

Ethics, Social Forces, and Politics in AIDS-related Research: Experience in Planning and Implementing a Household HIV Seroprevalence Survey

PETER HURLEY and GLENN PINDER

National Center for Health Statistics

IN SEPTEMBER 1987 THE U.S. CENTERS FOR DISEASE Control (CDC) announced plans to conduct a national survey to determine the extent to which the general population is infected with the human immunodeficiency virus (HIV). The National Center for Health Statistics (NCHS), a unit of CDC, was given the task of implementing the survey. We were part of the planning team for the project, an assignment we greeted with sober, professional enthusiasm but, in retrospect, with little sense of and no preparation for the political maelstrom into which we were descending.

Telling this story requires an explanation of how such a survey was first predicated. The strategy of measuring the prevalence of HIV infection using a national probability sample survey was advanced in a paper circulated during the summer of 1987 (Turner and Fay 1989). The survey would be only one of many methods for obtaining information on the epidemic under consideration by CDC. In fact, many people believed that a voluntary household-based survey would lead to a serious underestimate of HIV infection because (1) high-risk persons would not participate and (2) it would exclude persons not living in households (a population that some thought was more widely affected by the epidemic). At a June 1987 meeting, CDC staff focused on a broad system of surveillance rather than relying on a single method. Options for developing this system included using national surveys conducted by the

NCHS; seroprevalence studies in hospitals and sexually transmitted disease (STD) clinics similar to those that CDC had initiated in cooperation with many states and localities; and a new national survey.

In July 1987, President Reagan called for "a comprehensive program to determine the nationwide incidence of the human immunodeficiency virus and to predict its future occurrence and to initiate epidemiologic studies to determine the extent to which HIV has penetrated the various segments of our society." CDC then convened a meeting of outside public health and survey experts to discuss methods of estimating national prevalence. The debate about the need for such an estimate and the potential problems with its validity continued. Some participants thought that information from surveys taken of military recruits, blood donors, and newborns, and conducted in STD clinics and drug treatment centers in selected cities, along with model-based estimates, would be the best data to track the extent of the epidemic. Others criticized this approach because the surveys focused on special populations and were not probability based; this view was later documented in a report of the National Research Council (Turner, Miller, and Moses 1989). Participants agreed that a voluntary, household-based survey would be an operational challenge and that its estimate of HIV infection was probably subject to serious nonresponse bias. Still, the consensus was that the strategy had sufficient merit to be tested. CDC's final recommendations to the president and his Domestic Policy Council called for a national HIV surveillance system through a "family of surveys" conducted in a number of special subpopulations and feasibility tests of a national household HIV survey (U.S. Department of Health and Human Services 1987).

The scientific merits of survey estimates were obvious to all of us on the NCHS team, but the practical problems of mounting a successful study were also apparent. The use of a household survey to provide information about a phenomenon of such low frequency posed serious sample design and cost issues. Collecting blood samples and asking about extremely sensitive, sometimes illegal, behaviors were difficult requirements. In a November 1987 telephone conversation with the CDC director, we reiterated our concerns about the difficulty of the task, but we concluded that we should "give it the old college try." Our team's motivation now was to muster the best test we could. One other aspect of the undertaking was only just beginning to penetrate our collective thinking: anything dealing with AIDS and HIV infection was news.

The Best-laid Plans . . .

In a few short weeks at the end of 1987, our work group developed the contract specifications for the project, setting forth all the technical requirements for developing HIV seroprevalence estimates from a household survey. The difficult technical problems led to the design of a two-phase project: a three-site feasibility study, which, if results were acceptable, would be followed by the national survey. Our initial proposal was influenced by a number of practical and ethical considerations (Feinleib 1991). These became apparent as the study was implemented and are briefly described below:

- A test of the willingness of people to participate if they were promised confidentiality. Consultants had recommended an anonymous survey without any personal identifying information. However, NCHS has a long record of obtaining the identity of survey respondents with confidentiality guaranteed by public law (308[d] of the Public Health Service Act [42 U.S.C. 242m]), and personal identifiers would be crucial in measuring nonresponse bias and for other validation studies (U.S. Department of Health and Human Services 1984).
- A provision for survey participants to be able to obtain their blood test results if they wished. Some thought we had an ethical obligation to provide this information if people were being asked to give blood solely for the purpose of HIV testing. Also, there was evidence from the AIDS knowledge and attitudes questions on our National Health Interview Survey that people contacted in such a survey might find receiving their HIV test results an incentive to participate.
- The stipulation that the groups most affected by the AIDS/HIV epidemic be involved in planning and carrying out the survey. NCHS has a long history of fielding national surveys on a variety of health-related topics and using the advice of subject-matter experts. However, our experience with local governments and communities and activist groups was limited.
- A mandate to address the technical problems of nonresponse associated with this study. The success of the survey would depend on a high response rate and on quantifying the characteristics of persons who did not participate.

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- A mandate to address the technical problems of nonresponse associated with this study. The success of the survey would depend on a high response rate and on quantifying the characteristics of persons who did not participate.

