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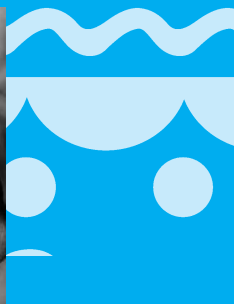
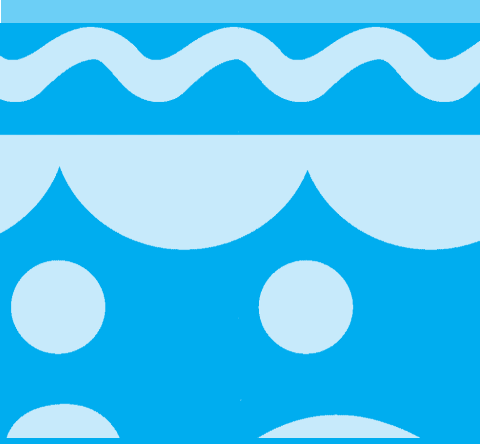
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Factors Affecting Enrolment of PLHIV into ART Services in India



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



This report is a result of a collaborative study between National AIDS Control Organisation and the Population Council. Financial support for this study was provided by National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India.

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Contents

Acknowledgments	ii
Abbreviations and Acronyms	v
Executive Summary	vi
1.0 Introduction	1
2.0 The Project	3
2.1 Objectives	3
2.2 Selection of study districts and study sites	3
2.3 Ethical approval	4
3.0 Secondary Data from ICTC and ART centers	6
3.1 Methods	6
3.2 Limitations and challenges	6
4.0 Integrated Counselling and Testing Centers	7
4.1 Gender	8
4.2 Marital status	9
4.3 Education Level	9
4.4 Occupational status	10
4.5 Route of Infection	11
5.0 ART Centers	12
5.1 Gender	12
5.2 Marital status	13
5.3 Education Level	14
5.4 Employment status	14
5.5 Immune status: CD4 cell counts	15
5.6 Registration at ART centers	15
5.7 Comparison of clients from ICTCs and ART centers	16
6.0 Conclusions (secondary data analysis)	18
7.0 Cohort study	20
7.1 Methods	20
7.2 Study design	20

7.3	Study sites	20
7.4	Study population and recruitment	20
7.5	Data collection and management	21
7.6	Limitations and challenges	21
8.0	Results	22
8.1	Recruitment and retention of cohort	22
8.2	Profile of study participants	23
8.2.1	Socio demographic profile of study participants	23
8.2.2	Employment and income	25
8.2.3	Poverty	26
8.3	HIV testing	27
8.3.1	Referrals	27
8.3.2	Reasons for undertaking HIV test	27
8.3.3	HIV testing and counselling services	29
8.4	Disclosure of HIV status	34
8.5	HIV Positive participants interviewed at ART centers	38
8.5.1	Time taken to reach ART center	38
8.5.2	Health care services accessed	39
8.5.3	Access to ART centers	41
8.5.4	Quality of services at ART centers	45
8.6	Clients interviewed in the community (did not register at ART Centers)	50
8.6.1	Health care services accessed	50
8.6.2	Registration at other ART centers	51
8.6.3	Reasons for not registering at ART	51
8.6.4	Awareness about the availability of free ART and CD4 Test	54
8.7	Registration at ART centers	55
9.0	Conclusions	58
	References	62
	Annex 1 Quick Poverty Score for India	63
	Annex 2 Informed consent form – Baseline	64
	Annex 3 Baseline Survey Questionnaire	66
	Annex 4 Informed consent form – Endline	79
	Annex 5 Endline Survey Questionnaire	81

