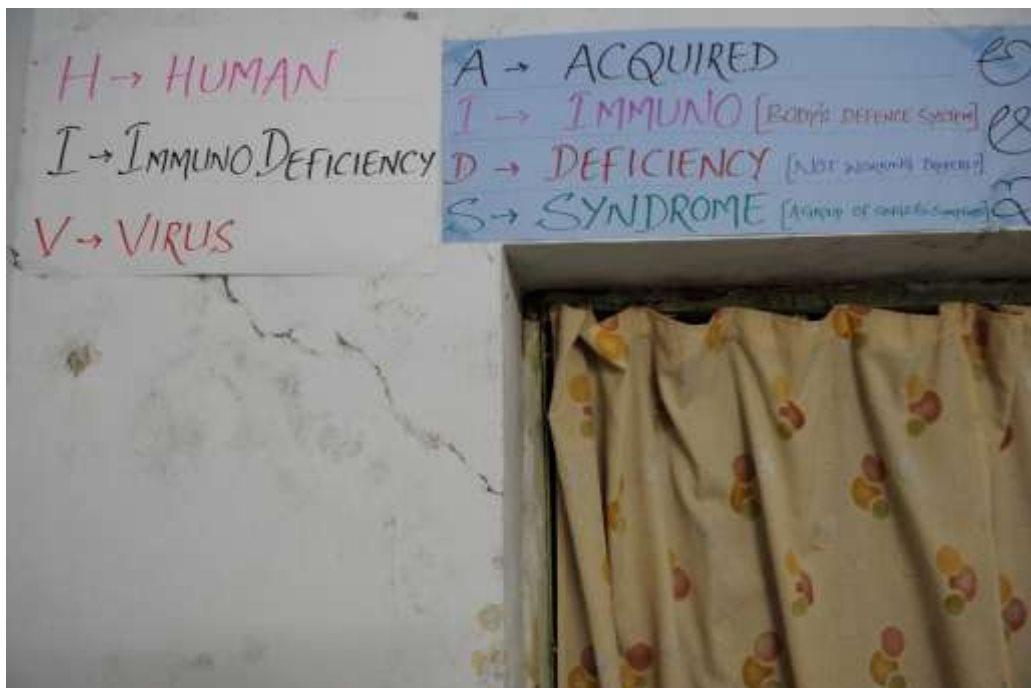


Changing Minds, Lengthening Lives

LEPRA Society: HIV Interventions



January 2011

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The Context

HIV in India

India's first case of HIV was detected in Chennai in 1986, and its first case of AIDS in Mumbai in the same year. In 2009, an estimated 2.4 million people in India (24 lakhs) were infected with HIV: the third-highest burden of the disease in the world, behind South Africa and Nigeria. With an estimated prevalence of 0.29% among the adult population in 2008, HIV/AIDS in India is currently concentrated mainly among certain high-risk groups (HRGs). It is primarily driven by unprotected paid sex, with 87.1% of new cases reporting this mode of transmission in 2009/10. Unprotected sex between men (1.5% of transmission via this mode) and injecting drug use (1.6%) are the other two important drivers of infection. The three HRGs, therefore, are:

- Female sex-workers (FSWs)
- Men having sex with men (MSMs); and
- Injecting drug users (IDUs).¹

Additionally, there are two important bridge populations engaging in unprotected paid sex, who then carry infection into the general population. These are migrants (particularly the 9 million short-term migrants in India) and long-distance truckers (of whom there are some 2 million). Both these groups have far higher rates of involvement with commercial sexual partners than the general population. 88% of male migrants in Andhra Pradesh in 2009, for instance, reported having commercial sex, in contrast to a rate of 5.6% among the general population. Figures for some other states are not as stark, but still reached 38.2% and 36.3% respectively in Maharashtra and Tamil Nadu, as against 7.1% and 2.2% for the general population. These bridge populations then carry the infection into the general population, through marital sex and contaminated blood products (which account for a further 1% of infections).



