

HIV SURVEILLANCE IN INDIA

Evolution and challenges

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India Knowledge Network

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Abbreviations

ANC Antenatal Care

ART Anti-retroviral treatment

FSW Female Sex Worker

HRG High Risk Group

HSS HIV Sentinel Surveillance

IDU Injecting Drug User

LDT Long Distance Trucker

MSM Men having sex with men

NACO National AIDS Control Organization

NGO Non-Government Organization

NIHFW National Institute of Health and Family Welfare

NIMS-ICMR National Institute of Medical Statistics-Indian Council for Medical Research

PLHIV People Living with HIV

PPTCT Prevention of Parent to child transmission

QA Quality Assurance

RI Regional Institute

STD Sexually Transmitted Disease

SACS State AIDS Control Society

SST State Surveillance Team

SW Sex Worker

TI Targeted Interventions

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1. Introduction

HIV was first detected in India among female sex workers in Tamil Nadu in 1986.¹ Over the last 25 years the epidemic has spread throughout the country, affecting a range of population groups and locations. It has been reported from all the Indian states and territories and currently an estimated 2.27 million people are living with HIV (PLHIV) in the country.²

HIV prevalence in India varies by district, state and region, with numerous isolated pockets of high prevalence. The distribution of regions or pockets of high prevalence has also varied over the years. For instance, in 2000-2004, HIV prevalence in the southern states was estimated to be about five times higher than in northern states.³ Since then while HIV prevalence has stabilized or even decreased in the southern states, new areas have seen a rise in HIV prevalence particularly in the northern and eastern regions.⁴

The HIV epidemic in India is mainly concentrated in high-risk groups (HRGs). Among these population groups the prevalence is estimated to be substantially higher than in the general population. According to recent estimates, while the prevalence of HIV among Ante-Natal Care (ANC) clinic attendees was found to be low (0.49%), it was considerably high among HRGs – Injecting Drug User (IDU) (9.2%), Men having sex with men (MSM) (7.3%), Female Sex Worker (FSW) (4.9%) and Sexually Transmitted Disease (STD) clinic attendees (2.5%).⁵

The primary drivers of HIV epidemic in India are unprotected paid sex/commercial female sex work, unprotected sex between men and injecting drug use.^{2,5} Of these, men attending sex workers remains the most important source of HIV infections. This observation is based on the 2006 National Behavioral Surveillance Survey finding that 2.4% of adult males had visited commercial sex worker during the year prior to the survey.⁵

Men who buy sex also constitute the largest infected population group in the country. These men then transmit the infection to their wives affecting several low risk women in the society.⁵ The spread of the infection in this way has fuelled concerns that the HIV epidemic in India may potentially transform from its present concentrated form to a more generalized epidemic.

To track the nature of the epidemic and to improve the scope and quality of information to inform decision-making about HIV prevention and care, a system for HIV Surveillance was established. It began around 1985 with the testing of blood donors and patients attending sexual health clinics by the Indian Council of Medical Research

(ICMR). Since then the process of estimating HIV prevalence and the population size of epidemic in India has progressively evolved. Up until 1992, surveillance was undertaken in 62 surveillance sites and nine referral centers. Following the establishment of the National AIDS Control Organization (NACO) in 1992, sentinel surveillance for HIV/AIDS was initiated, with sentinel sites initially confined to selected cities. In 1993–94, sentinel surveillance sites were established in antenatal clinics and sexual health clinics, and in 1994 the first HIV size estimation in India was done based on data from 52 sites.⁶ In 1998 NACO formalized sentinel surveillance and a systematic nationwide annual HIV sentinel surveillance (HSS) system was established. Under this system a network of sentinel surveillance sites were established that covered several population groups, including pregnant women, individuals attending STD clinics, FSWs, MSM and IDUs.⁶

Initially, sentinel sites were restricted to the high prevalence states, as a result of which many of these states have a strong network of sites, with each district having one or more sentinel sites. In 2007, it was estimated that 43% of ANC sites and 31% of HRG sites were in the six high prevalence states.⁶ Since 2006, the surveillance network has been expanded to cover all states in India, including the low prevalence states in Northern India.

Over a period of two-and-a-half decades, the country has established the largest HIV surveillance system in the world with 498 sites established in antenatal clinics and 717 sites reaching people belonging to HRGs, as reported in 2008.⁵

Table 1: Scale-up of Sentinel Sites by Year and Type from 1998-2008, India

Site Type	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008-09
STD	76	75	98	133	166	163	171	175	251	248	217
ANC	92	93	111	172	200	266	268	267	470	484	498
IDU	5	6	10	10	13	18	24	30	51	52	61
MSM	0	0	3	3	3	9	15	18	31	40	67
FSW	1	1	2	2	2	32	42	83	138	137	194
ANC-Rural	0	0	0	0	0	210	122	124	158	162	162
TB	2	2	0	0	0	0	0	7	4	0	0
Migrant	0	0	0	0	0	0	0	1	6	3	8
Eunuchs	0	0	0	0	0	0	0	1	1	1	1
Truckers	0	0	0	0	0	0	0	0	15	7	7
Others	0	0	0	0	0	1	0	0	1	0	0
Total	176	177	224	320	384	699	642	706	1126	1134	1215

Source: Annual Report 2009-10. NACO.

With the scale-up of sentinel sites, there has also been an expansion in the number of sites in the north-eastern states. Based on information available for 2008, the group-wise distribution of the sentinel sites in North-Eastern States for HIV Sentinel Surveillance is shown in Table 2.

