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Expert Consultation on

HIV Surveillance and Estimations in India

27–29 September 2016
New Delhi

National AIDS Control Organisation
Ministry of Health & Family Welfare
Government of India

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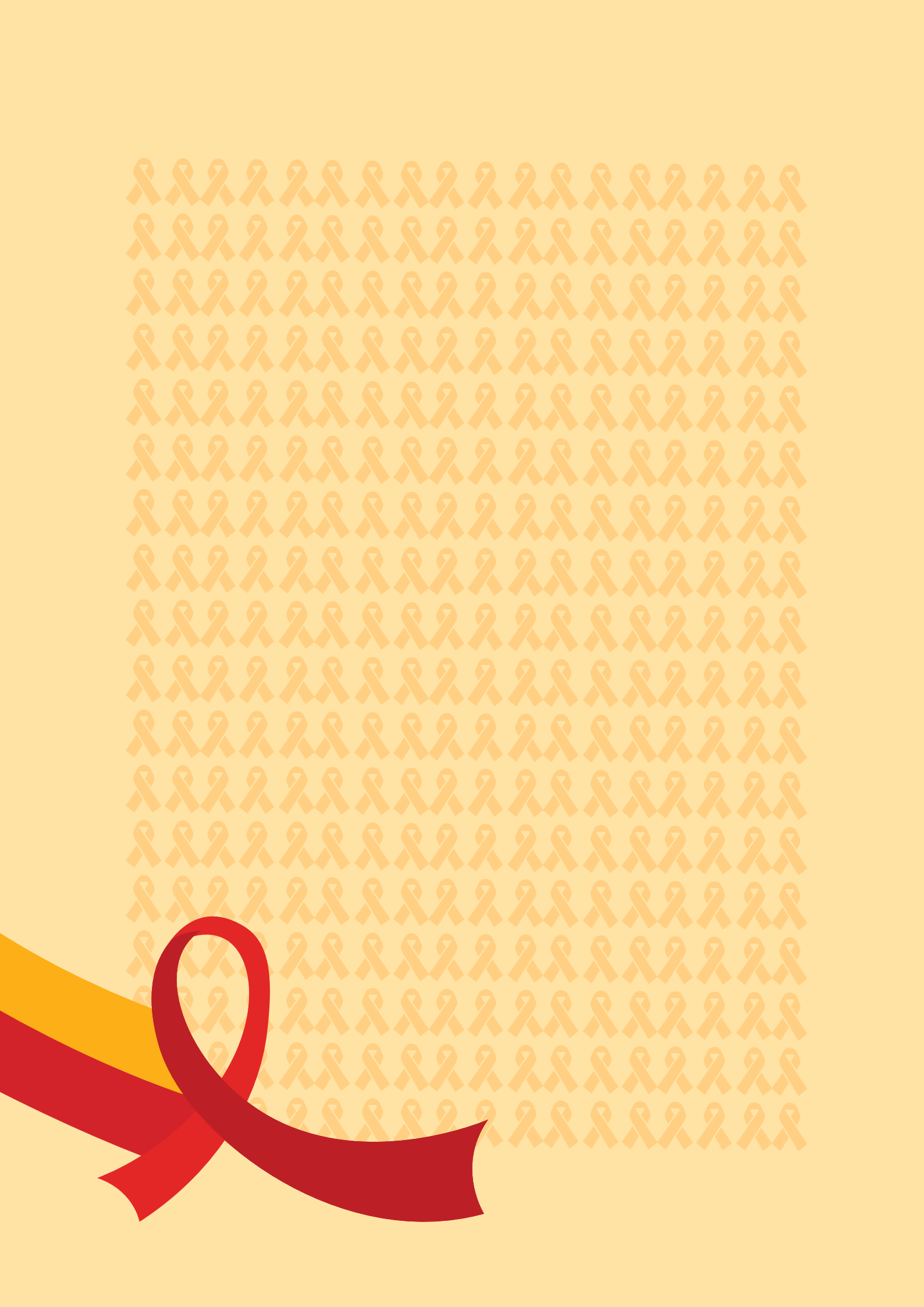

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सत्यमेव जयते

NACO

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FOREWORD

HIV Surveillance in India has been one of the oldest and most integral components of a comprehensive AIDS response in country. HIV sero-surveillance was initiated as early as 1985 by Indian Council of Medical Research (ICMR) and has been credited with discovery of first HIV case in 1986. Over the years, the system has evolved into one of the world's largest and most robust surveillance system in country.

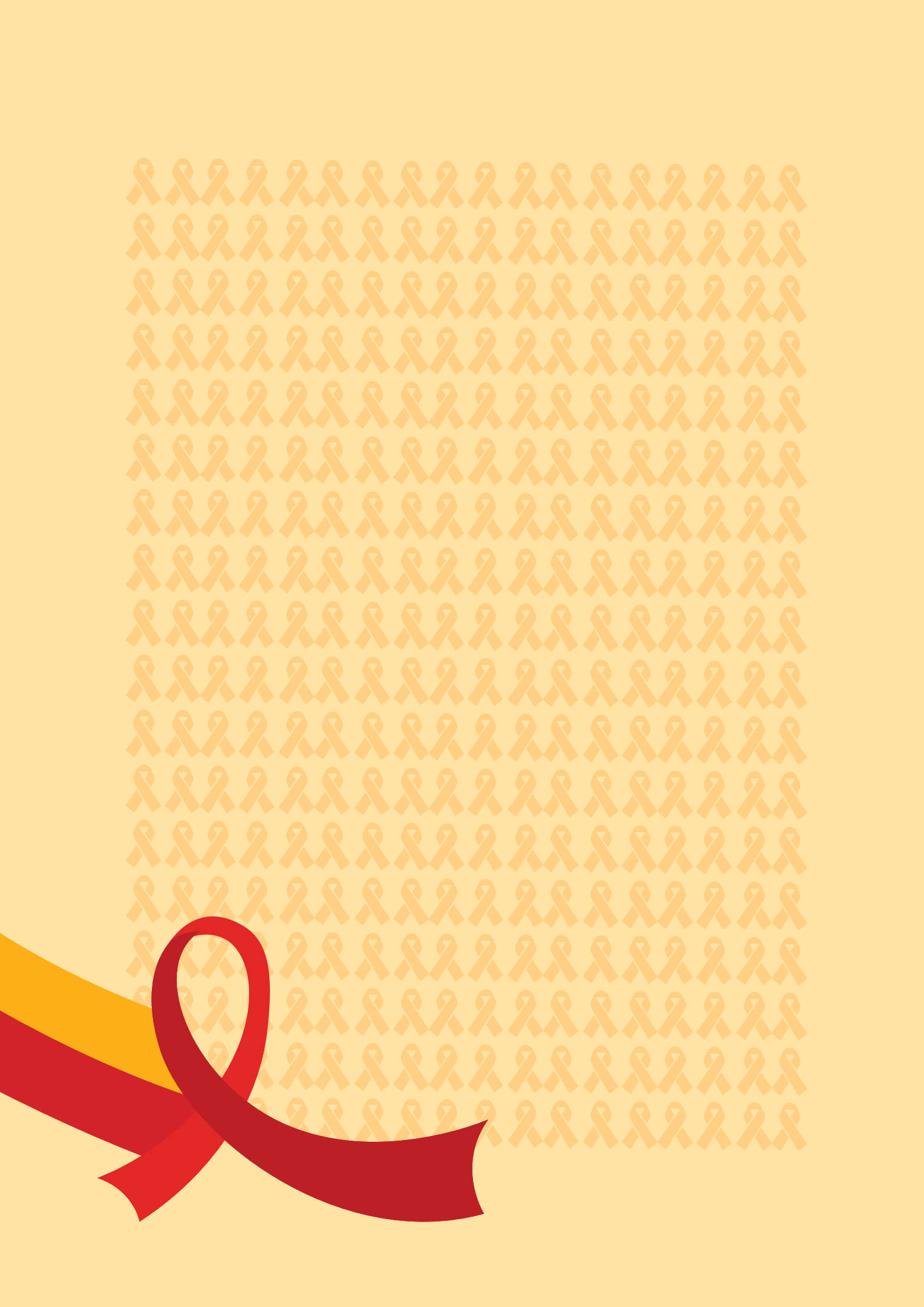
The first generation of surveillance focussed on monitoring HIV prevalence. As the programme matured, second generation of surveillance were launched which encompassed a comprehensive range of surveillance activities including that of behavioural surveillance. The current global context urges the system to not only provide evidences on level and trend of HIV prevalence, incidence and related risk behaviours but also on the progress on cascade indicators including that on virological status.

The Surveillance system in India evolved concurrently with the programmatic need and epidemiological considerations. The system, which was formally launched in 1998 at annual HIV sentinel surveillance at 196 sites, also implemented world's largest integrated bio-behavioural surveillance in 2014-15. However, as country committed to achieve End of AIDS as a public health threat by 2030, information needs increased in the form of country efforts to monitor the progress on fast-track targets. Also, the need for the integration of additional bio-markers like hepatitis in HIV sentinel surveillance has been considered a natural progression in view of similarity in route of transmission and at-risk population group. New and efficient surveillance strategy providing the periodic status on critical behaviors, knowledge and service uptake indicators has been an unmet need. Also, the information needs for district level planning and monitoring increased as programme managers demanded for district level estimation to measure the AIDS response progress.

In the light of the global developments in the form of END of AIDS and Fast Track targets, epidemiological considerations and programme need, National AIDS Control Organization, in collaboration with UNAIDS India, WHO India and CDC India, organized technical consultations on next generation of HIV surveillance and estimation activities in 2016 and 2018. The meeting was attended by wide range of stakeholders including, national and international experts as well as representatives from national institutes (Indian Council of Medical Research [ICMR], National Institute of Health and Family Welfare [NIHFW], National Institute of Medical Sciences [NIMS], All India Institute of Medical Sciences [AIIMS], National Institute of Epidemiology [NIE], National AIDS Research Institute [NARI], Post Graduate Institute of Medical Education and Research [PGIMER], National Institute of Cholera and Enteric Diseases [NICED], Regional Institute of Medical Sciences [RIMS]), State AIDS Control Societies (SACS) and partner agencies, Family Health International (FHI360), Population Council etc. The technical discussions from these meetings are being published the form of reports.

The expert consultations have been extremely rich in terms of quality of deliberations. While the consultations aimed to provide roadmap to the India's epidemic monitoring system, the contents may be relevant of any country aiming to upgrade its surveillance system. I am confident that the reports will be reference documents locally as well globally as countries aim to developing a surveillance system monitoring the progress on End of AIDS by 2030.

(Sanjeeva Kumar)



आलोक सक्सेना
संयुक्त सचिव
Alok Saxena
Joint Secretary

राष्ट्रीय एड्स नियंत्रण संगठन
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PREFACE

Evidence driven policy making, intervention design and programme implementation is one of the hallmarks of India's AIDS response. A strong, institutional mechanism and an evolving surveillance system for epidemic monitoring has been the core to the spectrum of strategic information under national programme. Initiated as early as 1985, the surveillance system has evolved into one of the world's largest and most robust HIV surveillance system.

The national programme undertakes technical consultations periodically to review the current status and work out the future roadmap of HIV epidemic monitoring in India. Experts consultations in year 2016 and 2018 were in the series of such consultations to augment the HIV Surveillance and Estimations System in India in the era of Sustainable Development Goals.

The reports present the objectives, methodology, recommendations and rationale from expert consultations on HIV surveillance and estimations in India. The publication of these report is particularly timely and relevant, as the country has started to take many new initiatives not only to augment the epidemic monitoring but also to strengthen the programme response to achieve the 'End of AIDS' as a public health threat by 2030. Many of the recommendations from these expert's consultation are either already implemented or vetted by Technical Resource Group (TRG) on HIV Surveillance and Estimation in India for future adoption. One of the key changes is to return HIV test results to participants facilitating linking with treatment services as well as to provide the cross-sectional progress update on treatment cascade. District level HIV burden estimation is under process; BSS lite has been in-principle approved by TRG while modalities for integration of Hepatitis are being worked-out.

The reports of 2016 and 2018 expert's consultations will be useful to all stakeholders as they further underline the outcome driven approach under the surveillance system of the National AIDS Response. I hope that these reports will be referred to by those who are working in the area of HIV epidemiology to understand why and how a disease surveillance system evolves and provides relevant evidences in the most efficient way to strengthen the decision support systems.

(ALOK SAXENA)

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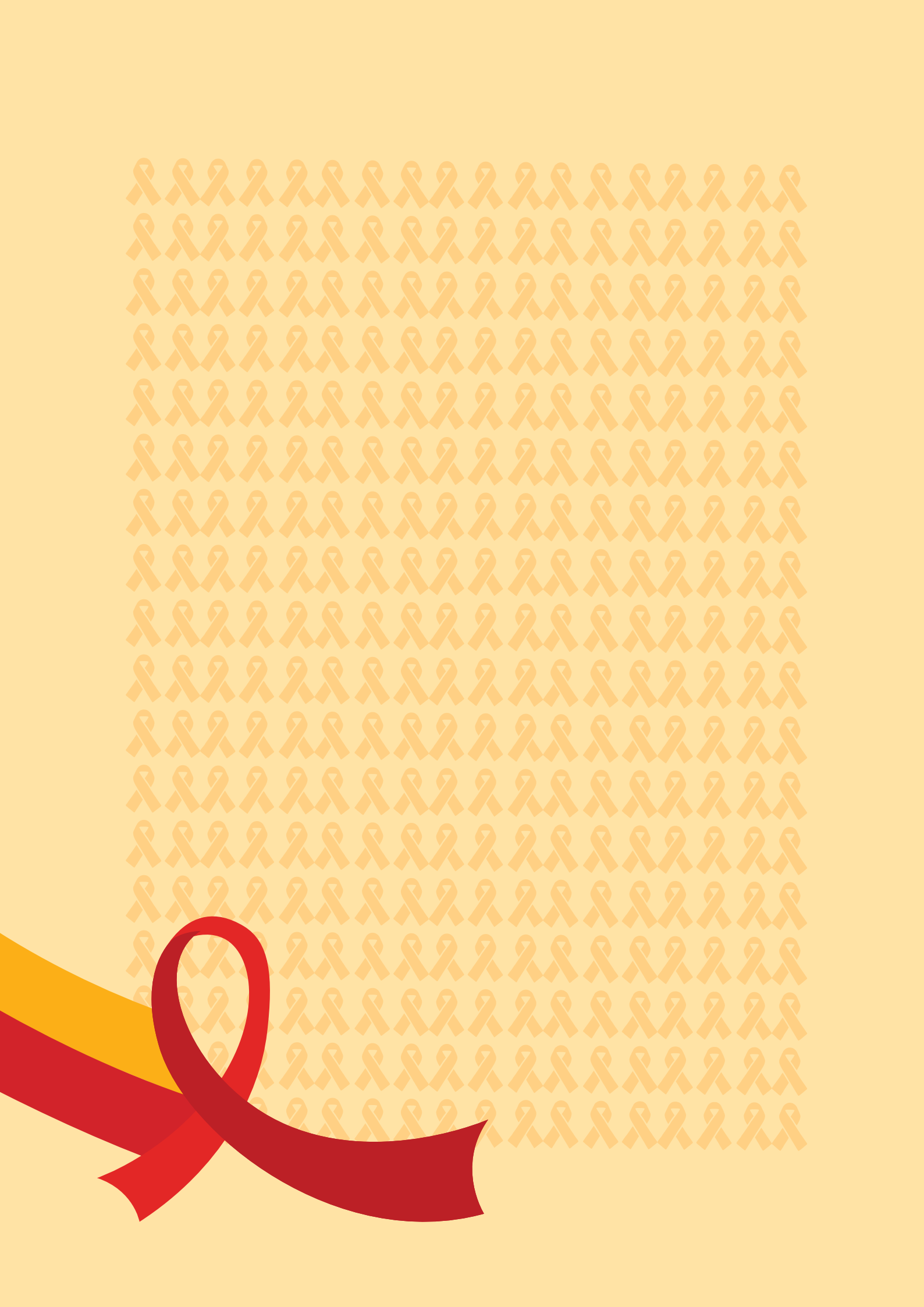
अपनी एचआईवी अवस्था जानें, निकटतम सरकारी अस्पताल में मुक्त सलाह व जाँच पाएँ
Know your HIV status, go to the nearest Government Hospital for free Voluntary Counselling and Testing



MESSAGE

Ending the AIDS epidemic is only possible when adequate and timely strategic information is produced and used to guide the response. India has shown strong global leadership in this regard since the start of the epidemic in 1986. The HIV surveillance that was introduced at that time has over the years grown into a comprehensive system involving many sources of data. The strategic information system has regularly been assessed and findings used to further strengthen it.

The Expert Consultation Meeting on HIV Surveillance and Estimations held by the National AIDS Control Organization (NACO) on 27-29 September 2016 in Delhi was a critical step in this process. Overall, the participants acknowledged that each individual data source has both strengths and limitations, hence the need to use them in combination. Concrete recommendations were put forward which will help NACO to further strengthen the strategic information outputs and guide the response to the epidemic.

