INTRODUCTION AND GLOBAL SCENARIO
Thirty-one years ago, a 31-year-old gay man was admitted to the medical center at University of California, Los Angeles with prolonged fever and unexplained weight loss of 28 kg over few months. He was diagnosed to have Pneumocystis carinii pneumonia, seen at that time among immune suppressed patients like cancer patients receiving chemotherapy, etc. He was found to have severe immunodeficiency, which could not be explained at that time. During the same time, on the other coast of the United States, a theater actor presented to New York University Medical Center with purple spots on the face and was diagnosed as having a rare skin cancer, Kaposi sarcoma. Dr Gottlieb in the Centers for Disease Control and Prevention (CDC) Morbidity and Mortality Weekly Report (MMWR) of 5th June 1981, described a syndrome of unusual illness that was termed as “gay-related immune deficiency” (GRID), as most of initial cases were reported among gay people. Later, similar cases were reported among drug addicts, people who received blood transfusions and other persons, indicating that the syndrome was not just limited to gay men. In 1982, the CDC formally coined the term “acquired immunodeficiency syndrome” (AIDS) for these group of illnesses. In 1983, Dr Robert Gallo and his colleagues at the National Cancer Institute in the United States and Luc Montagnier in France identified the causative organism of the disease, which was later named as human immunodeficiency virus (HIV). In the same year, blood tests for diagnosis of HIV infection also became available. In July 1985, Rock Hudson became the first public figure to announce that he had AIDS and he died 3 months later. In 1987, CDC identified Gaetan Dugas as “Patient Zero,” linking him to 40 of the first 248 cases in the United States. Almost 6 years after the disease was identified, the first treatment emerged, which was a huge step in the fight against HIV/AIDS. The drug zidovudine (AZT) was approved by the Food and Drug Administration (FDA) on March 19, 1987, which was used in high doses to treat people infected with HIV. The World Health Organization (WHO) declared 1st December as World AIDS Day in 1988 and the red ribbon was recognized as the international symbol of AIDS awareness in 1991. The triple-drug therapy for HIV was announced in 1996 during world AIDS conference in Vancouver and it literally changed the way HIV would be looked few years later. David Ho in 1997, advocated for a new treatment strategy: “hit early, hit hard.”

No other disease has attracted so much money and attention. Despite billions of dollars and the ingenuity of scientists, we are yet to find a cure or an effective vaccine for the disease, though the ART has changed the outlook of the disease from a virtual death sentence to a chronic manageable disease.

HIV IN INDIA—HISTORY AND OUR RESPONSE
There are an estimated 4.2 million people living with HIV in Asia, 90% of them are in India, China and Thailand. India contributes 49% of it (2.4 million people).

The first few cases of HIV in India were detected in 1986 among sex workers in Chennai and the first AIDS case was reported in 1987 in Mumbai. Like in other countries, HIV was accompanied with stigma, discrimination, depression, suicidal tendencies and violence. Right from the beginning of the epidemic in India, an AIDS task force was established by the Indian Council of Medical Research (ICMR) for screening risk behavior of such groups. As more cases began to be detected, a National AIDS Committee was set up under the Union Ministry of Health and Family Welfare in 1986. The objective of this committee was to control the spread of the infection and promote community and family-based care to people with HIV/AIDS. The National AIDS Control Organization (NACO) was established in 1992 and the first National AIDS Control Programme (NACP) was launched. Its main objective at that time was to undertake surveillance to know modes of spread, to screen blood and increase awareness. By early 1990s, cases of HIV infection had been reported in every state of the country and it was clear that individual states had different prevalence rates. In 1998, 176 surveillance sites were established and a nationwide surveillance was done, which revealed that there might be nearly 3 million HIV-infected persons in India.

