DISCUSSION

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The potential results (and ambiguities in the results) of an HIV seroprevalence survey must be contrasted with the information that is currently available on the spread of HIV in the American population.

In that regard, I would remind the audience that although more than 135 thousand Americans were diagnosed with AIDS and more than half of those persons died during the first decade of this epidemic, we are entering the second decade of this deadly epidemic without a trustworthy statistical system for estimating the prevalence and tracking the future spread of HIV infection in our population.

As you may know, the NAS Committee on AIDS Research conducted a study of the adequacy of our current understanding of the epidemic. While we concluded that "approximately 1 million" was a *reasonable* estimate of the number of persons infected circa 1989, we found that a number as low as 0.5 million or as high as 2 million would also be consistent with the evidence available. This wide range of "reasonable estimates" reflects the very considerable uncertainties that attend the data used and the heroic assumptions employed in the two methods that have been used to estimate HIV prevalence (i.e., back calculation methods, and the components method used in the 1987 Coolfont Report).

Even more importantly, it was our committee's strong conclusion that not only does our nation lack an adequate basis for assessing the current state of the HIV epidemic but we also concluded that the statistical systems that have been put in place (with the exception of the survey of newborns) cannot provide the data the nation needs about the spread of HIV in the population at large or in subpopulations of substantive interest. This failing derives from the fact that current data systems rely upon samples of convenience (e.g., 40 medical centers in 30 cities).

Our committee has recommended that: (1) the statistical systems that have been put in place to monitor the spread of HIV be reformulated to use probability samples; and (2) PHS continue testing the feasibility of conducting a series of national seroprevalence surveys.

FUTURE NEEDS. It should be clear to everyone here that the HIV epidemic is not going away. It is likely that even the youngest among us will retire from this field and cede this problem to another generation of public health officials and scientists. Given that conclusion about what the future holds in store for us, our committee did not believe it would be wise for the U.S. Public Health Service to continue to "make do" with estimates derived from convenience samples. There is a pressing national need for better statistical systems to monitor the course of this epidemic. Accurate estimates of prevalence and incidence are prerequisites for mounting an effective and efficient national response to the AIDS/HIV epidemic.

Without better information on the incidence of new infections, the United States will lack a scientifically adequate basis for determining whether current strategies for controlling the spread of HIV are working. Without better information on the prevalence of HIV in the population, we cannot prepare adequately for future demands for hospital beds and health care services. Without better data, scientists, policymakers, and the American public can anticipate endless debates about whether the virus is spreading "rapidly" or "slowly;" whether the epidemic has crested or continues to grow.

Messrs. Langmuir, Fumento, and Hay are precursors of future legions of dissenters from official estimates of the state of the HIV epidemic. The debate may be endless and rancorous. The allocation of money and other resources will be contested in a climate charged with the fears and passions aroused by a disease that continues to take the lives of many otherwise healthy and relatively young men and women in our nation and around the world. If these debates continue to be waged with data from samples of convenience, inconsistency in conclusions is to be expected, and there will be little basis for informative scientific debate.

What is needed to inform such debates, to plan for future health care needs, and to evaluate the overall effects of national AIDS control strategies, are data derived from research designs that can provide estimates of prevalence and incidence in well-defined populations of substantive interests.

If our nation is to have a better understanding of the HIV/AIDS epidemic when we enter the third decade of this epidemic in the year 2000 than we have now at the beginning of the second decade, the investments in the requisite statistical systems must be made *now*. Delays in committing resources to the development and

implementation of such systems would be a false economy. Such a policy only postpones unavoidable expenditures while forcing scientists and policymakers to "make do" with piecemeal and potentially misleading data on the current magnitude and future course of this epidemic.

REACTION TO CDC CONSULTANT'S REPORT. As some of you know, a paper that Bob Fay and I wrote in the spring of 1987 served as an early stimulus of the effort to mount a national seroprevalence survey. It was my belief then and it was our committee's conclusion in 1989 that such an effort should begin in an exploratory spirit anticipating the possibility that pilot efforts might indicate that such a survey was not feasible or that it would produce estimates that were no better than the poor estimates of prevalence and incidence we currently have.

I was pleased to hear that the NCHS consultants who reviewed the feasibility study results recommended that the survey go forward. Indeed, I was surprised that I am more hesitant about going forward than the NCHS consultants appear to be.