Abbreviations and Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Ante-Natal Check-up
ANM	Auxillary Nurse and Midwife
ART	Antiretroviral therapy
ARTC	Anti Retroviral Treatment Center
ARV	Anti Retroviral
ASHA	Accredited Social Health Activist
BPL	Below Poverty Line
CBC	Complete Blood Count
CBO	Community-Based Organization
CCC	Community Care Centers
CD4	T lymphocyte with CD4 receptor
CHC	Community Health Center
CLHIV	Children Living with HIV
ELISA	Enzyme Linked Immuno Sorbent Assay
HIV	Human Immunodeficiency Virus
ICTC	Integrated Counselling and Testing Centers
IDU	Injecting Drug User
IQR	Inter Quartile Range
MOHFW	Ministry of Health and Family Welfare
NACO	National AIDS Control Organisation
NGO	Non Governmental Organization
PHC	Primary Health Center
PLHIV	People Living with HIV
PLHA	People Living with HIV and AIDS
QPS	Quick Poverty Score
RMP	Registered Medical Practitioner
STI	Sexually Transmitted Infection
TB	Tuberculosis

Executive Summary

India had an estimated 2.31 million (1.8 - 2.9) people living with HIV at the end of 2007, with a HIV prevalence of 0.34 per cent (NACO Annual Report, 2008-09). Despite the low HIV prevalence, these statistics place India among countries with a large number of people living with HIV (PLHIV). To address the care and support needs of PLHIV, the Ministry of Health and Family Welfare (MOHFW), Government of India, initiated a national programme in 2004 to provide free ART for PLHIV. At the end of March 2009, there were 211 functioning ARTCs and 254 CCCs across the country, and to date 2, 17,781 are receiving ART. A major challenge for the health system with its network of ART centers has been to increase utilization of ART services and enrolment into the program. It is important to understand the factors that contribute to utilization of ART services by HIV infected individuals.

The Population Council, with support from NACO, undertook a multi-site study in four high HIV prevalence and three low HIV prevalence states to understand the context and factors that influence the uptake of ART services.

Methods

The study was conducted in two phases. In Phase 1 we undertook analysis of secondary data collected from 30 ICTCs and 10 corresponding ART centers from ten districts across seven states. A cross sectional study design was used. The objective of the study was to understand and compare the socio-demographic characteristics of HIV positive people who were diagnosed HIV positive at ICTCs and those who registered for treatment at ART centers. This information was used to inform Phase 2. A total of 7814 people tested positive across the 30 participating ICTCs and 11568 HIV positive people registered for treatment at the 10 participating ART centers between October 1, 2008 and March 31, 2009.

In Phase 2, we conducted a prospective observational cohort study among newly diagnosed HIV-positive people tested at ICTCs. Individuals who tested positive at selected ICTCs were recruited into the study and followed till their registration at the referral ART center. Those who did not register at the referral ART center were tracked in the community for a follow-up interview. A total of 1057 newly diagnosed HIV positive people were recruited into the cohort from 27 ICTCs and followed prospectively for 2 months.

Key Findings

Phase 1: Secondary Data

There were more male clients than female clients at ICTCs (m: 56% vs. f: 44%) and ART centers (m: 51% vs. f: 49%); the low prevalence states had substantially fewer women. The median age for participants was 35 years (IQR: 30, 40).

The majority of clients at ICTCs and ART centers were married (ICTC: 78%; ARTC: 70%). The proportion of widowed clients was higher at ART centers (ARTC: 21% vs. ICTC: 14%). Women were more likely to be widowed at both ICTC and ART centers ($p < 0.001$). The trend was similar across states.

There were more illiterate people at ART centers (ARTC: 50% vs. ICTC: 42%); and fewer people with primary education (ARTC: 22% vs. ICTC: 28%). Secondary education (ARTC: 22% vs. ICTC: 23%) and higher education levels differed to a lesser degree (ARTC: 6% vs. ICTC: 7%). Substantial differences were observed across states.

At ICTCs, more than half (51.5%) of the participants were working as daily wage, unskilled manual labourers. At present, ICTCs do not collect information on unemployment as separate data, thus this information was not available. At ART centers, 81.2 per cent of clients were unemployed.

At ART centers, 63.4 per cent of newly diagnosed HIV positive people registered for treatment within one month (30 days) and 11.4 per cent registered within three months (31-90 days). However, 25.1 per cent registered after three months including 12.4 per cent who took more than a year to reach ART centers.

