

# DESPERATELY SEEKING SEXUAL STATISTICS

By RICK WEISS

Having made remarkable progress toward understanding the biology of the sexually transmitted AIDS virus, scientists who would control the disease's spread have struck an unexpected roadblock. Somewhat to their chagrin, they find they know more about the reproductive habits of the virus than they do about those of their own species.

The few large-scale surveys to lift the veil of secrecy shrouding U.S. sexual propensities are long outdated, experts say. And with the increasing spread of the virus in the population, that lack of information hinders health officials trying to map education and prevention strategies and predict the epidemic's costs.

"There's an extraordinary lack of information on human sexuality, especially in the United States," says June M. Reinisch, director of the Bloomington, Ind.-based Kinsey Institute for Research in Sex, Gender, and Reproduction. "What little data we have are only on white middle-class people; we have even less information on the many subcultures that make up very important parts of U.S. society," including those most at risk of AIDS.

In an effort to fill this epidemiologic black hole, the National Institute of Child Health and Human Development (NICHD) in Bethesda, Md., has allocated funds for a new survey to reveal in unprecedented detail what Americans do behind closed doors. Implementation of the survey has been temporarily stalled by Health and Human Services Secretary Louis W. Sullivan's insistence that the proposed questionnaire narrow its focus to points directly relevant to the spread of AIDS. Some members of Congress have protested that the survey's original design went beyond the realm of reasonable public health inquiry, representing a government intrusion into people's private lives.

While the questionnaire's final contents remain unsettled, the survey already has researchers asking difficult questions among themselves. How does one design such a sensitive inquiry? Are there ways to ensure the answers are honest and complete?

Phase one of the project, already underway, seeks to discover the ideal means of collecting such delicate data before implementing the full-scale survey itself. For example, says Reinisch, "if the research is not done in the vernacular—in the words of the group—then it doesn't do any good. You can ask some women who

are five or six months pregnant whether they've ever had sexual intercourse and they will answer 'no.' That's because 'sexual intercourse' are not the words they use to describe the behavior that helped them to get pregnant."

Beyond phraseology, researchers wonder who should do the interviews, where they should be held and how to structure the interview process. On the basis of research already completed, the NICHD has decided that live interviews lasting about one hour, rather than self-administered questionnaires, will best elicit the complex answers it needs and expects. For comparison, interviewers will also administer a shortened version of the questionnaire by telephone to a small study population.

Debate continues about who should do the interviews, says Marcie L. Cynamon of the National Center for Health Statistics in Hyattsville, Md. Sociologists remain divided on the value of matching the race, sex and age of interviewers and interviewees. So far, Cynamon says, "focus groups conducted for this survey repeatedly selected white, middle-aged female interviewers as the type of person with whom they would feel most comfortable" discussing such issues.

The NICHD plans to interview 2,300 adults aged 18 through 54. Of these, about 135 will later be "debriefed" in detail to determine their reactions to the interview process and to help researchers verify the validity of the data.

Interviewers will question about half the people in their homes. The rest will be quizzed in such locations as clinics and offices, Cynamon adds, "in order to test whether people will be more comfortable [outside their homes] reporting stigmatized behavior such as adultery, drug use and frequenting prostitutes." Interviewers hope to allay respondents' uneasiness by progressing from general questions to more specific ones. For the most sensitive and specific questions regarding sexual experiences, respondents will use a coded sheet that interviewers cannot interpret.

Interviewers will try to "jog people's memories" by focusing on partnerships rather than specific sexual acts. And they'll concentrate on individuals' most recent sexual encounters, in part to increase accuracy of recall. "For most of

us," Cynamon acknowledges, "there's not much to remember."

Interviewers themselves will receive two weeks of training before hitting the streets. "Our training is designed to teach interviewers how to handle potentially awkward situations," Cynamon says.

It remains unclear when this survey will get started. With the NICHD now revamping the questionnaire, Cynamon hopes for final approval by Sullivan and the White House Office of Management and Budget by the end of the summer. Despite political pressures, she says, "we are determined to keep the important questions in the questionnaire as they relate to AIDS and high-risk behaviors."

Answers to those questions may shock many people, says Reinisch of the Kinsey Institute. For example, she notes, "in a new study that we've done in middle-class college students in the Midwest, at least one out of four have already experienced anal intercourse, even though they became sexually active at the average age of 17 and are now... an average age of 22." Anal intercourse is a major risk factor for acquiring AIDS.

Moreover, she says, probably one in three white middle-class males have had sex with a prostitute; three out of four individuals who label themselves homosexual have had intercourse with partners of the opposite sex; and at least 30 percent of the "general" population of heterosexuals have had at least one sexual experience with a same-sex partner—all of which increase the chances of AIDS transmission from the traditional "high-risk" groups to a much broader population.

Indeed, Reinisch concludes, "the concept of high-risk groups is really not very helpful. It's at-risk *behavior* that's important with regard to the transmission of AIDS." With this in mind, she says surveys such as the NICHD's are extremely important not only in the United States but in other countries too.

Without data on human sexual behavior, warns Reinisch, "we will not be able to predict the spread of this disease epidemiologically, we will not be able to select the correct subjects for vaccine trials and treatment trials, and we will keep making mistakes all along the way in our development of education programs." □