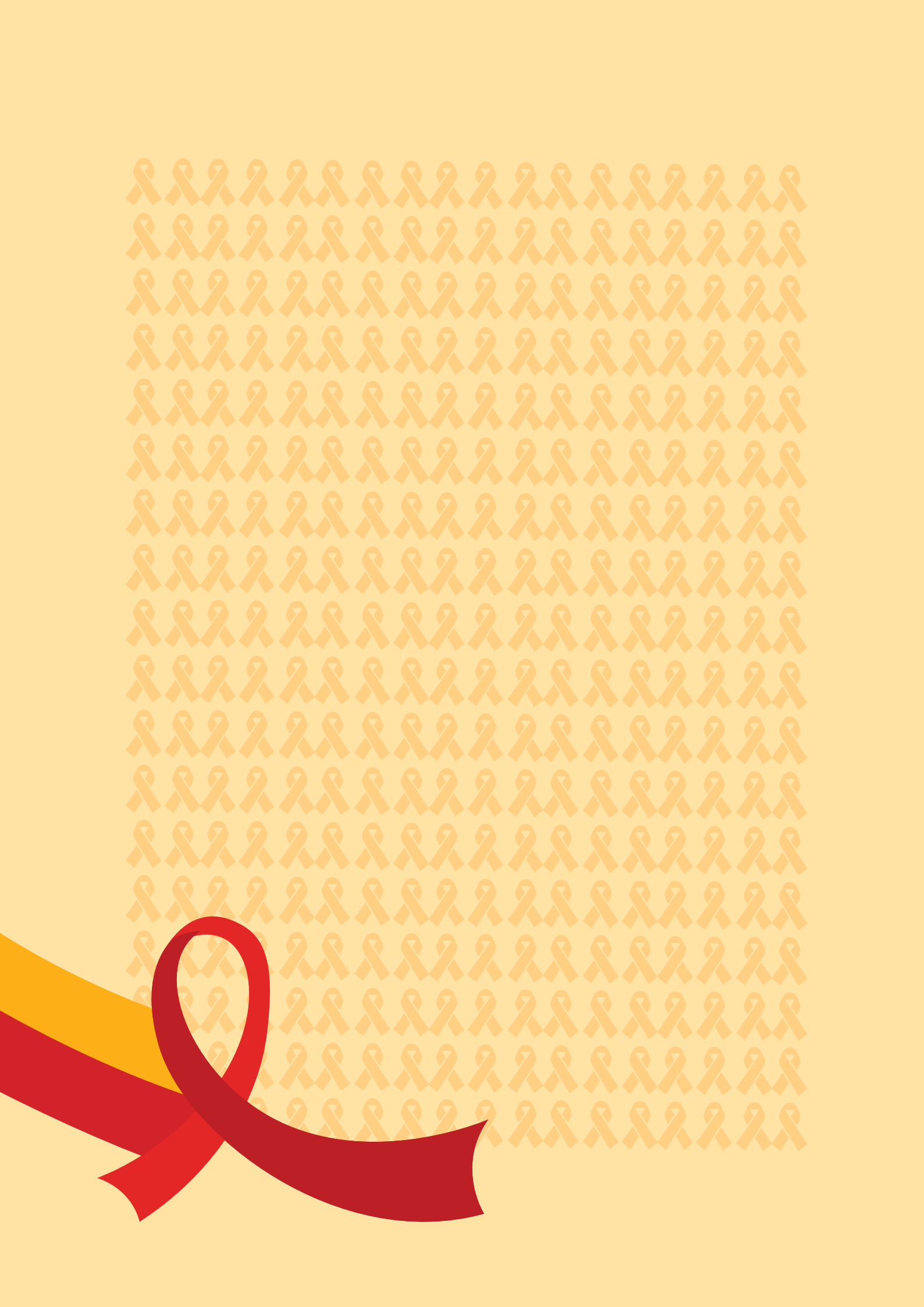
An important consensus from this consultation is that available data must be better used, while exploring more cost-effective ways to generate new data to fill strategic information gaps. Therefore, a more effective use of routine programme monitoring data is an important step. The vast expansion of HIV testing among pregnant women to prevent mother-to-child transmission of HIV and the data accumulated thereby present a great opportunity to progressively replace the more costly and time-consuming periodic sentinel surveillance to track the epidemic among pregnant women and the general population.

Use of routine monitoring data among key populations is more difficult because of persisting stigma and discrimination which limits their universal access to HIV services. Therefore, efforts need to be made to improve representativeness of these data to reflect the situation not only of people who are accessing and benefitting from the services, but also of those who are left out of service coverage.

As the epidemic in India remains concentrated, it is necessary to continue gathering both biological and behavioural data among the key populations. This will allow to assess trends, measure progress and identify pockets of populations and key locations where to focus interventions. In this regard the adoption of an HSS Plus approach will help, especially when large-scale integrated bio-behavioural surveillance surveys cannot be repeated. Adding biomarkers of Syphilis and Hepatitis C and return of test results in line with global recommendations are other measures that should be introduced.

Improvements in surveillance data will results in better estimations of HIV burden in India. Their quality depends, not only on the quality of the data inputted into the Spectrum tool, but also on the robustness of assumptions embedded in the model. It is therefore advisable to follow through on plans to better tailor epidemiological modelling assumptions in Spectrum to the Indian context. This, together with the update of key populations size estimates, as recommended again in this expert consultation, will help obtain the strategic information that is required to make AIDS a challenge of the past.

Dr Bilali Camara
Medical Epidemiologist
UNAIDS Country Director for India



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Dr Henk Bekedam (WHO Representative to India), Dr Oussama Tawil (Former UNAIDS Country Director for India), Dr Bilali Camara (UNAIDS Country Director for India), Dr Timothy H Holtz (Director, CDC-DGHT India) and Ms. Sara Heydari (HIV/AIDS Division Lead, USAID India) ensured limitless and unwavering support towards organizing these consultations.

Dr S Venkatesh (Former DDG, MES, NACO) and Dr Neeraj Dhingra (Former DDG, MES, NACO) provided the leadership to organize these high-quality consultations of global standards. Dr R.S. Gupta (DDG, NACO), Dr Naresh Goel (DDG, NACO), Dr Kuldeep Singh Sachdeva (Former DDG, NACO), Dr Asha Hegde (NPO, NACO), Dr TLN Prasad (Former Technical Expert), NACO Mr Kannan (Former Technical Expert, NACO), Dr Suman (PO, NACO), Dr Shivali Kamal (PO, NACO) and Ms H. MaringaihKim (PO, NACO) provided programmatic insights into epidemic monitoring.

Dr Pradeep Kumar (PO, NACO) designed and coordinated the expert consultations. Dr Savina Ammassari (UNAIDS, India) collaborated with national team on technical and operational aspects. Dr Taoufik Bakkali (UNAIDS, Bangkok) and Dr Nicole Seguy (WHO India) moderated the technical sessions. Dr Laxmikant Chavan (WHO India), Dr Pamela Ching, Ms Deepika Joshi (CDC India) and Ms Nalini Chandra (UNAIDS India) provided technical insights. Ms Mariyam (PO, NACO), Dr Bhavna Sangal (Former TO, NACO), Ms Anita Guliyani (Programme Assistant, NACO), Mr Sudarshan Mishra (IT support) and Mr Kaushlendra Upadhyay (IT support) ensured the successful organization of high-quality expert consultations.

(Shobini Rajan)

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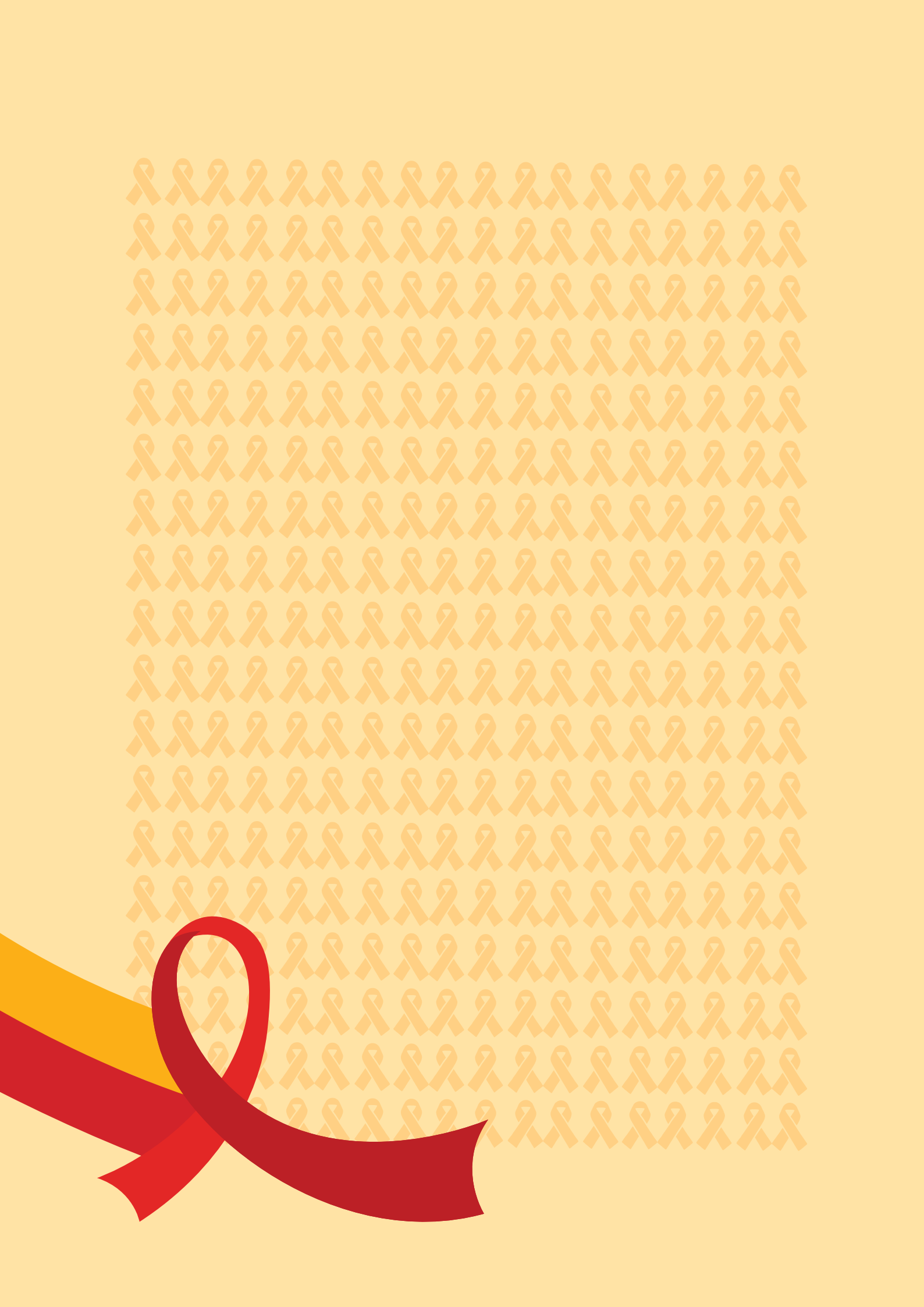
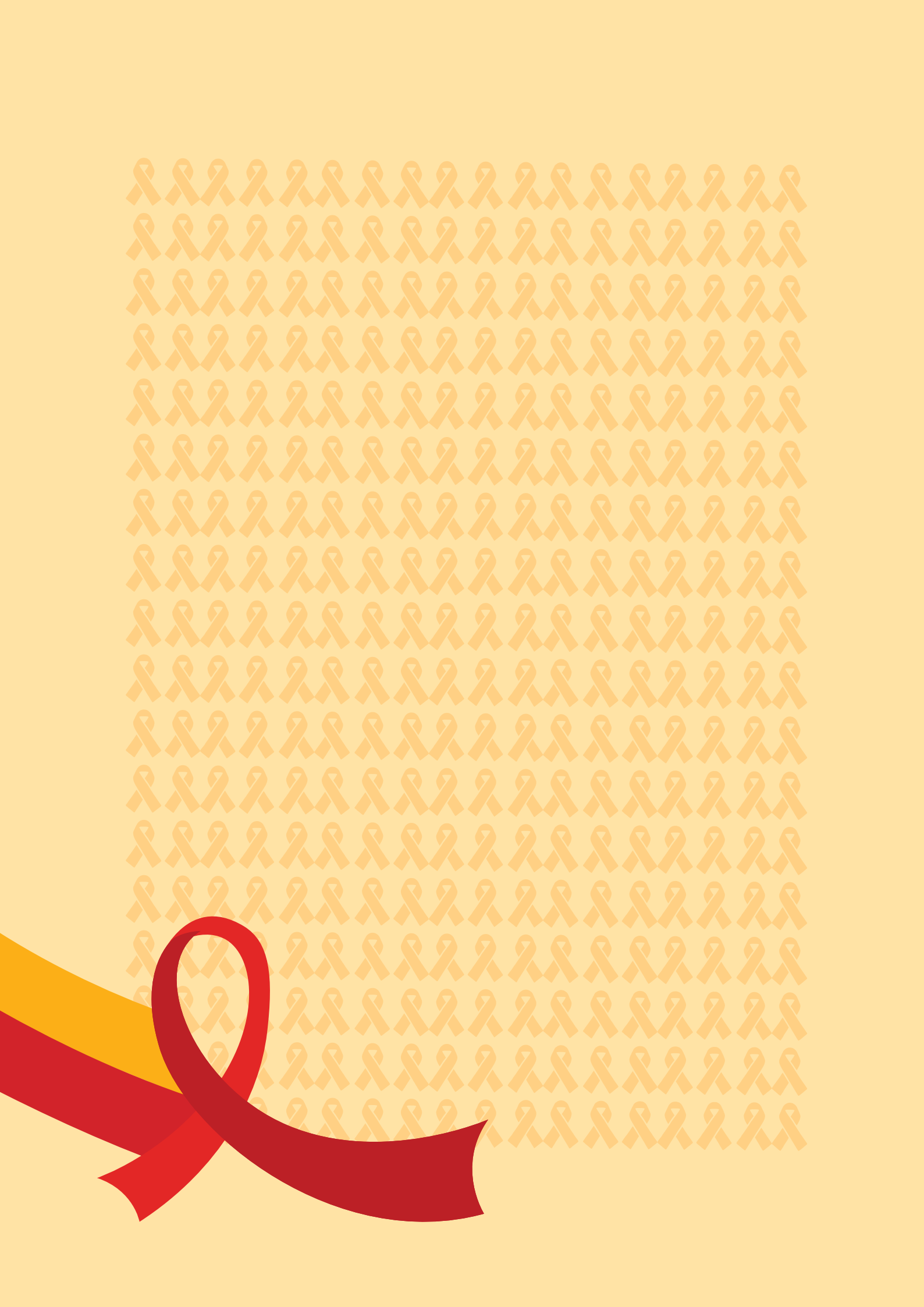


ACRONYMS

ACASI	Audio Computer Assessed Self-Interview
AEM	Asian Epidemic Model
AIIMs	All India Institute of Medical Sciences
ANC	Antenatal Care
ART	Antiretroviral Therapy
FSW	female sex worker
HSS	HIV Sentinel Surveillance
HARP	HIV/AIDS and ART Registry of the Philippines
HRG	High Risk Group
IDU	Injecting drug users
IBBS	Integrated Biological and Behavioural Survey
IHBSS	Integrated HIV Behavioural and Serologic Surveillance
IMS	Inventory Management System
ICTC	Integrated Counselling and Testing Centers
MSM	Men who have sex with men
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NIMS	National Institute for Medical Sciences
NFHS	National Family Health Survey
PALS	PMTCT ART Linkages System
PIPPSE	The HIV/AIDS Partnership: Impact through Prevention, Private Sector and Evidence-based Programming
PMTCT	Prevention of mother-to-child transmission
PWID	People who inject drugs
PLHIV	People living with HIV
RAV	Rapid Assessment of HIV Vulnerability
RDS	Response driven sampling
SIMS	Strategic Information Management System
STI	Sexually transmitted infection
TG	Transgender
TI	Targeted Intervention



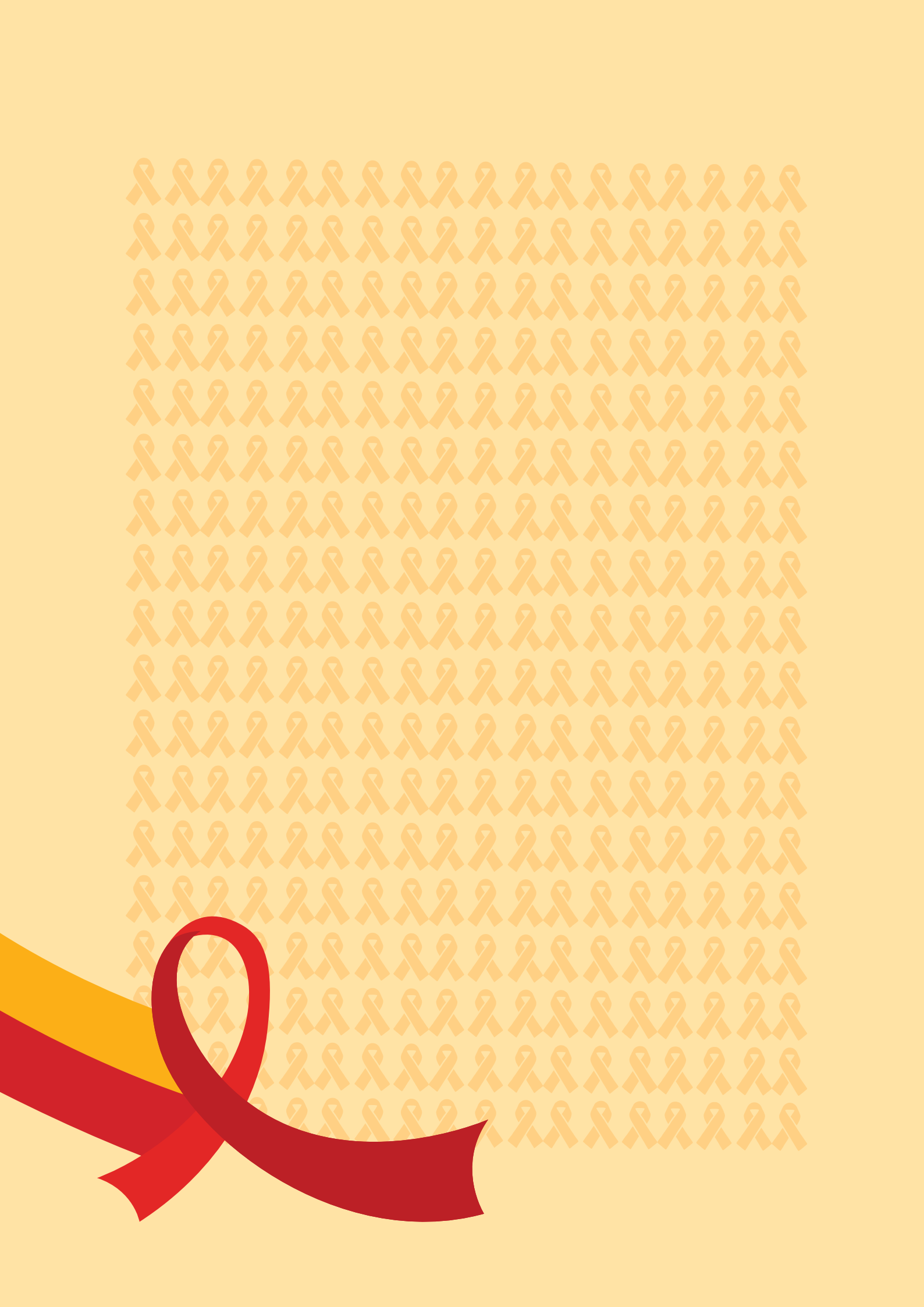
1 BACKGROUND

India's HIV surveillance system has grown in the past 30 years, since the first case of HIV was detected in 1986 in the state of Tamil Nadu. Today, the country has one of the world's largest networks of sentinel sites which, together with other sources including programme monitoring data, has generated a large amount of data that have been used to guide, monitor and evaluate the response to the epidemic at the national, regional, state, district and local levels.