During Phase I of the NACP (1992-1999), the focus was on awareness generation, controlling spread through blood, etc. The Phase II of the program was launched in 1999 with a strategic plan for HIV prevention. This plan established the administrative and technical basis for program management and also set-up State AIDS
Human Immunodeficiency Virus

Societies to streamline response to HIV/AIDS at the state level. It was during this phase that specific interventions were targeted toward FSWs, MSM, IDUs and policies for blood banks for screening for HIV were also introduced. The rollout of ART in April 2004 gave new hope to thousands of people living with HIV. Indian pharmaceutical companies developed innovative methods for manufacturing complex pharmaceutical products and marketed these products at very low cost that played an important role in ensuring the universal access of ART at affordable prices.

With the success and the confidence gained in NACP II, Phase III of NACP was launched in July 2007 with the goal to “halt and reverse the epidemic.” This was to be achieved over a period of 5 years (2007-2012) by scaling up prevention efforts and integrating them with care, support and treatment (CST) services. Prevention and CST formed the two key pillars of all HIV/AIDS control efforts in India.

It was also during NACP III (2008) that a “Department of AIDS Control” was set up under the Ministry of Health and Family Welfare (Figure 1). The major responsibilities of this department are intersectoral, interorganizational and interinstitutional coordination in areas related to HIV/AIDS control and prevention, providing institutional framework for research, dissemination of accurate, complete and timely information about HIV/AIDS and management of the NACO.

Now the program is entering its Phase IV and the primary goal of NACP IV is to accelerate the process of reversal and further strengthen the response through a cautious and well-defined integration process over the next 5 years.

CURRENT STATUS AND ACHIEVEMENTS OF AIDS PROGRAM IN INDIA

India currently has an estimated 2.1 million people living with HIV/AIDS (PLHIV), with a prevalence of 0.27%. The epidemic is heterogeneous with almost 195 districts being more severely. The epidemic is concentrated mainly in high-risk groups (HRGs) like FSWs (4.94%), MSM (7.3%), IDUs (9.19%) and the bridge populations like truckers (1.62%) and migrants (2.35%)

The heterosexual route is the major mode of transmission accounting for 87% of the total infections. During different phases of the program, the focus has been shifting from raising HIV/AIDS awareness to behavior change, creating national response to decentralized programs and to increase involvement of nongovernmental organizations (NGOs) and networks of PLHIV.

The program has succeeded in reducing the number of annual new HIV infections by 57% during the last decade. Wider access to ART has resulted in a decline in number of people dying due to AIDS. It is estimated that in 2010, deaths due to HIV was 172,041 as compared to 196,466 in 2005 and 199,502 in 2006 (a declining trend because of availability of ARTs).

There has also been remarkable decrease in the prevalence of HIV among HRG communities because of the success of the various targeted intervention (TI) activities. As per 2003 and 2010 data, prevalence among IDUs has reduced from 14% to 6%, antenatal clinic (ANC) (11–6%), FSWs (10.5–2.5%) and among MSM (8.1–4.5%).

As an outcome of combined prevention and treatment related activities, the prevalence of HIV in the country has been brought down from 0.41% in 2002 to 0.27% in 2011 which is a big achievement (Figure 2).

How We Achieved This?

Focused Work at NACO

In order to ensure that prevention and treatment activities are conducted across the country in a systematic and efficient manner. The type and status of major interventions are given below:

Targeted interventions (TIs): The TIs main objective is to improve health seeking behavior of HRGs and reduce their vulnerability and risk to acquire sexually transmitted infections (STIs) and HIV infections (Figure 3). This program is being implemented through NGOs and community-based organizations (CBOs), which provide services on behavior change communication, condom promotion, STI care, needle syringe exchange program, opioid substitution therapy (OST) and referrals for HIV testing and linking positives to ART.

A revised migrant strategy has been launched to provide HIV prevention services to migrants. Currently, there are 1,821 TIs providing prevention services covering 81% FSWs, 80% IDUs, 64% MSM, 40% migrants and 57% truckers.