Table 2 : State-wise Sentinel Site Distribution 2008 in NE States

State	STD	ANC	ANC-Rural	FSW	IDU	MSM	Migrant	Total
Arunachal Pradesh	7	6	0	3	2	0	0	18
Assam	9	16	0	14	2	1	0	42
Manipur	2	10	4	3	4	1	0	24
Meghalaya	3	1	6	0	0	0	0	10
Mizoram	2	8	0	1	5	0	1	17
Nagaland	1	11	8	1	8	0	0	29
Sikkim	1	3	0	1	2	0	0	7
Tripura	7	2	0	0	1	0	0	10

Source: Annual Report 2009-10. NACO.

As mentioned above, over the years the sentinel surveillance system has evolved remarkably both in terms of processes and implementing structure. While the expansion of the surveillance network has contributed to better estimates of HIV prevalence in the country, some limitations persist. Of these, probably the most evident is the application of HIV prevalence data among pregnant women attending antenatal clinics to generate national level estimates of people living with HIV.

However, despite some of the acknowledged shortcomings⁷ the sentinel surveillance data has been valuable in providing information about the geographical distribution of HIV and the relative magnitude of the problem in different groups. The data has also provided a basis to monitor trends in HIV prevalence over time, and identify groups or geographical areas for targeted efforts. Consequently, it has been used to inform the government's planning and budgeting, and to assess the effectiveness of interventions.

The key role played by surveillance data in understanding the nature of the epidemic has also highlighted the need to collect high quality data that provide an accurate estimate of the HIV prevalence. Poor quality data results in ill-informed policy and program planning, which may eventually contribute to an escalation of the HIV

epidemic. Thus ensuring representation of all key populations in the surveillance system, clear definition of the populations covered by the surveillance sample, adequate size of recruited samples, and comparability of surveyed populations between rounds, has remained a vital component of the surveillance system.

This document presents a description of the sentinel surveillance system in India, particularly in the light of the new operational guidelines prepared by the national program in 2008. In order to do this we have drawn on the available and relevant peer-reviewed and grey literature. The specific objectives of the document are to:

1. Describe the HIV surveillance system in India including its evolution and current organization.
2. Highlight the controversies, limitations and challenges surrounding the estimation of HIV prevalence and estimations of the number of people HIV-infected in India.

2. HIV surveillance in India

2.1 Background

The optimal method for estimating HIV prevalence and the nature of the surveillance system differs depending on the type of HIV epidemic the country is experiencing i.e. generalized or concentrated. In generalized epidemics HIV is mostly transmitted through sex between men and women in the general population i.e. people not necessarily recognized as engaging in high-risk behaviors. In this type of epidemic, a high proportion of the heterosexually active population is potentially infected with HIV, and HIV surveillance usually concentrates on pregnant women in antenatal clinics as a proxy measure of HIV infection among the general, sexually active population. In concentrated epidemics most infections are occurring in people from HRGs including IDUs, MSM and FSWs. HIV surveillance in concentrated epidemics focus on measuring HIV prevalence and risk behaviors among those most likely to be infected with HIV.

The HIV epidemic in India is generally considered to be a concentrated one though in some districts the epidemic has assumed a generalized pattern. Of 35 states and territories in 2005, 6 had a high HIV prevalence, as defined by an HIV prevalence of $\geq 1\%$ among women visiting antenatal clinics, and of $\geq 5\%$ among patients visiting STD clinics.⁶ The preliminary results of the 2008-09 HSS reveals that while HIV prevalence among ANC attendees has overall declined in high prevalence states, an increase has been observed in some low and moderate prevalence states such as Gujarat, Rajasthan, Orissa, Uttar Pradesh, Bihar and West Bengal. Of the 108 districts reporting an HIV prevalence $\geq 1\%$ among ANC attendees, a third of them (34 districts) were in

low prevalence states, and 87 districts reported an HIV prevalence of $\geq 5\%$ among HRGs.²

Information regarding the nature of the epidemic in India is derived mainly from the sentinel surveillance network. Over the years, this network has been scaled up in a phased manner, and the number of sentinel sites has expanded from a couple of centers through to 164 sites in 1998, and 1215 sites in 2008, providing a more representative picture of the epidemic.⁵

In earlier years of the epidemic, the emphasis of HSS was on heterosexual transmission, so sentinel sites were mainly located at antenatal clinics and STD clinics. However, in recent years the focus has shifted so there has been an increase in sentinel sites among HRGs. From 2003, the sentinel surveillance system has tracked prevalence trends in HRGs. Additional sentinel surveillance sites for bridging populations such as male migrants and long distance truckers have been introduced into the network.

Prior to 2003, almost all the surveillance sites were located in urban areas. To reduce the bias introduced by the extrapolation of HIV prevalence from urban to rural areas, sentinel sites were initiated in ANC clinics in rural areas as well, both at the district and sub-district level.⁸

In 2008, based on recommendations developed through a consultative process involving national and international experts, the HIV surveillance guidelines were revised by NACO. These revised operational guidelines have retained the overall objectives of the original HSS, but the methodology for HSS at the targeted intervention (TI) sites has changed. In the following sections we describe the HSS system in the country as outlined in the operational guidelines document prepared by the national program.⁸

2.2 HIV Sentinel Surveillance System

The HIV Sentinel Surveillance (HSS) system in India is one of the components of the second generation HIV surveillance in India.^a The system involves the conduct of cross sectional facility and Targeted Intervention (TI) based HIV sero-prevalence surveys at regular intervals among selected population groups, who are often referred to as "sentinel groups". The population groups monitored under HSS include pregnant

^a Additional components of the HIV sentinel surveillance system in India include:

1. The National Behavioural Surveillance Survey and the Integrated Biological & Behavioural Assessments Survey.
2. AIDS case & death reporting
3. STD Surveillance

women attending antenatal clinics, patients attending STD Clinics, FSWs, MSM, IDUs, high-risk migrants/ single male migrants and long distance truckers. Within these groups trends in HIV infection are monitored over time. The sentinel surveillance is conducted once a year in designated sentinel sites over a twelve-week period.