The response has achieved reductions in new HIV infections and AIDS-related deaths in the country, resulting in a reversal in epidemic trends at the national level. This reversal is attributable, among other things, to the way evidence has been generated and used for programmatic and policy decisions. The number of data sources has expanded many fold and data collection systems and methods have improved considerably over time. Capacity to generate, analyse and utilize data has also grown tremendously. There are now a range of different, yet highly complementary sources of data on the epidemic in India.

HIV remains concentrated in key populations, but vulnerabilities and risk behaviours are rapidly changing in a dynamic socio-economic, cultural and institutional environment, and there are large variations in epidemic trends and patterns across different areas of the country. Because of the diversity, data aggregated at the national level tends to obscure the important variations at the sub-national level where the epidemic may be declining, stabilizing or growing. These variations must be brought to light to insure effective and well prioritised responses. These challenges, which were highlighted in the recommendations from the Mid-Term Appraisal of the National AIDS Control Plan (NACP) IV concluded in July 2016, were one of the primary impetuses for this consultation.[1]

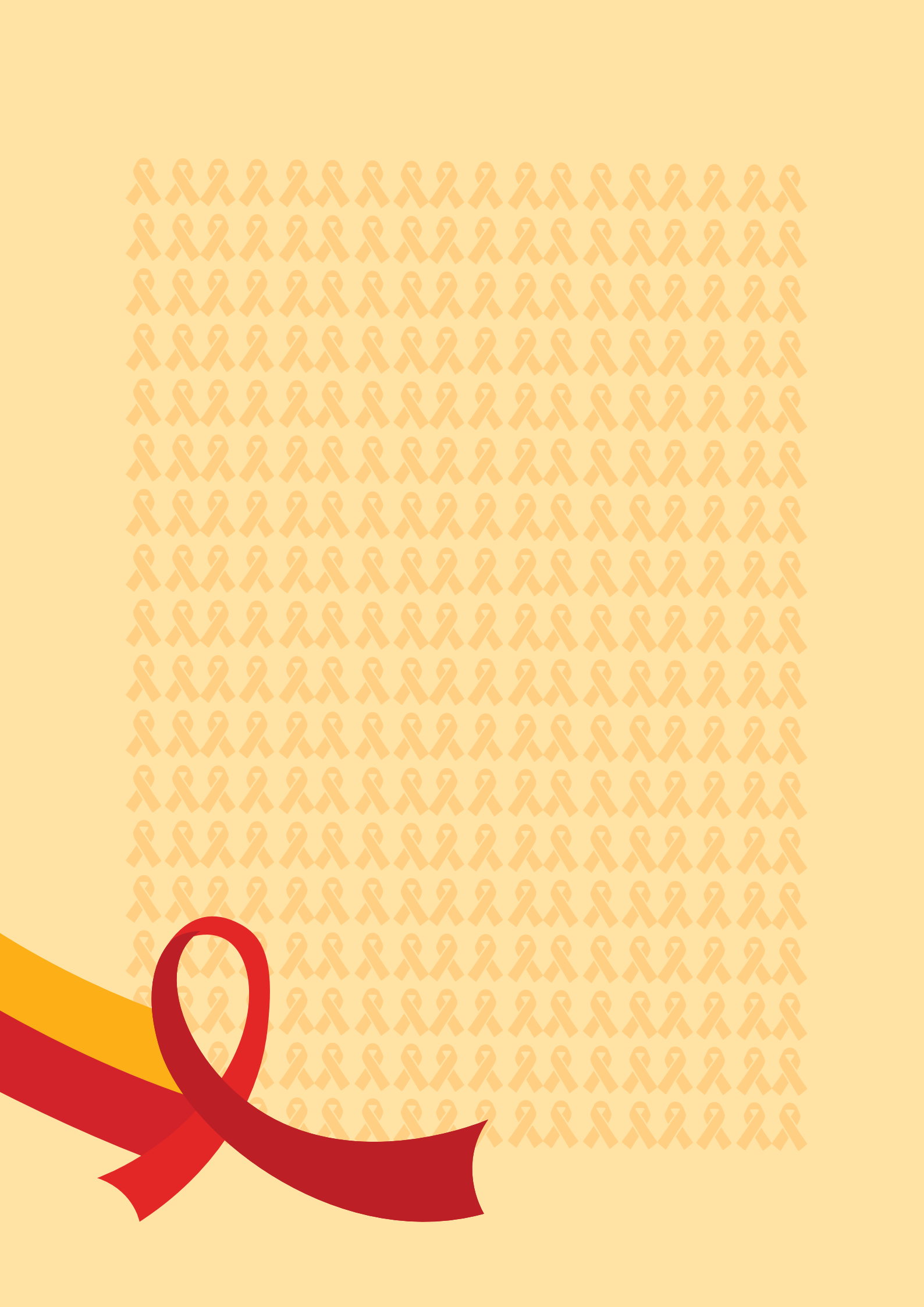
[1] Mid Term Appraisal of National AIDS Control Programme Phase IV, NACO, 2016.



2 INTRODUCTION

In September 2016, the National AIDS Control Organization (NACO) in collaboration with the Joint United Nations Programme on HIV/AIDS (UNAIDS) in India organized an International Expert Consultation on HIV Surveillance and Estimations. The meeting was supported by key partners, especially the World Health Organization (WHO) and the US Centers for Disease Control (CDC). It was attended by approximately fifty national and international experts on HIV surveillance and estimations. These included representatives from NACO, the All India Institute of Medical Sciences (AIIMS), National Institute of Health and Family Welfare (NIHFW), Indian Council of Medical Research, the National Institute for Medical Sciences (ICMR-NIMS), with national and sub-national surveillance institutes, the headquarters, regional and country offices of UNAIDS, WHO, CDC, the World Bank, Population Council, FHI360, and other partner organizations. Surveillance experts from several countries in the region, including China, Philippines and Vietnam, also came to share their experience. The agenda of the meeting and list of participants can be found in Annex 2 and Annex 3 respectively.

Group photo: Expert consultation on HIV surveillance and estimations 2016



3 OBJECTIVES

The aim of the meeting was to review existing HIV surveillance data systems in India, assess how well they are working, discuss alternate models and methods, and develop a roadmap to improve epidemic tracking and further strengthen programmatic responses.

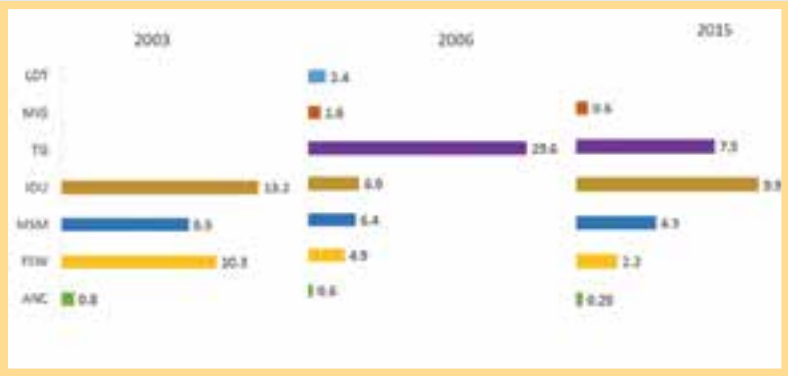
The specific objectives were to:

1. Critically review the existing system of surveillance and estimations with specific focus on its mechanisms, methodology, outputs and cost implications;
2. Make recommendations on the key components of surveillance for the future i.e. biological surveillance, behavioural surveillance, service uptake (detection, linkage and retention) surveillance, and burden estimation in terms of need, population and location granularity, and frequency;
3. Examine the alternative models available for delivering on the surveillance components with specific focus on methodology, implementation mechanism and cost implications and recommend a feasible model or a mix of models given the local context; and
4. Identify follow-up actions to strengthen HIV surveillance and estimations with timelines to implement the recommended system strengthening actions.

Existing data systems were considered considering their ability to meet the surveillance objectives outlined in Box 1.

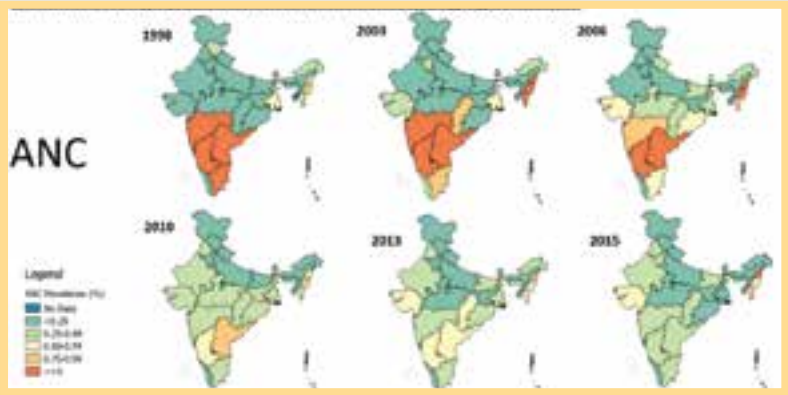
Box 1: Objectives of HIV Surveillance in India

1. To monitor HIV epidemic trends over time among general and key population
2. To monitor geographic spread of HIV in the country and identify emerging hotspots
3. To estimate HIV burden (HIV incidence, prevalence, number of PLHIV, AIDS- related deaths, ART and PMTCT needs)
4. To assess the impact of HIV prevention and treatment interventions in reducing annual new HIV infections and annual AIDS-related deaths

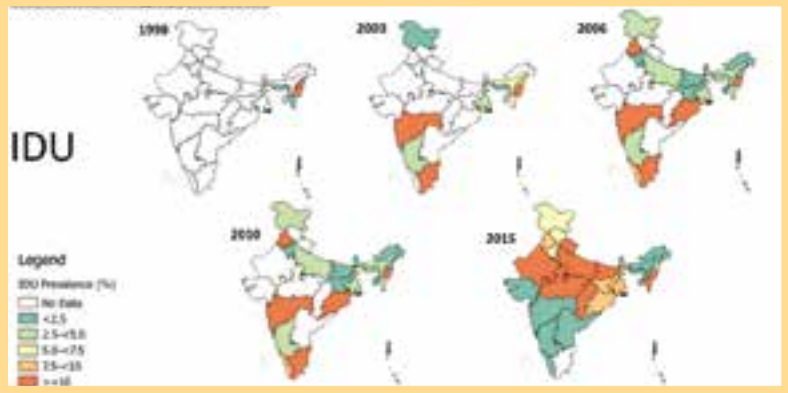


Telling the big picture of HIV Epidemic over years

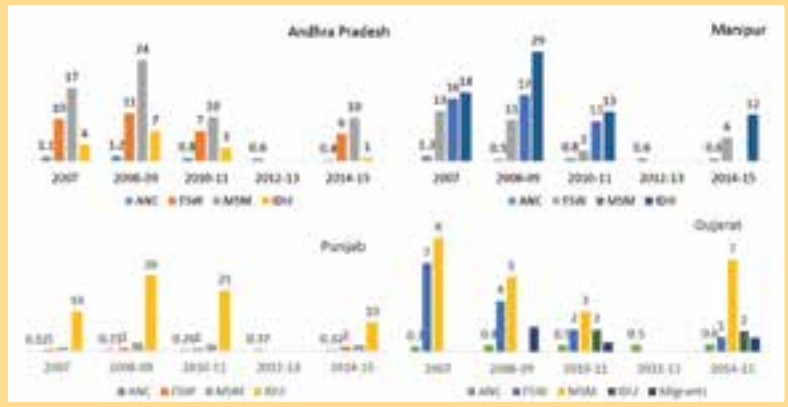
HIV Epidemic in India is concentrated in nature and continue to be so



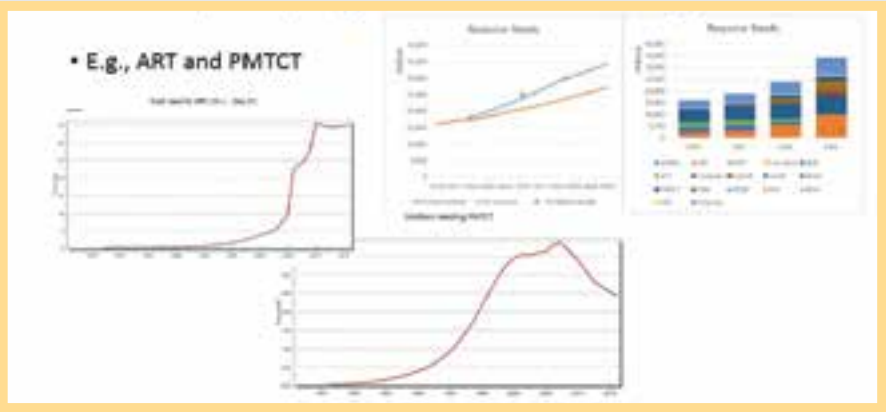
The spread of epidemic is heterogenous with locations of high prevalence and has been changing over time



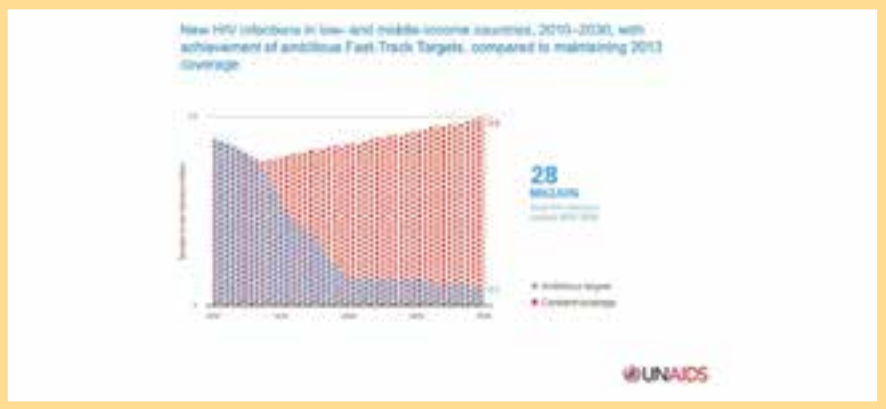
Epidemic is dynamic with emergence of new locations of high prevalence



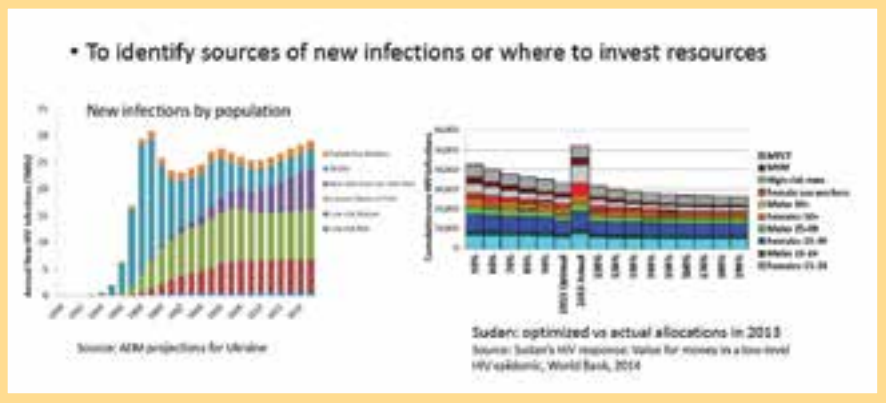
Every state has its own driver of epidemic



