Supporting Safe and Effective ARV Treatment in India: Building Treatment Friendly Communities

Rapid Assessment Study: Manipur and Andhra Pradesh

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The Research Team would like to convey their heartfelt appreciation to all the stakeholders involved in this study, especially the people with HIV and their supporters who so generously shared their personal experiences and stories with us. We highly value the co-operation and support received from the Project Directors of the Manipur and Andhra Pradesh State AIDS Control Societies. Their support will be key to operationalising the study findings. We would like to acknowledge the technical advisors and team members of the International HIV/AIDS Alliance from India and the United Kingdom and Resource Center for Sexual Health and HIV/AIDS (RCSHA), New Delhi.

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International HIV/AIDS Alliance was established in 1993 as a global partnership of people, organisations and communities working towards a shared vision that supports effective and integrated community responses to HIV/AIDS. This approach is based on the belief that those at the frontline of the struggle against HIV/AIDS must have resources to take on the challenges that the epidemic presents.

The India HIV/AIDS Alliance was established in 1999 as part of the International HIV/AIDS Alliance with a strategic goal to increase community action for and access to, HIV/AIDS prevention, and care and impact mitigation efforts in India. This is achieved through improving coverage of effective community focused AIDS efforts; strengthening leadership and capacity of civil society to respond to AIDS; and improving institutional, organisational and policy environments for community responses to HIV/AIDS.

India HIV/AIDS Alliance currently provides programmatic, technical, strategic, organizational development and financial support, guided by a commonly agreed Strategic framework to four Lead partners and one State partner in Delhi, Tamil Nadu, Andhra Pradesh and Manipur states, in addition to its state program in Andhra Pradesh. In turn these partners provide similar support to more than 70 implementing NGOs/CBOs.

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<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral treatment</td>
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<tr>
<td>ARV</td>
<td>Antiretroviral</td>
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<tr>
<td>CBO</td>
<td>Community based organisation</td>
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<tr>
<td>G 8</td>
<td>Group of eight industrialised nations</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IDU</td>
<td>Intravenous Drug User</td>
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<td>IDI</td>
<td>In-depth Interview</td>
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<tr>
<td>JNH</td>
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<tr>
<td>NACO</td>
<td>National AIDS Control Organisation</td>
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<td>NACP</td>
<td>National AIDS Control Programme</td>
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<tr>
<td>NGO</td>
<td>Non Governmental Organisation</td>
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<tr>
<td>PLHA</td>
<td>People or Person living with HIV</td>
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<tr>
<td>PoART</td>
<td>Person or People on antiretroviral treatment</td>
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<tr>
<td>PPTCT</td>
<td>Prevention of parent to child transmission</td>
</tr>
<tr>
<td>RIMS</td>
<td>Regional Institute for Medical Sciences</td>
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<tr>
<td>SASO</td>
<td>Social Awareness Service Organisation</td>
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<tr>
<td>SW</td>
<td>Sex Worker</td>
</tr>
<tr>
<td>TNP</td>
<td>Telugu Network of Positive People</td>
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<tr>
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Backdrop

Although, India will be entering the third phase of the ‘National AIDS Control Programme’ (NACP) by mid-2006 with a major focus on government sponsored supply of free anti-retroviral treatment (ART), little is yet known about the psychological, social and material needs of those who are on ART. Data is also scarce on the challenges faced by people on ART and quality of the existing services. A rapid situation assessment was therefore planned by ‘India HIV/AIDS Alliance’ with the following objectives:

1. To assess the psychological, social and material support needs of people on ARV treatment in relation to supporting adherence and protective behaviour.
2. To assess the current situation vis-à-vis the psychological, social and material support networks of people on ARV treatment in relation to supporting adherence to ARV treatment and protective behaviour.
3. To assess the experience of disclosure by people on ARV treatment.
4. To assess the experience of stigma and discrimination for people on ARV treatment and their supporters

Methodology

The study was conducted in two sites; Imphal, the capital of the north-eastern state of Manipur, and Vijaywada, the commercial centre of Andhra Pradesh in the south of India. A team comprising study coordinator, supervisor and eight investigators (4 from Manipur and 4 from Andhra Pradesh) was responsible for carrying out the study, including the initial orientation and training, within a period of 4 months starting from mid-October, 2005.

Based on the inputs provided by the members of the research team, instruments developed and used by the International HIV/AIDS Alliance for similar studies in other countries were adapted for use in the Indian context. The instruments included:

1. One-to-one interviews with people on ART (PoART)
2. Key informant interviews with treatment supporters (family members/ employers)
3. Key informant interviews with health care providers
4. FGDs with community members
5. Case studies on PoART

Qualitative responses obtained from the participants of FGDs, PoART, key informant interviews and case study interactions were transcribed and translated in a timely manner by the field investigators. The transcripts were subsequently sorted for analysis. A data analysis format was developed in a participatory consultation with the research team; this allowed triangulation of information on any issue obtained from different sources. The software Epi-Info (Version 6.4b) was used for entering and analysing the quantitative data generated through one-to-one interviews.
Socio-demographic profile of the people on ART

Of the 151 PoART who were interviewed in one-to-one, 60% were from Manipur and the rest from Andhra Pradesh. In Manipur the age of PoART ranged from 28 – 43 yr (mean 34 yr), whereas in Andhra Pradesh, it was 24 – 58 yr (mean 32 yr). Just over half of the total participants (54%; 82/151) reported being married (48% in Manipur and 64% in Andhra Pradesh). Widowed women accounted for 20% of all respondents, comprising 25% of respondents in Imphal and 11% in Vijaywada. Under half (41%) of all respondents reported to be working; 13% of the study participants reported that they had been working previously but were currently unemployed. The mean monthly income of PoART in Imphal was Rs 1689 (range Rs 1200 to Rs 5800), and in Vijaywada this was Rs 2500 (range Rs 1250 to Rs 6000). About 85% of PoART in both the states were Hindus and the next most common religion among the respondents was Christianity - 13% in Manipur and 9% in Andhra Pradesh. While 87% of the respondents in one-to-one interviews in Manipur said that they had been living in their own house, only 44% said so in Andhra Pradesh; the rest were in rented places.

HIV testing and counselling

Government run health care centres within the study sites were reported to be most accessed by respondents for HIV testing. Some respondents mentioned accessing private laboratories for HIV testing but noted that these were not offering counseling support for people seeking HIV test. Notably, the quality of counseling offered within government settings was reported as being of poor quality. Most often people seeking an HIV test were accompanied by a family member or friend.