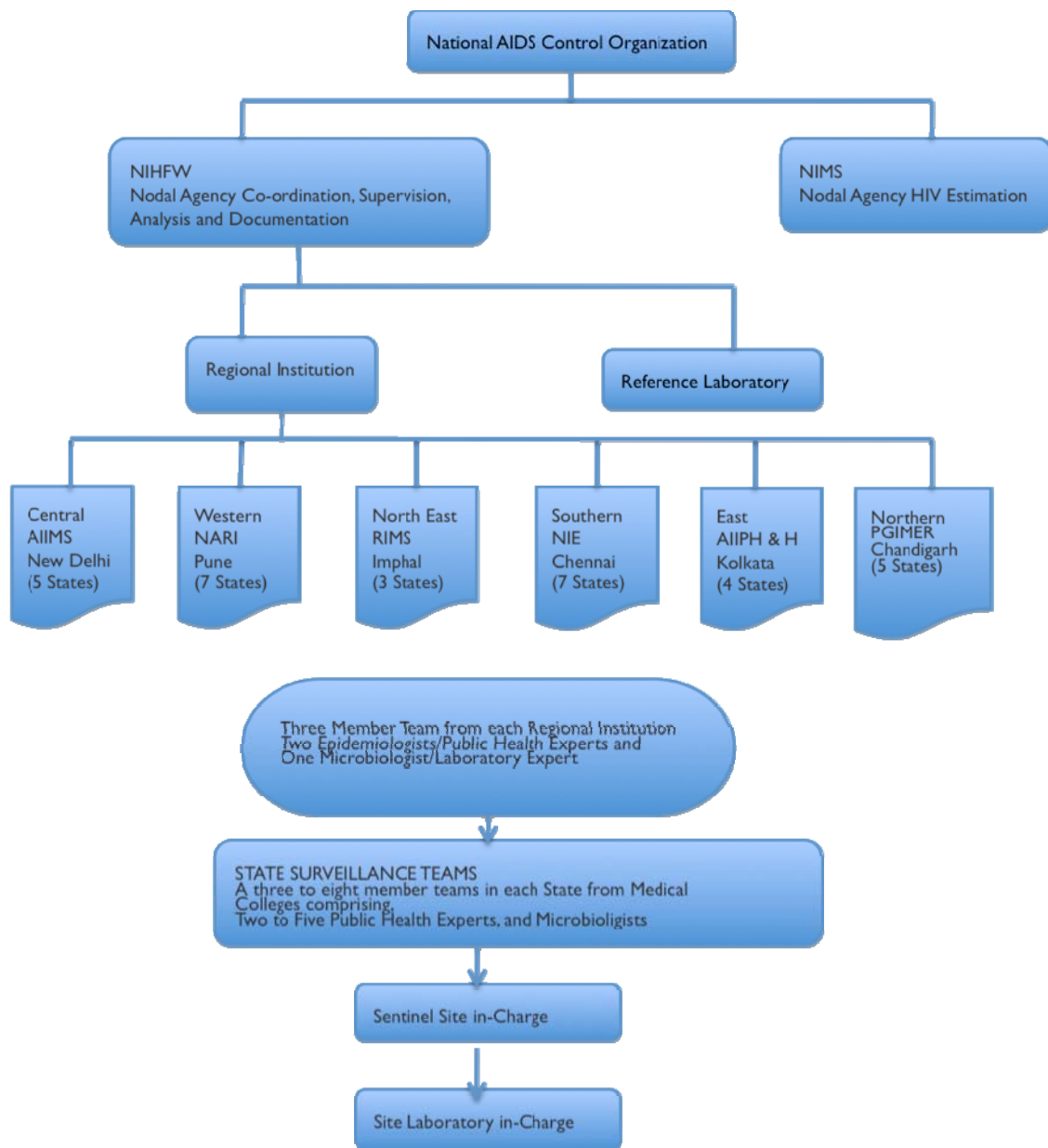
The main objectives of the HSS are to determine the prevalence of HIV infection in different population sub-groups and in different geographical areas, to monitor trends in prevalence of HIV infection over time, and to generate data for use in HIV estimations and projections. The HSS provides data to assist with public health planning in relation to advocacy, targeting, planning and prioritizing prevention and care programs, and monitoring and evaluation of these programs.

2.3 Organization structure of the HSS

The HSS is coordinated by the National Institute of Health and Family Welfare (NIHFW) and National Institute of Medical Statistics-Indian Council for Medical Research (NIMS-ICMR). They are also responsible for centralized data management with support from NACO. Seven regional institutes, appointed by NACO, are responsible for training, supervision, monitoring, data entry (data entry in addition to State AIDS Control Society) and analysis of regional and state level data. In addition, state and national reference laboratories have been identified that are responsible for HIV testing and Quality Assurance (QA) procedures in coordination with the regional institutes. The organization structure for the HSS is shown in Figure 1 below.