- A strategy to assure a sample of HIV-infected persons sufficient to characterize accurately the extent and nature of HIV infection. An efficient sample would employ stratification. The strategy was to stratify the sample according to risk status of the population. Geographic areas would be organized into three categories: areas with a high concentration of gay men, those with a high concentration of intravenous drug users, and all others. The initial plan was to define these areas according to information from knowledgeable people in the community.
- The development of a design that could be implemented nationwide within a relatively short time. The idea of tailoring the survey for a particular locality or creating ways for the community to participate in an active manner was not considered initially.

In addition, our contract specifications included a suggestion to use Washington, D.C., as a model to illustrate the specifics of an approach to the first pilot test. Washington seemed a reasonable site because it was a metropolitan area with a large number of AIDS cases and was close to our offices in Hyattsville, Maryland.

We were aware that this epidemic had developed in a highly charged atmosphere because AIDS had first struck predominantly the male homosexual population and because the main means of transmission were found to be socially stigmatized and illegal behaviors. The disproportionate spread of HIV infection in minority populations, primarily as a result of transmission among injecting drug users and subsequent infection of sexual partners and offspring, has only elevated controversy. Issues of responsibility for care and treatment of infected persons and further discrimination against these "high-risk" groups added to already complex problems.

We were to find that any study focusing on AIDS and HIV infection would have to confront not only the legacy of this epidemic, but also the history of gay and minority groups' negative experience with the health care system. Homosexuality had for generations been classified as a mental disease by the medical establishment, and gays had suffered discrimination in immigration policy that was sanctioned by the Public Health Service (PHS). The black community's mistrust of the public health establishment as a result of the Tuskegee experiment, a PHS study that withheld treatment for 40 years from 400 black men with

syphilis, is documented in a recent article (Thomas and Quinn, 1991). There were also reports from government "sources" and speculation by other health professionals concerned about AIDS surveillance that CDC's decision to conduct this survey was motivated more by White House pressure than by scientific need (Colen 1987). We were to experience how suspicions deriving from many sources affect all our efforts to gain and to disseminate knowledge about the HIV epidemic.

Proposals submitted by potential survey contractors reflected considerable thought about the problems inherent in this undertaking. Foremost was the issue of privacy. Research Triangle Institute (RTI), which was selected for the project in May 1988, insisted that the survey would be possible only by providing anonymity to participants and, to meet our request for a test of confidentiality versus anonymity, proposed a *sham* experiment to test response under the different "conditions." One group of survey respondents would be told that any information they provided was "confidential" and the other that it was "anonymous," when actually the same procedures would be used for everyone; no names would be recorded and all addresses would be destroyed, making it impossible for even project staff to link data to individuals. NCHS staff, realizing that retaining personal identifiers was crucial to validity studies, clung to the possibility of a confidential survey and continued to debate with RTI staff for some time.

While developing their proposal, RTI formed an advisory group on the implications of suggested survey methods and procedures. National and local organizations and institutions involved with HIV/AIDS were represented on this Policy Advisory Panel.¹ The group was convened three times: in June and September 1988 and April 1989. These sessions provided the opportunity to discuss the plans for each survey site as they were developed. Members were kept up to date with written materials, and some became close consultants and advisers to RTI's outreach director, whose job forced him to deal with many of the problems the project faced.

RTI also had two subcontracts for specific services: one with the San Francisco AIDS Foundation to provide an information hotline during survey field work and one with the American Foundation for AIDS Research (AmFAR) to produce a videotape to explain the survey to selected participants and also to advise on outreach. Staff from both of these organizations strongly influenced RTI's proposals for outreach activities.

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Astray in Washington, D.C.

We were under considerable pressure to move ahead quickly with this study. Washington was the unquestioned place to begin because RTI staff had already made a number of local contacts in preparing their contract proposal, and we assumed that the area's proximity to both of our offices would make this first trial more manageable. Because the study was "just a pilot" for a national survey and there was no plan to release data, we did not anticipate any unusual problems. We were soon to learn better.

Our plan for evaluating the response from high-risk people and validating the risk behaviors reported on the questionnaire was to include in the survey an anonymous sample of persons whose risk status was known through sources such as gay organization rosters and STD clinic and drug treatment program records. This method of determining how accurately certain information can be collected in a survey by including known "cases" in the sample has been used in a number of studies; for example, cancer patients from registries have been used to determine how well cancer is reported in a household survey (Sirken et al. 1980). When an outside agent handles all information that would identify individuals, it is possible to maintain anonymity. Our plans to address the primary criticism of the household HIV survey—that the high-risk people would not participate—led to the proposal to embed such a sample of known cases in the early feasibility work so that response rates could be calculated for individuals at high risk. Investigating the means to implement this validation study was one of the early activities in Washington. While exploring ways of identifying high-risk people, a well-intentioned member of the RTI sampling staff created a stir when he requested the use of a membership list from the head of a local gay organization. This led to more active and direct contact with community representatives.