Access to ARV treatment

Most of the PoART reported that they were sourcing ART from the government program. This would not have been possible a few years ago. Currently the Government of India is providing free ART in six high prevalence states and in the state of Delhi, more people have the opportunity to access ART in the public sector. Although many (133/151; 88%) respondents who were on ART reported satisfaction with their current source of treatment, the minority expressed dissatisfaction with the quality of ART they were receiving. While reasons for dissatisfaction in Imphal were ‘lack of confidentiality’, ‘changes in brand of medicines’ and ‘side effects’, in Vijaywada, dissatisfaction was related to a perceived ‘lack of integrity and negative attitudes of medical staff’. PoART accessing ART from the government programme expressed anxieties about the sustainability of the program and the possibility of ‘viral resistance developing over a period of time with the regimen being supplied by the government. The cost of travel to the limited government ART sites in both states was also cited as matter of concern for a few of the respondents.

Adherence related issues and protective behaviour

About 30% (44/151) of the respondents reported ever stopping ARV treatment (38%; 34/90 in Imphal and 16%; 10/61 in Vijaywada). While financial problems was the reason for stopping treatment in 18% of PoART in Manipur and 80% of PoART in Andhra Pradesh, an overwhelming 53% (18/34) in Manipur cited ‘forgetfulness’ as main the reason. 10% of those who had ever stopped treatment did so due to side effects of the medicines. Stopping ART due to improved health, although rare, was reported by a respondent from Andhra Pradesh.

Thirty nine out of 61 PoART interviewed in Andhra Pradesh were married. 54% (21/39) of married respondents reported more frequent use of condom with regular sex partners after learning their HIV positive status. It was of concern to note that the figure in this self reported sexual practice of married PoART dropped from 54% to 41% (16/39) after they started ARV medicines. Forty three out of 90 PoART were married in Manipur and contrasting with Andhra Pradesh, the proportion reporting more frequent use of condom while...
having sex with regular sex partners increased in from 72% (31/43) before ART to 77% (33/43) once they started taking ARVs. Clearly there is a need to foster an environment where rates of consistent condom use in people who are HIV positive and also those who are taking ART are considerably higher.

**Support within families and communities**

PoART universally reported that relatives such as parents, brothers and sisters as well as friends were the people they could count on for emotional and psychological support. The majority of PoART (111/151; 73%) also reported receiving financial and nutritional support from family members. Often the poor economic background of the respondents limited the extent to which they could access such support. Support from public sector health care providers was found to be limited to the basic prescription of medicines. In general, PoART reported that NGO health care workers as well as family members were very supportive. NGO care and support services at community level, including psychosocial support, subsidised ARVs, other medication and limited nutritional support, were cited as valuable sources and types of support. However, PoART reported that there was a general lack of understanding by family and community members about the psychological and emotional issues arising from living with HIV and the support required by those taking ART. Many family members supporting PoART reported that they felt ill equipped and lacked the appropriate skills to provide adequate psychological support.

**Disclosure**

All PoART respondents in both the states except 2 in Andhra Pradesh reported having disclosed their HIV status to close family members; mothers, spouses and siblings featured commonly in this regard. Although many PoART mentioned the positive role that support groups played in their lives, some reported that they did not want to join such groups mainly due to a fear of disclosure and attendant fear of stigma and discrimination. Family members expressed the same fear about PoART joining support groups. Over 50% of PoART reported that they had disclosed their HIV status to their employers; it is interesting to note that many of those who disclosed to their employers and felt that their employers were supportive, were employed in HIV/AIDS NGOs. 3 out of 21 PoART who had lost their jobs were actually asked by the employers to quit.

**Stigma and discrimination within the community including health care settings**

In both study sites, perceived and actual stigma and discrimination at community level including that from public sector health care providers were key barriers restricting people’s access to HIV/AIDS care, treatment and support. The perceived risk of unfair and negative treatment by health care providers and physical and social isolation by the wider community prevented people from accessing care, treatment and support. Respondents also reported that the poorer people and drug users (former and active current) faced additional stigma and discrimination linked to poverty and behaviour.
Building HIV treatment friendly communities requires building on existing community strengths and structures as well as working at multiple levels: a) household and individual, b) communities including health care centers and hospitals and c) policy. The recommendations resulting from the study are categorized accordingly.

**Households and individuals**

1. NGOs, CBOs and groups of people with HIV should conduct comprehensive treatment literacy programmes in order to support the information needs of individuals requiring ART, those already on ART and their families. Treatment literacy programmes should include accurate, simple information about the names and types of medicines, how they work, managing side effects, dispelling myths and misconceptions about HIV and ART as well as safer sex practices.

2. NGOs, CBOs should provide psychosocial support to people on ART. This can be done by engaging and supporting people with HIV who are willing to act as peer supporters as well as support groups of positive people or PoART.

3. NGOs and CBOs should have strong outreach and skills building programmes to support women and young girls in order to alleviate the burden of HIV/AIDS care which often falls disproportionately on women and young girls.

4. NGOs and CBOs should have a strong outreach and skills building programmes for family centered care and treatment. This must involve building the capacity of PoART and their carers and supporters.

**Communities including health care centers and hospitals**

5. NGOs and CBOS should carry out community sensitization activities about HIV/AIDS and ART. This is essential for reducing stigma and discrimination and supporting safe and effective ART. Innovative partnerships between civil society organizations, educational institutions and private companies and employers should be developed to effectively engage communities in HIV care, treatment, prevention and support.

6. NACO and SACS, with civil society involvement especially the involvement of people with HIV, to roll out appropriate training for public sector health care providers including counselors on issues regarding confidentiality, consent, adherence including substance use, treating co-infection such as TB, Hepatitis B & C and prevention. The training programme should be combined with supportive monitoring of clinical practice with a view to improving the quality of HIV care and treatment provided in the public sector.

**Policy**

7. Advocate with national and state levels actors as well as with donors to provide support for community engagement for ART as an essential component of ART programmes.

8. Advocate with key national, state and district actors to support rapid and urgent roll-out of ART at district level so that at the very least the financial burden of long travel to ART centres is reduced.

9. Advocate with key national, state and district actors to support universal access to ART, prevention and care, including access to free ART at the point of service delivery.
Background

1.1 Introduction

In 2003, World Health Organization (WHO) and the Joint United Nations Programs on HIV/AIDS (UNAIDS) launched a global campaign to provide antiretroviral (ARV) treatment to 3 million people in resource-poor countries by the end of 2005. In 2005, the leaders of the G8 (Group of eight industrialized nations comprising USA, UK, Japan, France, Canada, Italy, Germany and Russia) and other United Nations member states issued a historic commitment calling for universal access to treatment and prevention for all those who need it by 2010. At the end of 2005, WHO and UNAIDS reported that there were 1.3 million people in resource-limited settings accessing life-saving ARV treatment. Delivering universal access to treatment and prevention will require an urgent, rapid response at a major scale.