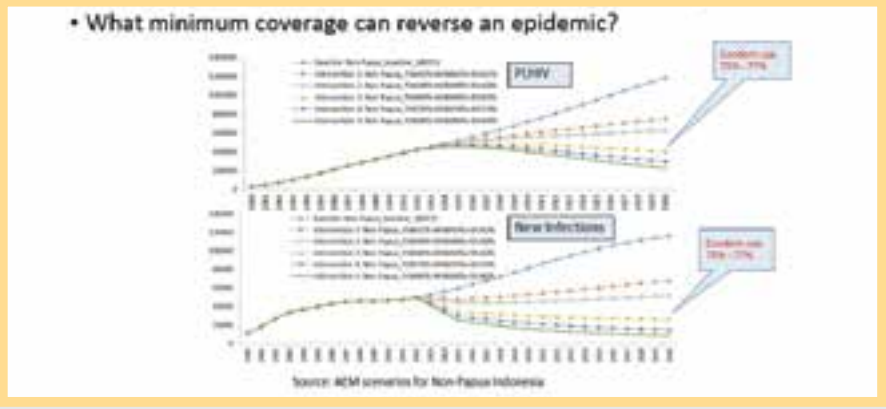
To anticipate program needs and budgets



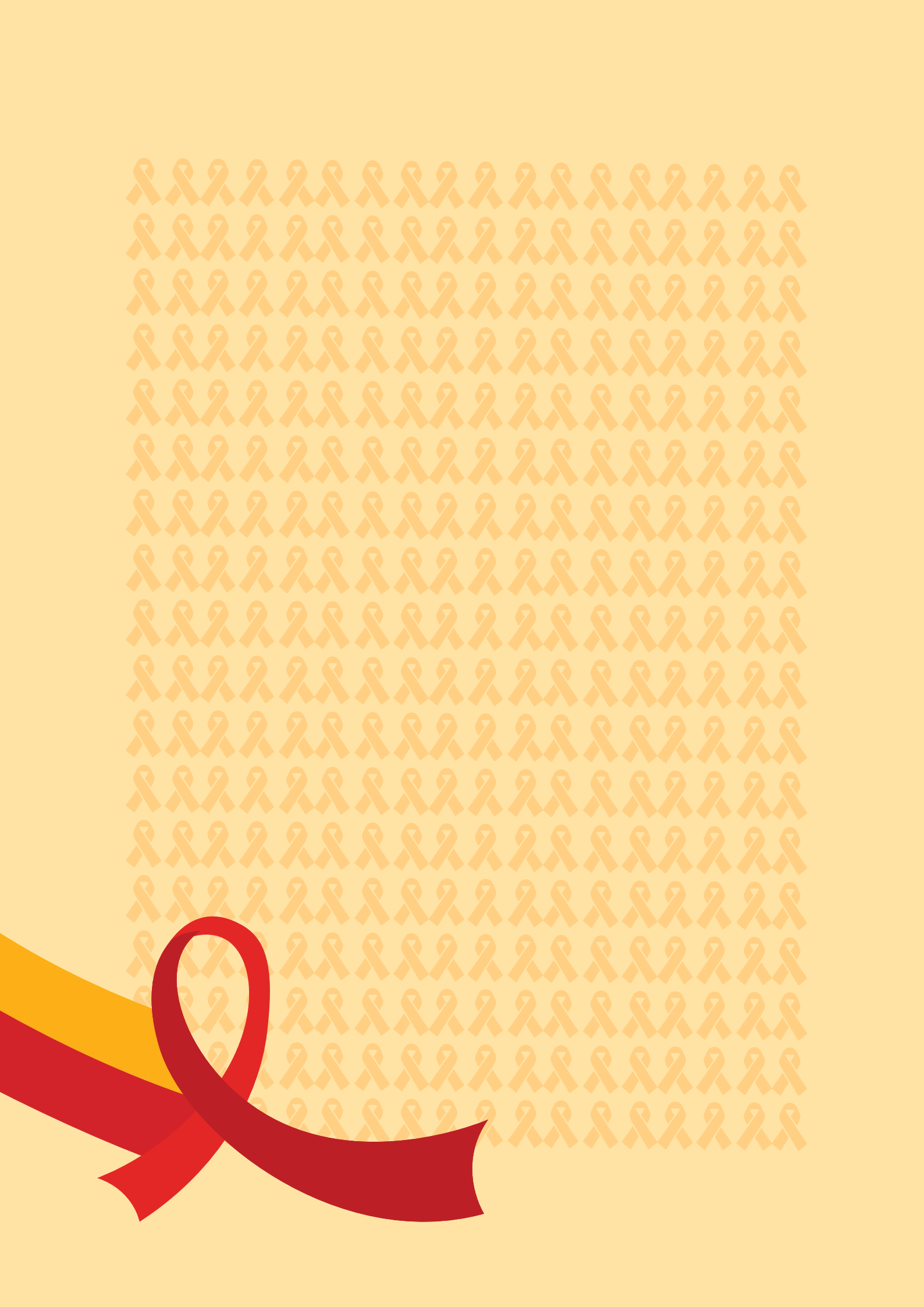
To set targets and measure progress



To guide programs and resource allocations



To assess impact of responses on an epidemic



4 MEETING STRUCTURE AND PROCEEDINGS

The consultation was organized over a three-day period during 27–29 September 2016. The time was divided between technical sessions with background presentations to lay the groundwork, panel discussions to consider the current system and evoke new ideas, and plenary discussions to solicit inputs from meeting participants. Panels consisted of 7–9 experts and a moderator to facilitate discussions.

Participants in the audience were able to intervene by asking questions and making comments and suggestions using an interactive tool called the Pigeonhole.[2] This mobile phone/tablet/ computer application allowed participants to ask and vote for questions that interested them, and helped facilitators and presenters prioritize various issues to respond to. The use of this innovative technology helped make the meeting highly participatory and saved time, as questions and comments/ suggestions were displayed on screens that could be seen by all participants in the meeting.

The consultation opened with global perspectives on HIV surveillance and estimation presented by international experts from UNAIDS, WHO, East-West Center (Hawaii), and the World Bank.

These were followed by separate technical sessions covering: 1) biological surveillance, 2) HIV estimation, and 3) behavioural surveillance. A final technical session on the last day generated recommendations to strengthen surveillance and estimation systems in the Indian context.

Inaugural Session - opening remarks by Dr Tim Brown

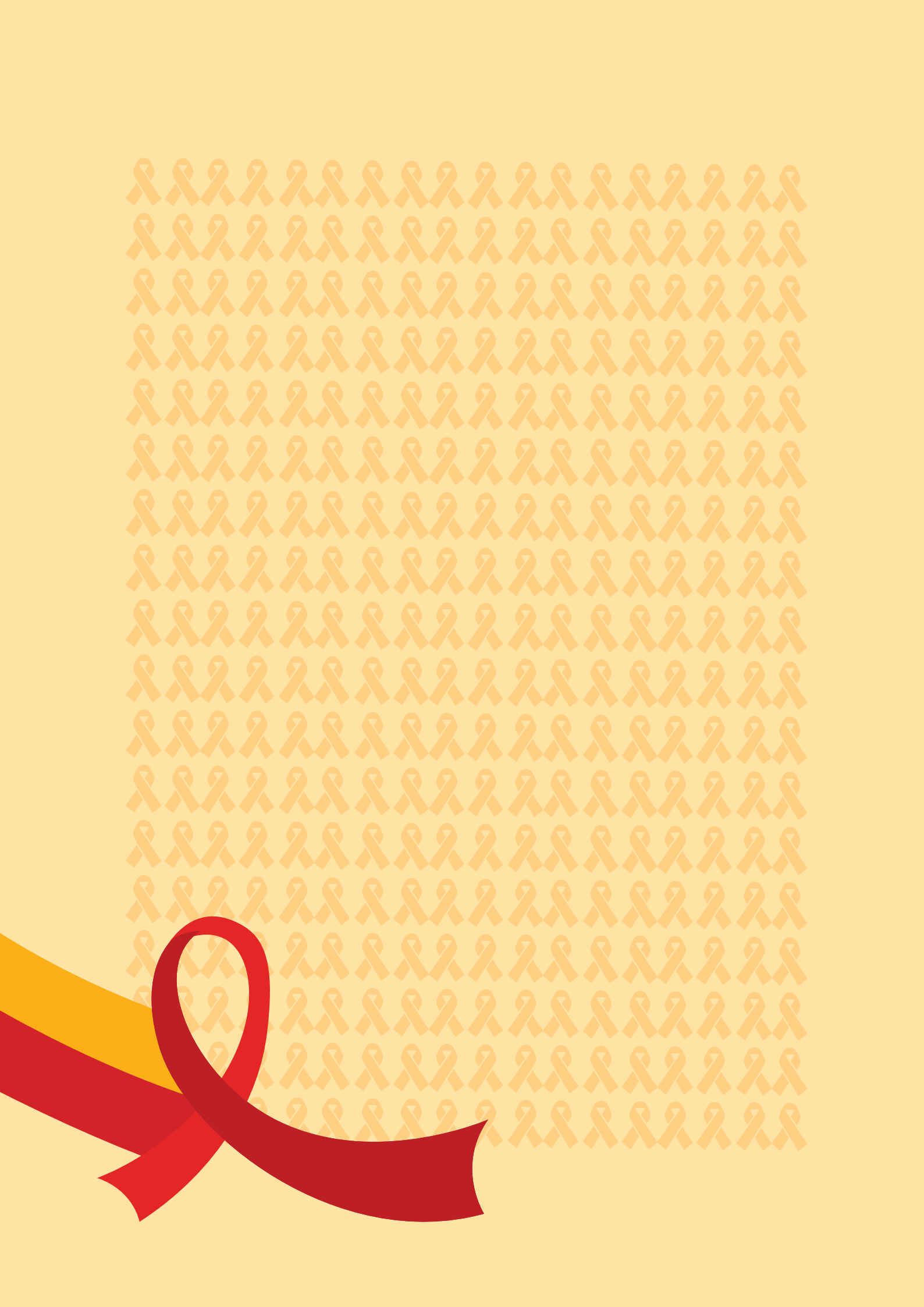
[2] https://pigeonholelive.com/

Inaugural Session - comments by Dr Swarup Sarkar on HIV surveillance methods evolution and present status

Panel discussion 1 on biological surveillance

Technical Session 1 - presentation by Dr Yujwal Raj on programme data issues and challenges

Comments from the floor during Q&A session



5 SUMMARY OF THE SESSIONS

5.1 Inaugural Session: Global Perspectives of Surveillance and Estimations of HIV

The inaugural session included talks by Dr Neeraj Dhingra (NACO), Dr Taoufik Bakkali (UNAIDS RST, Asia Pacific), Dr Chika Hayashi (WHO, Geneva), Dr Swarup Sarkar (WHO, SEARO), Dr Tim Brown (East-West Centre, Hawaii), and Dr David Wilson (World Bank). It concluded with keynote remarks by Dr CV Dharma Rao, Joint Secretary, NACO. Some of the key messages from the session included the following:

- To support fast-track commitments to end AIDS by 2030, there is a growing need for more granular (i.e. local level) data. Locally relevant data that are usable by frontline workers are critically important for guiding and managing local responses. Since it is not feasible to collect sentinel surveillance data everywhere, the focus at the local level should be on using other locally relevant data from as many sources as possible, including routine programmatic data. While at the national, state and district level, sentinel surveillance data should be used to answer overarching surveillance questions in a way that is broadly representative of the national picture.
- Globally, surveillance has evolved from the first generation, where the focus was on basic HIV sentinel surveillance, to the second generation, where differentiation of data needs by epidemic type, and the addition of behavioural data and size estimates of key populations came to the forefront. Now in the third generation, enhanced use of case-based surveillance and meeting the challenge

Technical session 1 - Presentation by Dr Tim Brown on HIV estimations rationale and models

of estimating incidence are paramount. Use of case-based surveillance data, which is routinely available everywhere, goes hand in hand with the need for efficient and sustainable approaches to obtain locally relevant data.

- Spectrum software is the "workhorse" for generating estimates on key epidemic indicators. It may be complemented by process models to understand the programme impact of various interventions at the local level. Process models are better designed for such purposes, though they require a lot of data, so their use must be limited to priority areas.
- Countries need to own their surveillance systems and fund them adequately to ensure that epidemic data are continuously generated and utilized by the country for fast-tracking and monitoring of core HIV indicators including those related to the 90-90-90 targets.

In conclusion, Dr CV Dharma Rao highlighted the importance of evidence- driven decision making through program monitoring, surveillance and research.

5.2 Technical Session 1 – Biological surveillance

The specific objectives for this session were to review the existing biological surveillance system in India and explore alternate models that would enhance the role of NACP programme data (such as routine HIV case-based surveillance) for biological surveillance purposes.

The session included presentations by Dr Wolfgang Hladik, (CDC, Atlanta), Dr Bui Hoang Duc, (MOH, Vietnam), Dr Pradeep Kumar (NACO), Dr Raman Gangakhedkar (NARI), Dr Neeraj Dhingra (NACO), and Dr Yujwal Raj (former NPO, NACO).

The session was initiated with a presentation elaborating the prevailing methods of HIV biological surveillance across the globe, including HIV sentinel surveillance, aggregate viral load measures, HIV incidence surveillance and HIV case-based surveillance. HIV sentinel surveillance is still the most common. However, with ART expansion, the interpretation of prevalence trends has become increasingly difficult. Viral load is a useful complementary measure which may provide a better indication of transmission potential than HIV prevalence trends, especially among key populations; and it has the advantage of providing data on viral load suppression for the cascade, as well as having lower sample size requirements than those required for HIV incidence surveillance. HIV incidence surveillance is attractive as a direct measure of incidence, however issues related to availability of testing kits, sample size and cost make it challenging to do at large scale. HIV case surveillance, on the other hand, is still in its inception phase and faces many challenges with respect to completeness of the data and avoidance of duplication of entries in health records as individual cases are potentially counted multiple times.

This general overview of biological surveillance approaches was followed by a presentation from Vietnam which described a modified HIV Sentinel Surveillance (HSS) which expands the standard surveillance data collection to include behavioural questions. First piloted in 2009, the system became part of routine annual surveillance in 2012 and had expanded to 30 provinces by 2015.

Technical Session 1 - panel members

Technical session 1 - presentation by Dr Gangakhedkar on HIV incidence surveillance in India: status and challenges

Known as HSS Plus, this appears to be a more cost-effective means to obtain both biological and behavioural data for key populations at the same time, without having to deal with the more labour and resource intensive IBBS approach (discussed in Technical Session 3). However, there are some limitations, including the representativeness of the respondents, who may be more likely to include key population members who have been exposed to interventions and to miss non-venue based key population members.

There was discussion on integration of surveillance for HIV, Syphilis and other bio-markers also such as Hepatitis B and C and maybe even TB. HIV, syphilis and hepatitis can be spread by the same behaviours and limited by similar prevention messages and activities. Separate surveillance may lead to missed opportunities to prioritize effective interventions while integrated surveillance may guide more effective and efficient public health action.

Following these more globally focused presentations, the attention turned to the Indian surveillance system, starting with a review of the HSS system, followed by a more in-depth look at HIV incidence surveillance in India, the Strategic Information Management System (SIMS) and other routine monitoring data sources.

- HIV Surveillance in India was initiated in 1985 in different population groups, and over the years has played a key role in providing evidence to shape the HIV response at the national, state and district levels. The system has expanded significantly over time and is now one of the largest systems in the world. The data have been used not only to track trends over time, but also to characterize drivers of the epidemic in different states, identify emerging areas of high prevalence, and pinpoint locations and population groups in need of attention. It was also noted that the HSS system currently uses roughly 0.65 % of the NACP budget for a two-year period.

- The presentation on HIV incidence surveillance described efforts to directly measure incidence in India, including a few small-scale pilot studies using incidence assays, and one effort to follow a longitudinal cohort using programme data under the The HIV/AIDS Partnership: Impact through Prevention, Private Sector and Evidence-based Programming (PIPPSE) project. The presentation highlighted the cumbersome nature of HIV incidence assays and the need for a large sample in India; because of the low incidence rates at the population level. It was suggested that detecting new cases with CD4, as a surrogate marker of new infections, could be an easier procedure.

- The session on the Strategic Information Management System (SIMS) described the complete Spectrum of strategic information under NACP, including aggregated monthly data compiled from around 30,000 reporting units in SIMS, as well as individual case-based reporting through the PLHIV ART Linkage System (PALS), the Inventory Management System (IMS) and the Targeted Intervention (TI) weekly and monthly reporting system. The presentation highlighted the routine programme monitoring data from

Technical Session 1 - presentation by Dr Yujwal Raj on programme data issues and challenges

more than 20 000 Integrated Counselling and Testing Centers (ICTC), more than 1600 Targeted Interventions (TIs) and 525 ART centers; and plotted their scale- up vis-à-vis the scale-up of HSS sites.The key outputs from SIMS in terms of HIV positivity include information from ICTCs, blood banks, TIs, and PMTCT, as well as prevalence estimates obtained from HSS for pregnant women, key population groups and bridge populations, as these are stored in SIMS.

- The final presentation in this session addressed the strengths, limitations, and potential uses of the vast data being collected under the above mentioned NACP managed data systems (ICTC for general clients, ICTC for pregnant women, TI data, and ART data). The presentation went through many levels of reporting and disaggregation. Information is being captured at both the individual and the aggregate levels though individual level data is not always available in an electronic format. The data are rich, and the potential for granular data analysis and use is large; however, issue of the duplication and clear attribution to a population group is challenging. But there are many challenges; so the roadmap must be well focused and carried out in a phased manner in conjunction with capacity building efforts. Some potential areas to prioritize include district level epidemiologic profiles, including potential for estimating prevalence with adjusted routine testing data, district specific cascades, and geo-spatial analysis using key indicator data. Triangulation with other data sources at the local level can allow for alignment with HSS and IBBS to inform calibration factors for some districts.

Session on behavioral surveillance and country experiences using various methods

5.3 Technical Session 2 – Estimation of HIV Burden

To address the strength of the surveillance system with respect to objective 3, estimating HIV burden, Technical Session 2 consisted of presentations providing a global overview of HIV estimation approaches, followed by a review of the current system of HIV estimation in India, and examples of systems used in other countries. Panelists were then asked to comment on the adequacy of the Indian system and to consider alternate models.

The session included presentations by Dr Taoufik Bakkali (UNAIDS, RST Asia Pacific), Dr Wolfgang Hladik (CDC, Atlanta), Dr Guo Wei (CDC, China), Dr Arvind Pandey (NIMS), Mr. Kannan (NTSU, NACO), Dr KS Sachdeva (NACO), Dr TLN Prasad (NTSU, NACO), Dr Suman (NACO) and Dr Neeraj Dhingra (NACO).