The State AIDS Control Societies (SACS) are responsible for implementation of the surveillance activities with support from the relevant regional institutes and State Surveillance Teams (SSTs). Each SST consists of 3-8 members, mostly from local medical colleges and comprising of 2-5 public health experts and 1-3 microbiologists. NACO provides guidance and budget for the conduct of the sentinel surveillance. An organizational chart for HSS at different levels of the health care system is shown in Figure 1. Both the regional institutes and the SACS are responsible for recruiting and training all staff involved in the HSS. The activities and responsibilities of the members of the sentinel surveillance team, is shown below (Table 3). The human resources required for each level of the HSS are detailed in Table 4.

Figure 1. Organizational Structure for HIV Sentinel Surveillance



Source: Annual Report 2009-10. NACO.

Table 3. Role and responsibilities of the HSS staff members

Staff Member	Key roles and responsibilities
Sentinel Site In charge	<ol style="list-style-type: none"> 1. Overall responsible for entire surveillance activities at her/his site 2. Ensures receipt of consumables/ data forms and prepares for surveillance 3. Obtains instructions for, (i) start / end date for sampling to begin, (ii) code for site, and (iii) sampling period 4. Attends training conducted by SACS and is well versed with eligibility criteria for the respective center 5. Trains all staff who might be involved in the clinic about eligibility criteria and HSS procedures on site 6. Ensures that guidelines are available for ready reference on site and other reference material such as flow charts/ booklets are made readily available to site personnel 7. Informs the clinic staff when to start collection of blood samples and data 8. Ensures eligibility criteria are being followed stringently 9. Ensures consecutive sampling 10. Ensures unlinked anonymous testing strategy 11. Makes provision for back up in case she/he is off duty during surveillance period including their training and sensitization 12. Ensures completion of data forms, checks and signs thereafter 13. Sends participants for venepuncture for syphilis screening 14. At end of each day, count number of data forms filled, ensure completeness of information, and duly sign each form
Nurse/Counselor	<ol style="list-style-type: none"> 1. Follows the direction of site in-charge 2. Assists site in-charge in identifying eligible people 3. Ensures that eligible person attends the site of blood collection, without fail 4. Ensures consecutiveness
Laboratory Technicians (ANC/STD sites only)	<ol style="list-style-type: none"> 1. Checks that the data form is complete and no item is missing 2. Collects blood specimen 3. Separates sera from collected blood as per guidelines 4. Ensures separate tips/ pipettes are used for each sample 5. Divides the sera obtained into two specimen vials (i) for syphilis testing on site and result, and (ii) for unlinked anonymous HIV testing at testing centre 6. Ensures unlinked anonymity of specimens 7. Stores coded vials at “+40C”, in a special box marked with sentinel site code and dates of collection for a maximum of 7 days only 8. Arranges for transport box with sera in icebox to HIV testing laboratory at end of week or daily if laboratory is nearby along with Transport Sheet in duplicate 9. Ensures cold chain is maintained 10. Ensures that biosafety procedures are followed at all times 11. Obtains (from the laboratory) a receipt for the sera transported on a copy of Transport Sheet

Staff Member	Key roles and responsibilities
Testing Centre in-charge	1. Ensures testing centre preparedness for the surveillance□2. Checks the availability of equipment, supplies and kits in appropriate amounts and in proper conditions□3. Follows the guidelines issued by NACO/ NIHFH for HIV and syphilis testing□4. Carries out and complete the testing at shorter intervals to prevent backlogs□5. Trains all the staff involved in HIV and syphilis testing□6. Participates in re-training of site lab technicians in case of deficiencies noted during surveillance period□7. Enters HIV/ Syphilis test reports on data forms and transfer to SACS□8. Participates in quality assurance by periodically sending samples to NRLs as per guidelines□9. Informs the clinic staff when to end blood and data collection□10. Forwards the completed forms to SACS/RI/NIFHW as directed
Laboratory Technician	1. Ensures quality of specimens received and checks the data forms received for completeness□2. Reports back to the survey site (through center in-charge) if poor quality of specimens received□3. Stores the samples as per guidelines□4. Fills the data forms for test results

Source: Operational Guidelines for HIV Sentinel Surveillance, NACO. 2008

Table 4. Health personnel involved in HSS

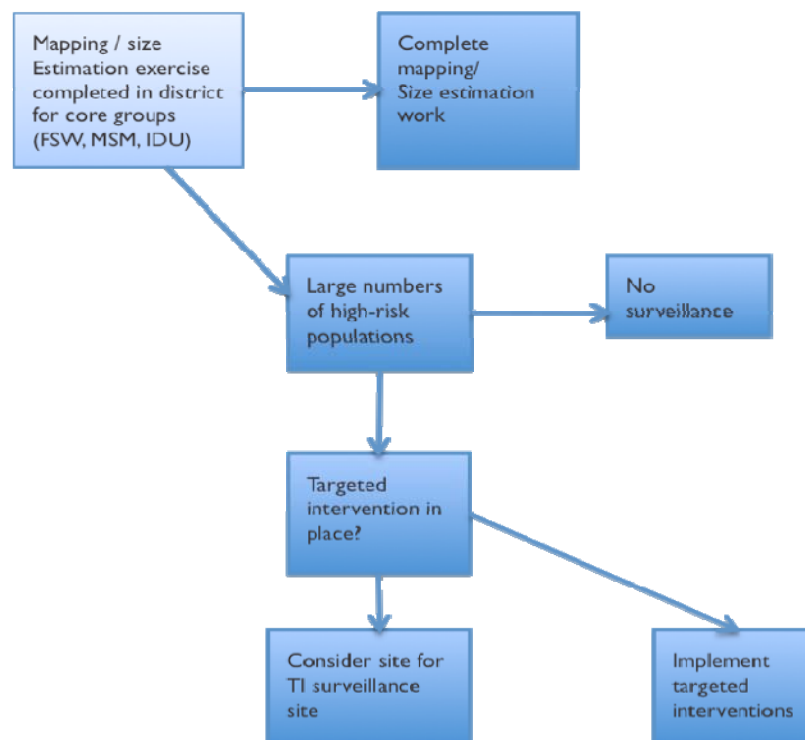
Institutions Involved	Cadre Involved
National AIDS Control Organization	Joint Director (Basic Services Division)□Technical Officer (Surveillance)
Technical Resource Group for Surveillance	As constituted
National Institute of Health and □Family Welfare, New Delhi	Nodal Person for HIV Sentinel Surveillance□Epidemiologist□Project Coordinator/ Research Officer□Data Manager/ GIS Technician□Computer Assistant
National Institute of Medical □Statistics, New Delhi	Director, NIMS, New Delhi Deputy Director, NIMS, New Delhi□Consultant for HIV Estimation
Central Team Members	As constituted
Regional Institutes (Seven)	Two Public Health Experts/□Epidemiologists□One Microbiologist□Project Coordinator/ Epidemiologist□Two Research Officers - Field and Lab□Computer Assistant/ Office Assistant□Data Entry Operators (Based on□Requirement)
State Surveillance Teams (One in□each State)	2-5 Public Health Experts 1-3 Microbiologists