Analysis comparing data from ICTCs and ART centers, using a cut off of two months (60 days) to register at ART centers, shows that younger clients (<30 years: 68.7% vs. 31-45 years: 72.7% vs. >46 years: 76%; $p < 0.001$) and female clients (female: 68.5% vs. male: 74.4%; $p < 0.001$) were significantly less likely to register within two months. Further, widowed and separated clients (widowed: 61.6% vs. separated: 55.8% vs. married: 70.5% vs. single: 73.4%; $p < 0.001$); and unemployed clients (unemployed: 69.7% vs. employed: 76%; $p < 0.001$) were also less likely to register within two months.

Phase 2: Prospective cohort study

A total of 1057 newly diagnosed HIV positive participants were followed over two months.

Almost three-quarters (73.5%; $n=777$) of the participants in the cohort registered at ART centers within two months and were interviewed at their respective ART centers. Of the remainder who did not register at ART centers within the reference period, 17.9 per cent ($n=189$) were traced and interviewed in the community, 5.6 per cent ($n=60$) were traced but not interviewed for various reasons (death: 32, migrated out: 14, refusals: 5, not available for interview: 8, registered elsewhere: 1) and 2.9% ($n=31$) were untraced and lost to follow-up.

Characteristics of the population

Overall 51.7 per cent of the participants were male. The mean age was 34.7 years (SD 8.9). The majority were married (65%) while 21.7 per cent were widowed. Female participants were more likely to be widowed (f: 34.8% vs. 7.6%; $p < 0.001$). Over half (56.2%) of participants were illiterate and 78.8 per cent were employed, mostly as agricultural labour (68%). The Quick Poverty Score card, India was used to assess poverty among study participants. Overall 38 per cent of the participants fell into categories with a higher probability of falling Below Poverty Line per national criteria.

HIV testing and counselling services

The majority of study participants were referred for HIV testing from public sector health facilities (40.9%). Other referral categories included self referrals (18.8%), referrals from private health facilities (16.9%), from NGOs (11.9%) and friends and relatives (11.5%).

Nearly a third of the participants (32.2%) reported multiple HIV tests. Among those with multiple tests, 75.8 per cent had their first HIV test in the private sector. The majority (92.6%) of study participants collected their HIV test result within one week (7days).

Overall 92 per cent of participants made a single visit to the ICTC for their HIV test; however, more than a tenth (13.2%) of the participants had to make multiple visits to collect their HIV test results.

ICTC counsellors spent a median of 10 minutes (IQR: 5, 15) on pre-test counselling and a median of 20 minutes (IQR: 15, 30) on post-test counselling. The majority of participants (86%), reported high levels of satisfaction with counsellors at ICTCs. However, some inadequacies in counselling procedures and content were documented. Overall, 30 per cent of clients were not told about how the HIV test works, 28 per cent of participants were not told about partner testing, 47 per cent did not receive instructions on condom use (demonstration), 21 per cent were not told about the CD4 test required for assessing eligibility for ART, and 13 per cent were not given a referral slip for the ART center. Importantly, 32 per cent of participants were not told that proof of identity and address is essential for registration at the ART center; it is important to provide clients with this information so as to avoid multiple visits to complete the registration process. Disclosure of HIV status to a partner/spouse or family members was not discussed with more than a quarter of the participants (26%).

Disclosure of HIV status

Overall 69.3 per cent of participants had disclosed their HIV status to someone; disclosure was less frequent in the low prevalence states. Less than two-thirds (65.5%) of participants disclosed their HIV positive status to sexual partners. Disclosure of status was significantly lower among participants interviewed in the community compared to those interviewed at ART centers (54.8% vs. 72.9%; $p < 0.001$).

Fifty-eight per cent of those who had disclosed their HIV status to someone regretted their decision to disclose. Nearly a fifth (18%) of all participants reported that they had been discriminated by friends and 8.5 per cent by their extended family.

A third of all participants knew one or more households in the community with a HIV positive family member.

Clients who registered at ART centers within two months

In all 777 (73.5%) participants registered for treatment within two months and were interviewed at the ART center. Participants reached ART centers after a median of 7 days (IQR: 3, 18); 59.8 per cent participants regis-

tered within a week and a further 30 per cent within one month. Most participants were accompanied by family members (66.3%). Only 7.3 per cent had been assisted by a PLHA network member or out-reach worker (3.9%).