The session started with a presentation on overview of models for HIV estimates. It highlighted that the estimates are used for national and international resource mobilization, national programme planning, evaluating the effectiveness of existing programmes, policy planning, resource allocation and global reporting. The presentation emphasized that UNAIDS uses Spectrum for estimation and projection, as global reporting requires a standardized tool for comparable results. It also highlighted the fact that Spectrum is continuously evolving and improving over time and it incorporates the latest knowledge on HIV epidemiology. The presentation also mentioned the limitations of the current version of Spectrum, its non-use of behavioural data as inputs and its inability to measure impact of individual programme components, asides from prevention and treatment.

The presenter described three process models – Asian Epidemic Model (AEM), GOALS and OPTIMA. These process models can simulate the transmission dynamics of HIV and can estimate the programme effects, but have more intensive data needs, and can only be implemented in settings with high quality bio-behavioural and programme data. The presentation also highlighted the need for district level estimates in the context of heterogeneity of the epidemic as well as decentralised models of programme implementation in India. The presenter advocated existing estimation methods (like the Spectrum state disaggregation method, Workbook, etc.) at the district level, to meet the information needs for more granular planning.

This general overview of models of HIV estimates was followed by a country presentation on the national HIV surveillance system of the United States, which highlighted case-based surveillance and national behavioural surveillance among key population groups as key components. The presentation also highlighted HIV incidence surveillance as an additional component of case-based surveillance at sentinel sites. However, this component is likely to be phased out by the end of 2017 due to the increasing cost per new case detected, as a result of sharp declines in HIV incidence. The presenter mentioned the on-going operations research on feasibility of using CD4 depletion models for estimating HIV incidence in the future.

Technical Session 2 - presentation by Dr Taoufik Bakkali on overview of HIV estimations across the globe

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This was followed by a presentation from China describing that country's current HIV surveillance and estimation system. China's system consists of case reporting, sentinel surveillance, new infection surveillance and surveys with case reporting. The sentinel surveillance system, covering nearly 1900 sites across the country and a target sample of 90,000 was mentioned as the backbone of the entire surveillance system. This system collects not only demographic information, but also data on key HIV risk behaviours, knowledge and utilization of programme services. The presentation highlighted the fact that China generated local evidence to customise a number of underlying assumptions of Spectrum.

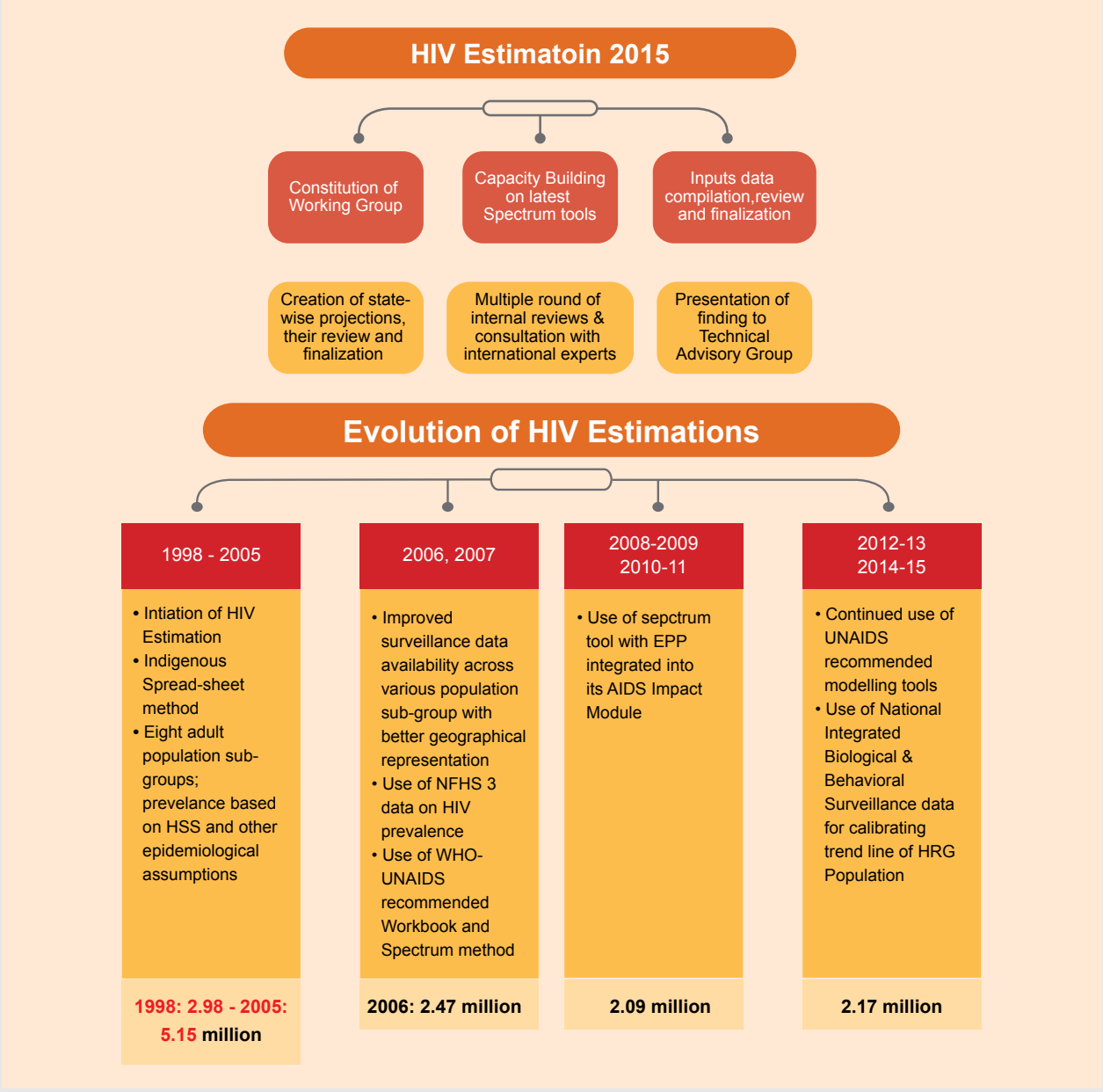
Following these country presentations, the attention turned to the Indian context, starting with an overview of HIV estimation and projections in India, followed by a more in-depth look at available programme data from TIs, ICTCs, STI clinics and ART centers. Finally, some key analytical issues related to HIV estimation, projection and analysis of programme data were presented and discussed.

- HIV estimation efforts in India were initiated as early as 1994 using an indigenous spreadsheet method, based on HSS data and some basic epidemiological assumptions. Starting in 2006-07, India started using the WHO-UNAIDS recommended Workbook and Spectrum method, as quality surveillance data were available for several population groups across many geographical areas. NFHS 3 data was used to calibrate the trend in HIV prevalence among ANC clients. In subsequent rounds, India used EPP and Spectrum, incorporating trends of key populations, using High Risk Group (HRG) surveillance, calibrated with national IBBS data in 2014-15. The presentation described the rigorous process of HIV estimation, explaining its utility in improving programmes and resource allocation, and for providing key epidemiological information and impact indicators (e.g., total number of PLHIVs, HIV prevalence, HIV incidence, AIDS related mortality, ART need, PMTCT need, etc.). The presenter also highlighted the limitations of the Indian HIV estimation process including absence of data on clients of sex workers or any bridge group in the current epidemic structure of the model, and dependence on assumptions that are formulated, based on evidence from other countries.
- The potential of programme data was highlighted through presentations on data collected by TIs, ICTCs, STI clinics and ART centers. The TI team of NACO presented the list of 31 key programme monitoring indicators, collected routinely. They also presented HIV positivity data among various key population groups, based on TI data and compared it with HSS estimates at the state level. It also highlighted the fact that TIs are using programme data for fine-tuning response strategies. Massive scale-up of ICTC facilities (20 000+ facilities in 2016) over the recent period was presented by the ICTC team of NACO. They highlighted significant increases in HIV testing over time but decreases in HIV detection, particularly among pregnant women. Reporting of positive cases from the private health sector was

Technical Session 2 - presentation by Dr Neeraj Dhingra on variance in estimation and key programme data

identified as one of the major challenges. The CST team presented the service delivery system under the world's second largest ART programme and outlined the evolution of eligibility criteria as well as treatment regimens under NACO. The monitoring system with unique identifiers was also highlighted.

- The final presentation in this session raised and discussed some key analytical issues in relation to the HIV estimation and projection exercise and programme data. It presented the consistently declining trend in total HIV burden, HIV prevalence and HIV incidence in India since 2007. It also presented distribution of detected cases by baseline CD4 count during 2015-16. The presentation made very interesting comparisons between HIV prevalence rates among ANC mothers across different states of India based on ANC HSS data and HIV positivity being reflected in PMTCT data. Similarly, HIV prevalence rates among FSW, MSM and PWID across different states were compared based on HSS data and TI positivity r data. A few fundamental questions were raised and discussed: How can we best analyse and use the programme data for improvement of the programme? Can't programme data, with a huge denominator, provide good estimates of the key indicators? Can programme data be used to satisfy all the three objectives of the Indian surveillance system? If yes, how? If not, why?



5.4 Technical Session 3 – Behavioural surveillance

The specific objectives for this session were to review the existing Behavioural Surveillance System in India and to discuss alternate methods for behavioural surveillance using rich programme data under NACP.

The session included presentations by Dr Avi Hakim (CDC, Atlanta), Dr Genesis May Samonte (Dept. of Health, Philippines), Dr Pradeep Kumar (NACO), Ms Vinita Verma (NACO) and Dr Fauzdar Ram (IIPS).

The session started with a presentation that gave a global overview of HIV behavioural surveillance. It highlighted the need for Integrated Biological and Behavioural Surveillance (IBBS), using representative sampling approaches to track key biological and behavioural indicators including HIV prevalence, number and type of sex partners, last time and consistent condom use with different types of sex partners, and knowledge about different prevention methods etc. It also measures exposure to interventions and identifies prevention, testing and treatment needs. The presentation complimented India for successfully completing the biggest and most complex IBBS ever conducted anywhere in the world. However, it highlighted the fact that IBBS needs to be more cost effective and time efficient in the future. The presentation recommended exploring alternative models like HSS plus/BSS lite in the Indian context (presented for Vietnam in technical session 1), and also suggested the use of audio computer assessed self-interview (ACASI) for minimizing "social desirability bias".

The global overview was followed by a country presentation from the Philippines. The HIV surveillance system in the Philippines is comprised of case-based surveillance (HIV/AIDS and ART Registry of the Philippines – HARP) and Integrated HIV Behavioural and Serologic Surveillance (IHBSS). HARP is name based, and is the strongest and longest running surveillance system in the Philippines (since 1985), although only data from HIV positives is coded into the system. HSS and BSS started as separate activities in 1994, but got integrated in 2005 as IHBSS, carried out regularly across ten sites, once every two years. These surveillance data are complemented by Rapid Assessment of HIV Vulnerability (RAV) which focuses on questions related to HIV risk behaviours and programme exposure among selected population groups in selected geographical locations, using purposive or convenience sampling approaches. The results of RAV are not nationally representative but are very helpful for advocacy and programme planning.

Following the country presentation, the attention turned to India's first IBBS among key populations in 2014-15, starting with an overview of the methodology, the implementation design and the

Technical Session 3 - Presentation by Dr Genenis Samonte on integrated bio-behavioural surveillance systems in the Philippines

Technical Session 3 - HIV behavioural surveillance

cost implications. Finally, the methodology of the fourth round of National Family Health Survey (NFHS 4) was presented with a specific focus on the HIV component of the survey.

The national IBBS of India covered a total of 138,400 eligible participants among six population groups (FSW, MSM, H/ TG, IDU, Migrants and Currently Married Women in out-migration districts) across 258 sampling domains (districts/ group of districts) in 31 States or Union Territories of the country. IBBS adopted probability sampling approaches, conventional cluster sampling among fixed groups and time-location cluster sampling among mobile groups, to recruit survey participants. It was implemented in four different phases: (1) Pre Surveillance Assessment, (2) Sampling Frame Development, (3) bio-behavioural data collection, and (4) data analysis and dissemination. Community consultation and engagement was a key component of each phase of the national IBBS. The survey followed stringent ethical protocols and had strong respondent protection measures. Multiple agencies were involved at various levels of implementation with very specific roles and responsibilities. The presentation mentioned unit cost (cost per sample) of implementing national IBBS as around 60-65 USD with 82% of the total cost coming from domestic budget.

Technical Session 3 - presentation by Dr Pradeep Kumar on integrated biological and behavioural surveillance in India

Technical Session 3 - Presentation by Dr Pradeep Kumar on integrated biological and behavioural surveillance in India

The presentation on national IBBS was followed by a presentation on methodology of the fourth round of National Family Health Survey (NFHS 4) with a special focus on the HIV component of the survey. The presentation highlighted the fact that NFHS 4 will measure the HIV prevalence among general population for 11 states or state groups as compared to the same measured for only 6 high prevalence states during NFHS 3. The presentation also outlined various key behavioural indicators and knowledge as well as attitude related indicators (e.g., paid sex during last 12 months, last time condom use, consistent condom use, comprehensive knowledge of HIV/ AIDS) that will be available from NFHS 4. The presentation suggested that the household surveys like NFHS should embrace innovations at every step of survey planning, implementation and dissemination. It recommended involving more and more national IT companies to develop tools for data capturing, management, analysis and dissemination.

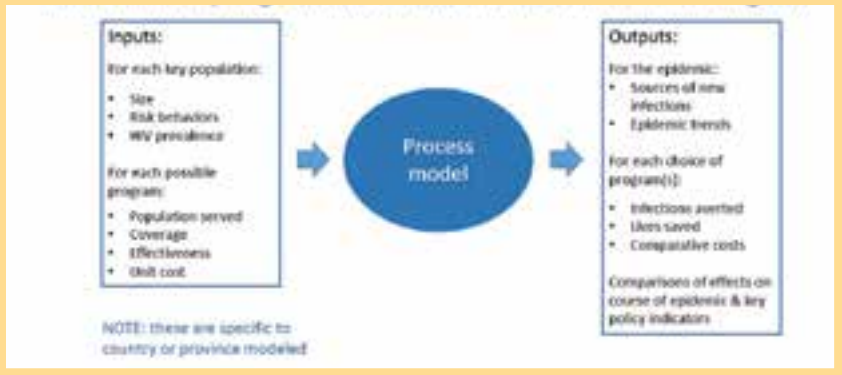
5.5 Key Themes Emerging from Technical Sessions

Each of these technical sessions was followed by a panel discussion, and on the last day of the consultation, two panels were convened to discuss and debate as to what should be the key features of India's HIV surveillance system going forward.

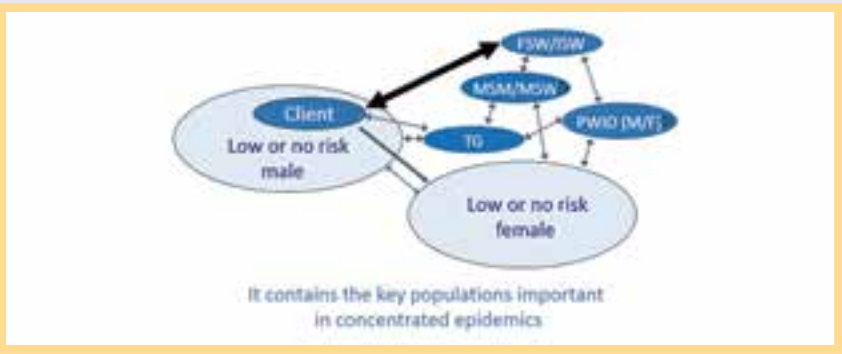
Themes that emerged repeatedly from the technical sessions included:

- Although the HSS system and the process for estimating HIV burden is strongest at the state and national level in India, the critical need for locally relevant data to guide programmes toward achieving the fast-track targets of reduced HIV incidence and high treatment coverage was recognized.
- In view of the challenge of collecting rigorous sentinel surveillance data, and estimating the burden of infection in all locations of the country at the most granular level, the discussion focused on how and to what extent, routine programme data can be used in together withsurveillance data to guide and support local programmes.

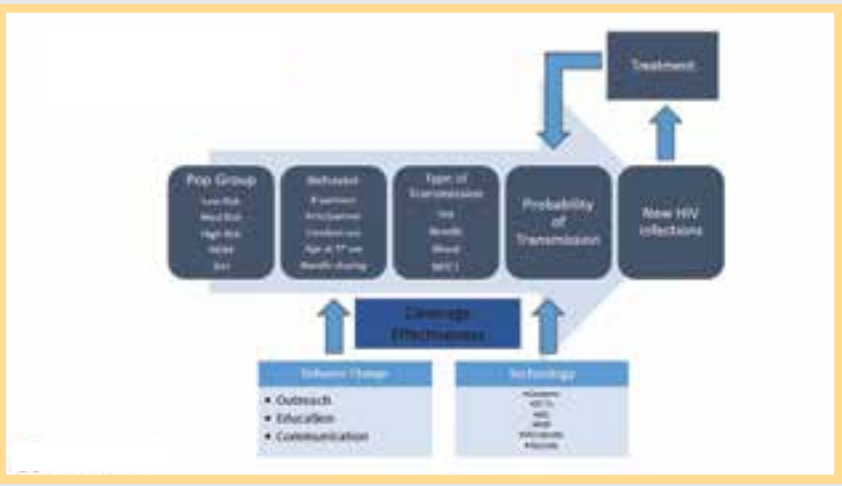
In this regard, many alternative models were presented, and their merits debated. Out of these discussions, the recommendations presented in Part III of this report were developed.