Institutions Involved	Cadre Involved
State AIDS Control Society	Deputy Director (Surveillance) <input type="checkbox"/> State Epidemiologist <input type="checkbox"/> Focal Person at SACS for TI Programme <input type="checkbox"/> Constituted Team for Supervisory Visits
Sentinel Sites	Site In-charge (Medical Officer/ NGO <input type="checkbox"/> In-charge) <input type="checkbox"/> Lab Technician <input type="checkbox"/> Nurse/ Assistant
Testing Labs in states	Lab In-charge (Medical Officer) <input type="checkbox"/> Lab Technician
National Reference Laboratories <input type="checkbox"/> for EQAS of venous samples from <input type="checkbox"/> Testing Labs in States	Lab In-charge (Medical Officer/Professor) <input type="checkbox"/> <input type="checkbox"/> Lab Technician
Designated Laboratories for Testing DBS Samples	Lab In-charge (Medical Officer/Professor) <input type="checkbox"/> Lab Technicians (Based on Requirement)
NARI, Pune for EQAS of DBS <input type="checkbox"/> Samples	Lab In-charge (Medical Officer/Professor) <input type="checkbox"/> Lab Technicians (Based on Requirement)

Source: Operational Guidelines for HIV Sentinel Surveillance, NACO. 2008

2.4 Sentinel sites

HIV surveillance is conducted in sentinel sites identified by the national program. Since the initiation of HIV surveillance in India there has been a substantial increase in the number of sites, and at present almost every district in the country has at least one sentinel site for recruitment of people from one or more of the sentinel groups. According to the NACO Operational Guidelines,⁹ while the program does not plan to increase the number of ANC sites in the near future, it does plan to increase sites that recruit members from HRGs such as FSW, MSM and IDU. In areas with low HIV prevalence, the SACS have been encouraged to add new HRG sites based on the results of mapping exercises. A decision tree for selection of these new HRG sites has been developed (Figure 2).

Fig. 2 Decision tree for selection of sentinel sites for HRGs

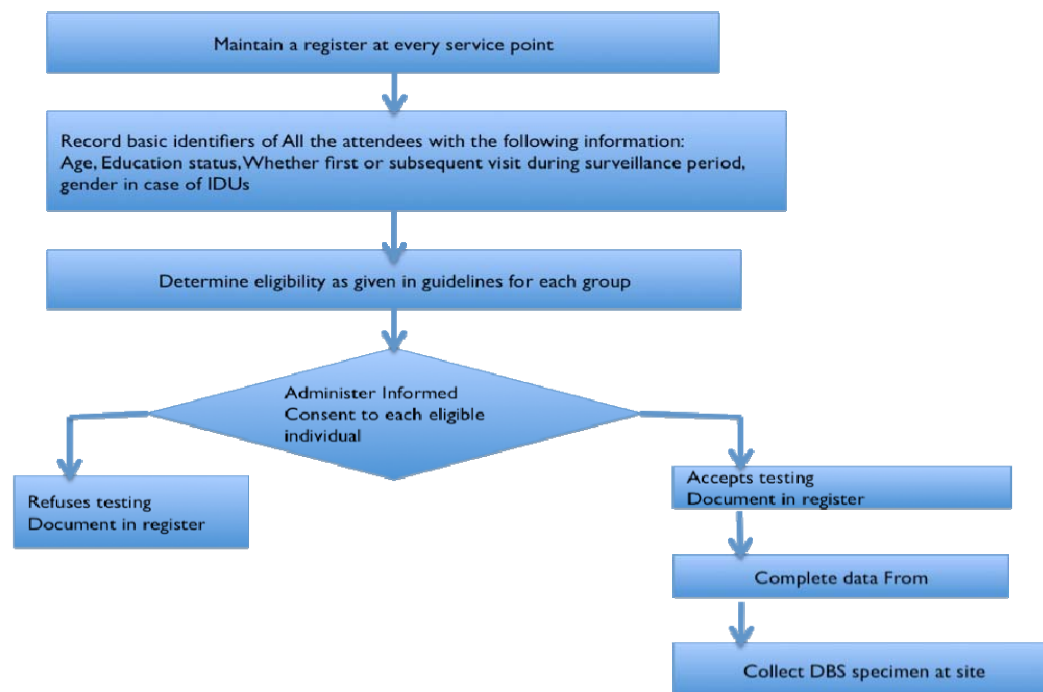
Source: Operational Guidelines for HIV Sentinel Surveillance, NACO. 2008