The success of ARV treatment is dependant on achieving high levels of adherence, sustaining protective behaviors and reducing stigma at the personal and community levels. Poor adherence can compromise the health of a person with HIV by enabling a rapid increase in the amount of virus in the person’s blood and permitting the HIV to change itself so that ARV treatment is less effective or stops working.

Stigma remains one of the greatest challenges for most people with HIV, especially when they need access to services and support. Even in communities where services are available and accessible, they are often not used as a result of the stigma associated with HIV/AIDS. There is some concern that ARV treatment may lead to increased sexual risk-taking behavior. It is also conceivable that carrying out prevention work with people living with HIV is likely to have a greater impact on the epidemic than preventive interventions aimed at people who are HIV-negative.

Sustaining adherence to life-long treatment, protective behavior and reducing HIV/AIDS related stigma will require much more than the reliable provision of ARV drugs. There must also be effective community and individual education about ARV treatment including: how to take and adhere to drugs; how to manage treatment side effects; how to prevent HIV transmission; and how to access supportive care. Communities also need information on issues such as equity of access and criteria for enrolment into ARV treatment programs. Specific efforts must be made to combat stigma, both in communities and in health services.

Partnerships with affected communities, especially people living with HIV themselves, will help to improve health-seeking behavior, acceptance of ARV treatment and the extent to which barriers to care and treatment (for example, stigma and discrimination) are reduced or eliminated. Community engagement for ARV treatment includes educating those taking ARV medication, working with service providers, involving people with HIV and strengthening community mechanisms to support and promote adherence, prevention and stigma reduction. Such an approach aims to support adherence and prevention for people with HIV through improving knowledge and support, and can result in reducing stigma and building social capital among people with HIV and the wider community. Experience has also shown that functionally linking community support with health services and enhancing their interface as well as the involvement of affected communities, especially people with HIV, is critical to the success of HIV treatment, care and prevention programmes.

4 Although there are various definitions of ‘social capital’, one of the most frequently used is that developed by the World Bank in which social capital is defined as consisting of processes between people that establish networks, norms and social trust, and facilitate coordination and cooperation for mutual benefit.
1.2 National HIV/AIDS response

HIV/AIDS rates are increasing faster than any other disease in India, creating a devastating impact on the lives of millions infected with the virus and millions of others who are affected by the epidemic. It is estimated that India is home to 5.1 million people with HIV. Accounting for almost 13% of the global HIV prevalence, the Indian HIV epidemic is the largest in Asia and the second largest in the world after South Africa. Although India has an overall low national HIV prevalence, the epidemic is diverse and complex and there are a number of sub-epidemics throughout the country where HIV prevalence among ‘at-risk’ populations such as sex workers (SWs) and intravenous drug users (IDUs) is well above 5%.

HIV infections in India are projected to rise over the next several years, along with the related burden of disease increasing until 2010, with individuals and households finding it increasingly difficult to cope with economic hardships associated with treatment costs and reduced income due to illness and loss in productivity. According to a recent study conducted by the World Bank, if HIV/AIDS continues to spread at its current rate, the epidemic could socio-economically devastate in just three generations. The distribution of HIV infection in India suggests that over 60% of HIV cases are in the high prevalence states including Andhra Pradesh and Manipur and presently there is very little difference between urban and rural sero-prevalence.

Increased political will and dramatic reductions in the price of ARVs have made providing ARV treatment a realistic option in many developing countries. Joining the global movement to scale up ARV treatment in resource-poor settings, in April 2004 the Government of India announced that it would provide ARV treatment through public sector hospitals in the six high HIV prevalence states of Andhra Pradesh, Maharashtra, Karnataka, Manipur, Nagaland and Tamil Nadu. Some of the low HIV prevalence states also followed suit with initiatives to provide ARV treatment. These are particularly significant events as the Indian government’s HIV/AIDS response has till now focused predominantly on prevention; the move to provide ARV treatment as a part of the national efforts to mitigate the impact of HIV/AIDS offers critical opportunities to meaningfully integrate prevention and treatment in India.

India’s National AIDS Control Programme (NACP) is at the end of the second phase (1999 – 2006) and has covered 35 states and Union Territories. The National AIDS Control Organisation (NACO) is responsible for carrying out the AIDS programme which, to date, has focused largely on prevention though there is now solid evidence of an increasing commitment to care, treatment and support. During the second phase of the NACP, NACO supported targeted prevention interventions, blood safety, youth campaigns, voluntary testing and counselling (VCT), prevention of parent to child transmission (PPTCT), care and support and social mobilisation. NACO is currently planning for the third phase of NACP, due to start in July 2006. NACP III is intended to address gaps identified in phase two including decentralising and scaling up the response.

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1.3 Antiretroviral Treatment

Low cost care and support were prioritised in NACP II with an emphasis on piloting delivery of ART services and establishing Community Care Centres. In terms of ART, the NACP has placed a special focus on six high prevalence states: Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland, Karnataka and Delhi which is a low prevalence state. Currently 26,000 AIDS cases are getting free treatment at the public sector hospitals and centers. 10,000 individuals are getting free treatment at the centers run by Railways, postal and steel companies. The Govt. plans to increase the number of people on free ART to 100,000 patients in the next three to four months. The private sector is providing treatment to 25,000 individuals.

To date, the public sector ART sites have been concentrated in urban centres and enrolment has been slow. This may be attributed to a variety of factors including the following: training of health workers, infrastructure, supply management, concentration of services in urban centres, fear of stigma and discrimination, lack of involvement from people with HIV and communities and traditionally poor utilisation of public sector health services.

Successful ARV treatment in India will be achieved not only through quality health care and medicines, but also from effective patient and community support. Communities have a crucial role to play in the safe delivery and use of ARV treatment. In fact community engagement for ART is key to supporting adherence and prevention, reducing stigma and discrimination as well as reducing the burden on the public health care system that may become overwhelmed by the pressures of scaling up HIV testing, counselling, care and treatment.

It is hoped that this study will provide some understanding about the psychological, social, and material needs of people taking ART and form a basis from which to design community engagement interventions to support the national scale-up of ARV treatment in India.
2.1 General Objective

The overall objective of the study was to gain a greater insight into the psychological, social and material needs of people taking ART and assess how those needs impact on adherence and prevention for people on ART.