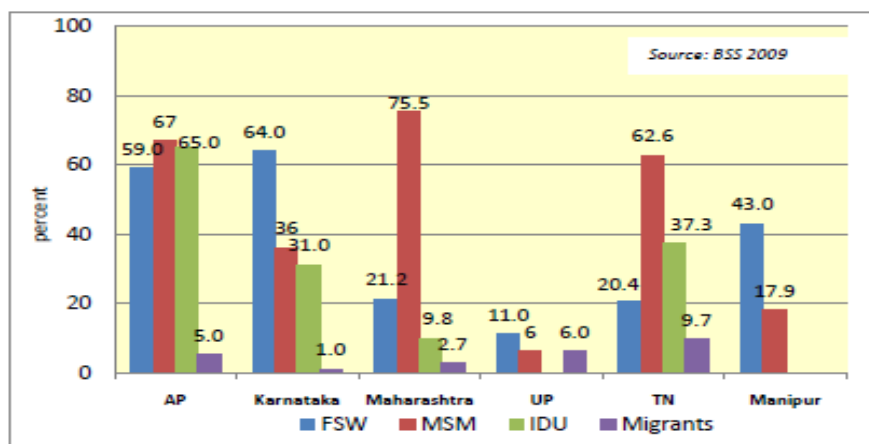
¹ World Health Organization, Regional Office for South-East Asia, HIV/AIDS in the south-east Asia region: progress report 2010, p.1; UNGASS Country Progress Report India, March 31 2010, p.1

Statistics show HIV infection concentrated in six high-prevalence states in two main areas: the south (Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu) and the north-east (Manipur and Nagaland). The epidemic in the north-east is of a different nature, being driven primarily by IDUs and resulting from the mass export of Burmese heroin along the national highways in these states.²

The National AIDS Control Organisation (NACO), founded in 1992, focuses its work on these high-risk groups and high-prevalence areas. Phase III of the National AIDS Control Programme (NACP-III), running from 2007 to 2012, has four strategic objectives:

1. Prevent infection by saturating coverage of HRG through targeted interventions (TIs) and scaled-up interventions in the general population.
2. Provide greater care, support and treatment to larger numbers of PLHIV.
3. Strengthen infrastructure, systems and human resources at district, state and national levels.
4. Strengthen the nationwide strategic information management system.

The NACP has achieved some successes, with FSWs in Andhra Pradesh reporting rates of condom-use as high as 83% in 2009. The overall prevalence of HIV in India has declined slightly over recent years, from 0.41% in 2004 to 0.34% in 2007 and 0.29% in 2008. These successes, however, and the apparently low levels of HIV in many north-western states, should not be cause for complacency. While considerable effort has been invested in interventions focused on FSWs, other HRGs have been less well covered. In particular, migrants show a very low awareness that they are at risk (5% in AP in 2009, and 2.3% in Maharashtra). Indeed, HRGs in general, even in high-prevalence states, do not show high enough levels of awareness of being at risk. FSWs and IDUs in Maharashtra showed respectively 21.2% and 9.8% awareness in 2009, and even in AP no at-risk group in that year showed an awareness of more than 67%. See **graph 1**.



Graph 1. Awareness among HRGs in selected states that they are at risk of HIV.³

² Beyrer, S., M. H. Razak, et al. (2000). "Overland heroin trafficking routes and HIV-1 spread in south and south-east Asia." *AIDS*, Vol. 14, No. 1, pp. 75-83; UNGASS, pp.4, 16, 18, 23

³ UNGASS, pp.15, 24-25, 27; Department of AIDS Control, Ministry of Health and Welfare, *Annual Report 2009-10*, p.i

Moreover, as the World Health Organization's South-East Asia Region noted in its 2010 progress report on HIV/AIDS, surveillance data is subject to important limitations. Data on incidence and prevalence is dependant on individuals coming forward for testing. This may be restricted by fear of stigma (a phenomenon less apparent in focus states, where there has been extensive education of the population) or, conversely, individuals may be double-counted through being tested several times at different institutions. Similarly, when surveyed on risky behaviour, some respondents may exaggerate desirable behaviours, producing data that is not consistent with high prevalence of HIV in a locality. The steady decline of recorded HIV prevalence in India should therefore be treated with some caution.⁴

LEPRA and HIV

LEPRA was founded as the British Empire Leprosy Relief Association (BELRA), which started work in India in 1924. After independence the Indian Council of BELRA continued work as Hindu Kusht Nivaran Sangh in India. In 1989 LEPRA returned to India and formed LEPRA India, registered in Andhra Pradesh with its office in Secunderabad.