The WHO-NACO Technical Consultation report¹¹ mentions that problems were encountered in maintaining the validity of data in the previous rounds of the HSS. It further mentions that in some places this was due to pressure on local recruiters (such as NGO staff) to recruit sample sizes that exceeded the number of people who would routinely come to the sites. To overcome this problem, in the revised operational guidelines⁹ a provision has been made for geographic areas where members of the target population are shared among multiple agencies, and where placing a sentinel site at any single location is not likely to achieve the recommended sample size of 400 for ANC or 250 for STD. In such areas, additional sites termed ‘sub-sites’ can be established. The sub-sites combined constitute one ‘composite site’, and each sub-site has to contribute at least 50 samples. Each sub-site is included in all subsequent HSS rounds, and the proportion of the sample provided from each sub-site remains constant over time.

Prior to the collection of data, informed consent is taken from all individuals participating in the surveillance. Along with the blood sample for HIV testing, a minimal amount of socio-demographic information is collected using prescribed forms (Figure 3). All specimens collected for HIV testing are de-linked from all individual identifiers, and a

unique code number is provided that links the forms, specimens and laboratory results.

Figure 3. Procedure for data collection



Source: Operational Guidelines for HIV Sentinel Surveillance, NACO. 2008

3. Surveillance of the different sentinel groups

3.1 Surveillance at ANC sites

Pregnant women attending antenatal clinics in the government sector are recruited during the HSS. Typically these sites are selected according to patient numbers and the number of days the clinic functions to ensure that the desired sample size of 400 is achieved during the HSS period.

To avoid selection bias, consecutive sampling is used for recruitment. All pregnant women between the ages of 15-49 years visiting the designated antenatal clinics during the surveillance period are included. Women who have been recruited once, and who are attending the clinic again during the current surveillance period are excluded. Those women who have registered with the antenatal clinic prior to the surveillance period but are reporting to the clinic after the initiation of HSS are eligible for inclusion. In order to maintain the quality of data collection, it is recommended that in a day, at each site, not more than 20 consecutive attendees are included.

3.2 Surveillance at STD sites

The STD sentinel site consists of either the STD or the Gynecology clinics. These clinics may be in the same hospital or in two different hospitals designated by SACS for HSS in the same city or town. Consecutive new cases attending these clinics and diagnosed syndromically as cases of STD (i.e. cases of genital ulcer, urethral or cervical discharge and genital warts) are included. From each of the STD clinics a sample of 150 attendees and from Gynecology clinics sample of 100 are recruited.

Among the Gynecology clinic attendees, eligibility of women for inclusion into the sample is determined by visualization of the cervix to verify the presence of cervical discharge. Women with complaints of vaginal discharge not confirmed by physical examination are not eligible for inclusion. Women presenting to the Gynecology clinic with genital ulcers or ano-genital warts are included in the survey. All eligible women should be in the age group of 15-49 years.

In the STD clinics, new cases are defined as those reporting with a new STD episode during the HSS period. Cases that have been prescribed treatment for their STD and are attending for follow up for the first time during the period of HSS can also be included. Individuals with recurrent or new STDs who have visited the STD or Gynecology clinic in the previous years, who may or may not have been included in the previous rounds are eligible for recruitment in the present round if they present with a new STD episode. Similarly, referrals from private providers to the survey sites can be included in the sample.

3.3 Surveillance at Targeted Intervention sites

Traditionally, Targeted Intervention (TI) sites under HSS are defined as sites run by non-governmental organizations (NGOs) that serve high-risk populations like MSM, FSW, IDU, trans-genders, long distance truckers (LDTs) and migrants. These sites participate in HSS by recruiting clients from their clinics, drop-in centers, drug treatment centers (for IDUs), truck depots and stops (for long distance truck drivers), and other specially set up facilities or camps.

Recruitment of a sample of 250 members is recommended from these sites. While the sample requirement is considered to be valid for NGOs that have memberships above 250, to avoid artificial increases in the numbers through special campaigns or drives, a concession has been made for smaller TI sentinel sites. For those NGOs that have fewer than 250 clients registered, a "take all" approach has been suggested i.e. include all the beneficiaries who are eligible for surveillance. In the event that a TI sentinel surveillance site does not meet the required sample size, data from this site is still considered valuable and analyzed.

The different types of high-risk groups included in HSS and the required sample size for each group are shown in Table 5. The sample size required for high risk groups is lower than that specified for ANC populations as prevalence found among high risk groups is generally higher and the size of the high risk group population is relatively smaller in some geographic areas.

Table 5: High Risk Groups included in HSS (TI based)

Sentinel groups	Number of Samples per group
Female Sex Workers	250 or "Take all" approach
Men who have Sex with Men	250 or "Take all" approach
Injecting Drug Users	250 or "Take all" approach
Eunuchs / Trans-genders	250 or "Take all" approach
Single Male Migrants	250 or "Take all" approach
Long Distance Truckers	250 or "Take all" approach

Source: Operational Guidelines for HIV Sentinel Surveillance, NACO. 2008

Each TI surveillance site has to collect consecutive blood samples from target group members visiting the NGO clinics, drop-in centers, detoxification centers etc, from the start of the surveillance period till the predetermined sample size is reached or the surveillance period is over. In case of small TI sentinel sites, collection of samples from all the registered beneficiaries at the NGOs during the surveillance period is advised. The inclusion criteria for sampling for each sentinel group are described below.