A meeting was called for May 24, 1988, with the Washington, D.C., health commissioner and a number of representatives of gay groups and other concerned parties. The commissioner did not attend personally, but was represented by staff from his AIDS program. Members of RTI's Policy Advisory Panel were invited and several attended. Representatives from the Whitman-Walker Clinic, Washington's gay-oriented and primary AIDS service organization, and the National Gay and Lesbian Task Force attended. The plan for the survey, which was complex and included elements to address all of our initial specifications plus a mon-

etary incentive test, was presented at the meeting. Several aspects of the plan raised concern among the individuals who were attending. Their fear centered around public perception of particular survey procedures. For instance, stratified sampling, instead of being viewed as an accepted strategy to make the survey more efficient, was characterized as unfair "targeting." The representatives were fervent in their opposition to the seeding experiment. The idea of the government having a "list of high-risk people" would be so threatening to their constituents that they could not support it. Other concerns surfaced. The Whitman-Walker Clinic and health commission people insisted that adequate counseling be provided to respondents who received HIV test results, and they were concerned that our proposal to use counselors in local testing clinics was open to abuse. The city's AIDS program representatives indicated that they already felt overburdened with CDC's data collection in the recently established family of surveys.

As a result of this meeting, we modified the survey design and strategy, dropping the idea of seeding the sample with people at known risk and emphasizing protection of privacy. We made changes in the data processing and developed plans for creating a complete diagram of how a person's privacy would be protected, from sample selection through reporting survey results. The start of the survey, scheduled for early July, was delayed to allow time to make these changes and allay community concerns. These representatives had now become "gatekeepers" to the community. Their support, or at least acquiescence, was vital to the success of the study.

The RTI outreach director redoubled his efforts to enlist the involvement of the Whitman-Walker Clinic and other local resources for test-result reporting and counseling and to obtain broader community support. We held meetings with the D.C. health commissioner on July 5th and 26th, at which time he expressed what seemed to be mild discomfort about the study's taking place in D.C. and voiced misgivings about the need for a national survey, but our impression was that he would not obstruct it.

After clearance of the Washington survey plan by the Federal Office of Management and Budget and by RTI's internal review board for the protection of human subjects, training of the interviewers began on July 25, 1988. However, two days before household visits were to begin, a front-page *Washington Post* article reported growing controversy over the survey in D.C. (Boodman 1988a). The article contained a quote

“from sources” that the health commissioner was “very, very nervous that people in the black community would think they’re being used as guinea pigs.” The commissioner telephoned a top CDC HIV program official to convey his concerns. CDC officials immediately decided to announce postponement of the D.C. study. A few excerpts from a *Post* article that appeared the next day illustrate the situation in Washington:

Chief among [D.C. Health Commissioner, Reed] Tuckson’s concerns was the message the CDC was sending by choosing the District, where 65 percent of the residents are black, and mistrust of the federal government runs deep.

An official at Research Triangle Institute . . . said his firm tried to ensure ample confidentiality protection . . . the District was chosen not for racial reasons, but because it is urban, “has a mix of people we want to study, we have a Washington office and it would be cost-effective.”

Jackie Sadler, director of AIDS education for D.C. public schools, said she believed that few of those people contacted would cooperate. “People are already suspicious of CDC because of the Tuskegee experiment. . . .”

Jim Graham, director of the Whitman-Walker clinic . . . praised the decision to delay the survey. “It’s important to pause and consider whether this is really important for the District of Columbia,” he said.

“This was bungled all the way along,” said a source who requested anonymity. “There’s nothing worse than the government being perceived as sneaking around trying to foist something on people, but that’s exactly what happened here.” (Boodman 1988b)

We began this project with a general awareness of the topic’s sensitivity, but we were not prepared for the extent to which the broader community’s fears and concerns would influence almost everything we would do. The newspaper articles added a dimension to the study that was not in the experience of the planning team. Our survey was *news*!

A point of interest is that gay opposition to the study never surfaced, as it was to do later in Dallas. The *Washington Blade*, D.C.’s gay newspaper, carried two impartial articles on the survey during this period. In late May 1988 an article simply detailed plans for the survey, emphasizing a need for data and the intent to work with the community in planning (Chibbaro 1988). The other appeared on July 29th, the same day as the

second *Post* article, and was again a straightforward report detailing the real problem of a nonresponse bias in such a survey and pointing out that a number of local agencies, including the Whitman-Walker Clinic, were involved in plans to provide test results to participants (Sullivan 1988).

Nevertheless, the stories in other local newspapers and media placed the Washington study in an untenable position. "Targeting a black city" became a big issue. Major attention had been attracted to survey details and to key personalities, making it difficult to continue on both scientific and political grounds. For example, a test of the use of an incentive to obtain better response was impossible because the newspaper reported that we were planning to offer some people \$50 and others nothing. (The experiment was actually structured so that all participants would receive the payment.) Also, many of the people who were needed to develop public support were now on record as having grave concerns about the effects and value of the study. The pilot test would have to be done elsewhere.