After making its name supporting the National Leprosy Elimination Programme in poorly-served or hard-to-reach districts of AP and Orissa, LEPRA first entered the HIV/AIDS field in 1995, with a pilot project to improve treatment-seeking behaviour for sexually-transmitted infections (STIs) among truckers and reduce the prevalence of HIV. The project introduced many innovative ideas, highlighting the importance of peer education, and improved awareness of sexual health and safe sex practices among the target group. Gradually, ownership was handed over to peer educators and halt point organising committees at the various halt points, and the project finished in 1997.

LEPRA started to become involved in HIV work on a large scale from 2002, at the request of the Andhra Pradesh State AIDS Control Society (APSACS). From one project in 2002, two more started in 2003 and others in 2005. In 2005 LEPRA also began HIV/AIDS projects in Madhya Pradesh (MP) and Orissa, in the former case at the request of MP State AIDS Control Society.

LEPRA has brought to the field of HIV its expertise drawn from years of experience of working with leprosy. Both diseases present problems of stigma for those affected by it (even greater in the case of HIV), and fear of contagion among the population. Also, like those living with HIV, leprosy-affected persons often need not just medical but also psychological, social and economic rehabilitation. LEPRA's long history of working with and through communities to counter stigma and provide education about disease, and its experience in providing livelihood options, educational support and social re-integration to leprosy-affected persons, have made it well-placed to provide the same services to people living with HIV (PLHIVs).

⁴ UNGASS, pp.15, 24; WHO SEAR p.84

Additionally, LEPRA's extensive web of projects, often in remote areas, give it an admirable reach, especially in some tribal areas, where its close relations with tribes developed over decades of leprosy work make it trusted, and able to deliver similar interventions for HIV.

LEPRA currently has a broad portfolio of projects on HIV/AIDS, providing interventions right across NACP-III's strategic priority areas, from TIs with HRGs through extensive prevention work with the general population, to the provision of care and support for PLHIVs and technical assistance to build the capacity of other implementing organisations. In a number of areas it has introduced innovative new methods, while in others its projects have been rated among the best in the country.

The bulk of LEPRA's HIV-related work is focused on AP, the state with the highest recorded incidence in India according to the 2007 sentinel survey, at 21% of the total cases nationwide. Its Orissa operations include the high-prevalence districts of Angul and Ganjam.

Supporting the National Control Programme

Prevention

Targeted interventions

In tune with NACP-III's priority focus on TIs for HRGs, LEPRA currently operates five such projects, three in high-prevalence districts in Orissa, one in Bihar, and one covering specific mandals across five districts of AP. Avahan project, spread across Nizamabad, Ranga Reddy, Medak, Adilabad and Hyderabad districts of AP, supports both FSWs and MSMs. It reaches out to and empowers the at-risk communities. As well as disseminating information on safer sex practices and managing STIs and referring HRGs for HIV testing, it engages in advocacy and networking, establishing rapport with local police officers. 4,138 FSWs and 902 MSMs are currently working with the project.



LEPRA's project for IDUs in Bhubaneswar was identified in 2008 as one of the best TIs in the country for IDUs because of its success in mobilising local communities against drug addiction. In 2009 it covered 340 people under its needle-syringe exchange programme. 101 focus-group discussions reached out to 1,537 beneficiaries, and 143 police officers were among those sensitised.

LEPRA's Bhubaneswar project was identified in 2008 as one of the best TIs in India for IDUs

In Koraput district of Orissa, LEPRA operates two TIs, including one addressing a new type of at-risk group whose importance was flagged-up by NACP-III: at-risk and vulnerable adolescents. In 2010, across the two projects, 3,964 community awareness meetings were held, sensitising 19,326 members of the at-risk populations. 158,090 condoms were distributed (free or through social marketing), and 1,672 people motivated to go for HIV testing.

The TI in Bhagalpur, Bihar, currently has 156 IDUs registered with it. These are referred for HIV and STI testing, and for treatment of STIs and abscess management. The project maintains a needle and syringe exchange programme for IDUs, and distributes condoms.

Bridge Populations

Since its early work with truckers, LEPRAs has recognised the importance of working with the key groups who transmit HIV infection from HRGs to the general population. Reflecting NACP-III's recognition that much work remains to be done with these bridge populations, LEPRAs is currently operating a workplace intervention for migrant construction workers and their families in Hyderabad and Secunderabad. With large-scale construction activity taking place, the Twin Cities are a major focus for migrant labour, and LEPRAs works at 5 construction sites at Hi-tech City and Gachibowli, and 3 labour addas (waiting areas). In 2008 and 2009, awareness programmes, sensitisation meetings and film shows reached 9,500 people from the target population, of whom 717 went for HIV testing and 7 were found HIV positive.