Health care services accessed

About 4 per cent (n=31) of these participants had used ARV medications in the past, prior to registering at the ART center. Thirty-four (4.4%) participants were concurrently registered at other centers for treatment; most of them (27/34) at other government ART centers.

A small proportion (3%; n=25) had consulted private allopathic physicians after their HIV test. Less than one per cent (n=7) of participants had consulted a traditional health practitioner; although 11 participants reported that they were taking traditional medications.

Immune status at registration for treatment

The majority (96.4%) of participants had undertaken CD4 count test at the ART center. Overall 55 per cent of participants had CD4 cell counts less than 250 cells/ml making them eligible to start ART immediately. A higher proportion of participants in low prevalence states had CD4 cell counts less than 250 cells/ml.

Problems faced in reaching ART centers

Participants were asked about difficulties that they may have faced in reaching ART centers; open ended qualitative responses were recorded. Three-fourth (75.5%) of participant faced no problems in reaching ART centers. For the remainder the most frequently cited problem were transportation difficulties and distance to ART centers (11.3%); financial difficulties and loss of wages at each visit to the ART center (5.7%); ill health and associated difficulty in travelling distances (5.3%); locating the ART center within the hospital (3%) and multiple visits required due to strike by health workers (1%).

Quality of services at ART centers

Forty per cent of participants had to visit the ART center two or more times to complete the registration process; this includes 10.8 per cent participants who made four or more visits.

Overall, waiting time to meet health providers was short; around two-third of the participants met counselors and doctors within 30 minutes. At the registration visit, ART Counsellors spent less than 20 minutes with the majority (90%) of participants. Doctors spent less than 10 minutes with the majority (85%) of participants.

The majority of participants found ART counsellors sympathetic (84.4%) and the counselling session private (74.3%). Satisfaction levels were high; 94 per cent of participants were fully or somewhat satisfied with their interaction with the counsellor. Some inadequacies in counselling content were observed. Thirty per cent of participants were not informed about HIV testing for spouses/partners and children; CD4 tests to assess eligibility for ART was not discussed with 46 per cent of participants; and the need for regular follow-up for ART was

not mentioned to a third of the participants. Linking clients with PLHA network members for support (and as an important tool for follow-up in the community) was done for less than a quarter (24%) of the participants. Almost a third of the participants felt counsellors did not encourage asking of questions (30%).

Most participants found doctors sympathetic (74%) and 88 per cent of the clients were satisfied with their interaction with the physician. However, doctors appeared not to focus on the prevention of HIV transmission: 30 per cent of participants were not told about prevention of transmission of HIV; the importance of condom use was not mentioned to 60 per cent of participants and HIV testing for partners/spouse and children not discussed with 46 per cent of participants. With regard to ART, treatment adherence was not discussed with 53 per cent of participants and CD4 tests not discussed with half the participants. Around 41 per cent of participants felt that doctors did not encourage questions.

Clients interviewed in the community (did not register at ART centers)

A total of 189 participants, who did not register at ART centers, were interviewed in the community. Researchers tracked them with help from ICTC counsellors, out-reach workers and PLHA networks linked to the ICTC.

Health care services accessed

A small minority (4.9%, n=9) of participants had undertaken additional HIV tests to confirm their HIV diagnosis. Less than a tenth (9.6%) had undertaken a CD4 test to assess eligibility for ART.

A very small number of participants (n=25) had consulted a physician after their HIV test; most of them visited other government hospitals (13/25), while a few consulted private allopathic physicians (6/25) and traditional healers (6/25).

About a tenth (9.6%, n=18) of the participants had registered for ART at other health facilities; more than half (8/18) registered at government ART centers in other districts for a variety of reasons including stigma, distance to ART center, transport concerns and financial difficulties.

Reasons for not registering at ART centers

The most frequently cited reason for not registering for treatment was being in good health and feeling well (29.8%). Other reasons included being busy with work or family engagements (22.2%), coming to terms with their diagnosis and fear of inadvertent disclosure of their status (8.8%), financial difficulties (8.8%), opposition by family members (5.3%), and distance to ART center linked to ill health and travel problems (4.7%). Other less frequent reasons were: not having someone to accompany them to the ART center (3.5%), the need to confirm their HIV diagnosis with another HIV test (3.5%), waiting to complete treatment for tuberculosis (2.9%), and health worker strike (2.3%). A few clients did not have the documents required for registration (ration card, proof of identification, voter card etc), while some others were taking traditional medicines or consulting temple priests and did not want ART.