Link Worker Scheme is a rural-based intervention for the prevention and care needs of HRGs and vulnerable population of rural areas including referral to Integrated Counseling and Testing Centers (ICTC) services and STI services, condom promotion and
Chapter 14  HIV/AIDS in India: Journey So Far and the Road Ahead

Section 2

Districtwise Scenario of HIV/AIDS

<table>
<thead>
<tr>
<th>Category</th>
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<tr>
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<td>B</td>
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<td>Total</td>
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**Figure 2:** Heterogeneous distribution of HIV/AIDS in India (District categorization based on HIV prevalence)

**Figure 3:** Route of HIV transmission in India

**Figure 4:** Estimated number of new annual HIV infection

Distribution, information related to HIV prevention and related services. Link worker scheme is currently functional in 153 districts.

The link worker scheme has covered about 122,701 HRG, 899,130 vulnerable population and 34,033 people living with HIV during 2011-2012.

**Management of sexually transmitted infections (STI)/reproductive tract infection:** Provision of STI or (RTI) reproductive tract infection (RTI) services is aimed at preventing HIV transmission (Figure 3). Enhanced syndromic case management through color coded drug kits, with minimal laboratory tests, is the cornerstone of STI or RTI management under NACP III. Presently, NACO is supporting 1,112 designated STI or RTI clinics which are providing STI or RTI services based on the enhanced syndromic case management. 98.83 lakh STI or RTI patients were managed during 2011-2012.

**Blood safety program:** Department of AIDS Control is making all efforts for augmenting voluntary blood donation and ensuring provision of safe and quality blood in the country by reducing HIV transmission through blood to less than 0.5%. There are 1,149 blood banks supported by NACO which include 171 blood component separation units and 28 model blood banks. During the year 2011-2012, 93.32 lakh blood units were collected across the country of which 50.68 lakh was collected through NACO supported blood banks and 83.5% of the blood collected was through voluntary blood donation (Figure 4).

**Information education and communication:** NACO’s communication strategy has moved from creating general awareness to behavior change communication. It aims to motivate behavioral
change among at risk populations, raise awareness and risk perception among general population, particularly youth and women, generate demand for HIV/AIDS-related health services like condoms, ICTC/prevention of parent-to-child transmission (PPTCT) facilities and create an enabling environment that encourages HIV-related prevention, care and support activities and to reduce stigma and discrimination at individual, community and institutional levels.

Red Ribbon Express (RRE) is the world's largest mass mobilization campaign on HIV/AIDS. It is a special exhibition train which travels across the country disseminating the messages on HIV/AIDS and general health in rural and remote areas of the country. Along with the train, special outreach programs are organized in the villages through information education and communication (IEC) exhibition vans and folk troupes. NACO has implemented two successful phases of the campaign and the Phase III is currently being implemented. In Phase I and II of this program, between 62 and 80 lakh people, respectively, were reached.

Integrated Counseling and Testing Centers: The Integrated Counseling and Testing Programme offering counseling and testing services for HIV, includes three main components: (1) ICTC, (2) PPTCT and (3) HIV-TB collaborative activities. The ICTC services are provided through 10,515 ICTCs (which includes 4,533 stand-alone ICTCs and 5,018 facility integrated ICTCs in Government facilities and 964 under Public Private Partnership model). During the year 2011-2012, 194.75 lakh persons including 85.63 lakh pregnant women were provided counseling and testing services.

Care, support and treatment program: The CST program provides prevention and treatment of opportunistic infections, ART (first line and second line), psychosocial support, home-based care, positive prevention and impact mitigation (Figure 5). In 1996, national pediatric HIV initiative was launched to increase access to ART for children and in 2010 program for early infant diagnosis (EID) among HIV-exposed infants and children under 18 months of age was launched. Currently, 358 ART centers, 725 Link ART centers and 253
community care centers are providing treatment to 5.76 lakh people living with HIV. Thirteen National Reference Laboratories and 117 State Reference Laboratories provide quality assurance for HIV testing (Figures 6 and 7).

**Monitoring and evaluation-surveillance:** India has a robust system of annual HIV sentinel surveillance for monitoring the HIV epidemic in the country among the general population as well as HRGs. The sentinel surveillance network has been expanded to over 1,300 sites covering all the districts. Epidemiological profiling of HIV/AIDS situation at district and subdistrict levels, using data triangulation has been undertaken in around 500 districts in 25 states in two phases in 2009 and 2010. The outputs from this exercise have been used for recategorization of districts for priority attention.