The General Population – Integrated Counselling and Testing

To prevent the spread of HIV from HRGs and bridge populations, large-scale testing of the general population is essential. NACP's mechanism for achieving this is the Integrated Counselling and Testing Centre (ICTC), which forms an entry point for both HIV prevention and care. Having run many ICTCs in the early stages of the programme, LEPRAs took the concept a stage further with the development of the Mobile ICTC: a major innovation (see **Box 1**).

Box 1. Mobile ICTC. To enhance accessibility and availability of HIV testing services, especially in remote and hard-to-reach areas, not well-served by static ICTCs, LEPRAs in December 2006 introduced the concept of mobile ICTC (MICTC) vans, first in East Godavari district then in Hyderabad and Secunderabad. These were the first of their kind, working in accordance with NACO ICTC guidelines. They were so successful that APSACS adopted the concept, introducing MICTCs in two phases. In the first phase 8 vans were introduced, one for every two districts, with LEPRAs being given 2 vans for Guntur, Prakasam and West Godavari districts. Since their introduction, the four vans have tested 56,441 people for HIV, of whom 1,772 were found positive. The success of this model has led APSACS to replicate it in all 23 districts of AP.



Dr. Y.S.Rajasekhara Reddy, late Honourable Chief Minister of AP, inaugurates the Hyderabad MICTC on 25th March 2008.

Beyond this, LEPRAs work through its network of projects, many focusing on multiple disease areas, to educate populations about HIV, make them aware of the health services that are available, and mobilise individuals to come forward for testing. It has long used a variety of methods of information, education and communication (IEC), adapted to the needs of particular communities. These include mobile IEC vans (which show films as well as distributing leaflets), street plays in local languages and extensive outreach activities through link workers in the community. Many local volunteers working with LEPRAs have since become Accredited Social Health Activists (ASHAs) since the scheme was introduced in 2006-7.

	Number tested for HIV	Number found positive
Andhra Pradesh	22,233	712
Madhya Pradesh	728	3
Orissa	1,982	55

Table 1. LEPRAs Society HIV testing 2009

Mainstreaming

A major aim of NACP-III is to mainstream HIV and AIDS issues into civil society, to make the response to the epidemic everyone's agenda. LEPRAs has taken this forward with a major project in AP, in collaboration with APSACs and the Society for the Elimination of Rural Poverty (SERP). The intervention uses 3 flip-book modules in story form to educate the members of women's self-help groups (SHGs), starting with broader societal issues in rural communities, then moving on

to sexual health and finally focusing on HIV. During 2009 and 2010, 291,559 SHG women at village level were sensitised and 25,391 were tested for HIV. LEPRA's role has been in providing technical support to SERP, training 60 master trainers and 2,980 community resource persons, who then train district-level health activists.



Building on the success of its mainstreaming work with women, LEPRA has recently extended this in a pilot intervention for men in 8 high-prevalence mandals of Krishna district, AP. The demand came from SHG women, who wanted their menfolk to be given the same training on sexual health issues. The project works through community-based organisations such as youth clubs and Panchayati Raj Institutions, using picture cards to illustrate its messages. Since the project began in February 2009, 20,433 men have been sensitised on HIV and sexual health issues, 1,400 have been treated for STIs, and 189 tested positive for HIV.

Treatment and Support

Community Care Centres

Community Care Centres (CCCs) are NACP-III's primary mechanism for providing care and support to PLHIVs. Linked with centres providing anti-retroviral therapy (ART centres), CCCs provide care, support and treatment services, including psycho-social support, ensuring drug adherence and providing home-based care and treating opportunistic infections (OIs). LEPRA operates two such centres: Spandana, in Indore, MP, and Ashraya, in Koraput, Orissa. In 2010, Ashraya was awarded an A+ grading in a national-level assessment carried out by NACO, making it one of the best in the country. It has

In 2010 the Koraput CCC was awarded an A+ grading in a national-level assessment by NACO, making it one of the best in the country.

worked to build the capacity of the district-level positive network, the Network of Koraput Positive People.