What happened? Why did we suddenly find ourselves in the position of being prepared to do a study in a city that did not want us? In retrospect, we find five fatal flaws in our approach to the first field test of the survey:

- The first two can be viewed as problems of communication. Initially, our problem was in hearing what others were saying. Concerns about privacy protection measures, methods for measuring validity, and stratification in sample selection were expressed in our discussions with the D.C. health commissioner, other local leaders, and our own advisory groups. We did not see them as insurmountable obstacles to gaining support, as they later appeared to be in the news articles. We had altered methods to address some concerns and felt we had presented a convincing case for the benefits of other questioned procedures. No one voiced opposition to using Washington as a test site in any of our meetings, nor did anyone raise the race issue.
- The second communication problem was in explaining our plans. Our inexperience in justifying statistical methods and survey procedures in places other than scholarly and scientific forums became evident. An interesting illustration arose with the problems over the proposal to stratify the sample by some measure of HIV risk

status. The technique had scientific merit in that it increased the probability of having enough HIV-positive people in a sample of reasonable size to provide reliable population estimates. Although it required no personal identifiers, the procedure was viewed as targeting particular groups and individuals, with implications of malevolent redlining. From a scientific vantage, the procedure was needed and the concern unfounded. We were unable to appreciate the importance of social and political ramifications as seen by others and did not address them in our explanations. In the context of AIDS/HIV, some of these methods assumed a foreboding and malignant nature.

- The third flaw was our focus on the project as a national survey, that is, on developing a prototype design easily duplicated in a number of locations and capable of giving the best national estimates. We were reluctant at this stage to alter specifications in response to particular local agendas because we intended to use a standard design for all locations.
- Fourth was a schedule that severely limited the time we had to work out local concerns. The timetable presented to the Domestic Policy Council allowed 13 months for the pilot work plus 15 months for the national survey. This meant that data from the first pilot had to be available by the end of September 1988—a schedule that demanded every step proceed like clockwork. Keeping to the schedule was of prime importance to CDC officials.
- Fifth, we were not prepared to be “news.” It is the nature of the media to focus on conflict and controversy. What we read in the paper sounded different from what we heard in our meetings. Did the concerns expressed in meetings change to lack of support because of the media attention, or was real support never present? We will never know. Certainly, this project contained the seeds of controversy, and their sprouting in Washington led to a reevaluation of how to proceed.

The Way! . . . in Pittsburgh, PA

As we began the search for a site to begin again, we were joined by staff members from CDC's HIV program office who had experience working

with local health departments. They helped us adopt the following principles in considering new locations:

1. The project would be an important *local* activity as well as a prototype of a national survey.
2. We would begin with a basic study containing the minimum essentials and build toward a more complex design.
3. We would do the study only where we had complete and active support of the local health authorities.

Because the primary task was to determine if we could collect blood from enough people to warrant testing of other aspects of the survey, we dropped a number of the particularly troublesome proposals from the pilot design. These included stratifying the sample by risk, providing blood test results, and conducting studies to check the quality of the response. We were even prepared to drop the idea of collecting information about risk behavior through a self-administered questionnaire. We felt these elements could be added in later studies. We thought our decision to conduct the study with teams of professional interviewers and phlebotomists and to provide anonymity for all respondents would continue to play well.

On September 9, 1988, we visited the Allegheny County (Pennsylvania) Health Department to discuss with them the possibility of doing a pilot in their jurisdiction with these changes in our plan. Allegheny County, comprising Pittsburgh and environs, was one of several sites considered. The county officials were interested in participating in any CDC research effort to measure the extent of HIV infection, but they did not want a replay of the situation in D.C. After reviewing tentative plans for the project, the health department agreed to move ahead on the condition that a local committee would advise them on the survey's acceptability to the community. The Community Advisory Committee, composed of 21 local civic leaders and concerned citizens² appointed by the health department, would be the mechanism for providing community guidance on survey design issues and developing broad local support. In our first discussion with the advisory group, we developed a set of guiding principles for designing and implementing the Allegheny study. Some of these reiterated our approach and the basic methods we had proposed, such as the importance of privacy and provision of anonymity for participants. We raised the prospect of including a risk ques-

tionnaire and were surprised that everyone saw its utility and was willing to include it in the survey. Other principles stressed the use of culturally sensitive field procedures; adequate information about the survey to the total community and to the selected participants; and procedures designed to avoid discrimination against any person or group, based on race, sex, ethnicity, or sexual orientation. The original priority of keeping to schedule was dropped, and community acceptance became a major criterion. Over the next few weeks the planning team and advisory committee shaped the final plans for the survey.

The kind of sample became an important issue for the Community Advisory Committee and the health department because once more the idea of stratification with oversampling of high-risk groups was viewed as targeting. Therefore, all households in Allegheny County would have an equal chance to be selected for the survey, and the sample was designed to reflect the demographic distribution of households in the county.