Strategic information management system (SIMS), a web-based application, has been rolled out across the country through which over 14,000 reporting units submit monthly reports on service delivery.

**Mainstreaming:** Thirty-one Union Ministries and Departments of the Government of India have mainstreamed HIV/AIDS prevention in their day-to-day functioning. All these organizations have developed their own action plan covering critical elements from their own funds (Figure 8).

### Role of Nongovernmental Organizations (Multilateral, Bilateral Partners)

India has been able to halt the spread of the HIV epidemic because of a committed partnership between the government, NGOs, network of positive people, CBOs and various donors and civil society partners. In the last two decades many organizations have contributed significantly to India’s battle against HIV. In the early days of the epidemic, World Bank provided major assistance in terms of financial aid, technical assistance, strategy development and implementation. In fact, it was the assistance from some of these multilateral and bilateral organizations (like the Global Fund, UNAIDS, the World Bank, UK Department for International Development) and some foundations that put the fight against HIV/AIDS on a different platform. In 1992, the World Bank launched its first HIV/AIDS project in India which has been followed by many more projects. The urgency for the roll out of this project was based on the need for timely intervention for greater impact. It was also realized that for optimal results, a multipronged approach needs to be adopted with emphasis on HRGs for cost-effective measures and controlling sexually transmitted diseases (STDs). Besides this, dealing with sociocultural determinants was also considered crucial to halt the spread of this disease.

The United States Agency for International Development (USAID) was also one of the very early agencies that came to support India in its fight against HIV. One of the oldest bilateral programs with the Indian Government in the field of HIV/AIDS is the AIDS Prevention and Control Project (APAC) rolled out in 1992, in the states of Tamil Nadu and Pondicherry, and a project on averting HIV and AIDS (AVERT) was rolled out in 1999 in Maharashtra. APAC primarily focused on sexual prevention of HIV, adult care and support, orphans and vulnerable children (OVC), strategic information, and health system strengthening. AVERT adopted a comprehensive prevention approach. The focus of this project was toward behavior change, modify interventions to reduce STIs among HRGs, interventions to reduce violence and establish referral linkages for counseling and testing for HIV. In October 2006, another project called *Samashti* was rolled out in select districts in the states of Karnataka and Andhra Pradesh. This project aimed to reduce the transmission of HIV and the effect of HIV on those affected by this disease.

With time, more organizations provided assistance in a specialized manner, focusing on newer areas related to HIV prevention and treatment. In mid-2003, The Bill and Melinda Gates Foundation launched their *Avahan* project in India in consultation with the Government of India. The focus of this project was targeted approach toward prevention package designed to address both proximate and distal determinants for HIV risk.

As the HIV awareness related activities increased, the Clinton Foundation came to scale up integrated treatment and prevention activities in India in 2004. Assistance was in the form of providing effective care and treatment for people living with HIV and support for laboratory upgradation. For the first time in India, a uniform patient information system was established at NACO, resistance monitoring capabilities were established, laboratory testing capabilities for initiation of ART were set up and program monitoring and evaluation tools were developed with the support of India country office of WHO.

The contribution from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) for testing, counseling, CST-related activities has been enormous and has contributed in a major way to scale up treatment services and consequently reduce mortality and morbidity.

### CHALLENGES AND ROAD AHEAD

Today, we stand at a vital threshold. India has come a long way in controlling the HIV epidemic. In fact, India is heading toward halting and reversing the epidemic by the year 2015 as outlined in the Millennium Development Goal (MDG) 6. But all this has come after lots of struggle and hard work. The challenges in the fight against HIV were many. They varied from lack of evidence and data on the severity of the epidemic, trained manpower, health delivery systems, availability of funds and skilled manpower to develop and implement various programs. Foreign funding along with political commitment gave push to the program. Over time, assistance was given not only in terms of financial aid but also in the form of training and other technical assistance. Guidelines were developed, protocols established and TIs were planned and implemented. Next, the big issue of discrimination which was hampering the success of...
the program had to be addressed. Massive awareness campaigns were conducted and people infected and affected by HIV/AIDS were counseled. The challenges India has faced to overcome this epidemic have been enormous. A lot still needs to be done to achieve universal access to HIV prevention and treatment.