	PLHIVs registered	No. of PLHIVs on ART	Bed utilisation rate
Indore	225	112	60%
Koraput	318	143	86%

Table 2. LEPRA Society CCCs, 2009

Supporting those living with HIV

Alongside CCCs, LEPRA also has a range of projects to support PLHIVs, providing services that go far beyond the framework of the NACP. These projects, all in AP, not only support but empower PLHIVs, helping them to lead lives that are as independent and fulfilling as possible.

LEPRA provides care and support services that go far beyond the framework of the NACP

To maintain the health of PLHIVs, projects combine anti-retroviral therapy (ART) with high-value nutrition supplements. As a result, many PLHIVs have seen their immune levels actually *increase* since they started ART. Alongside this, regular weekly clinics greatly reduce the incidence of OIs among PLHIVs, an important factor in keeping them healthier for longer. The Sreyassu project, in a high-prevalence mandal of Krishna district, treated 559 PLHIVs at its weekly clinics during 2009 and 2010, and provided nutrition supplements for 221 who are on ART.

Counselling plays a key role in helping those living with HIV to cope effectively with their illness. Counselling is provided not just for PLHIVs but also for their families, to help them understand the



care and precautions that need to be taken. This is supplemented by support groups, which enable PLHIVs to provide support to each other. The Cheyutha project, in two districts of AP, is dedicated specifically to helping women living with HIV.

To empower PLHIVs, LEPRAs also provides vocational training, both for those *living* with HIV and those *affected* by it. This includes training in computing, spoken English and tailoring, the latter a trade which allows PLHIVs to work from home, avoiding heavy labour which would cause their condition to worsen. In 2009 and 2010, 1,138 PLHIV in AP received vocational training from LEPRAs projects.

The CHAHA project, in six districts of AP, funded by the Global Fund for AIDS, TB and Malaria to address an identified gap in the NACP, focuses on helping children, both those living with HIV (CLHIVs) and those affected by it (CABAs). In common with other LEPRAs projects, it provides not only income-



generation support for households but educational support for children. In 2009 and 2010, 1,310 children received educational or vocational support from CHAHA project, while LEPRAs other projects gave educational support to a further 711 CLHIVs and CABAs across AP.

Alongside its care and support projects, LEPRAs has also pioneered a new innovation in counselling: the Positive Prevention Toolkit (see **Box 2**).

Box 2. The Positive Prevention Toolkit (PPTK). Developed by the Centres for Disease Control, Atlanta, the PPTK is a tool to help counsellors to support PLHIVs in handling the kind of situations they face after being declared HIV-positive. LEPRAs is the first organisation to implement it in India. The PPTK consists of six modules, each in the form of a flipchart with text and illustrations to facilitate discussions between counsellor and client. The modules cover facts PLHIVs need to know, safer sex, disclosing HIV status (both to your partner and more widely), mental health issues, and how to cope with stigma and discrimination. LEPRAs has trained 126 counsellors working across all 23 districts of Andhra Pradesh, who have counselled some 35,538 PLHIVs. The success of the programme has led to its being replicated by Karnataka State AIDS Control Society, and APSACS has asked LEPRAs to train university faculties in its use, to enable further training of counsellors across the state.

Prevention of Parent to Child Transmission

Alongside its work supporting PLHIVs, LEPRAs has a dedicated project for prevention of parent-to-child transmission (PPTCT), another key focus area of NACP-III in preventing the spread of HIV among the general population. LEPRAs intervention is focused on outreach, connecting the target population to the NACP's PPTCT programme. It operates in 8 districts of Andhra Pradesh. Between 2008 and 2010, the project has motivated 4,213 HIV-positive mothers to deliver their babies in institutional settings, and administered Nevirapine to 7,256 to prevent transmission. It also provides strong follow-up service, supporting the family, and testing the child at 18 months of age. 697 children of HIV-positive mothers have been tested for HIV, of whom only 67 were found to have become positive.

HIV-TB co-infection

LEPRAs concurrent work with tuberculosis (TB) makes it well-placed to counter TB-HIV co-infection, one of the most frequent causes of death among PLHIVs. It currently runs two projects specifically focused on TB-HIV co-infection, one in MP and one in AP. Alongside this, its TB-specific projects refer patients with TB symptoms for HIV testing.