By the end of the process we had the unanimous support of the Community Advisory Committee, including personal endorsements by key members at a press conference. The health department public affairs staff was exceptionally helpful in developing positive media relations, and they issued press releases at key points during the planning process and field work.

When the survey teams went out, the cooperation of county residents was outstanding. Slightly more than 81 percent of persons in the sample gave a blood sample and completed a questionnaire. The item response to the questions, including the sensitive ones, was 95 percent or better, and some persons reported high-risk behaviors (Research Triangle Institute 1990).

The study produced a response rate higher than many thought possible, which was encouraging, and demonstrated that the survey could be done without jeopardizing privacy. Working closely with the health department, simplifying the survey protocol, and involving the community in decisions seemed key to the success. However, involving the community greatly expanded the time and cost necessary to carry out the study. We could not, of course, address the issue of nonresponse bias, and the limitations of the sample design would make it inadequate for a national study. Nevertheless, we could now test whether a study with the necessary scientific rigor could be developed with this strategy.

Discussion, Dissension, and Determination in Dallas

The planning model developed in Allegheny County served as the guide for selecting the next test site. We developed a list of potential sites based on CDC's knowledge about the strength and likely cooperation of a number of health departments. In December 1988, we made initial contact with the directors of the health departments in two of those areas: Dallas County, Texas, and San Diego County, California. Both expressed interest in a pretest of the national HIV seroprevalence survey. We met with health department officials and a group of community representatives convened by the department in each city to explain the objectives of the project. Both cities subsequently extended invitations to proceed with planning for a survey, and we found ourselves in the enviable position of having to choose between two positive situations. Our final choice was Dallas. We had approached Dallas first, the health department staff had previously proposed a county survey and was willing to use their local data to aid in sample design, and the trip to Dallas was shorter and cheaper.

As in Pittsburgh, the health department was to take the lead in setting up the process. The director of the Dallas County Health Department proposed a similar community advisory committee. The 29 members of this group³ were recommended by the department, but were appointed by the Dallas County Commissioners' Court, making this panel an even more official voice of the community. The health department director and staff were remarkably enthusiastic about the survey. They had attempted to launch an HIV seroprevalence survey of Dallas County three years previously, but had been prevented by local political conflicts and inadequate funds. Unlike the Allegheny study, one of the objectives in Dallas was to provide them with a seroprevalence estimate.

There were other important differences between Dallas and Pittsburgh. First, the AIDS epidemic had more severely affected the Dallas area. The Dallas County Health Department had a large and growing AIDS/HIV program. There were established gay activist groups. The community had experienced a great deal more controversy about AIDS/HIV.

Second, although members of the community advisory groups appeared similar in their organizational affiliations, the Dallas representa-

tives were far more diverse in their interests and agendas. The Allegheny committee had not dealt specifically with AIDS issues in the past. Most of the Dallas panel had served on a countywide task force that had studied and produced a report on the AIDS/HIV epidemic in Dallas County and were old hands in HIV-related conflicts.

Third, media attention and style were different. The media in Pittsburgh treated the survey as an acceptable government activity and reported the story on the basis of health department press releases and conferences. Dallas media saw it as a controversial story to be investigated and exposed. A reporter from the *Dallas Morning News* attended most of the advisory committee meetings, developed lines of communication with project staff, and became familiar with details of the survey plan. Her beat was AIDS/HIV, and she was familiar with the local gay activist community. Other print media and several of the local television news organizations actively followed and reported the survey story. The public TV station, KERA, produced a 10- to 12-minute documentary on the survey that was aired on a regular half-hour program after the field work began. The companion segment was on an equally controversial topic: abortion!

Because the budget was now insufficient for three field tests as initially planned, Dallas would be the last feasibility study. Therefore, the objectives were more extensive and complex than those in the Pittsburgh study. Faced with a large and diverse community advisory group in a community where the issues of AIDS and homosexuality generated a lot of heat, we had our work cut out for us. We had to define the goals of the survey, describe the need for it and clearly explain its methodology (some of it complicated statistical and survey techniques), and then elicit their cooperation and endorsement. We divided the community group into three subcommittees to deal with statistical methods, privacy, and community relations, respectively. The group would meet as a whole on several occasions for updates and consensus decisions. The county epidemiologist and head of the AIDS program in the health department were codirectors of the project and worked closely with RTI and NCHS staff as plans were presented for consideration by the panel.

The first meeting of the advisory panel was held at the end of January 1989. Here again we faced the situation of planning every detail of the survey in open meetings. We decided from the first to invite local media in the hope that they would increase public awareness of the proposed survey and the process for planning and decision making. We did this

with some trepidation, knowing we had little control over what stories might develop. Soon afterward we established that all meetings of the committee and subcommittees would be open to anyone and that all materials would be universally available. To some extent we did this to comply with the Texas open records law, but mainly we took this step because our team had come to agree that appearing to hide any aspect of the survey plan only led to heightened suspicion and greater resistance in any community.

