### **Epidemiology of HIV in India and Scotland**

#### Dear Editor.

AIDS (Acquired Immune deficiency syndrome) is an infectious disease caused by a retrovirus called HIV (Human Immuno deficiency Virus) which attacks CD4 cells resulting in suppressed immune response.<sup>[1]</sup>

### HIV EPIDEMIOLOGY IN INDIA

The statistical data in WHO epidemiological fact sheet on HIV/AIDS was available from 1990 onwards and the overall trend showed a steep rise from 1990 to 2001 followed by a slow decline. The total number of adults (15+) and children living with HIV decreased from 2 700 000 (2001) to 2 400 000 (2007) of which 39% are females and 3.5% are children. The prevalence % (15-49) dropped from 0.45 to 0.34 during the same period though an increase of 0.2% was observed among young people (15-24) from 2005-07. [2]

If we monitor adult prevalence % (15-49) more specifically within the states (2006), Andhra Pradesh being the only state carrying a burden of more than 0.69% whilst rest of them shared a rate between 0.08% to 0.69% exempting Uttar Pradesh (less than 0.08%).<sup>[3]</sup>

Some of the preventive indicators such as Prevention of mother to child transmission (PMTCT) supported the current declining trend as the number of pregnant women receiving ART have increased from 4289 (2004) to 8816 (2007). Similarly in 2007 donated blood unit screening was also 100%. [2] The NACO annual report highlighted an increase of men having sex with men (MSM) and injecting drug users although sex continues to be the main mode of transmission. It continue its program NACP III (2006-2011) primarily preventing new infection amongst high risk group as well as offering care and support to PHLA (People living with HIV/AIDS). It aims to work in collaboration with Non Government Organisations (NGO), Community based Organisations (CBO), Tribal Strategy and Implementation Plan etc targeting rural populations.[4]

## HIV EPIDEMIOLOGY IN SCOTLAND

According to Health Protection Scotland (HPS) there are 5718 HIV positive cases in Scotland (2008) out of which 4154 (73%) are males and 1564 (27%) are females. It was

estimated that 38% of the total cases acquired infection abroad especially Africa whereas almost one third (2017) thought to be unaware of their AIDS status. [5] In 2008 Scotland 412 new cases were reported and Greater Glasgow and Clyde (141) along with Lothian (120) shared 63% of total Scotland's HIV/AIDS burden. [6]

The HIV/AIDS diagnosis, AIDS deaths and CD4 monitoring run in close proximity and parallel to each other during 1992-1996 and remain low as well. But since the introduction of combination HAART (Highly Active Antiretroviral Therapy) in 1996 the whole trend changed. The AIDS deaths declined thereafter whilst the diagnosis and CD4 monitoring showed a momentous rise. The diagnosis is usually made at GUM (genitor-urinary medicine) clinics and STISS (Sexually transmitted infection surveillance systems). There is an increase of 71% amongst people undergoing HIV tests from 2004-2008. [6-8]

The risk groups continue to be men having sex with men (MSM) and heterosexual non drug users as compared to injecting drug users (IDU) although prevalence % of MSM dropped from 4.4 (2007) to 3.1 (2008) and IDU increased slightly from 0.3% to 0.5% yet the overall scenario remains pretty much the same. [6-8]

# DESCRIPTION AND CRITICAL APPRAISAL OF HIV SURVEILLANCE SYSTEM IN INDIA

National AIDS Control Organisation (NACO) is a division of Government of India's Health Ministry which works for prevention and cure of HIV/AIDS when it was detected in India (1986).<sup>[9]</sup> It started NACP (National AIDS Control Program) since 1992 which is now in its third phase (NACP-III) and did most of its surveillance via HIV sentinel surveillance system (HSS) though it has also included other surveillance systems such as Behavioural Sentinel Surveillance (BSS) and PPCTC (Preventing Mother to Child Transmission) as well. [10] In general HSS is responsible for monitoring level, trend and spread of HIV/AIDS throughout the country along with the enlightenment of risk factors.

We will use the CDC's Framework for Program Evaluation in Public Health<sup>[11]</sup> to describe HSS as it forms the core of NACP

strategies and policies for combating HIV/AIDS epidemic. As per Task 'A'<sup>[11]</sup> which requires engagement of stakeholders for evaluation is partly described in the form of health professionals (practitioners, nurses and allied health staff) but data providers, and representatives of organisations are missing.<sup>[12]</sup> Although their involvement is inevitable it's perhaps their description which is missing from the surveillance report.