In my following remarks, I detail some of the more important reactions I had to the presentations of Drs. Horowitz, Massey, and their colleagues. I should begin by noting that whatever one believes about the ultimate desirability of proceeding with such a survey, Drs. Horowitz, Massey, and all their colleagues deserve our congratulations for doing a fine job in mounting this effort and presenting us with a wealth of information on the feasibility of this approach.

SUMMARY CONCLUSION. Given my own past involvement with this initiative, *my heart* wants to find evidence that the survey is do-able and any biases can readily be adjusted for. *My head* insists, however, on noting clear evidence that this survey will underestimate actual HIV prevalence. In particular, I note that

- nonresponse occurs disproportionately in those census tracts with a relatively large number of unmarried men;
- this pattern is consistent with the fact that there was[2] political opposition to the survey in some sectors of the gay community;
- there does not exist a great deal of experience or trustworthy data to help impute the magnitude of such biases (*but see below for a way of adducing such data*);
- in assessing future trends in prevalence from a series of such surveys one might encounter relatively large measurement biases whose magnitude fluctuated over time -- as political opposition to the survey waxed or waned. This would bedevil attempts to infer trends in HIV prevalence over time.
- the authors conclude, rightly I suspect, that *individual-level* record check studies would not be politically feasible even if there were designs that did not pose serious ethical problems.[3]

While the above suggests a negative conclusion, there are three considerations which argue persuasively in the opposite direction:

- First, as I noted previously, the flaws in this undertaking must be judged against the substantial failings of the other data we are likely to have available in the near future.
- Second, the present papers demonstrate that such a survey can be mounted with quite high levels of response.
- Third, and most importantly, I believe that there are alternatives to individual-level validation which might be exploited to provide needed data to calibrate the extent of the nonresponse bias in this survey -- and to track that bias over time if the survey is repeated. These alternatives are described below.

Given the above positive and negative factors, I believe that one might reasonably take the position that: (1) the feasibility of *conducting* such a survey has been adequately demonstrated; but (2) there are crucial questions of *validity* that need further exploration -- either in a separate study or in conjunction with the main study.

USE OF GROUPED DATA FOR VALIDATION AND ADJUSTMENT. The fact that it will be politically impossible to do "record-check" studies on *individuals* does not preclude obtaining validation data to assess the bias in NHSS survey estimates and to adjust those estimates.

There now exist many large (although idiosyncratic) samples for which we have excellent estimates of HIV prevalence based upon HIV testing done in clinical settings (e.g., patients in 40 sentinel hospitals, newborn babies, etc.) The estimates obtained for these samples were derived from "blinded" blood specimens, so that no individual's serostatus is known. Nonetheless, the prevalence of HIV among patients in sentinel hospitals, women who give birth, and so forth is known with great precision.

Applying the NHSS protocol to one or -- even better -- *several* such samples would provide a second independent estimate of HIV prevalence. This estimate doubtlessly would differ from the estimate obtained in the blinded seroprevalence study done in sentinel hospitals, etc.[4] The deviation of the NHSS-type estimate of HIV prevalence for a potential group from the true preva-

lence for this group (derived from the blinded blood samples taken in the hospital, etc.) would provide a direct estimate of the bias in the NHSS survey estimate. (Note that the NHSS estimate would be affected by nonresponse while the blinded estimate would not be.)

While a validation design of this sort does not require knowing the serostatus of any identifiable individual, it does provide a way of directly estimating and adjusting for bias in NHSS survey estimates of seroprevalence. (There remain some difficult issues in using this technique, e.g., how to cumulate estimates of bias from various convenience samples and apply them to a population sample. Without denying much hard work that will need to be done to employ this method, I would suggest that using group-level data may permit us to get beyond the current impasse in assessing the bias in estimates derived from the NHSS protocol.)