2.2 Specific Objectives

1. To assess the psychological, social and material support needs of people on ARV treatment in relation to supporting adherence and protective behaviour.

2. To assess the current situation vis-à-vis the psychological, social and material support networks of people on ARV treatment in relation to supporting adherence to ARV treatment and protective behaviour.

3. To assess the experience of disclosure by people on ARV treatment.

4. To assess the experience of stigma and discrimination for people on ARV treatment and their supporters

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9 NACO. Press release 2005
10 NACO Annual Report 2002-2004, chapter 2, Pg 13
2.1 Study Team

The study team comprised a Coordinator, a Supervisor and eight Investigators. In preparation for the study, the eight Investigators (4 from Manipur and 4 from Andhra Pradesh) participated in a three day orientation workshop carried out by the Coordinator and Supervisor. While all the investigators from Manipur belonged to the partner NGO ‘Social Awareness service organization’ (SASO), the investigators from Andhra Pradesh were recruited from the local NGO and the Telugu Network of positive people. The orientation covered the following:

a) HIV and AIDS general knowledge

b) Background to the study

c) Sampling procedures and identification of sample source and sample

d) Mock exercises with questionnaires for ease in administration and recording.

The study was launched by the Supervisor in the two districts and follow-up visits were made by the Coordinator and Supervisor to check data collection and monitor quality. Capacity building of the partner NGOs and individual investigators was an important part of the study. A summary timeline of the study is given below (Table 1).

Table1: Work schedule of the present study

<table>
<thead>
<tr>
<th>Work done</th>
<th>Time</th>
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<tr>
<td>Orientation of the team of investigators about the study, training on how</td>
<td>4th – 6th October, 2005</td>
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<tr>
<td>to use different methods for data collection such conduction of FGDs,</td>
<td></td>
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<tr>
<td>interviewing etc. and development of study tools in Delhi</td>
<td></td>
</tr>
<tr>
<td>Launching of the study</td>
<td>15th October, 2005- Manipur</td>
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<tr>
<td></td>
<td>25th October, 2005- Andhra Pradesh</td>
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<tr>
<td>Training on data entry in Kolkata using Epi-Info</td>
<td>3rd – 6th November, 2005</td>
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<tr>
<td>Hands-on-training on data quantitative data analysis, development of</td>
<td>7th – 10th November, 2005</td>
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<tr>
<td>analysis plan for both quantitative and qualitative information as well</td>
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<tr>
<td>as generation of format for report writing</td>
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<tr>
<td>Data entry</td>
<td>16th November – 10th December, 2005</td>
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<tr>
<td>Analysis</td>
<td>11th – 23rd December, 2005</td>
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<tr>
<td>Generation of draft report</td>
<td>3rd – 14th January, 2006</td>
</tr>
<tr>
<td>Finalization of the report</td>
<td>21st – 24th February, 2006</td>
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3.2 Study Sites and Selection

The study was conducted in two sites- Imphal, the capital of the north-eastern state of Manipur, and Vijaywada, the commercial centre of Andhra Pradesh in the south of India. In the north eastern state of Manipur, HIV transmission is primarily driven by injecting drug use and male to female sexual transmission. HIV in Andhra Pradesh is driven by sexual transmission - first reported in female sex workers, HIV is now found in the general population.

Manipur is one of the smaller states of India both in terms area and population. It is spread over an area of 22327 sq. km, with a population of 23.88 lakhs. It has population density of 107 persons per sq km. The sex ratio of the state stood at 978 females per thousand males. Sixty nine percent of the population is literate, with wide gap in male –female literacy levels. Nearly 78% of males’ vis-à-vis 59% of females are literate. Agriculture and allied activities are the main economic activities in both the hills and the valleys of Manipur. Manipur is geographically proximate to the “Golden Triangle” (between Myanmar, Thailand and Laos) where more than 20% of the world’s heroin is reported to be produced. Pure heroin, known locally as No. 4, is easily available in injectable form in the state, which gradually transited from a trafficking place to a user state.

According to NACO, Manipur has 2866 people with HIV. The Regional Institute of Medical Science (RIMS) and Jawaharlal Nehru Hospital (JNH) are the two major hospitals in Manipur providing ARV treatment. Till September 2005, both these centers were providing ARV treatment for 300 people each. SASO, an NGO started by former injecting drug users and the Manipur Network of Positive People (MNP+) are supporting the government treatment efforts. SASO also provides subsidized ARV medicines to those on treatment. SASO receives support from several agencies including the International HIV/AIDS Alliance.

Imphal, the state capital of Manipur, is the hub for HIV/AIDS treatment, care and support program in the state. ART and specialist medical facilities are accessible only in Imphal.

14 Project Implementation Plan 1999-2004, Manipur, Pg 4, NACO.
15 NACO website
16 On field discussions with the Heads of the ART centre of the hospitals
Andhra Pradesh is the fifth most populous state in the country. It population is 75,727,541 persons, The population density is 275 persons per sq.km and the sex ratio is 978 females per 1000 males. Sixty one percent of the overall state population is literate with 50% female literacy rates as compared to 70% literacy rates for men.

According to NACO, there are 12 349 people with HIV in Andhra Pradesh. The state has 88 voluntary Counseling and testing Centers (VCTC), with more than one VCTC in each district. The government is providing free ARV treatment in Hyderabad, Vishakhapatnam, and Guntur. Numerous international agencies, including the International HIV/AIDS Alliance, are rolling out HIV programmes in the state. There is a strong NGO presence in the state, including a Telugu network of positive people (TNP+).
3.3 Characteristics of the study participants, their number and recruitment

In each of the study states one-to-one interviews were carried out with people on ART (PoART). While in Manipur 90 PoART were interviewed (20 from the beneficiary list of SASO, 35 from JNH and 35 from RIMS), 61 were interviewed in Andhra Pradesh (50 from the register of TNP+ and the rest from the records of a local doctor treating PoART). Limited time available for the study and variation in the pattern of PoART accessing ART centres did not allow researchers to conduct interviews based on probability sampling prepared by the ART centres.

Signed informed consent was taken from all respondents. Focus group discussions (FGDs) were also held. This allowed for triangulation of findings. Case studies were developed based on detailed interactions with 3 PoART from Manipur and 5 from Andhra Pradesh. Table 2 provides a detailed account of the respondents. All the tools were translated into Telugu and Manipuri. The interviews and Focus group discussions were conducted in the local language.