The TI sites recruit members of the different sentinel groups including FSW, MSM, IDU, eunuch/transgender, long distance truck drivers, and male migrants. Male migrants include men in the transport industry, agriculture, quarry, or other factory work. Due to the separation from their regular partners, these men are more prone to have sex with FSW or MSM. For this reason, populations of migrant males serve as a proxy for the bridge population of male clients of sex workers.

The inclusion criteria for all sentinel groups are people aged 18-49 years who have not already been included in the current round of HSS. Those with known HIV status (positive/negative) can be included in the survey if they are registered with the participating NGO.

A major limitation of the HSS is that by definition the targeted individuals from each of

the sentinel groups are those who are reached by the intervention, and they are more likely to have been in contact with outreach staff and had exposure to behavior change communication, as well as being able to access free condoms, needles & syringes and STD services.

Table 6 summarizes the definitions, methods of recruitment, and limitations related to HSS among the various sentinel groups.

Table 6: Summary of definitions, methods of recruitment, and limitations for HSS among each of the sentinel groups

Target group	Definition	Recruitment sites and strategies	Group specific limitations
Female sex workers	Women who have sold sex for money /engaged in consensual sex for money or payment in kind as a principal means of livelihood in the last 6 months	All FSWs who receive services during the surveillance period In case of small TI sites, all registered FSWs are contacted and encouraged to participate	FSWs in touch with NGO services are more likely to be those who are comfortable identifying as sex workers and have been working for longer Part-time or home based FSWs are less likely to be represented
Men who have sex with men	Men who have engaged in sex - anal or oral - with another male at least once in the previous month	All MSM who receive services during the surveillance period In case of smaller TI sites, all registered MSM are contacted and encouraged to participate	MSM in touch with NGO services are more likely to be kothis/ receptive partners or male sex workers
Eunuch / transgenders	Participants who self-identify as eunuch / trans-gender	All eunuch / trans-genders who receive services during the surveillance period In case of smaller TI sites, all registered eunuch / transgender clients are contacted and encouraged to participate	
Injecting drug users	Participants who are either current or shadow drug users who have injected at least once in the previous six months	All IDUs who receive services during the surveillance period In case of smaller TI sites, all registered IDUs are contacted and encouraged to participate	IDUs in contact with NGOs are more likely to be dependent longer term users, so casual users are under-represented

Target group	Definition	Recruitment sites and strategies	Group specific limitations
Long distance truckers	Truckers who travel more than 800 km one way between source and destination	The typical recruitment sites for the LDT sentinel groups include truck stops, truck depots, Trans-shipment Locations (TSL) where TI sites (run by the NGOs) have interventions During the surveillance period, all LDTs presenting at recruitment sites are invited to participate NGO TI sites are invited to participate	
Male migrant workers	Men who are living at a place other than "place of usual residence" without spouse or family members for more than 6 months for purposes of work	The recruitment sites for male migrant sentinel groups include drop-in centers, clinics or other specially set up facilities run by NGOs All male migrants who receive services during the surveillance period In case of small TI sites, all registered male migrants are contacted and encouraged to participate	

4. Challenges faced by the HIV Surveillance System in India

India's HIV surveillance system has evolved over the years and has supported the National AIDS Control Program (NACP) by fulfilling several needs ranging from estimating the size of the HIV epidemic, identification of vulnerable groups, identification of areas for focused interventions, recognition of new and emerging hotspots, and assessing the impact of interventions. Despite efforts by NACP, the surveillance system continues to have limitations including insufficient coverage in some areas, selection biases that threaten the representativeness of the data, ethical issues due to unlinked anonymous testing, inadequate sample sizes, under-reporting of AIDS and STD cases, and lack of timely analyses of data.⁹ Some of these limitations are discussed in details below:

4.1 Limited coverage of high-risk groups

Since the establishment of the first sentinel surveillance network in 1998, the number of sentinel sites has increased more than 15-fold, but still HIV surveillance coverage is inadequate. This is particularly true for populations with high-risk behaviors. Almost half the districts in the country do not have sentinel sites for at least one of the HRGs.⁸ In 2006, only 386 districts out of a total of 609 had at least one sentinel site for either a defined population with high-risk behavior or STD patients. This suggests that for the remaining districts, there is no information on populations with high-risk behaviors.¹⁰

Moreover, the number of ANC sentinel sites exceeds the number of TI sites. This is a concern as in low level and concentrated epidemics like the Indian epidemic, ANC attendees would represent women who do not typically engage in risk behavior themselves hence would often be the terminal end of a chain of transmission that starts through commercial sex or unsafe injections. They are not considered useful as an early warning system of a potential local HIV epidemic as by the time ANC prevalence reaches 1%, the epidemic is already an established one, signaling the need for care, support, and treatment programs as well as prevention.⁷

Based on the above argument, surveillance in HRGs and setting up sentinel sites with the TIs is particularly important. This is the direction that the national program is currently heading. However, given that the HRGs are widely distributed, identifying suitable sentinel sites that will be able to contribute the required sample size continues to be a challenge.

4.2 Over-representation of urban sites

HIV prevalence in India is overall higher among urban than rural populations, but in states like Punjab, Tamil Nadu and Uttar Pradesh, the prevalence is slightly higher among the rural populations. The accuracy of HIV-infection estimates and projections, which are based on sero-prevalence data and limited surveillance coverage, has been questioned because of the limited capacity of the national surveillance network to reach vulnerable populations in rural and low-prevalence areas.¹⁰

In 2006, of the 628 ANC sites in the country, only one-fourth i.e. 158 were in designated rural sites. Moreover, even in the rural areas, the sentinel sites are mainly located in Community Health Centres (CHCs) in small towns or large villages which may not be typical of a rural location, thus they may not effectively capture women living in more remote rural areas. Data collected via the current sentinel surveillance system may therefore under-represent the rural populations. Rural areas have traditional forms of sex work, and rural women sometimes migrate for sex work.⁶ Despite this, sentinel sites for HRGs in rural areas have not been well established.