SPECIFIC COMMENTS. I have a number of specific comments upon the findings reported by Drs. Horowitz, Massey, et al. and the arguments they make. I note them in a summary fashion below:

- *Multiple Frames Needed.* A household frame must be supplemented by other frames in order to estimate the prevalence of HIV in the USA. Persons who are not attached to households (e.g., homeless persons and persons in prisons, hospitals, and other institutions) must be included to derive a plausible estimate of HIV prevalence. There is a wide array of evidence indicating that HIV prevalence is often considerably higher in these groups than in other segments of the population. This being so, a household survey will inevitably understate the HIV prevalence rate of the population. (In the initial considerations of the usefulness of such a survey, the need for multiple frames was noted.)[5]

  Comparisons made between NHSS estimates for Dallas and back-calculation estimates should thus be expected to reflect the difference in the population groups covered (i.e., household members versus the entire population). Viewed in this light, the "low estimate" obtained in the NHSS is perhaps not surprising[6].
- *Indirect versus Direct Estimates of HIV Prevalence.* The attraction of the NHSS method is that it could, in theory, provide a direct estimate of HIV prevalence. Nonresponse introduces a need for imputation and other indirect estimation procedures. The attractiveness of the NHSS method, to my mind, decreases as the amount of indirect estimation increases and the assumptions used become more speculative. I was thus disheartened to note that a substantial component of the HIV prevalence estimate for Dallas is attributable to the imputation procedures (the raw 0.25 prevalence was adjusted upward to 0.42 as a result of the imputation of missing data).
- *Questionable Imputation in Present Report.* Frankly, although I understand the difficult choices the authors faced, I must say that I thought the assumptions made in the imputation procedures were heroic. One must be suspicious, for example, of assuming that the same functional relationships exist between HIV serostatus and risk factors, etc. among those persons who gave a blood sample and those who did not. (The "group-level" procedures described earlier [see point 5] may provide a more plausible method for making such adjustments.)
- *Using Hepatitis B as a Supplementary Indicator of Nonresponse Bias.* The comparison shown in the present report is not particularly convincing since it compares an out-of-date estimate of Hepatitis B prevalence in the entire USA to an estimate of Hepatitis B prevalence in Dallas today. The strategy of obtaining a surrogate indicator of the nature of nonresponse bias in HIV prevalence is, however, a good one, and Hepatitis B is an excellent surrogate since it is transmitted by the same behaviors that spread HIV. National estimates of Hepatitis B prevalence from the current round of NHANES could be usefully compared to Hepatitis B prevalence from the NHSS, if the NHSS goes forward.
- *Fallible data on Risk Behaviors.* The authors note that 7.7 percent of men in the NHSS report having engaged in male-male sex within the last 10 years and 2 percent within the last year. These results are considered "plausible" and they are taken to indicate that a substantial number of men who have sex with men participated in the NHSS survey. These estimates do compare quite well with estimates derived from probability samples of the U.S. population in 1970 and 1988-89 (Fay, Turner, et al., 1989). There is, however, good reason to believe that all of these estimates are subject to substantial negative bias due to underreporting of such behaviors by respondents (see, for example, Chapter 6 of Miller, Turner, and Moses, 1990).

  Thus, while the estimates of risk behavior in the NHSS look "reasonable," it would be a mistake to place too much faith in this result. What ultimately is needed to validate the NHSS is direct and independent evidence of HIV prevalence in populations for which we

also have an NHSS estimate of HIV prevalence.

NOTES

1. In my initial remarks, I draw upon reports issued in 1989 and 1990 by the NAS Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences. I serve as Director of that Committee, and my initial remarks reflect the published conclusions of our committee. My particular remarks on the papers presented at this meeting are my individual responsibility and they should not be attributed to the Committee or the National Academy of Sciences.

2. My evidence is second hand because this aspect of the project was not treated at length in the papers. Given the nature of this survey, a detailed discussion of political response and media coverage would be helpful in future reports.

3. "Seeding a sample" with individuals of known HIV status and subsequently measuring nonresponse among persons who were known to be seropositive and seronegative would provide a basis for gauging the bias introduced by nonresponse in the survey. It is, however, unethical to violate the pledge of confidentiality ordinarily given in a HIV testing situation. Thus it would not be ethically possible to use data on HIV status obtained in such testing to obtain the special sample needed for such "seeding."

4. These and other samples are being tested in CDC's Family of Seroprevalence Surveys.

5. E.g., Turner and Fay (1987/1989) and comments by M. Sirken of NCHS at CDC consultation of Seroprevalence Surveys (Atlanta; June, 1987).

6. This factor must, however, be balanced against the inability of back calculation to provide estimates of recent HIV infections (i.e. within last 1-2 years).

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