A Frustrating Glimpse of the True AIDS Epidemic

To find out how many Americans are infected with the AIDS virus, the government wants 50,000 Americans to be tested; but about one-third will not roll up their sleeves

EACH week the Centers for Disease Control (CDC) dutifully performs its grim arithmetic and updates the number of reported AIDS cases. Yet more and more public health officials have come to see CDC's tally of full-blown AIDS cases as only a frustrating glimpse of the true epidemic. "It's like an astronomer looking through a telescope at a supernova. He knows he is looking at something that happened thousands of years ago," says Donald Burke of the Walter Reed Army Institute of Research in Washington, D.C. Burke refers to the fact that today's AIDS cases are only a snapshot of the epidemic as it was 5 or 10 years ago when those individuals who are now ill were first infected with the virus.

In recent months CDC has been trying to figure out a way to do an extensive national survey to ascertain the extent of human immunodeficiency virus (HIV) infection in the general population. It was originally hoped that 50,000 randomly selected Americans would roll up their sleeves and give blood to Uncle Sam. But CDC is learning that it is easier to propose some projects than to execute them.

A recent survey conducted by the National Center for Health Statistics (NCHS) found that 31% of the public said they would not allow their blood to be tested as part of a national seroprevalence study, even though assurances of privacy were given. The question was raised during a 15-minute interview with 2250 persons. CDC is understandably concerned that the people who refuse to participate might be more likely to have risk factors and thereby harbor the virus. A sort of epidemiological catch-22 develops. CDC seems to want what it cannot have, which is something approaching unanimous participation. What if 90% agreed to be tested? Ronald Wilson of NCHS says even 90% might not be enough.

James Curran, director of CDC's AIDS office, says feasibility studies for the large national survey will be "proceeding both rapidly and cautiously." What this means, says Curran, is that the national survey has not been abandoned, though it is possible that the study will be scaled down.

No one knows how many Americans harbor the AIDS virus. The government's best guess is that 1 million to 1.5 million citizens are infected. But these figures, arrived at by panelists at a Public Health Service conference in Coolfont, West Virginia, in May 1986, are extremely soft. A more accurate picture of infection would be useful for marshaling prevention and education efforts, allocating resources, and charting the future course of the epidemic.

As it now stands, CDC relies on reported AIDS cases and data obtained by the labors of others to draw its picture of HIV infection. Both blood banks and the Department of Defense actively test their recruits, so to speak, and CDC relies on their numbers. Yet there are problems with making too many assumptions based on either population.

At American Red Cross blood banks, the incidence of HIV infection among blood donors today is extremely low, down to 17 cases per 100,000. This low incidence is almost certainly due to constant warnings to potential male donors not to give blood if, for example, they have had sex with another man since 1977, injected illegal drugs, or been with a prostitute in the previous 6 months.

The national survey has not been abandoned, though it is possible it will be scaled down.

Making assumptions based on data gathered by the military is equally tricky. Since October 1985, the military has tested 1.4 million civilian applicants for service. Approximately 1.5 applicants per 1000 are seropositive. Burke of Walter Reed cautions against using applicants as an indicator of seroprevalence in the population. "You can make a case against our numbers either way," says Burke. Either the military's numbers are low because homosexuals and active drug abusers are turned down by the military, or the numbers are high because the bulk of the applicants come from the lower rungs of the economic ladder.

While CDC mulls over the difficulty of doing its national survey, it has decided to rapidly expand what is known as the "family of surveys," a collection of smaller epidemiological studies being done by state and local health departments. How many surveys are in the family? "Nobody in the country has a precise number," says Timothy Dondero of CDC, whose office is busy trying to identify all the AIDS epidemiology being done. The family as it now stands seems to be a rather ragtag assemblage of unknown proportions.

What CDC wants to do is expand or initiate surveys in 30 metropolitan areas, of which 20 cities are assigned high-risk status (such as New York) and 10 are relatively low risk (such as Salt Lake City). Anonymous blood samples will be collected from a variety of health care settings. At least two are familiar turf for AIDS epidemiologists: sexually transmitted disease clinics and treatment centers for intravenous drug abusers. CDC hopes to add tuberculosis clinics, "sentinel" hospitals, women's health clinics, and blood samples from newborns. Down the road, CDC also plans to do surveys in federal prisons, on college campuses, and with the Department of Labor's Job Corps, whose ranks are made up of disadvantaged, mostly teenaged, youths. Only scant information such as age, race, and sex is affixed to the blood samples. Since no prior consent is required, and since the samples are not linked to individuals, CDC will not be informing patients whether or not they have the AIDS virus.

The most revealing information about infection in the general population will probably come from the sentinel hospitals and the newborns. Since September 1986, CDC has been quietly gathering blood from four hospitals. Four more have recently been added, and Dondero hopes to have 40 hospitals participating in the program by next year. The hospitals provide the government with 300 samples a month, with the emphasis on young adults and children.

Collecting blood from newborns is a common practice done to test for metabolic disorders and hereditary disease. Massachusetts recently developed a system to test for HIV infection, working with the same blood specimens on filter paper it already uses to test for metabolic disorders. According to Lloyd Novick of the New York State Health Department, looking at the infection rate of newborns is among the best ways to get a representative picture of the general population because a baby's blood reveals the status of the mother. Then it will be up to CDC to make sense of so large and scattered a family. ■ **WILLIAM BOOTH**