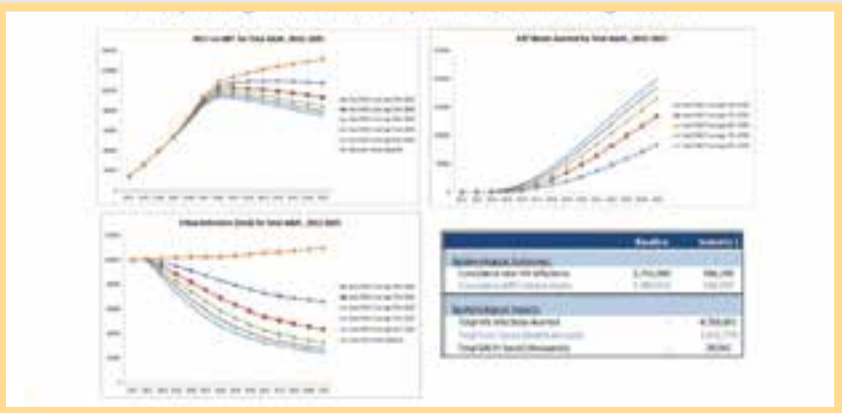
Process models simulate the transmission of HIV and can include program effcts... but data needs are higher



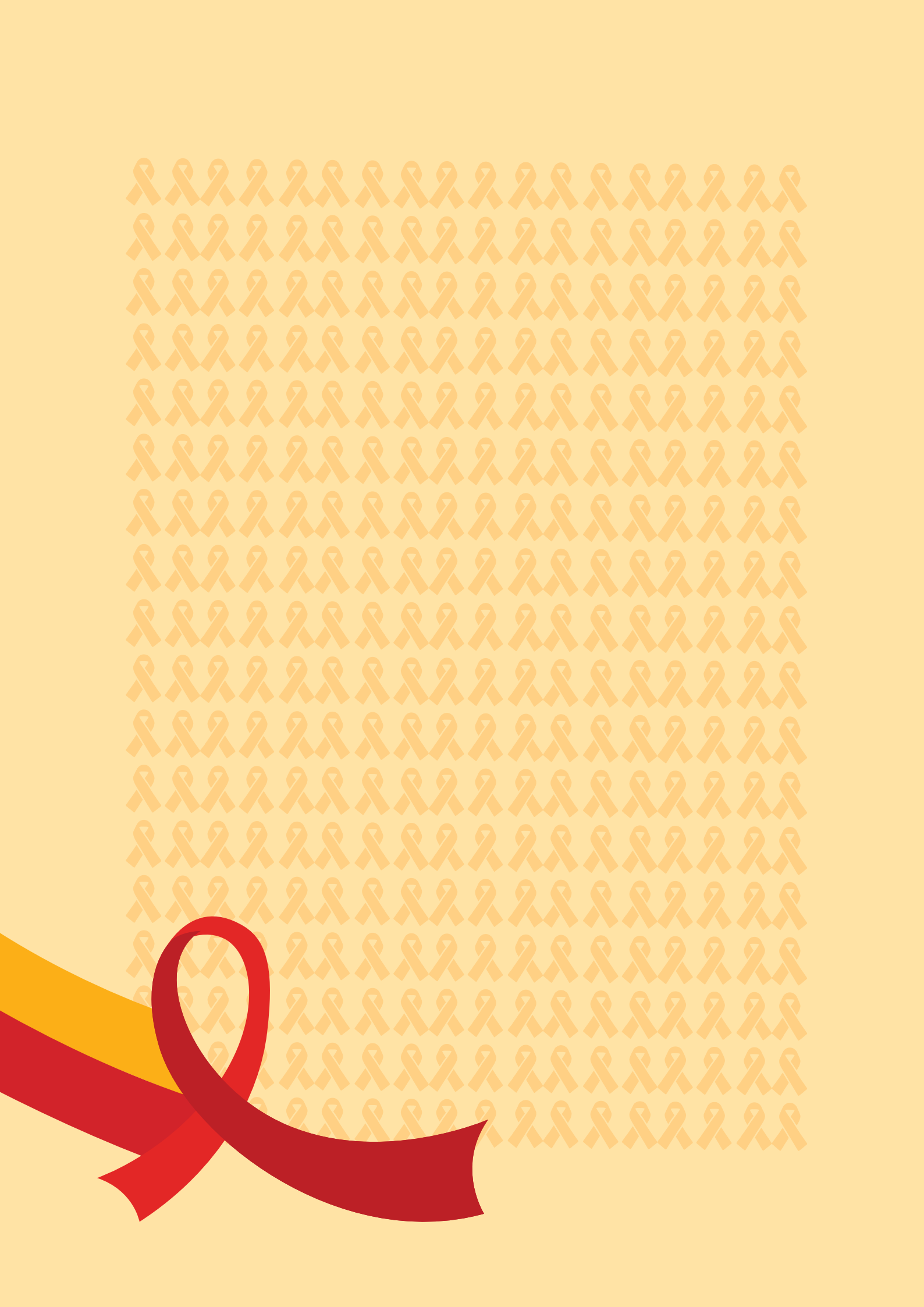
AEM: a behavioral process model for projecting concentrated epidemics



Goals Model



Process models allow for scenario analyses comparing different responses, including costs



6 RECOMMENDATIONS

Overall recommendations on strengthening HIV sentinel surveillance and strengthening the HIV estimates and projections process that arose out of the technical sessions are described below. This is followed by a section describing the various data sources.

6.1 Strengthening HIV Sentinel Surveillance

HIV Sentinel Surveillance (HSS) among ANC and HRG populations should be continued to provide key epidemiological information at different levels. However, HSS could be further strengthened by taking the following measures:

1. For the states with high PMTCT coverage (more than 80%), both ANC surveillance and PMTCT based surveillance should be implemented for at least three rounds concurrently. A minimum of three data points will be required to establish the trend for PMTCT surveillance as well as necessary calibration of the long- term ANC trend. Importantly, data coming from ANC as well as PMTCT surveillance over three concurrent years need to be critically reviewed to make an evidence-based decision regarding phasing out of the ANC surveillance and completely shifting to PMTCT based surveillance in high PMTCT coverage states.
2. For the states with low PMTCT coverage (less than 80%), ANC HSS should be continued and scaled up (having a larger number of sites across the state) to track progress of the epidemic, particularly in the northern and eastern low prevalence states with emerging epidemic.

Technical Session 3 - presentation by Dr Genesis Samonte on integrated bio-behavioural surveillance systems in the Philippines

3. The representativeness of the HRG surveillance was improved recently through random sampling of the participants from the updated line- list available with TI. However, the HRG surveillance still may not represent the population outside of the TI coverage area. Therefore, the representativeness should be further improved through coverage of HRGs beyond the Targeted Interventions (TI) Programme. Application of a response driven sampling (RDS) approach or rapid listing exercise covering non-TI areas need to be piloted.
4. HSS Plus/BSS lite should be piloted and scaled up across the country. Both ANC and HRG HSS should explore the possibility of including key additional biological markers e.g., hepatitis B, hepatitis C, syphilis, viral load, etc. and a minimum set of behavioural questions to replace the costly IBBS, and also to generate the required information to calculate the 90-90-90 indicators. Of course, HSS Plus/BSS lite need to cover both the TI as well as non-TI areas to make it representative.
5. Alternative system for HIV incidence surveillance could be piloted through establishment of epidemic cohorts among HRGs in some states where coverage of TI is fairly high, and the quality of TI data is of very good quality. Also, a pilot study could be taken up in a couple of states to estimate the total number of new infections within a given period of time, based on CD4 counts.
6. Sincere and concrete efforts need to be made to develop and establish a "case-based surveillance system" in the immediate future. All the existing isolated information systems (e.g., SIMS, PALS, IMS) need to be linked with each other and a comprehensive and integrated information system needs to be developed and established to track every single individual throughout the entire cascade - from prevention to treatment to care and support.
7. In-depth analysis of programme data (ICTC, PMTCT, ART etc.) needs to be undertaken to identify and prioritise emerging population groups (including bridge groups) and geographicareas. The programme data has huge potential and it needs to be analysed thoroughly and used extensively for improvement of the programme. Approaches might include profile analysis of all the clients at ICTC, PMTCT, ART etc., sero-discordance analysis, geo-spatial analysis, geo-prioritization based on the programme data etc.

6.2 Strengthening HIV Estimations and Projections

India has one of the best systems and strong capacity for HIV estimations and projections. The country uses the outputs of Spectrum very efficiently to understand the overall dynamics of the epidemic, as well as to make important programmatic decisions regarding targets and resource allocation, and assess programme impact at the macro level. However, the current system can be further strengthened and improved through the following key measures:

1. Continue using the current model for estimations and projections- Spectrum, as it helps meet global needs. However, the existing model could be further improved so that it sheds more light on what is happening with key and bridge populations both nationally, and at a more granular level. Better customized data to include both higher risk MSM (e.g. MSW and TGs), and lower risk MSM, as well as important bridge populations like clients of sex workers, with improved size estimates for these populations would make the estimates more useful.
2. Pilot alternate process models that focus on key populations and enable looking at programme impacts. These models require significant amounts of additional data, but could be used in states like Maharashtra or Andhra Pradesh, where good quality data is more available.
3. Pilot use of PMTCT data, instead of ANC HSS data, to better understand the issues related to PMTCT data for modelling. Examine the results based on PMTCT data with those of HSS to arrive at appropriate interpretations and decisions.

Panel discussion 4 on tracking the bio-behavioural parameters of the epidemic - panel members

4. Validate some of the underlying assumptions of the existing model such as fertility of HIV positive women compared to HIV negative women, HIV transmission probabilities, and survival patterns of HIV positive persons over time, using India specific data.
5. Attempt district level estimations and projections for select states. Multiple methods, starting from simple spreadsheets and back-calculation procedures to more complex models like Spectrum or AEM etc. could be piloted in these districts.

6.3 Key Recommendations by Data Source

Many of the more detailed recommendations, related to individual data source are described below. Table 1 provides information about the methodologies for collecting these data, keeping in mind the need to address the recommendations that have been outlined.

The table is followed by a set of diagrams which provide a visual representation of how the different data sources contribute to the various surveillance objectives at the local, district, state and national levels in an integrated fashion.

FIGURE: HIV Sentinel Surveillance, Estimations, Programme Monitoring, and Research and Evaluation are key information sources for programme planning

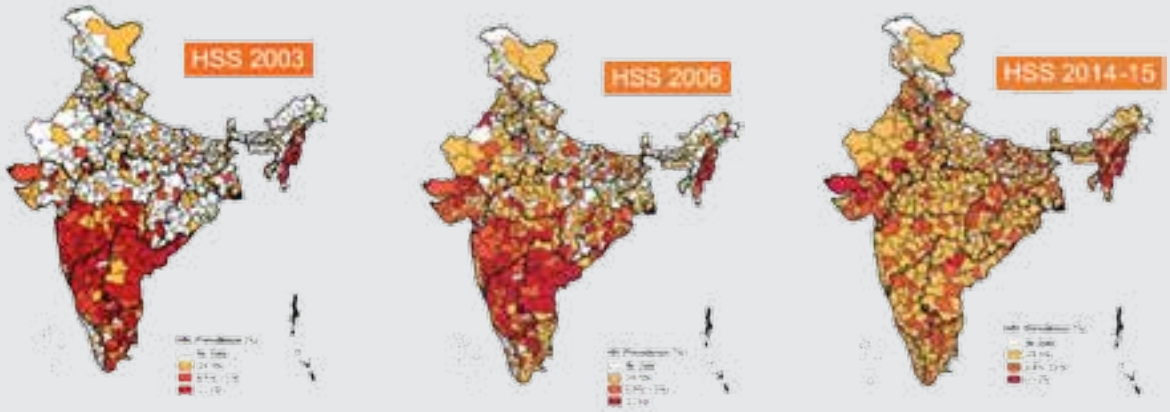


Table 1 in Annex 1 includes the following surveillance data sources:

1. HSS for ANC
2. PMTCT testing data
3. HSS Plus/BSS lite for key populations (TI)
4. ICTC testing data (General Clients)
5. Line-listed key populations living with HIV
6. IBBS among key populations
7. IBBS among Bride Populations (BP)
8. Population Size Estimates for key populations
9. NFHS

HSS for ANC – ANC sentinel surveillance produces routine data on HIV prevalence which is considered to best reflect the HIV situation in the general population despite the known limitations. The primary use of ANC data is to help produce estimates and projections of number of people living with HIV, new infections, AIDS-related deaths etc. Estimates of new infections and AIDS-related deaths provide an assessment of HIV prevention and treatment programme impact. Spectrum, the modelling tool used for this purpose in India, requires long-running trend data, which is why ANC sentinel surveillance, with appropriate adjustments and calibrations, is an ideal data source. Since the standard of care for ANC women now is increasing including systematic HIV testing for preventing parent to child transmission of HIV (PMTCT), another data source is available that can complement the analysis.

PMTCT – PMTCT data, which documents positivity among pregnant women, can be used for complementing surveillance purposes, including providing evidence to help detect emerging HIV outbreaks, to prioritise interventions geographically, and for producing HIV estimates and projections at district, state and national levels. This data source has the advantage of being available in all districts and in multiple types of testing facilities (both public and private), making it potentially more granular than ANC surveillance data. However, before formalizing a shift from ANC surveillance to using PMTCT data for surveillance purposes, strong trend data will be needed from parallel ANC and PMTCT systems and comparisons performed to provide evidence for how PMTCT data need to be adjusted and calibrated to overcome potential biases. In fact, PMTCT positivity reflects the situation of pregnant women with unknown HIV status accessing health services and suffers from the limitation that HIV positive pregnant women who already know their status will not be tested again. Also, their known HIV positive status may not be properly recorded again. Hence, positivity obtained from PMTCT testing data is very likely to provide an underestimate of prevalence in the overall population of pregnant women which is a major limitation from epidemic monitoring perspective.

HSS Plus/BSS lite for Key Populations – HSS for key populations (key populations) in India is conducted at Targeted Interventions (TI) sites. The data are used to track the epidemic among key populations, and to contribute to estimates of people living with HIV at the state and national level. There have been several rounds of HIV sentinel surveillance data for key populations in the past, although there was a long pause since 2011 because the IBBS 2014-15 was implemented. The sample for TI-based HSS is drawn onlyfrom key populations who are registered with TIs, so the data do not represent all key populations in a given catchment area, district or state. Segments of key population groups, that will not be represented in the surveillance data, include those who choose not to register with TIs, those who are unknown to TIs, those outside of TI catchment areas and those in districts with no TI surveillance sites.

Recommendations for overcoming these problems include: 1) using random sampling from TI registers to include known HIV positive key populations (as opposed to consecutive sampling among TI attendees), and 2) piloting more representative sampling approaches that can reach beyond registered key populations, such as rapid hotspot mapping (for time location sampling), or respondent driven sampling (RDS), which includes both venue and non- venue-based key populations. In addition, it is proposed to add a questionnaire which collects behavioural and service uptake data for key M&E and treatment cascade indicators.

Integrated Counselling and Testing Centres – India has nearly 20,000 Integrated Counselling and Testing Centres (ICTC) that routinely collect data on people tested for HIV and positive cases, along with such diverse variables as age,

gender, potential route of transmission, history of migration, and others. This information is available for clients with different points of entry into the system, including voluntary walk-in, provider-initiated, and TI referred. While individual level data are available in primary registers, the main limitations are: a) the absence of unique identifying information that can be used to avoid double-counting people tested and people diagnosed, and b) the challenge of obtaining accurate information on exposure history among those tested and those diagnosed. Nonetheless, these testing data can be used for many purposes, including district level epidemiologic profiling, detection of emerging epidemics, geo-spatial analysis, geographic prioritisation, and tracking of HIV positivity rates, which, under certain conditions, can be back-calculated to produce proxy prevalence trends for specific populations such as key populations.[3]

Integrated Bio-Behavioural surveys (IBBs) among Key and Bridge Populations – IBBS surveys contribute to programme evaluation and reporting of M&E indicators at the state and national levels. They also provide data for estimates and projections at state and national level. NACO conducted one round of IBBS for key populations at the national level in 2014-2015. However, IBBS is very resource intensive and cannot be done on a regular basis. IBBS surveys may be done intermittently to provide evidence for calibrating more routinely available data from other sources, such as ICTC and HSS.

Line-listed Key Populations Living with HIV – These data are maintained by the TIs and include information on individual key populations, their testing history, positivity status, linkage to ART, etc. These individual-level data can contribute to estimation of proxy HIV prevalence trends and measurement of service uptake (e.g. prevention and treatment cascade indicators). However, the information is limited to those registered with TIs, who represent an unknown proportion of the overall key population. If good size estimation data are available in the TI catchment area, or the district where the TI is located, it is easier to interpret how well the line-listed data represent the overall situation.

Population size estimates for Key Populations – Population size estimates are needed for virtually every surveillance objective including detecting emerging epidemics, geographic prioritisation, estimates and projections (for key populations) at the district, state and national levels, and measuring service update including prevention and treatment cascades. What is important to note about size estimates is that different types of size estimates are needed for different purposes, and there is no one number that can be used for all. A higher level of accuracy is needed for local programme implementation than for national level estimates and projections. But these more accurate estimates are not required everywhere. They are only required in high priority geographic locations. In non-priority areas, rough extrapolated estimates can suffice. For that reason, it is important to have a stratified approach to key population size estimation, which includes systematic and operationally practical approaches to updating of local size estimates in higher priority areas, and less frequent, less data intensive approaches for updating size estimates in lower priority areas.

Details of key population size estimates were not explicitly addressed during this surveillance consultation. However, methods for obtaining size estimates are an integral part of surveillance and cannot easily be separated from other data collection systems, because size estimates are a secondary outcome of other surveillance activities such as IBBS, HSS and NFHS surveys.