### Table 2: Sample size & type of respondents

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Manipur</th>
<th>Andhra Pradesh</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-to-one interviews with PoART</td>
<td>90</td>
<td>61</td>
</tr>
<tr>
<td>FGDs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Outreach workers</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>involved in HIV care project</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Higher secondary school teachers</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>- Religious leaders</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>- Panchayat members</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Women’s group</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>- Youth Clubs</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>- Students’ organization</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>- Truck drivers</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>- Police officials</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>In-depth interviews with key informants</td>
<td>21*</td>
<td>24**</td>
</tr>
<tr>
<td>Case studies</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

*Key informants in Manipur included 13 family members and 8 health care providers  
**Key informants in Andhra Pradesh included 9 family members and 15 health care providers

3.3.1 Recruitment

Family members and employers were recruited through PoART who were specifically asked to identify people who supported them within the family and/or in the community (treatment supporters). It is worth noting that PoART in Manipur only referred 2 employers and these were employers from partner NGO, SASO while none of the PoART referred any employers for interviews.

Community members having influence to change community perceptions about PoART, were recruited to participate in the FGDs

Health care providers that participated in the in-depth interviews as key informants included:

- Auxiliary Nurse Midwife
- Doctors in Government hospitals
- Private doctors
3.4 Data collection

The study was conducted using instruments developed and used by the International HIV/AIDS Alliance for similar studies in other countries. The tools were adapted for use in the Indian context based on the inputs provided by the study coordinator, supervisor and field investigators and included:

1. One to One interviews with Po ART
2. Key informant interviews with treatment supporters (family members/employers)
3. Key informant interviews with health care providers
4. FGDs with community members
5. Case studies of PoART

The actual field work was completed within a period of 6 weeks starting from mid-October, 2005. Interviews, FGDs and case studies were carried out by the 8 Investigators who were trained on how to employ these methods. All interviews were carried out in regional languages, such as Manipuri and Telugu, as appropriate. The questionnaires used for data collection were bilingual and had questions in both English and regional languages that were translated and back-translated before finalisation.

3.5 Data Processing and analysis

While training on how to employ different data collection methods helped in enhancing the skills of the field investigators, cross-checking of the completed questionnaires on a daily basis helped in quick identification and correction of wrong entries. The team member trained in using Epi-Info took primary responsibility for data entry in Manipur and training another team member who computerised the quantitative data for Andhra Pradesh. Qualitative responses obtained from FGD participants, key informant interviews and case study interactions were transcribed and translated within a short time of data collection by the field investigators. A data analysis format, developed in consultation with the research team members and technical advisors, allowed for triangulation of findings. The analysis of this data forms the basis of this report.

3.6 Limitations

In both Manipur and Andhra Pradesh it was difficult to collect data regarding treatment supporters within families as many were not willing to be interviewed. The limited budget that was available for the study did not allow the research team to travel to far off districts. Instead the respondents on ART were asked to come to the study sites for interviews which many could not do. Accessing employers was difficult due to the fear of stigma and discrimination, as previously discussed. Finally, the limited time available for field work restricted the data collection as in some instances the interviewees left the interview procedures halfway through. However with all these limitations, the present study has been first of its kind that has explored a range of aspects of HIV treatment, especially the support that is required by PoART and their families and communities.
4.1 Demographics

Of the 151 PoART interviewed, 60% were from Manipur and the rest from Andhra Pradesh. As indicated in the pie chart below (figure 1), those on ART were mostly male.

4.1.1 Age profile of PoART

In Manipur, the age of PoART ranged from 28 – 43 yr (mean 34yr), whereas in Vijaywada, it was 24 – 58 yr (mean 32 yr). While 53% of the respondents fell into the age group of 35 yr or less in Manipur, 75% were in this category in Andhra Pradesh.

4.1.2 Marital status

Just over half of the total participants (54%; 82/151) reported being married (48% in Manipur and 64% in Andhra Pradesh). Widowed women accounted for a fifth of all respondents, comprising 25% of respondents in Imphal and 11% in Vijaywada. Fourteen of 23 women (61%) who had lost their husbands were in their early 30s (equal to or below 35 yr of age) in Manipur and all 7 widows from Andhra Pradesh were in this group.

4.1.3 Socio-economic status and other demographic details

Under half (41%; 62/151) of all respondents reported that they were working; 13% of the study participants reported that they had been working previously but were currently unemployed; this was largely attributed to having become ‘physically too weak to go to work’, (figure 2). Thirty five percent of all female respondents reported that they were working.

Respondents' occupations included ‘auto repair’, ‘farming’, ‘clerical work’, ‘small-scale business’ etc. Thirteen percent of the study participants reported to be working in a private company, while 3% were employed by government.

The mean monthly income for PoART in Manipur was Rs 1689 (range Rs 1200 to Rs 5800), and in Andhra Pradesh this was Rs 2500 (range Rs 1250 to Rs 6000).

Of the total respondents who lost jobs (21/151), drug use being the reason for loss of employment was cited by 1 out of 12 respondents in Andhra Pradesh and 2 out of 10 respondents in Manipur. This underlines that drug use is just not restricted in the north-eastern part of the country and different aspects of HIV treatment including adherence needs to be examined from the perspective of alcohol use and use of other substances. The other demographic details are given below (table 3).

About eighty five percent of the people on ART in both the states were Hindus. The next most common religion was Christianity - 13% in Manipur and 9% in Andhra Pradesh. 87% of the respondents in Manipur said that they lived at their own house, and 44% of respondents from Andhra Pradesh reported living at their own house.
Table 3: Demographic details of PoART

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Manipur (n1= 90)</th>
<th>Andhra Pradesh (n2=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Male</td>
<td>54 (60%)</td>
<td>36 (40%)</td>
</tr>
<tr>
<td>- Female</td>
<td>39 (64%)</td>
<td>22 (36%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Illiterate</td>
<td>01</td>
<td>18</td>
</tr>
<tr>
<td>- Literate</td>
<td>89</td>
<td>43</td>
</tr>
<tr>
<td>Primary</td>
<td>25 /89 (28%)</td>
<td>18/43 (41%)</td>
</tr>
<tr>
<td>Secondary</td>
<td>24/89 (27%)</td>
<td>03/43 (21%)</td>
</tr>
<tr>
<td>Higher secondary</td>
<td>19/89 (21%)</td>
<td>08/43 (19%)</td>
</tr>
<tr>
<td>Graduation and above</td>
<td>21/89 (24%)</td>
<td>08/43 (19%)</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Unemployed</td>
<td>53 (59%)</td>
<td>37 (41%)</td>
</tr>
<tr>
<td>- Employed</td>
<td>36 (59%)</td>
<td>25 (41%)</td>
</tr>
</tbody>
</table>
Respondents reported accessing government run health care centres within the study sites for HIV testing and counselling. Respondents also reported being tested for HIV at government centres in locations outside the study sites and in private laboratories within the study sites (table 4). Some respondents mentioned that the quality of counselling in government run health centres was inadequate.