The first part of Task 'B'<sup>[11]</sup> dealt with the public health importance of the event under surveillance. The indices of frequency i.e. prevalence, mortality rates etc are disseminated as 'HIV Fact Sheet' separately<sup>[14]</sup> and severity measures of quality of life, years of healthy life etc are completely absent. Also it's not emphasised that they are responsible for making HIV/AIDS an important public health issue.

The second part is perhaps the most important one concentrating on the purpose and operationalization of surveillance system. The objectives seem quite convincing aiming to monitor disease prevalence over a period of time and in various geographic locations. The planned use and the citation of legal authority for data collection is vaguely written but the place where data evaluation is done in the organisation is skipped quite clearly. [13] Though it is said to be working in integration with PPCTC, BSS and ANC surveillance systems yet there isn't any hint of defining the extent and methodology of this collaboration. Flow charts are drawn throughout elaborating issues such as organisation and implementation of HSS in general, informed consent, HIV testing strategy, flow of data, quality assurance etc.[13]

Moving on to the components of the HSS, population under surveillance would be the data collected from people visiting ANC (Ante Natal Care) and STD (Sexually Transmitted Diseases) sites although high risk groups for HIV/AIDS in India are female sex workers (FSW) and injecting drug users (IDU) and this has been given less emphasis making results a bit dubious. [12, 14] Data collection is carried out every year but the exact period of time required is not mentioned.<sup>[13]</sup> It is collected in the form of blood samples of 5ml each from ANC and STD sentinel sites under the strategy of unlinked anonymous testing (UAT) with informed consent. The inclusion criteria for ANC sites would be the women (15-49 years) attending clinic for the first time and consecutive first time visitors are recruited to get a sample size of 400. For STD sites all new STI cases are included with a sample size of 150.<sup>[13]</sup> The methodology involved in collection of blood, its storage and transportation is quite clear but data informatics i.e. formatting, coding and backup is not precisely described

Patient privacy and data confidentiality is maintained throughout by the personnel taking all necessary steps for protocol adherence, collecting minimal socio-demographic information and using a unique code for linking data form to lab results. [13] Also not much is said about the government policies on data release although information is disseminated in the form of technical report and fact sheet on a regular basis.

**Resources:** The third part is all about resource description and no clear guidelines are provided here about the financial and other maintenance sources but there is a word about human resource engaged at certain levels of the system. [12, 13]

Task 'C' concentrates on the evaluation design and as stated earlier the purpose and the intended use of the surveillance system is quite definite. The problem might be the execution of designed strategy fairly consistently at all places.

Task 'D' uses different criterion to describe the overall performance of the surveillance system. It is useful in the sphere of its working but appropriate coverage is by far the biggest challenge keeping in mind the vast country size.

The second part evaluates HSS in terms of each system attribute. Simplicity: It works on the principle of simplicity as its data collection follows case ascertainment definition with the involvement of only few organisations and used methodology is quite straightforward. Moreover there is no special laboratory requirement for testing samples or multiple levels of reporting as well. [13]

<u>Flexibility:</u> It is somewhat flexible as it integrates with the Behavioural Sentinel Surveillance (BSS) in its third phase i.e. NACP-III which is one of the flexibility criteria of CDC evaluation framework. [10]

<u>Data Quality:</u> HSS relies on the site in charge for completeness of all forms and do periodic checks at HIV laboratories by External Quality Assurance Scheme (EQAS) to ensure data quality <sup>[13]</sup> but still missing statistics are found at some places in disseminated reports. <sup>[14]</sup>

Acceptability: The expanding agenda of the HSS manifests its acceptability to some extent but its inability to respond to a variety of recommendations owing to economic costs

<u>Sensitivity</u>: There are question marks over HSS sensitivity as the HIV prevalence

decreased from 0.45 (2001) to 0.36 (2007) [2] and there isn't any description about sensitivity anywhere in the surveillance report.

Predictive value positive: The use of DBS (Dried blood Spot) method of sample collection and then treating with either ELISA or Western blot is 100% and 93% sensitive and its cost effective as well especially when transportation is required from remote areas. [3] This might hint the existence of few false negative cases but predictive value positive again like sensitivity is nowhere discussed in HSS.

Representativeness: HSS seems to fulfil representativeness criteria as its reports shows the population characteristics, geographical distribution taking into account factors such as age and socioeconomic status. But are the sample sizes of 400 and 250 used at ANC and STD sites respectively large enough.

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