NFHS – This is a large-scale, multi-round survey conducted in a representative sample of households throughout India. NFHS Plus provides updates and evidence of trends in population, health and nutrition indicators, including HIV prevalence. Moreover, the survey covers a range of health-related issues, including fertility, infant and child mortality, maternal and child health, perinatal mortality, adolescent reproductive health, high- risk sexual behaviour, safe injections, tuberculosis, malaria, non-communicable diseases, domestic violence, HIV knowledge, and attitudes toward people living with HIV.
The information enables the GoI to provide data to national and international agencies to monitor

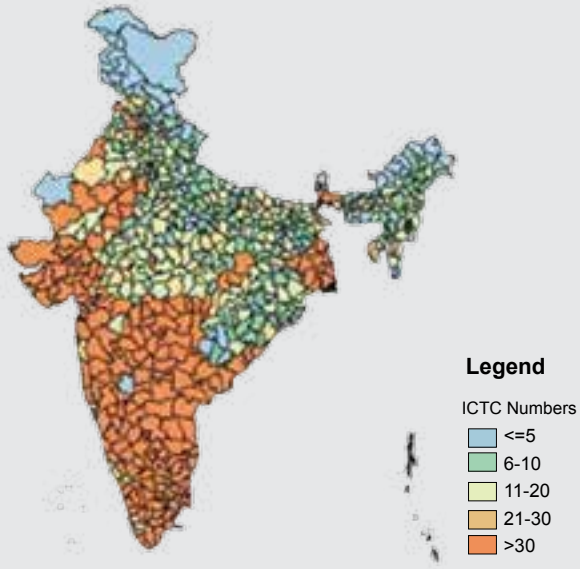
[3] Some of the conditions that must be met for calculating proxy prevalence trends include high testing coverage, availability of realistic local population size estimates, and minimal selection bias in those being tested.

and evaluate policies and programmes related to population, health, nutrition and HIV/ AIDS.

6.4 Recommendations on Analysis and Complimentary Use of Data

This section includes recommendations related to how the many components of India's HIV data systems can be analysed in a complimentary way to respond to the surveillance objectives and offer a better understanding of the epidemic and programme responses. These recommendations are:

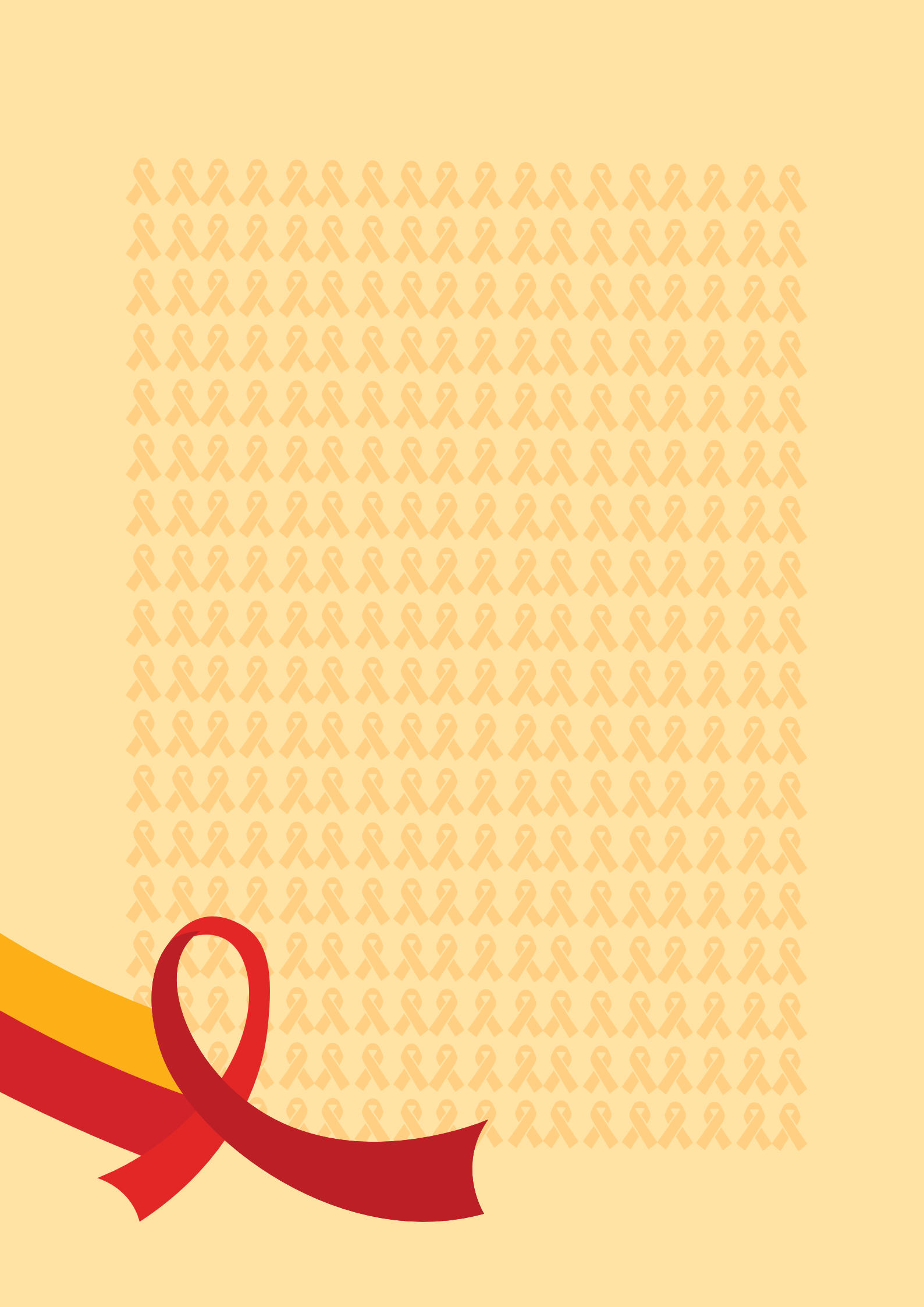
FIGURE: Integrated Counselling and Testing Centres, India, 2015



- Develop guidelines for effective use of programme data at multiple levels, with special focus on consistency, continuity and calibration.
- Develop and implement a phased data quality improvement plan to clean and validate programme data at reporting unit level, as well as at aggregated district and state level in an effort to improve programme data use.
- Renew focus on convergence of all programme component wise independent data sets for a detailed analysis across the continuum of prevention to care.
- Strengthen ICTC programme data, including
  - i. Secondary analysis and/or operations research for better characterisation of denominators and adjustments for duplication
  - ii. Promote analysis and use of ICTC client data at district and sub-district level for use in
    - a) Measuring levels and trends of HIV by exposure category
    - b) Profile analysis
    - c) Sero-discordance analysis
    - d) Geospatial analysis
    - e) District prioritization
  - iii. Case-based reporting of positive cases in PALS for general clients-
    - a) Move towards individual level reporting of positive cases in PALS
    - b) Establish strong data collection and quality control protocols
    - c) Establish analysis plan to estimate key epidemiological indicators
    - d) Consider adding behavioural questions
    - e) Link with ART database for longitudinal follow-up of disease progression and treatment outcomes
- TI-based HRG cohorts for epidemiological monitoring and modelling at state and national levels
  - i. Set up TI-based HRG cohorts at select TIs ensuring representativeness at regional/ national levels (well-performing NGOs with good data documentation practices). The data can be used to generate epidemic indicators of incidence, prevalence, etc. at state and national level, using back calculation methods using routine HIV testing data.
- Secondary analysis and/or implementation research for better characterization of TI HIV testing denominators so that positivity rates from TIs become more meaningful and representative
  - i. Use available HSS Plus/BSS lite or IBBS data to calibrate TI testing data.

Panel discussion 4 - Tracking the bio-behavioural parameter of the epidemic

Panel discussion 5 - on HIV estimations



7 CONCLUSIONS AND WAY FORWARD

The Expert Consultation Meeting has helped discuss both strengths and weaknesses of the current surveillance and estimation systems in India and other countries, including China, the Philippines and Vietnam, and define the right mix of methods that are required to track the epidemic and monitor and evaluate the response. Participants discussed the important issue of how to make a greater use for surveillance and estimates of expanding data derived from routine programme monitoring. They also debated on how to strengthen HIV case-based surveillance to reduce reliance over time on costly surveillance surveys and sentinel surveillance.

The need to acknowledge the limitations of each single source of data, and hence to intensify analysis and triangulation of data from a range of sources was emphasized by various national and international experts throughout the meeting. Participants concluded that various components of India's strategic information systems are complementary, and data derived from different sources should be used in conjunction to achieve a better understanding of the HIV epidemic and responses at different levels.

In surveillance, HSS among ANC clients and key populations should be expanded and improved, including by adding questions that allow to

Closing Session - panel members

get data to measure the 90-90-90 indicators. This should be combined with efforts to ensure a progressive shift to making greater use of programme monitoring data for complementing surveillance and estimation. A concrete roadmap should be developed to guide the transition from ANC HSS to PMTCT- data based surveillance. In addition, the quality of programme monitoring data will need to be improved.

Participants also recommended to continue IBBS if possible and use its prevalence estimates to serve as a calibration point in HIV estimation models.

But there was agreement that the scale and frequency of IBBS should be reduced, because nationally representative IBBS (as the one conducted in 2014/15) are too costly and time-consuming and not sustainable in the long run. HSS plus/BSS lite will be more feasible approaches going forward.

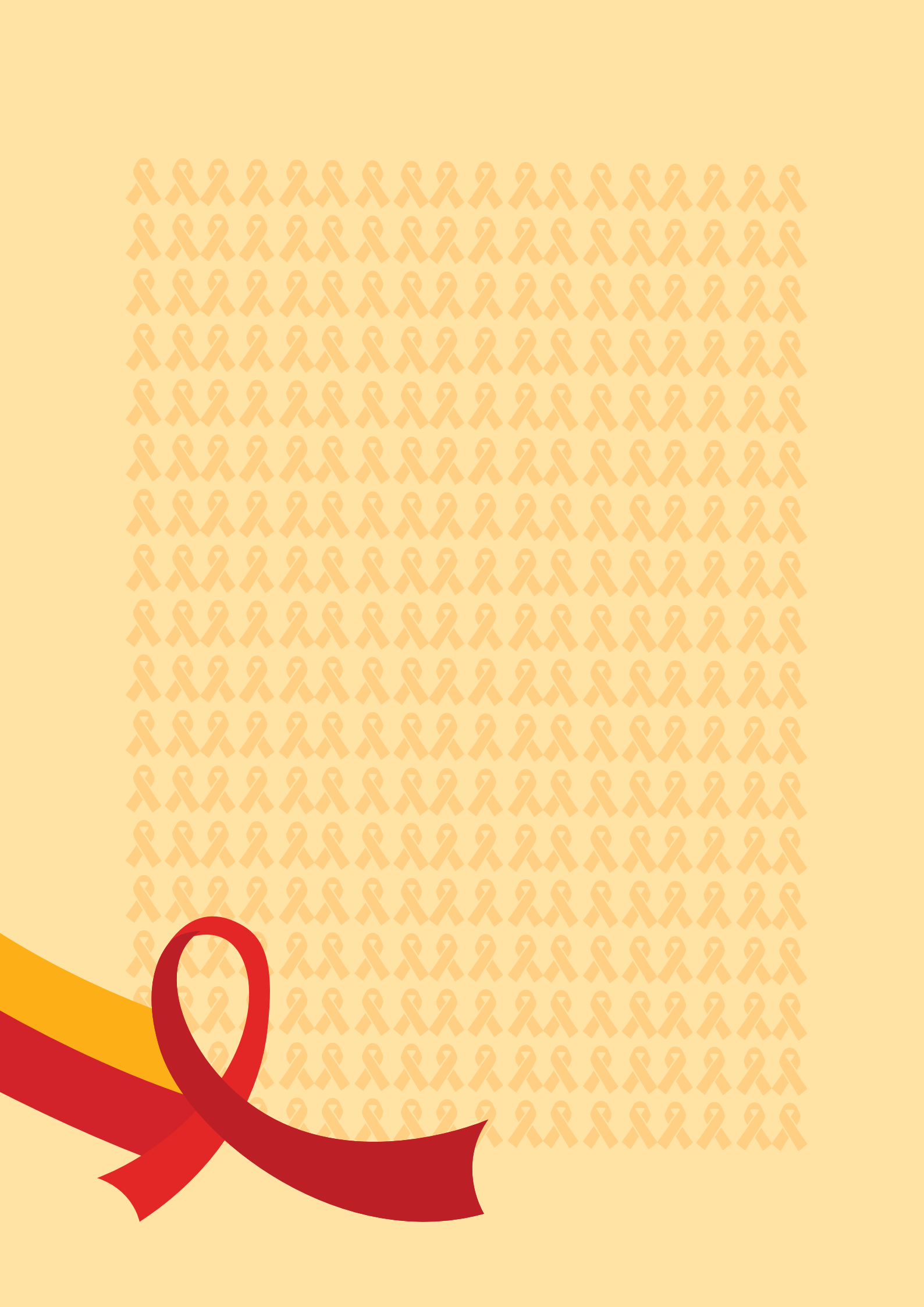
Regarding HIV estimation and projection, continued use of Spectrum was recommended as well as improved utilisation therein of programme data to customise Spectrum assumptions to the Indian context. Research to generate India-specific data needed to adapt Spectrum to local conditions, may need to be undertaken, if such data is not already available. The need to develop district level HIV estimations will have to be looked into carefully, and suitability of different estimation methods assessed to select one that can be applied in different data-rich and data-poor contexts.

Development of cohort-based HIV incidence assessments should also be pursued to obtain estimates for different key populations. In addition, proxies for new cases could be developed by using CD4 data. TI-based key population cohorts should be used for the monitoring of epidemic trends and to guide localized responses.

There was consensus among participants that population size estimations for all the key population are very important. They urgently need to be updated for use as denominators to measure the first 90 across key population groups. The need to prepare an options paper documenting lessons learned and best practice with implementation of different size estimation methods, as recommended by the Mid- Term Appraisal of the NACP IV, was highlighted. Monitoring the prevention to treatment cascade is a top priority, hence the importance of having up-to-date estimates of the number of people living with HIV and members of key populations.

The importance to strengthen not only key programme monitoring data, but also case-based surveillance was universally recognized by participants. This will also require investment in the integration of many distinct data management systems into one single system and the strengthening of unique identifier systems to track clients across the continuum of prevention to treatment and care, and monitor and ensure the quality of data. This will also require efforts to expand and standardise the use of a unique identifier for the tracking of individuals across different services.

The expert consultation meeting provided a vibrant forum, with experts who were able to critically review and discuss HIV surveillance and estimation systems, including their mechanisms, methods, outputs and cost implications. Key recommendations put forward to strengthen these systems in India will help decision-makers to come up with concrete decisions to improve strategic information on the epidemic and the response. Several options are available, and the best suited ones should be chosen by decision-makers, with guidance from strategic information experts to ensure that the evidence that is needed for policy and programme development can be obtained in a cost- effective and sustainable manner.



ANNEXES

ANNEX 1

RECOMMENDED METHODOLOGIES FOR SURVEILLANCE DATA SOURCES

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
1	HIV Sentinel Surveillance for ANC Women	For eligible participants during the surveillance period: • Number tested for HIV (as denominator) • Number HIV positive (as numerator) • Number tested for syphilis (as denominator) • Number syphilis positive (as numerator) • Viral Load for HIV positives • Hep B and Hep C • Additional cascade questions • CD4 as proxy for HIV incidence	• Pregnant Women	It is useful to have ANC surveillance data in all districts in the country until such time as alternative is available. However, prioritise districts with the following: • High concentration of any one key population group e.g. > 500 (absolute) or comprising more than 1% of the population). • High prevalence of HIV in any one key population group (e.g. 5% or more). • High proporton (e.g. 1% or more) of males who migrate to and from high prevalence areas.	Biennial • 2017 » 2019 » 2021 • 2023	• Strengthen HSS for ANC in districts in northern and eastern states. (Keeping in mind that in low prevalence areas without targeted interventions, ANC is not sufficient as an early alert for HIV outbreak among key populations). • Continue to strengthen linked testing as part of HSS to ensure that all positives detected through surveillance are linked to relevant services.
2	PMTCT	• Number of pregnant women tested for HIV • Number of pregnant women who are HIV positive[4] • Number of pregnant women tested for syphilis • Number of pregnant women who are syphilis positive • Viral Load for Positives	• Pregnant Women	• All public ANC sites public (and private to the extent possible)	• Ongoing	• Operational framework for replacing ANC surveillance by PMTCT based surveillance to be developed and implemented (in established high PMTCT coverage states first) • Systematic, evidence-informed shift to take place after 3-4 rounds of strong trend data from both systems and assessment of bias to inform necessary calibrations

[4] May come from stand-alone or integrated ICTC facilities where pregnant women are tested

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
						• Analysis will require data on already known positives, opt-out rates, and age disaggregation • Epidemiological analysis will be required to look into the validity of this data source for Spectrum purposes. **Limitations:** • Issue of duplication • Exclusion of women who are known positives
3	HSS Plus BSS Lite (TI)	Among eligible respondents: • HIV Status • Viral Load (for HIV positives) • Questions for measuring cross-sectional knowledge behavioural and prevention and treatment cascade indicators • Syphilis • Hep B and Hep C • CD4 as proxy for HIV incidence	• Key Populations	For District Level Purposes: • Prioritise districts with greatest concentrations of key populations where TIs exist (keeping in mind that in areas without targeted interventions, it is critically important to have other mechanisms for early detection of new HIV outbreaks, such as tapping into positive networks or working with CBOs in the area) For State Level Purposes:	Biennial • 2017 • 2019 • 2021 • 2023	• Random sampling from register of key populations who seek services at a TI site to improve representativeness. • Continue to strengthen linked-testing as part of HSS to ensure that all positives detected through surveillance are linked to ART. • Data to be compared to IBBS data, when and where available to assess representativeness. • Also, pilot strategies such as rapid hotpot listing for time location sampling or respondent driven sampling (RDS) to increase coverage beyond TI registered key populations.
				• Prioritize districts that represent the diversity of epidemic conditions within the state		
				For National Level Purposes:		
				• Prioritize states that represent the diversity of epidemic Conditions across states		