Notably, respondents in Manipur were most likely to seek HIV testing at a government run health centre either within or outside the study site. In the case of Andhra Pradesh, 60% (37/61) respondents reported accessing private laboratories for HIV testing. Respondents reported that most private laboratories were not offering counseling support for people seeking an HIV test.

In Manipur, 14% (13/90) of the respondents reported being accompanied by friends, a different 8% (7/90) mentioned going with a friend who was HIV positive and 37% went with a family member to get tested for HIV. The majority of the respondents in Andhra Pradesh (62%; 38/61) reported having been accompanied by a family member when seeking a HIV test; 16 PoART (26%) went alone for their HIV test.

Table 4: Utilization of HIV test centers by PoART

<table>
<thead>
<tr>
<th>HIV Test Location*</th>
<th>All (N=151)</th>
<th>Imphal n1=90</th>
<th>Vijaywada n2=61</th>
</tr>
</thead>
<tbody>
<tr>
<td>Government Centre within the study site</td>
<td>90 (60%)</td>
<td>83.33</td>
<td>24.59</td>
</tr>
<tr>
<td>Government Centre outside the study site</td>
<td>14 (9%)</td>
<td>14.44</td>
<td>1.64</td>
</tr>
<tr>
<td>Private laboratory inside the study site</td>
<td>37 (24%)</td>
<td>1.11</td>
<td>60.66</td>
</tr>
</tbody>
</table>

* Private and government laboratories outside the state were other sources from where the respondents got their HIV tests done

In Manipur, 14% (13/90) of the respondents reported being accompanied by friends, a different 8% (7/90) mentioned going with a friend who was HIV positive and 37% went with a family member to get tested for HIV. The majority of the respondents in Andhra Pradesh (62%; 38/61) reported having been accompanied by a family member when seeking a HIV test; 16 PoART (26%) went alone for their HIV test.
Antiretroviral Treatment

Ninety seven percent of the PoART (87/90) in Manipur knew the names of the medicines they were taking whereas only half of the respondents (30/61) from Andhra Pradesh could name the medicines they were taking. While higher literacy level in Manipur (78% in males and 59% in females as opposed to 70% and 50% respectively for Andhra Pradesh) could explain this difference, it was disturbing to note that a few respondents from Manipur reported taking either one or a combination of just two ARV medicines. In the light of the present day recommendation for ‘highly active anti-retroviral therapy (HAART)’ with three or more ARVs, auditing of prescriptions, training of clinicians and appropriate treatment literacy is crucial for supporting safe and effective ART.

It was interesting to note that a small percentage of respondents (11%) reported to have sought traditional Ayurvedic medicine as complementary treatment in addition to their ART and other prescribed medication. It was also intriguing at the same time hear from a public sector health care provider in Andhra Pradesh that “Ayurvedic medicines have less side effects and are as effective as ARVs”. Similar misconceptions that discussed a possible cure for HIV/AIDS in Ayurveda were echoed in a FGD with truck drivers from Andhra Pradesh.

6.1 Access to ART

Although many (133/151; 88%) respondents who were on ART reported to be ‘satisfied’ with their current source of ART, a significant minority expressed dissatisfaction. While reasons for dissatisfaction in Manipur were related to quality issues such as lack of confidentiality, changes in brand of medicines, and side effects, in Andhra Pradesh, dissatisfaction was related to a perceived lack of integrity and negative

<table>
<thead>
<tr>
<th>Previous source of ARVs</th>
<th>Imphal(n1= 90)</th>
<th>Vijaywada(n2=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I used to buy it from a chemist shop</td>
<td>30 (33%)</td>
<td>14 (23%)</td>
</tr>
<tr>
<td>NGO/CBO sponsored or arranged getting the ARVs for me at low cost</td>
<td>27 (31%)</td>
<td>03 (5%)</td>
</tr>
<tr>
<td>One of my friends sent me the medicines from aboard</td>
<td>01 (1%)</td>
<td>-</td>
</tr>
<tr>
<td>Government program</td>
<td>30 (33%)</td>
<td>27 (44%)</td>
</tr>
<tr>
<td>My family bought it for me</td>
<td>02 (2%)</td>
<td>03 (5%)</td>
</tr>
<tr>
<td>I used to get my supply of ARV from my physician /private hospital</td>
<td>-</td>
<td>14 (23%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current source of ARVs</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I buy it from a chemist shop</td>
<td>-</td>
<td>11 (18%)</td>
</tr>
<tr>
<td>NGO/CBO sponsor or arrange getting the ARVs for me at low cost</td>
<td>20 (22%)</td>
<td>03 (5%)</td>
</tr>
<tr>
<td>One of my friends sent me the medicines from aboard</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Government program</td>
<td>70 (78%)</td>
<td>38 (62%)</td>
</tr>
<tr>
<td>My family buy it for me</td>
<td>-</td>
<td>02 (3%)</td>
</tr>
<tr>
<td>I get my supply of ARV from my physician /private hospital</td>
<td>-</td>
<td>07 (12%)</td>
</tr>
</tbody>
</table>
attitudes of medical staff. Dissatisfaction was also related directly to the advance payments required in order to access medication from chemist shops.

A positive shift in sourcing ARVS and accessing ART has taken place over the last two years as is evident from the table above. (table 5) This is probably linked to the roll out of the government program supporting free first line ART in these states. Some respondents accessing treatment through the government ART program expressed anxieties about the continuity of the government’s programme and the emergence of viral resistance over a period of time and the lack of availability of free second line on the government programme. Cost of travel to access the limited number of public sector ART sites was also a matter of concern for a few respondents. Interviews with the government health care providers corroborated this finding and made the case for establishing government ART sites in different districts a priority. Respondents accessing ART either on their own or with the help of NGO subsidized supply, were worried about financial implications of being on a life-long therapy. The poor economic condition of many PoART (vide section 5.1.3) and loss of husbands to AIDS were at the heart of this concern for several women who did not have the skills to get work but had to fend for themselves and their children.