The final elements developed for the Dallas study resembled those for the Allegheny study with two important additions: the sample was stratified, and methods to determine data quality were implemented. Although members of the advisory group attacked as a targeting ploy the plan for increasing the number of high-risk people in the sample through stratification, they were finally persuaded of its scientific merit. A key to acceptance was use of aggregated public health data to identify high-risk areas, such as information from STD clinics and data on AIDS cases that carried no threat to individuals' privacy. They also saw the need for attempting to determine effects of nonresponse on estimates. Although the project team had continued to press for a study that included a sample with persons of known risk status, discussions with RTI's policy advisory panel laid the idea to rest. Everyone on the panel thought the method was politically impossible, and some thought it unethical unless individuals had given prior consent. This method was not presented as an option to the Dallas group, but they did agree to a non-response follow-up study. Their acceptance of some rather complicated methodology illustrates how much understanding and cooperation can be obtained from community groups *if time is taken* to work with them.

A few other observations on the process in Dallas may offer a clearer picture of the extent of our successes—and failures. In negotiations with the community panel, we encountered major concern about contacting sample persons more than once, especially after they had expressed no interest, toward the end of May 1989. Earlier, a number of the procedures often employed by interviewers in conducting household surveys had been rejected. For example, the Policy Advisory Panel thought obtaining information from neighbors about the number, age, race, and sex of persons living in a household where no one was at home on repeated visits was an undue invasion of privacy. Therefore, we had limited interviews with neighbors to questions about whether the household

was occupied and, if so, when might be the best time to find someone at home. This new issue regarding the usual follow-up visits to persons who have refused was resolved for the Dallas survey by restricting the interviewers to one contact with a person who was not interested in participating.

Also at about the same time, the president of the Dallas Gay Alliance (DGA) wrote a letter to his fellow advisory panel members informing them that he and his organization intended to actively oppose the survey. In order to deal directly with DGA's announced position, we arranged a meeting between the DGA executive board and the AmFAR president, who was a member of RTI's advisory panel. The AmFAR president argued that DGA's opposition perpetuated the idea of "AIDS as a gay disease," whereas support of a national survey could be used as a vehicle to "mainstream" the epidemic, a development that could serve to increase needed resources. His case failed to convince anyone. We realized that this epidemic had touched deeply the lives of many in the DGA group, and their pain had turned to anger and rage. The situation was clearly *them against us*, and the survey was another symbol of *them*. They ended the meeting with a reaffirmation of their position.

Our work with the community groups spanned about five-and-a-half months, with meetings every two or three weeks. On June 21, 1989, a substantial majority of the members publicly endorsed a final plan for the survey, with only the DGA president voting in opposition.

In its first report on the survey, the local gay newspaper, the *Dallas Voice*, delivered a combination news article and editorial comment opposing the project. In these pieces the editor stated that the idea for a national survey was spawned by a homophobic White House staffer, who intended it to demonstrate that HIV infection had not achieved the prevalence suggested by CDC figures and was not spreading into the heterosexual population, in essence, to isolate the epidemic as a problem of "gays" and "drug abusers." He pointed out that a new president had taken office, but suggested that the survey still had the taint of malicious origins in the Reagan administration.

Further, the *Voice* article questioned the value of the project by unearthing some of the differing opinion among CDC staff. The editor sided squarely with DGA and its president. However, the other five gay members of the Dallas panel, one who represented the Dallas Lesbian/Gay Political Coalition, and the others from three AIDS service organizations, had voted in favor of the survey, and two became visible

spokespersons. The *Voice* writer attempted to marginalize these panel members as "conservatives" who did not have the real interests of the gay community at heart (Vercher 1989a). A second major article, which appeared as the survey field work began in September, focused on widespread opposition to a national survey from gay organizations and AIDS activists (Vercher 1989b).

Because our health department colleagues and other supporters feared we might lose momentum in the face of opposition mounted by DGA, special efforts were made to bolster the CDC/PHS presence in Dallas in the weeks just before the start of field work. These included a visit to the health department and several service organizations by CDC's deputy director for HIV activities and a press conference on September 26 when letters explaining the survey were mailed to the 2,528 addresses selected for the sample.

On the day of the press conference, opponents of the study caught media attention with a demonstration on the steps of the health department where members of DGA and the Gay Urban Truth Squad (GUTS) dumped 90 life-sized dummies representing, they said, the people who would die from AIDS in Dallas while the survey was going on. This theme, that we already knew enough about the AIDS/HIV problem and that further study was wasting money better spent on treatment and medical research, was the primary thrust of the survey opposition. Their initial attempts to raise fears about survey participation leading to identification and discrimination were apparently countered by the open planning process and the procedures to protect everyone's privacy. Therefore, issues regarding how the survey was conducted became secondary to the essential question of whether the survey was needed at all.

