is not free. The actual costs would vary, depending on the precise tests used and costs of the laboratory facilities. But the costs for specimen collection and laboratory analyses are small and incremental compared with the basic costs of a nationally representative in-person survey. The vast majority of costs are associated with setting up the core interviews, including costs for sampling, for training, and transporting interviewers, screening and contacting respondents, and interviewing them. Again, the specific cost would vary, depending on a number of factors, including the nature of the population being sampled. Costs and effort are greatly reduced compared with studies such as NHANES.

How could integrated behavioral and clinical data be used? One key use would be to provide statistically based national estimates of the prevalence of *C. trachomatis* and *N. gonorrhoeae.* But, depending on the content of the interview components of the surveys, many other analyses are possible. First, it will be more feasible to examine the behavioral, demographic, and health factors correlated with STD infection, including factors such as number of partners, use of condoms, substance use, history of STD, geographic location, age, race, and educational level. Infection status can also serve as a validity check for self-reported data. If a person reports no sexual activity or 100% condom use but is infected, then the report appears questionable. (It is also possible that people may use condoms 100% of the time but become infected because of improper use or breakage.)

An important factor that cannot be readily determined through survey research is the infection status and infectivity of prior sexual partners. But it may be possible to obtain data about partners that might serve as risk factors (e.g., partner gender, age, race, where and how this partner was met, whether the partner was a prostitute or drug user, perception of partner's promiscuity). These could help us understand more about the sexual networks that promote transmission of STDs.

Behavioral data, such as attitudes toward sex and condom use, self-efficacy, and degree of worry about STD and AIDS, can be used to identify the attitudinal correlates of risky sexual practices and STD infection. Data about prior sex, AIDS, or STD education received by respondents can help us understand the effects of educational prevention efforts not only on risk behaviors but on actual STD infections, although they should not be viewed as replacements for more rigorous experiments or field trials of intervention programs.

Another potential use of integrated survey efforts might be to understand the relation between infection and seeking medical testing or care for STDs. What proportion of those who are infected have symptoms? Those with symptoms are most likely to seek care. What proportion of those with symptoms seek medical care? What is the influence of factors such as type of insurance, frequency of contact with the medical system, and education? What proportion of those who are infected have received recent medical care but still do not know that they are infected? For bacterial STDs, such as *C. trachomatis* and *N. gonorrhoeae,* medical treatment with antibiotics is an integral step not only to cure the infected person but to prevent transmission to future partners.

The ability to integrate behavioral and clinical data also brings new challenges to research. An important one is the need for collaboration across disciplines, including both medical and social science researchers. Clinical researchers would need to understand the special challenges of large-scale survey research, and survey researchers would need to adapt procedures to collect specimens. Together, the researchers will need to learn how to modify survey methods to optimize rates of participation for both interviews and specimens and how to address ethical issues to safeguard respondents' health and confidentiality. The fact that infection for some STDs is uncommon also means that sample sizes will need to be considered carefully. For example, in the 1988 to 1991 NHANES HIV tests, only 29 positive cases were found among 5,430 per-

sons tested, making subgroup analysis problematic. Although the new DNA amplification tests perform much better than prior nonculture tests, they do not have 100% sensitivity and specificity. Because representative surveys would have low prevalence rates, the potential of misclassification owing to false-positive results grows more serious and further increases the need for adequate sample sizes.[47]

The new technologies and recent interest in large-scale nationally representative surveys of sexual behavior offer new possibilities to integrate clinical and behavioral survey research about STD and to use probability-based representative samples. We believe that our pretest and subsequent use of urine-based STD testing in the full national survey demonstrate that these efforts are feasible and can become more widely adopted.

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