Respondents from Manipur reported concerns about political turmoil, frequent strikes and economic blockades preventing essential commodities including ARVs from reaching their destinations. Several respondents from Manipur also raised issues about associated hepatic problems as adding to the worry by complicating decision making about ART. This was specific to Manipur probably reflecting a high prevalence of hepatitis B and C among current or former drug users, many of whom were on ART.

6.2 Adherence related issues

About 30% (44/151) of the respondents reported ever stopping ART (38%; 34/90 in Imphal and 16%; 10/61 in Vijaywada). While financial problem were cited as the reason for stopping ARV in 18% cases in Manipur and 80% cases in Andhra Pradesh, an overwhelming 53% (18/34) in Manipur stated ‘forgetfulness’ as the reason, which in some cases may be related to issues of associated substance use. The proportion of respondents who took steps to remember what time to take their medication varied from 8% in Andhra Pradesh to 51% in Manipur. Strategies adopted by PoART for remembering to take ARVs on time included setting an alarm and asking family members or friends to remind them.

One tenth of respondents, who reported ever having stopped ART, did so due to side effects of the medicines. Stopping ART due to improved health, although rare, was reported by one respondent from Andhra Pradesh.

6.3 Substance use, sexual practices and HIV diagnosis and treatment

Noticeable difference was observed between states when the respondents on ART were asked about change in pattern of use of alcohol or other types of substance following detection of HIV infection or initiation of ART (Box 1). In Manipur, a reduction in consumption of alcohol was reported by a few and some of the respondents reported doing more drugs or relapsing into injecting every now and then. Contrasting with these responses, the PoART from Andhra Pradesh largely reported stopping alcohol use either after detection of HIV or starting ART. Cases were reported in both states describing situations where use of alcohol or other substances increased after receiving an HIV positive test.
result; however these were rare instances. The reason for difference in patterns of use of ‘dependence producing substances’ following HIV positive test results or after the initiation of ART in two states probably lies in the fact that the commonly used substance in Manipur is heroin, an opiate, which is mostly injected, whereas that in Andhra Pradesh is alcohol, which follows a different natural history of use.

Thirty nine out of 61 PoART interviewed in Andhra Pradesh were married. 54% (21/39) of married respondents reported more frequent use of condom with regular sex partners after learning their HIV positive status. It was of concern to note that the figure in this self reported sexual practice of married PoART dropped from 54% to 41% (16/39) after they started ARV medicines. Forty three out of 90 PoART were married in Manipur and contrasting with Andhra Pradesh, the proportion reporting more frequent use of condom while having sex with regular sex partners increased in from 72% (31/43) before ART to 77% (33/43) once they started taking ARVs. Clearly there is a need to foster an environment where rates of consistent condom use in people who are HIV positive and also those who are taking ART are considerably higher.
Support system and types of support for PoART

7.1 Support within the families and outside

PoART universally reported that close relatives such as parents, brothers and sisters and friends could be counted on for emotional and psychological support. Most PoART reported receiving financial (111/151; 73%) and nutritional support from family members. Interviews with family members (13 in Manipur and 9 in Andhra Pradesh) revealed that in many of them, had general awareness that ART extended the lives of the people they were supporting and helped them to avoid opportunistic infections.

Support from government health care providers was found to be limited to the prescription of medicines. The quality of counselling was reportedly poor in government settings. In contrast, NGO health care workers were reported to be carrying out awareness raising activities with community members including ‘Health Check up Camps’. In general, PoART and their family members perceived NGO health care workers to be very supportive (Box 2). NGO care and support services at community level included psychosocial support, subsidised ARVs and other medication, and training for those supporting PoART. Some respondents mentioned churches or spiritual leaders were as a source of comfort and support. Many people with HIV reported renewing their faith in God or turning to religion as a coping mechanism. In Imphal, fellow former drug users were cited as providing support to HIV positive IDUs along with support groups.

7.2 Types of support extended to PoART

While immediate family members (Box 3) and/or spouses and in a few cases friends were the care support providers for the majority (134/151), about 10% of PoART (16/151) reported not getting health care support at home. However, support from friends and family was often expressed as sympathy - most not fully understanding what was happening. The burden of care, in many instances fell on female family members; (54%; 73/134 named mother as care provider whereas 38% mentioned about their spouses). Many respondents commented that extended family members were not as supportive and often stigmatised or discriminated against the person with HIV.

In some cases, other PoART were cited as providing support to their peers especially with nutrition. However, there was a recognised need for PoART to form support groups. Youth and women’s groups were also mentioned as providing moral support, most notably in Imphal.

7.3 Quality of support being received or given

Quality of support in terms of being able to access adequate information without much difficulty has improved over time in Andhra Pradesh as opposed to that in Manipur (table 6). It was also of concern that
Table 6 Ease of getting information about ARV as reported by people on ART

<table>
<thead>
<tr>
<th>Past versus present</th>
<th>Manipur (n1=90)</th>
<th>Andhra Pradesh (n2=61)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Was enough information available during initiation</td>
<td>79 (88%)</td>
<td>11 (12%)</td>
</tr>
<tr>
<td>of ARVs without facing difficulty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is sufficient information about ARVs presently</td>
<td>76 (84%)</td>
<td>14 (16%)</td>
</tr>
<tr>
<td>obtainable</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10 out of 90 respondents (11%) in Manipur who were on ART expressed that they did not get an opportunity to discuss various aspects of taking their medicines at the centres they were accessing ART, potentially having a negative impact on adherence and protective behaviour.

PoART reported that there was a general lack of understanding by family and community members about the emotional issues involved with HIV/AIDS and what support was needed by those on ART. Many family members supporting PoART felt that they were ill equipped to provide adequate psychological support. Many felt they lacked the required skills. Many PoART reported that they did not receive proper counselling at the government ART centres and hospitals.

7.4 Support required for improving the quality of care services

In general, those supporting PoART reported that they had insufficient financial capacity to buy medicines, pay for diagnostic tests and provide nutritious food (Box 4). Many respondents mentioned bank loans and government sponsored employment initiatives as potential ways of increasing financial capacity and support.

Greater availability of care and support services from NGOs as well as availability of support groups for PoART was mentioned as crucial to alleviating the burden of care and support on family members.

In general, those supporting PoART are aware of the importance of a nutritious diet but most are unable to provide such food. Many suggested the government and NGOs as potential sources of nutrition supplements and subsidised food. For those PoART who had children (59 out of 90 in Manipur and 40 out of 61 in Andhra Pradesh), the burden on supporters and PoART themselves of providing enough food for everyone was intensified. Many respondents suggested that the food and educational costs for children of PoART should be covered by government. Support groups and networks of people with HIV were also identified as a potential source of financial and nutritional support in times of financial crisis.