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
4	ICTC	• Number tested for HIV by exposure category • Number positive for HIV by exposure category including: **Males** » Injecting drug use » Sex with other men » Heterosexual sex with casual or commercial partners » Heterosexual sex with regular partners only **Females** » Injecting drug use » Sex with commercial partner (clients) » Heterosexual sex with casual partners » Heterosexual sex with regular partners only	• All locations with ICTCs	• Prioritize locations with TIs	• Ongoing	• Programme data such as ICTC can be used extensively for district level profiling purposes. • ICTC register to include information on » Entry point (TI referral/ general walk-in) » HIV exposure history » Whether first time or repeat test. • Requires good characterisation of all who are tested (not only people who test HIV positive). • Proxy prevalence estimates for key populations to be developed using back calculation procedures. » For better quality, sub-analysis can be done for subset of key populations referred by TIs, which is a group that should be well-characterised. Capacities for analysis and use of these data to be increased **Limitations:** • Issue of duplication • Difficulty in assigning the population groups to which the data belong
5	Line-listed key population living with HIV	• Individual tracking of CST service history for HIV positive key populations (referred for testing by TI or identified as key population in general ICTC)	• Key Populations	• Districts with ART Centers	• Ongoing	Strengthen cross linkage between TIs and ART to generate these data

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
6	IBBS among key populations	• HIV status (for trends) • % VL suppressed) • Characteristics of population (typology, age, migration, risk behaviour) • Programme level outcomes (% reached with prevention package, % tested and know status, % with access to services • Questions for measuring cross-sectional treatment cascade • Data to calibrate HSS among key populations (HIV prevalence by sub-type, overlap between TI and ICTC testing, % not tested in either TI or ICTC)	• Key Populations	• First priority is to choose districts (sampling domains) with largest number of key populations • Secondary priority is to choose districts that represent epidemic diversity within and across states	• Once in 4-5 years	• Use probability sampling of all key populations (not only intervened subset) » Use TLS for venue-based key populations » Use RDS to reach beyond venue-based key populations (including virtual networks of key populations) • Extend sampling frames /seeds beyond TI coverage areas **Limitations:** • Resource intensive and therefore available only intermittently and in a limited number of locations • Can be difficult to interpret » Potential for HIV prevalence trends to mask underlying incidence patterns without models or incidence assays » Potential for differential refusal between known positives and other respondents » Requires asking key populations to share their HIV status and Number/ proportion of positives in the sample may be too small to reliably calculate the cascade indicators (2nd and 3rd 90)

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
7	IBBS among Bridge Populations	• HIV status (for trends) • % VL suppressed • Characteristics of population (age, migration, risk behaviour) • Programme level outcomes (% reached with prevention package, % tested and know status, % with access to services • Questions for measuring cross-sectional treatment cascade	• Clients of sex workers or occupational groups with higher proportions of men who buy sex (e.g. truckers, male migrants, and others) • Clients using the virtual space to access commercial sex	• First priority is to choose districts (sampling domains) with largest number of bridge populations • Second priority is to choose districts that represent epidemic diversity within and across states	• 5-year intervals	• See above (IBBS for key populations)
8	Population Size Estimates for Key Populations	Part I: Collation of proxy variables that can be used to assign districts to expected high, medium and low strata e.g. » # of reported HIV cases by exposure category » # of reported STIs » Rough size estimates obtained from key informants	• Key Populations	• All districts	• Update annually	• Use data for district level epidemiologic updates » Identify potential for emerging epidemics • Use data to feed into PSE part II (for stratification purposes)
		Part II: Direct Size Estimation in Selected Districts • Mapping, multiplier surveys or capture-recapture	• Key Populations	• Districts prioritised on the basis of stratification (see methodology)	3-4 year intervals	• Use information from PSE Part II to develop high, medium and low strata • Select which districts will have district size estimates and which will be extrapolated
		• Part III: Extrapolation	• Key Populations	• Districts with no direct size estimation data		• Use data from districts with direct size estimates to extrapolate to districts without direct estimates (by strata)

[5] May come from White Card, IMS or TI application

	Component	Type of data to collect	Populations	Geographic locations	Frequency and timing	Recommendations and optimization of methodologies to meet surveillance objectives
9	NFHS	• HIV Status • HIV risk behaviours and programme exposure variables • Information to be used for Key Population Size Estimates » Clients of sex workers (% of males who buy sex) » MSM (% of males who have sex with males) » FSWs (% of women who sell sex) » PWIDS (% of males and females who inject drugs) » Data for treatment cascade indicators » % of PLHIV tested and know their status (first 90) » % of PLHIV on ART (second 90) » % of PLHIV retained on ART » % of PLHIV virally suppressed (third 90)	• General population males and females of reproductive age	• Nationally representative sample	• 5-year intervals	• Probability sample of men and women of reproductive age selected from households to form a nationally representative sample • Cascade Indicators **Limitations:** • Can be difficult to interpret » Potential for differential refusal between known positives and other respondents » Requires asking respondents to share their HIV status and number/proportion of positives in the sample may be too small to reliably calculate the cascade indicators (second and third 90 targets)
10	PMTCT ART Linkages System (PALS)	• # of pregnant women tested and found positive for HIV	• Pregnant women undergoing ANC care	• All ANC sites	• Ongoing	• Addition of unique identifiers (possible linkage to national identifiers or biometrics) for case-based surveillance, keeping in mind confidentiality issues
11	Strategic Information Management System (SIMS)	• # of PLHA by exposure category[5] for » Sub-districts » Districts » States	• All diagnosed PLHIV	• All ART sites	• Ongoing	

ANNEX 2

AGENDA OF THE EXPERT CONSULTATION ON SURVEILLANCE AND ESTIMATIONS OF HIV

08:45	**Registration**	
Inaugural Session Session: Global Perspectives of Surveillance and Estimations of HIV		
09:30-09:45	Expert Consultation Meeting: welcome, rationale and expectations	Dr Neeraj Dhingra,DDG, NACO
09:45-10:00	HIV epidemic profiling and responses	Dr Taoufik Bakkali, UNAIDS
10:00-10:15	HIV surveillance methods: evolution and present status	Dr Swarup Sarkar, WHO SEARO Dr Chika Hayashi, WHO Geneva
10:15-10:30	HIV estimations -rational and models	Dr Tim Brown, EWC, Hawaii
10:30-10:45	HIV surveillance for decision making in HIV control programmes	Dr David Wilson, World Bank
10:45-11:00	Key note remarks	Dr C.V. Dharma Rao, Joint Secretary, NACO
11:00-11:30	**Tea break**	
Day 1: Technical Session 1: HIV Biological Surveillance Session: HIV Biological Surveillance Present and Future – Special Context to India Session Chair: Dr Arvind Pandey Session Co-Chair: Dr Salil Panakadan Moderator: Dr Nicole Seguy		
11:30-11:50	Global overview of HIV biological surveillance	Dr Wolfgang Hladik, CDC
11:50-12:10	Vietnam's HIV surveillance system	Dr Bui Hoang Duc, Vietnam
12:10-12:40	HIV surveillance in India	Dr Pradeep Kumar, NACO
12:40-13:00	HIV incidence surveillance in India: Status and challenges	Dr R. Gangakhedkar, NARI
13:00-14:00	**Lunch break**	
14:00-14:20	Strategic Information Management for HIV in India	Dr Neeraj Dhingra, NACO
14.20–14.40	Programme data: issues and challenges	Dr Yujwal Raj
14:40-15:00	Questions/clarifications/comments to presenters	
15:00-15:30	**Tea break**	
15:30-17.45	**Panel Discussion 1: Biological Surveillance** • Critique of the present surveillance system • Options of improving surveillance in India • Extensive programme data for surveillance	**Panellists:** Dr Chika Hayashi, WHO Geneva Dr Salil Panakadan, UNAIDS Dr Tim Brown, EWC Dr Neeraj Dhingra, NACO Dr Wilson Lo, GFATM Dr Mark Berry, CDC Dr Yujwal Raj Dr Virginia Loo, PEMA
17:45-18:00	Major take away of the discussions of Day 1	Dr Shashi Kant, AIIMS
18:00-18:15	Wrap up	Dr Savina Ammassari, UNAIDS

Day 2: Technical Session 2: Estimation of HIV and AIDs **Session: Models of HIV Estimation: Strengths and Challenges – Alternative Mechanisms?** Session Chair: Dr L.M. Nath Session Co-chair: Dr Anindya De Moderator: Dr Taoufik Bakkali		
Time	**Title**	**Presenter**
09:00-09:20	Overview of HIV estimations across the globe	Dr Taoufik Bakkali, UNAIDS
09:20-09:40	HIV burden estimation in USA	Dr Wolfgang Hladik, CDC
09:40-10:00	Methods of HIV burden estimation in China	Dr Guo Wei, China
10:00- 10:20	Overview of HIV estimations in India	Dr Arvind Pandey, NIMS
10:20-10:35	Programme data: TI	Mr Kannan, NTSU, NACO
10:35-10:50	Programme data: ICTC and PMTCT	Dr Kuldeep S. Sachdeva, NACO
10:50-11:05	Programme data: STI	Dr T.L.N. Prasad, NTSU, NACO
11:05-11:20	Programme data: ART	Dr R.S. Gupta, NACO
11:20-11.30	**Tea break**	
11.30-11:45	Variance in estimation and key programme data	Dr Neeraj Dhingra, NACO
11:45-12:00	Questions/clarifications/comments to presenters	
12:00-13:30	**Panel Discussion 2: HIV estimations** • Estimation models/methods and findings • Programme data key results • Estimation options for India	**Panellists:** Dr Arvind Pandey, NIMS Dr. R. Gangakhedkar, NARI Dr. Salil Panakadan, UNAIDS Dr. Tim Brown, EWC, Hawaii Dr. Neeraj Dhingra, NACO Dr. David Wilson, WB Dr. Anindya De, CDC Dr. Wiwat Peerapatanapokin, EWC Hawaii
13:30-14:30	**Lunch Break**	

Day 3: Technical Session 3: HIV Behavioural Surveillance Session: Existing Methods for Behavioural Surveillance- Challenges and Future Methods Session Chair: Dr R. Gangakhedkar Session Co-chair: Dr David Wilson Moderator: Dr Sheela Godbole		
Time	**Session**	**Presenter**
14:30-14:50	Global overview of HIV Behavioural Surveillance	Dr Avi Hakim, CDC
14:50-15:10	Integrated Bio-behavioural Surveillance System in Philip-pines	Dr Genesis Samonte, Philip-pines
15:10-15:30	Integrated Biological and Behavioural Surveillance in India	Dr Pradeep Kumar, NACO
15:30-15:50	NFHS – methodology and key parameters for HIV	Dr F. Ram, IIPS
15:50-16:10	Questions/clarifications/comments to presenters	
16:10-16:30	**Tea Break**	
16:30-18:00	**Panel Discussion 3: Behavioural Surveillance** • Challenges in the present method of capturing the behavioural data • Opportunities of capturing behavioural data with Biological Sentinel Surveillance • Can behavioural indicators be captured in programme data?	**Panellists:** Dr Niranjan Saggurti, Population Council Dr Neeraj Dhingra, NACO Dr F. Ram, IIPS Dr Tobi Saidel, PEMA Dr Wolfgang Hladik, CDC Dr Lakshmi Ramakrishnan, SAATHI Dr Savina Ammassari, UNAIDS

Day 3: Concluding Session: Recommendations Session: Recommendations for Indian Surveillance System Session Chair: Dr C.V. Dharma Rao Joint Secretary, NACO Session Co-Chair: Dr S. Venkaesh, Director, National Centre for Disease Control		
Time	**Title**	**Presenter**
09:00-09:30	Recap	Dr Pradeep Kumar, NACO
09:30-11:15	**Panel Discussions 4: Tracking the Bio-Behavioural Parameter of HIV Epidemic:** a. What shall be mission and vision of HIV surveillance system? b. Programme data for monitoring HIV epidemic? c. Improve the programme data for HIV surveillance? d. Methods to improve current HSS? e. Addition of key bio-markers for tracking level and trends of key co-morbidities? f. What risk behaviours/practices will be tracked? g. Frequency h. Quality management	**Panellists:** Dr L.M. Nath Dr Shashi Kant, AIIMS Dr Neeraj Dhingra, NACO Dr Swarup Sarkar, WHO Dr Wolfgang Hladik, CDC Dr Tobi Saidel, PEMA Dr Guo Wei, China Dr Genesis Samonte, Philippines Moderator: Dr Nicole Seguy, WHO
11:15-11:45	**Tea break**	
11:45-13:15	**Panel Discussions 5: HIV Estimations** a. Relevance of HIV estimations in India in view of programme data results? b. How to improve estimations with the use of programme data? How do they supplement each other or are independent of each other? c. What estimates need to be provided by the surveillance system? d. What should be the degree of granularity of these estimates? e. Estimates for programmatic decision making- concurrent and mid-term?	**Panellists:** Dr Arvind Pandey, NIMS Dr R. Gangakhedkar, NARI Dr Salil Panakadan, UNAIDS Dr Neeraj Dhingra, NACO Dr Tim Brown, EWC Hawaii Dr David Wilson, WB Dr Anindya De, CDC Dr Bui Hoang Duc, Vietnam **Moderator** Dr Taoufik Bakkali, UNAIDS
13:15-14:00	**Lunch break**	
Day 3: Closing Session: Way Forward for the Indian Surveillance System **Session: Summary of Recommendations for HIV Surveillance and Estimations in India**		
14:00-14:10	Welcome of dignitaries	Ms Mariyam Zainab, NACO
14:10-14:30	HIV surveillance and estimations in India: summary of key recommendations	Dr Neeraj Dhingra, NACO
14:30-15:20	Concluding remarks	Dr Timothy Holtz, CDC Mr Oussama Tawil, UNAIDS Dr Henk Bekedam, WHO Dr C.V. Dharma Rao, Joint Secretary, NACO
15:20-15:30	Vote of thanks	Dr Pradeep Kumar, NACO
15:30-16:00	**High tea**	

ANNEX 3

LIST OF PARTICIPANTS IN EXPERT CONSULTATION

A Elangovan	HIV Surveillance Focal Person	National Institute of Epidemiology – NIE
Anindya De	Statistics Team Lead	CDC HQ
Arvind Pandey	Director	National Institute of Medical Statistics
Asha Hegde	NPO, ICTC	NACO
Avi Hakim	Clinical Surveillance	CDC HQ
BB Rewari	NPO, ART	WHO SEARO
Bui Hoang Duc	Deputy Head, Division on Surveillance, Monitoring, Evaluation and Laboratory	Viet Nam Authority of HIV/AIDS Control (VAAC)
Chika Hayashi	Monitoring and Evaluation	WHO HQ, HIV/AIDS Department
CV Dharma Rao	Joint Secretary	National AIDS Control Organization
Damodar Sahu	HIV Surveillance Focal Person	National Institute of Medical Statistics – NIMS
Daniel Rosen	Branch Chief, Strategic Information	CDC India
David Wilson	Director, HIV/AIDS Programme	World Bank
Deepika Srivastava Joshi	Public Health Analyst	CDC India
F Ram	Director	International Institute for Population Sciences - IIPS
Genesis May Samonte	Epidemiologist and HIV Unit Manager	Epidemiology Bureau - Department of Health
Govind Bansal	Team Leader, NTSU	NACO
Kannan Mariyappan	NTSU	NACO
KS Sachdeva	Deputy Director General (Basic Services)	NACO
Lakshmikant Chavan	Surveillance and M&E Officer	CDC India
L M Nath	Former Director	All India Institute of Medical Sciences - AIIMS
Madhuri Thakkar	Apex lab in charge	National AIDS Research Institute – NARI
Mariyam Zainab	Technical Officer (M&E)	NACO
Mark C Berry	Key Population Surveillance Team	CDC HQ
Melissa Freeman	Monitoring and Evaluation	USAID
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Nicole Seguy	Technical Officer HIV/STI	WHO India
Nirajan Saggurti	Director	Population Council

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Praveen Gupta	PO (M&E)	NACO
PVM Lakshmi	HIV Surveillance Focal Person	Postgraduate Institute of Medical Education and Research – PGIMER
Puspanjali Swain	HIV Surveillance Focal Person	National Institute of Health & Family Welfare – NIHFW
Rajatashuvra Adhikary	Consultant	FHI 360
Rajesh Rana	AD Media, IEC	NACO
Raman Gangakhedkar	Director	National AIDS Research Institute - NARI
RS Gupta	DDG (CST)	NACO
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Sanjai Rai	HIV Surveillance Focal Person	All India Institute of Medical Sciences – AIIMS
Savina Ammassari	Senior Strategic Information Advisor	UNAIDS India
Shahsi Kant	Professor	All India Institute of Medical Sciences - AIIMS
Sheela Godbole	HIS Surveillance Focal Person	National AIDS Research Institute – NARI
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Tejas Mulik	Technical Associate, BSD	NACO
Tim Brown	Senior Fellow, Research Program	East West Centre, University of Hawaii
TLN Prasad	Technical Expert-STI. NTSU	NACO
Tobi Saidel	Consultant	Partnership for Epidemic Analysis (PEMA)
Vinita Dhar	PO, Lab Services	NACO
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HIV Surveillance in India has been one of the oldest and most integral components of a robust epidemic monitoring in country. It was initiated as early as in 1985 by Indian Council of Medical Research (ICMR) and has been credited with discovery of first HIV case in 1986. Over the years, the system has evolved into one of the world's largest and most robust surveillance system in country.

In the light of the global developments in the form of END of AIDS and Fast Track targets, epidemiological considerations and programme need, National AIDS Control Organization, in collaboration with UNAIDS India, WHO India and CDC India, organized technical consultations on next generation of HIV surveillance and estimation activities in 2016 and 2018. While 2016 consultation provided the broad contour for next generation, the 2018 consultation detailed specific initiatives for augmenting the epidemic monitoring.

The report presents the objectives, methodology, recommendations and rationale for same from expert consultations on HIV surveillance and estimations in India. These reports further underline the outcome driven approach under the surveillance system of the national AIDS response. These reports will be of great help to all those who are working in the area of HIV epidemiology to understand why and how a disease surveillance system evolves and provide relevant evidences in the most efficient way to strengthen the decision support systems.

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