The interviewer/phlebotomist teams began contacting households on September 30, 1989. For the next seven weeks, the teams in the field encountered no incidents other than what might be expected in a complex survey. The teams were certainly alert to the controversial nature of their undertaking. Newspaper stories about the survey had been highlighted during their training and they had heard presentations on cultural sensitivity from the gay-oriented Oak Lawn Community Services and the Dallas Hispanic Health Coalition. They learned that DGA's campaign included an offer of \$200 for a set of the interviewer's survey forms, which meant that they began work facing the threat of someone trying to take their forms. About two weeks into the survey, forms were mailed to the DGA president, who provided them to a reporter for a

story about the survey's failure to safeguard confidentiality (Jacobson 1989). However, the forms turned out to be sample documents for use in training. To our knowledge no one tried to claim the \$200 nor were the interviewers put in unusual jeopardy.

The survey teams felt that the organized opposition had provided some people with the rhetoric for articulating their feelings about the survey, but that its actual effect on participation was negligible. In the last week of October, we made our only formal public progress report: the survey was going smoothly and response was good. Several news reports followed; these comprised the media coverage through the completion of the survey on November 19, 1989.

Between November 29 and December 20, a few of the original survey teams went back for the follow-up study to contact a sample of persons who had initially refused to participate. By increasing the amount of the incentive offer and by modifying the survey so that some respondents were asked only to complete the questionnaire, we hoped to expand the basic response and learn something about individuals who had not responded at first contact. We increased incentives from \$50 to as much as \$175 for persons who would both donate blood and answer the questionnaire. Our concern about public reaction to the announcement of this sizable increase at the beginning of the follow-up study proved unfounded. Even though DGA members labeled it even bigger "blood money," little more was said by anyone, and the study was completed just before Christmas 1989. The response rate for persons providing both blood and questionnaire responses, combined for both parts of the study, was 82 percent.

On May 11, 1990, we presented a report on the survey's findings to the health department in an open meeting of the Dallas County Public Health Advisory Committee, the forum where the idea had first been publicly presented in January 1989. The Dallas County Commissioners' Court and the Community Advisory Panel were also invited. The report focused on the behavioral data and seroprevalence estimates of interest to Dallas County (National Center for Health Statistics 1990). We included for comparison HIV prevalence estimates from several back-calculation models, based on current AIDS case numbers, that had been computed especially for Dallas by CDC and the National Cancer Institute. The survey estimate was lower, and we cautioned that this might be the result of a lower rate of participation by infected and higher-risk

people. Although the local opposition said their campaign had been successful so that survey information was inaccurate and useless, health department officials and other community leaders believed the study added useful knowledge about the epidemic in Dallas.

What Does It All Mean?

The technical difficulties and complexities of this survey led CDC to ask a number of outside public health, epidemiologic, and survey experts to review and comment on the Dallas plan and again on the findings. We have not discussed in detail the purely technical challenges presented by this survey. We must say here, however, that the follow-up study in Dallas was our only mechanism for looking at nonresponse bias. In this study, a significantly higher proportion of follow-up respondents reported risk behaviors than individuals who had participated on first contact. RTI used this demonstration of probable bias in the initial survey response to generate adjustments for producing the final seroprevalence estimates. These adjustments still resulted in an estimate of HIV prevalence that was substantially lower than model-based estimates using reported AIDS cases in Dallas County. Much of the concern among the experts in their final consideration of the household survey's value focused on whether any practical method could truly account for the bias and provide valid estimates.

There was no clear consensus on the scientific merit of a national survey, and little enthusiasm for the project among any relevant constituency. Congress had specifically limited funding to what was necessary for the feasibility study and seemed unlikely to appropriate money for the national survey. These considerations, and the fact that most people seemed satisfied with data from ongoing serosurveys and prevalence estimates based on models, led the director of NCHS to recommend to the director of CDC that the national survey not proceed. He stated, however, that further methodological work would be profitable and that the overall surveillance system might be strengthened by further household survey development. The recommendation not to proceed with a nationwide survey was accepted up through the department, communicated to the Domestic Policy Council, and publicly presented in January 1991 (U.S. Department of Health and Human Services 1991).

Survey Science in the Trenches— A Concluding Comment

Our experiences are worth recounting as they illustrate what happens when methods and procedures in scientific research apparently conflict with social values and political forces. Many of the methods we proposed for this survey are standard practices. For example, the techniques of stratification and oversampling seem to take on negative connotations of targeting only when the affected group does not want the specific information or is suspicious about the motives of the data collectors. These methods are used in obtaining health information about the black population in national surveys where even *negative* findings, such as higher infant mortality and excess illness, are generally viewed by black activists as essential to their interests. We are, in fact, currently facing pressure to target Hispanics in order to obtain better data for them. The social context is all important. When the group is composed of HIV-infected people in 1988 in the United States—when the effects of discrimination and persecution have been bolstered by the idea of quarantining HIV-positive people emanating from the highest halls of government—the purest of scientific motives may, and probably should, be questioned.

When we finally understood the *reality* of the *perceptions* of a large body of gatekeepers, we were able to devise a process to obtain acceptance for the project, and we completed a respectable study. However, the work was time consuming and expensive, which must be considered in any cost-benefit analysis of such a project.