Many respondents suggested that training for health care providers on ART, counselling and, in many cases, the basics of HIV and AIDS was essential.
8.1 Family members, employers and HIV

All PoART respondents in both the states except 2 in Andhra Pradesh reported having disclosed their HIV status to close family members; mothers, spouses and siblings featured commonly in this regard. However some respondents reported high levels of marginalisation and discrimination from family members especially in the initial phase of disclosure. It is worth noticing here that the proportion of PoART who were accompanied by a family member while going for HIV test was much 62% in Andhra Pradesh and much less in Manipur (37%). A minority proportion (3%) in both states could not manage to tell their family members that they were HIV positive and on ART. Although many of the PoART mentioned about the positive role that support groups played in their lives, in a few cases they did not want to join such groups due to the fear of disclosure of their HIV status, and the attendant fear of stigma and discrimination; their family members also shared their fears. (Box 5).

Over half of PoART reported that they had disclosed their HIV status to their employers; many commenting that their employers, who were mostly from HIV/AIDS NGOs, were supportive. However it is worth noting that 3 out of 21 PoART who had lost their jobs were actually told by the employers to quit their jobs.

8.2 Stigma and Discrimination at community level including health care settings

Stigma and discrimination at community level including that from employers and government health care providers were key barriers (Box 6) restricting people’s access to HIV/AIDS care, treatment and support. The perceived risk of unfair treatment by health care providers and physical and social isolation by the wider community prevented people from accessing care, treatment and support. Respondents reported that the poorer people and drug users (former or current) faced additional discrimination linked to poverty and drug using behaviour.

Closely linked to stigma and discrimination was the issue of confidentiality and a lack of faith that government health care providers would respect confidentiality. In some cases confidentiality protocols reportedly were not followed. Medical files were often marked inappropriately to indicate HIV infection and there were instances when doctors freely discussed the HIV status of a patient without an informed consent for doing so. Many respondents described an urgent need for health care providers to be made aware of the psychological and emotional needs of PLHAs and to be trained in counselling skills.

Self stigmatisation was reported to be experienced by some people with HIV who often suffered blame, guilt and isolation and, in many cases experienced depression and suicidal thoughts. These feelings were generally reported to be more intense before starting ART, especially when people were first informed of their positive HIV status or when they became sick or weak. The majority of respondents reported that access to free ARV treatment and care and support from NGOs had helped those living with HIV to re-build their lives, re-integrate themselves into the community, live healthily, find work, and had given them renewed confidence and a sense of hope and a future. Most respondents commented that there was a crucial need for a dramatic increase in HIV/AIDS and ART awareness raising programmes for community members, health care providers, family members and schools; observing ‘World AIDS Day’, ‘using various media platform’ were some suggested means.

Box 5

“Some people like my brother are not interested in joining a group because they do not like to be exposed as HIV positive….even me and my family do not want to expose his HIV status…because it will damage our name in the community”

- Family member, Imphal

Had I known any of them, I would not have lost my children…even now I do not know of one….just my physician gives [my pills] and I take them.”

- Person on ART, Vijaywada
8.3 Stigma and Discrimination experienced by families of PoART

Family members of people with HIV reported facing stigma and discrimination from a wide range of community members, in particular neighbours, other family members, friends, and teachers.

Community members often felt that people with HIV were in a helpless situation. Community members generally had little or no knowledge of ARVT. People on ART, however, reported a decrease in stigma and discrimination from neighbours and other community members when they themselves took initiative to sensitise others to their situation, shared their experiences and talked openly about HIV and AIDS:

Additionally, in areas where NGOs had carried out awareness raising activities, levels of stigma and discrimination towards people with HIV and their family members was reportedly less and there was more openness about talking about HIV and AIDS.

Box 7

“...many people asked me about my husband's positive test and said it was the result of his earlier behaviour.....I got help from our neighbours.....those who knew our situation.....I talked to them and they helped me to confront the effects”
- Family member, Imphal

“If a new person is coming and asking for our address people in the community tell them these people are AIDS people.....they talk badly about us.....we are seen as untouchables.....my house has become famous as AIDS people’s house.....my son is made to sit aside in the school
- Family member, Imphal

Now I can talk to different people in the community and share my views and help other positive people. There is more awareness from the different programmes being carried out by the NGOs and other organisations
- Family member, Vijaywada
Building HIV treatment friendly communities requires building on existing community strengths and structures as well as working at multiple levels: a) household and individual, b) communities including health care centers and hospitals and c) policy. The recommendations resulting from the study are categorized accordingly.

**Households and individuals**

1. NGOs, CBOs and groups of people with HIV should conduct comprehensive treatment literacy programmes in order to support the information needs of individuals requiring ART, those already on ART and their families. Treatment literacy programmes should include accurate, simple information about the names and types of medicines, how they work, managing side effects, dispelling myths and misconceptions about HIV and ART as well as safer sex practices.

2. NGOs, CBOs should provide psychosocial support to people on ART. This can be done by engaging and supporting people with HIV who are willing to act as peer supporters as well as support groups of positive people or PoART.

3. NGOs and CBOs should have strong outreach and skills building programmes to support women and young girls in order to alleviate the burden of HIV/AIDS care which often falls disproportionately on women and young girls.

4. NGOs and CBOs should have a strong outreach and skills building programmes for family centered care and treatment. This must involve building the capacity of PoART and their carers and supporters.

**Communities including health care centers and hospitals**

5. NGOs and CBOS should carry out community sensitization activities about HIV/AIDS and ART. This is essential for reducing stigma and discrimination, and supporting safe and effective ART. Innovative partnerships between civil society organizations, educational institutions and private companies and employers should be developed to effectively engage communities in HIV care, treatment, prevention and support.

6. NACO and SACS, with civil society involvement especially the involvement of people with HIV, to roll out appropriate training for public sector health care providers including counselors on issues regarding confidentiality, consent, adherence including substance use, treating co-infection such as TB, Hepatitis B & C and prevention. The training programme should be combined with supportive monitoring of clinical practice with a view to improving the quality of HIV care and treatment provided in the public sector.

**Policy**

7. Advocate with national and state levels actors as well as with donors to provide support for community engagement for ART as an essential component of ART programmes.

8. Advocate with key national, state and district actors to support rapid and urgent roll-out of ART at district level so that at the very least the financial burden of long travel to ART centres is reduced.

9. Advocate with key national, state and district actors to support universal access to ART, prevention and care, including access to free ART at the point of service delivery.