	Patients referred from ICTCs for TB testing	Number found TB positive	Patients referred from TB services for HIV testing
Andhra Pradesh	711	53	1,063
Madhya Pradesh	3,274	340	178
Orissa	10	6	835

Table 3. LEPRAs Society HIV-TB cross-referrals, 2009

Capacity Building

Many of LEPRAs HIV projects provide training for health workers, in the government, NGO and private sectors. In particular, LEPRAs has worked to sensitise private medical practitioners on HIV, so that they can advise clients on how to avoid infection, and where to go for testing and treatment.

LEPRAs most prolific capacity-building activity has been the Andhra Pradesh Counsellors Project, founded in 2003 at the request of APSACS to provide technical and programme support to all counselling and testing centres and PPTCT centres in Andhra Pradesh, and to ensure quality. 2003-2010, the project trained 154 counsellors, while a toll-free telephone number introduced in 2006 allowed clients to ask questions about HIV and to provide feedback on the

services provided by the centres, and was also used by counsellors and technicians to ask questions of their own. In January 2011, the project was handed over to APSACS, which is taking the work forward.

LEPRA also runs a nurse mentoring project, supported by the Clinton Foundation, which aims to strengthen the nursing system in CCCs. 92 nurses were mentored under this project in 2009 and 2010.

LEPRA also runs a major project in AP to build the capacity of CCCs as a whole. The Samastha project provides technical support to 4 CCCs and 6 drop-in centres in 5 high-burden districts of AP. Training has been provided to CCC staff on stigma reduction, infection prevention, basic and comprehensive HIV care, HIV-TB, home-based care, and computerised management information systems. The unique approach is the use of mentoring, with visits to centres every two months by a team consisting of a doctor, programme manager and monitoring and evaluation officer. The project has led to considerable systems-strengthening. A sequence of care at CCCs has been established to provide services on an organised plan, and infection prevention practices have been established and are regularly monitored. The success of the project can be seen from the fall in death rates among PLHIVs accessing the centres, from 16% in 2007, when the project started, to 3% in 2010. The number of TB co-infection cases diagnosed also increased from 36 in 2007 to 154 in 2010, and lost follow-ups of patients on ART declined from 13% to 2% over the same period. District AIDS Prevention and Control Units have requested LEPRA to carry out similar work with other CCCs in the districts.

Future Directions

In its HIV-related work over the coming years, LEPRA will

- Continue to focus on quality interventions to prevent HIV among HRGs and bridge populations (including migrants and at-risk adolescents), using public-private partnerships where possible;
- Seek partnerships with state AIDS control societies and with NACO to implement ARTCs and link ARTCs;
- Align itself with NACP Phase IV, complementing it with additional services where appropriate; and
- Provide technical support and capacity-building, particularly for the National Rural Health Mission as it increasingly plays a greater role in NACP.

LEPRA will also conduct both applied and clinical research related to HIV, including through its Blue Peter Public Health & Research Centre. This will include studies on;

- Early biomarkers for TB among HIV patients;
- Drug resistance among HIV and STI clients;
- The molecular epidemiology of HIV clients;
- The epidemiology of HIV among tribal populations;
- Incidence of STIs among HIV-positive patients; and
- The management of common OIs among HIV patients.



Acronyms

AP	Andhra Pradesh
APSACS	Andhra Pradesh State AIDS Control Society
ART Centre	Centre providing anti-retroviral therapy
ASHA	Accredited Social Health Activist
BELRA	British Empire Leprosy Relief Association
CABA	Child affected by AIDS
CCC	Community Care Centre
CLHIV	Child living with HIV
FSW	Female sex-worker
HRG	High-risk group
ICTC	Integrated Counselling and Testing Centre
IDU	Injecting drug user
IEC	Information, education and communication
MICTC	Mobile Integrated Counselling and Testing Centre
MP	Madhya Pradesh
MSM	Man having sex with men
NACO	National AIDS Control Organisation
NACP-III	National AIDS Control Programme, Phase III
OI	Opportunistic infection
PLHIV	People living with HIV
PPTCT	Prevention of parent-to-child transmission
PPTK	Positive Prevention Toolkit
SERP	Society for the Elimination of Rural Poverty
SHG	Self-help group
STI	Sexually-transmitted infection
TB	Tuberculosis
TI	Targeted intervention