Some of the newer challenges that face the NACP are the dual problems of the HIV epidemic, driven by unsafe sex and injecting drugs, not only in the North Eastern states but among emerging pockets in metros and some Northern states. Till now the interventions that have been rolled out were very focused toward particular high-risk behavior. Now newer interventions need to be envisaged that deal with more than one high-risk behavior. Besides this, keeping track of the migratory population and their behavior is one of the most important challenges that the program is facing today. It is important to ensure that all the people who have risk behavior for HIV, get tested and counseled, and if positive, get registered at an ART/Link ART centers for timely initiation of ART and management of opportunistic infections. Another aspect of the treatment that needs attention is the emergence of drug resistance. As the program is maturing, more patients will be identified with treatment failure and toxicity related issues. It is important that more clinical trials are conducted to understand the side effects of ARTs in India’s context and advocate for the availability of more options for second-line ART and alternate first-line ART. The issue of treatment for coinfections like hepatitis B and C is another challenging area.

So far the treatment for HIV has been affordable due to cheap generic drugs from Indian pharmaceutical companies, which provide 89% of drugs in developing countries. The looming threat of patents on newer antiretrovirals can push up costs significantly and we may come back to a situation of the year 1998, where only 5% of those requiring ART could afford treatment.

During the last 25 years, many domestic and international organizations have contributed to India’s fight against HIV. As a result many “stand-alone” HIV control programs have come up both at national and regional levels. The major challenge is to integrate them and align them with the national program. Another major issue is integration of the HIV program with the general health system for long-term sustainability.

ROAD AHEAD AND CONCLUSION

The HIV/AIDS is still a major health problem and a lot needs to be done to ensure the sustainability of this program. We need to evolve mechanisms to ensure that HIV care is provided along with general health care. While mainstreaming, it is important to ensure that the quality of interventions is not diluted. Certain interventions like TIs and other NGO/CBO programs cannot be fully mainstreamed due to the special nature of these interventions, which have shown results. The battle against HIV/AIDS is a remarkable example of coordination between government and nongovernment agencies, hard work and dedication and scientific innovation. Active participation of the private sector in HIV prevention and treatment related activities needs to be encouraged. We now need to ensure that mother-to-child transmission of HIV is reduced and no new child gets HIV infection. Despite all IEC activities, 40% of HIV-infected people do not know their status. Hence, we must encourage HIV testing for all those people who are unaware of their HIV status by increasing the level of awareness about HIV/AIDS. During Phase IV of the NACP, new policies and strategies need to be devised in order to ensure sustainability, and for this it is essential that operational research projects are undertaken in various prevention and treatment related areas.

It is important that new prevention technologies/interventions like microbicides, pre-exposure prophylaxis, etc. are brought out, keeping the country’s status in mind.

The talks about an AIDS cure have begun, following cure of HIV in a German patient through bone marrow transplant, though that is not replicable on a large scale. But this has provided a new strategic direction for the scientists to work on. The “economist” carried an article that the beginning of the end of AIDS has started. UNAIDS has set a target of zero new infections, zero AIDS-related deaths and zero stigma and discrimination by 2015.

Our focus should be to strengthen our health care facilities, train manpower and ensure universal testing for HIV along with access to ART through robust supply chain management for antiretroviral (ARV) drugs and strengthen systems for quality assurance, monitoring and evaluation of the various services under the program. The issue now is not how to treat patients, but how to find patients, test them, get them into medical care early, keep them there and not lose focus on prevention, while doing all this. We have moved from despair to hope, from denial to acceptance, from stigma to reduction in stigma, from a death sentence to a chronic manageable disease and should now aim for donor funded to domestic funded program and standalone to more integrated programs. The opportunity to end the sufferings of 30 years is within our grasp. We need to tighten our hold at this vital threshold and ensure that there is no complacency. Now is the time to accelerate efforts once for all and finish the job.