Even though we were able to complete two field studies, some among our own planning team and consultants felt we had sacrificed too much in our compromises. Good survey science demands methods to evaluate results—methods we were not able to achieve. One of the techniques proposed required use of personal information related to risk of HIV infection or preferably information about infection status. Use of such sensitive information always raises issues of personal privacy. There were long and at times heated discussions in our advisory forums. The emphasis on privacy in the context of AIDS/HIV elevated concern about the use of *any* health and medical records in *any* research; and we found some of our advisers taking a position that would strictly prohibit use of any information not specifically permitted by the individual. Because of resistance to methods that would provide further information about the response bias in the survey and the evidence from other sources that se-

reprevalence estimates were low, the quality of the survey data remained in question. Our disappointed team members and outside critics notwithstanding, it does not seem likely that studies using data on HIV risk or infection status, even with complete protection of individual identities, will be practical until the stigma of AIDS diminishes.

Some of our country's most perplexing problems involve human behaviors that are difficult to measure, such as sexual practices and alcohol and drug use. Obstacles to obtaining information about these phenomena arise at two levels: the social and political resistance to investigation of these sensitive areas; and our lack of knowledge about how to measure them. Survey scientists who accept the challenge of gathering data on sensitive issues must confront the task of efficiently building a climate of acceptance for their work. They must communicate the methods of science better to the public. Scientists must also continue research into ways of eliciting accurate reporting on sensitive topics and methods to measure survey error.

We went into the trenches with this project. Our experiences have convinced us that survey scientists need not be shy about tackling controversial problems, but that we must approach them with an understanding of their historical, social, and political context while demonstrating sensitivity to people's legitimate concerns.

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Address correspondence to: Peter Hurley, Associate Director, Office of Vital Health Statistics, National Center for Health Statistics/Centers for Disease Control/DHHS, 6525 Belcrest Road, Hyattsville, MD 20782.

Appendix Notes

1. Although there were slight changes in specific people and affiliations over the time of the project, the core of the Policy Advisory Panel was composed of representatives from the following organizations: American Foundation for AIDS Research (AmFAR); AIDS Activity Office, San Francisco Department of Health; Christian Life Commission, Southern Baptist Convention; National Hemophilia Foundation; Association for Women's AIDS Research and Education (AWARE), San Francisco; Women and AIDS Resource Network, New York City; Gay Men's Health Crisis, New York City; National Association of People with AIDS; and The Kinsey Institute for Research in Sex, Gender, and Reproduction. Other members who attended at least one meeting or provided telephone and written counsel were representatives of the following: Americans for a Sane AIDS Policy; American Medical Association; National Coalition of Hispanic Health and Human Services Organizations; United States Catholic Conference; Oregon State Health Division; BEBASHI, Philadelphia; New Jersey Department of Health; Narcotic and Drug Research, Inc., New York City; American Civil Liberties Union; and the Lambda Legal Defense Fund.
2. Representatives of the following served on the Allegheny County committee: Pittsburgh Chapter, American Civil Liberties Union; Episcopal Diocese of Pittsburgh; College of Humanities and Social Sciences, Carnegie-Mellon University; Persad (local gay community service organization); Pittsburgh Black Action (drug treatment program); Pittsburgh Inter-Agency Council on AIDS; Allegheny County Medical Society; Pittsburgh Board of Education; Alma Illery Medical Center (clinic serving the black community); Pittsburgh Foundation; Gateway Publications (publisher of local community newspapers); University of Pittsburgh, Pitt Men's Study (one of the federally funded gay men's cohort studies); Consad Research Corp.; Pittsburgh AIDS Task Force (gay support organization); KDKA-TV; Pennsylvania Department of Health; *Pittsburgh Post-Gazette*; Kane Regional Center/McKeesport (county hospital); School of Nursing, Duquesne University; a person with AIDS (PWA).
3. Representatives of the following served on the Dallas County panel: Eagle Forum; AIDS ARMS Network (provider of casework services to PWAs); Dallas Lesbian and Gay Political Coalition; C.V. Roman Medical Society; North Carolina National Bank-Oak Cliff; DeSoto

Health Authority; City of Richardson and its Independent School District; Dallas County Court; St. Paul United Methodist Church; Dallas County Medical Society; *Dallas Times-Herald*; City of Lancaster; Oak Lawn Community Services (a gay counseling and AIDS education/service organization); Grand Prairie Independent School District; City of Garland; Statistics Department, Southern Methodist University; Dallas Consilio of Hispanic Organizations; AIDS Services of Dallas (a primarily gay provider of housing for PWAs); Hispanic Chamber of Commerce; KERA News (public TV station); Dallas Independent School District; Baylor Medical Center; Lemon Avenue Bridge (a black social services organization); Texas Planning Council for Developmental Disabilities; Dallas Gay Alliance (the oldest and largest political action group, also providing some AIDS services); Dallas Blood Center.