4.3 Lack of representation of private sector health facilities

The private sector in India plays a dominant role in the provision of health care services. In fact, it has been estimated that it accounts for 82% of outpatient visits, 58% of inpatient expenditure, and 40% of births in institutions.¹² Despite the importance of the private sector, in 2006 it was reported that all ANC and STD sentinel sites were located in government clinics.⁸

There is a high probability that the sentinel surveillance system misses a large proportion of pregnant women who seek care from private practitioners and individuals with STDs who attend private clinics. It has been reported that the data obtained from sentinel surveillance among ANC attendees is likely to overestimate HIV prevalence among all women in the community because: (1) women from a lower socio-economic status (who usually have higher HIV prevalence) are more likely to attend governmental facilities; (2) HIV-positive women may be disproportionately referred from private to governmental clinics.⁹

It can also be argued that HIV prevalence among HRGs and STD patients is likely to be underestimated because a large proportion of these individuals may not be seeking care at health facilities or attending the private sector clinics. Many STD patients do not ever attend health care clinics and instead self-medicate with over-the-counter drugs, and of those who seek care, three-fourths access the private sector.¹⁰

4.4 Over-representation of tertiary level facilities

At present most of the existing STD sentinel sites are located in tertiary-level health facilities such as teaching or referral hospitals. It is likely that these facilities cater predominantly to patients with chronic or recurring STDs. The same could lead to an overestimation of HIV among STD patients.⁹

4.5 Variability in coverage of antenatal check-ups

The percentage of women in India who have had at least one ANC visit varies between the states, and ranges from 56% in Jharkhand to almost complete coverage in Kerala.¹³ Given such variability, it is likely that in states with lower ANC utilization rates, the sentinel surveillance misses a large number of women who either do not come for antenatal check-ups or deliver at home.

4.6 Problems of sample size

The required sample size for monitoring changes in HIV prevalence over time depends on two variables: (i) the baseline HIV prevalence, and (ii) the magnitude of change in prevalence that the program wants to detect from one time point to another. The

smaller the baseline prevalence, the larger is the required sample size; the smaller the magnitude of change in prevalence that the program wants to detect over time, the larger is the sample size required to detect a statistically significant difference.⁹

For instance, in India, even among the high HIV prevalence states and districts, the prevalence is usually between 1% and 2%. To detect a 30% decrease in prevalence (from 1% to 0.7%) in areas with a baseline prevalence of 1%, at 95% confidence level and 80% power, a sample size of 14,000 is required. Thus, the sample size of 400 tested at ANC sites does not have enough power for monitoring site-wise and district-level trends even in high prevalence areas.¹⁰ Similarly, the sample size of 250 for the TI sites may not have enough power to monitor changes in trends.

However, increasing the sample size may not be feasible, not only because of the cost and logistics involved but also because of inability of the current sentinel sites to recruit the present sample size. For instance, in 2006 it was reported that nearly 40% of the STD sites were unable to recruit a sample of 250 during the surveillance period.⁹

4.7 Limitations of ANC data

The main purpose of ANC surveillance data is to understand the extent of HIV spread among the general population and to monitor HIV trends so that resources can be allocated appropriately. However, it has been suggested that the women attending ANC clinics are young and sexually active and do not use protective measures. For these reasons, data generated from ANC surveillance may be biased i.e. the prevalence in the general population may be over-estimated.⁸ Moreover, the use of ANC surveillance data to represent the general population is highly compromised by absence of data regarding the male population.

4.8 No provisions for the calculation of incidence data

The current surveillance system measures HIV prevalence in different population groups. With expanding Anti-Retroviral Treatment (ART) coverage and increasing life span of patients, the pool of HIV-infected persons is likely to increase in the future; therefore, measuring HIV prevalence alone may not accurately reflect the trends and current dynamics of the epidemic. For a better understanding of the current spread of infection, it will be important to measure HIV incidence. This is especially true for a concentrated epidemic, where measuring the incidence in populations with high-risk behaviors would be important to monitor trends and to assess the impact of interventions.¹⁰

4.9 Variable quality of surveillance data

The accuracy of HIV-infection estimates and projections, as based on surveillance data,

has been questioned over the years.¹¹ This questioning is not only due to limited coverage of the country by the surveillance network, but also because of concerns regarding the quality of the data collected at sentinel surveillance sites, mainly due to compromised adherence to established protocols.

5. Conclusion

In the past two-and-a-half decades, the HIV surveillance system in India has undergone remarkable changes both in terms of coverage, processes and implementing structure. Its network of sentinel surveillance sites has been expanded to include all districts in the country. This has helped to provide a more accurate estimate of HIV prevalence and has generated data to inform effectiveness of programs while guiding policies in the country. However, despite such contributions the surveillance system continues to have limitations that compromise the precision of HIV estimates generated based on information collected through the HSS.

In the context of the concentrated Indian epidemic, recent initiatives such the move to increase the number of TI sites in the surveillance network and the emerging potential to use new data sources such as provider initiated testing and counseling, prevention of parent to child transmission (PPTCT) and ART may improve our understanding of HIV transmission dynamics within the country and further strengthen the existing surveillance system.

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