By Sandhya Srinivasan

Do we have 2 million or 20 million HIV-positive in India? Or is there a plateauing of the epidemic? Speculative and alarmist figures about the number of Indians affected by HIV/AIDS have added to public confusion and affected the programme's credibility. This is the first in a series of articles on the issues and controversies surrounding HIV in India.

HIV and AIDS have been the centre of controversy since the early-1980s, when immune-deficiency illnesses were identified in otherwise healthy men in the US. The controversies have continued over the last two decades to the present day, even as huge amounts of money are being spent, internationally and in India, on prevention programmes, vaccine research and drugs believed to keep infection under control without cure.

This series of articles on HIV and AIDS will examine all these controversies and place several questions in perspective. The first big controversy has to do with the numbers. How accurate is the method by which official estimates and predictions of HIV infection are made? What is their relative significance when compared to other health problems in India? And does it make a difference? Other articles in this series will ask whether HIV prevention and treatment for AIDS should be a vertical programme or integrated into the health services; whether research into a vaccine will benefit India or whether Indians will be used as guineapigs; whether mandatory premarital testing is possible and ethical, and whether patients have the right to treatment or the right to refuse treatment. There are other issues too, but first, the numbers controversy.

In November 2002, a US government report predicting that India would have 20 million people with HIV in a couple of years received much press publicity as well as a lot of flak. This was only the latest in a series of speculative and alarmist figures that have added to public confusion and affected the programme's credibility. For some years now, India has been mentioned in international reports as leading in the number of people with HIV, sometimes the first in the world, sometimes the first in Asia. In 1996 we were told there were between three and five million people with HIV in India. In 2000, up to three lakh were said to have died as a result of AIDS in India. Indian government sources have announced figures disputed by international organisations, and vice versa, and all of it has been confusing. For most of us average readers, this would make our eyes glaze over.

Estimates of HIV infection are based on screening at designated sentinel surveillance sites in the country. The number of sites has grown over the years from 55 in 1994, to 180 in 1998 and 232 in 2000. As of August 2001, there were 320 sentinel testing sites under the supervision of the National AIDS Control Organisation (NACO). These include STD clinics and prenatal clinics, as well as other sites to look at the prevalence of HIV among injecting drug users, sex workers and men who have sex with men. The testing is meant to be anonymous and unlinked - the test results cannot be traced back to any individual.

Blood samples collected at these centres are tested for HIV. Based on various calculations - agreed upon by epidemiologists and bio-statisticians at NACO, WHO and UNAIDS -- estimates are arrived at on the prevalence of HIV among populations with high risk behaviour as well as the general population. The prevalence of HIV among the pregnant women surveyed is used to estimate the prevalence of HIV in the general population in that particular geographical area. All
these figures are used to estimate the number of HIV infections at the national level.

All that sounds very good, but there are a number of problems. For one, even NACO admits that the surveillance machinery needs improvement. Does the testing at these sites present a reasonably accurate picture of HIV prevalence in the population in various parts of the country? If it is bad now, it was worse earlier when there were fewer centres, and what do we make of the figures from those years? Third, who knows about the quality of data collection in states with abysmal health infrastructures and related facilities? And finally, the estimates have a low, medium and high estimate and the official estimate is always the high estimate. We must presume that the models and calculations by which the estimates are arrived at, are appropriate.

Estimates for the last four years might also raise further questions. According to the National AIDS Control Organisation’s website, the estimated number of adults living with HIV was 3.5 million in 1998, 3.7 million in 1999, 3.86 million in 2000 and 3.97 million in 2001.

If those figures are reasonably accurate, one might wonder what they mean. The number of new infections each year was 0.2 million in 1998-99, 0.16 million in 1999-2000, and 0.11 million in 2000-2001. So is there a gradual decrease in new infections? One might argue that the decrease is even more significant since the country's population has gone up over this period. NACO suggests that "over a period of time, the new infections may reduce to a negligible number, which is an indicator of the plateauing of the epidemic."

If indeed there has been a drop, should we believe that an effective AIDS prevention programme is responsible? Or should we believe that this is the result of a natural decline in the epidemic? How accurate are these figures anyway? It is interesting that the government acknowledges the limitations of the information from its existing surveillance system.

Others might argue that all this quibbling about numbers is irrelevant, that it doesn’t matter whether there are 2 or 20 million people with HIV -- surely the problem is obvious enough, and we should be concentrating our energy on preventing more people from getting infected, on providing treatment to those who are already HIV-positive, and on addressing the many associated socio-economic, ethical, and legal dilemmas that HIV has created.

It is also argued that HIV should not be compared to other illnesses because it affects all other diseases. So, for example, more people will die of TB because of HIV. Also, as a virus transmitted mostly by unprotected sex, it affects young people at the most productive stage of their lives. This will have enormous economic consequences, to families as well as the overall economy. Incidentally, the prevalence of HIV in India is relatively low but the large population results in a high overall number which could have a big impact.

There are many reasons why numbers are relevant. For one, inflated figures can be used to take resources and energy away from other equally important public health programmes. At the same time, underestimates can result in a problem being ignored. When inaccurate figures are challenged and proven wrong the programme can backfire. Finally, people have a right to accurate estimates of all health problems and their relative burden - on people’s health, the health care system, individuals’ finances and the economy. They also deserve access to health
and welfare services that meet their needs. It is not a good idea to quote high numbers without ensuring accessible and affordable health services to all who need them.

InfoChange News & Features, May 2003