The reasons provided here highlight key barriers to enrollment at ART centers.

Awareness about availability of free ART

Overall 82.9 per cent participants had received information about the availability of free ARV medications at government ART centers; and 77.5 per cent had been given referral slips for designated ART centers by the counsellors at ICTCs.

PLHA network support

Less than a fifth (17.1%) had been introduced to a PLHA network member for support.

Factors influencing registration at ART centers

On bivariate analysis, significant differences ($p=0.05$) were observed between participants who registered (R) for ART services and those who did not register (NR) at ART centers. Differences were noted on age, educational level, marital status, disclosure of HIV status, knowledge of HIV-positive people in the community and certain economic indicators such as principal occupation of the household, living in a pucca house (made of bricks, stone or concrete), or owning a pressure cooker.

Younger participants, especially those under 30 years of age (R: 15.1% vs. NR 20.1%; $p<0.086$); illiterate participants (R: 54.1% vs. 65.1%; $p<0.022$) and single/ never married participants were (R: 5.7% vs. NR: 10.6%; $p<0.04$) were less likely to register for treatment. Further, the proportion of participants who had disclosed their HIV status to atleast one person was lower among those who did not register for treatment (R: 72.9% vs. NR: 54.8%; $p<0.001$); and a higher proportion of participants who did not register for treatment knew household(s) in the community with a HIV positive family member (R: 34.7% vs. NR: 51.1%; $p<0.001$). Differences on certain economic indicators were also observed, suggesting that participants with lower incomes or those who were economically weaker were less likely to register for treatment - participants who worked as manual labour (R: 52.5% vs. NR: 66.1%; $p<0.003$) were less likely to register for treatment. Participants living in a pucca (brick) house (R: 64.5% vs. 57.0%; $p<0.057$) or those who owned a higher number of household goods ($P<0.001$) were more likely to register for treatment services.

There were no significant differences between groups with regard to gender, employment, having a family member on ART, owning agricultural land or owning a vehicle (bicycle, scooter, motor cycle). Satisfaction with ICTC counsellors and receiving referral slips were not significantly different between the two groups. CD4 cell counts were not included in this comparison as the majority of clients interviewed in the community had not undertaken this test at the time of interview.

The differences observed on bivariate analysis combined with the reasons given by participants who did not register for ART, provides a comprehensive view of barriers to uptake of ART services.

Conclusions

The study was designed to document the uptake of ART services in the public sector and to determine the reasons why some people do not access these services even when they are available. A cohort of 1057 newly diagnosed HIV-positive people was followed over 2 months. Almost three-fourths (73.5%; n=777) of the cohort registered at ART centers within two months of collecting their HIV test result. Of those who did not register at ART centers; 17.9 per cent (n=189) were successfully interviewed in the community and 5.6 per cent (n=60) were tracked but not interviewed and only around 3 per cent (n=31) participants were untraced and lost to follow-up. This provides evidence to the program that clients can be successfully tracked in the community.

The majority of the HIV-positive participants, who did not register at ART centers and were interviewed in the community, were not accessing ART nor had undertaken CD4 tests to assess their eligibility for treatment. This places these clients at risk of delaying treatment. A small number of HIV-positive clients (n=18) had registered at government ART centers in other districts for reasons of confidentiality, financial constraints and centers being close to their place of residence; however, this information was not available to the ICTC or referral ART center.

HIV-positive clients interviewed in the community did not register at referral ART centers for a variety of reasons. A perception of relatively good health removed the urgency to register immediately for several clients (30%), while work and family engagements kept others away from the ART center (22%). The fear of disclosure of their HIV status, being recognised by villagers or relatives and resulting stigma was the overriding concern for many others (9%). Although ART is offered free at government centers, financial difficulties and travel expenses were deterrents for several participants (9%). Family opposition comprised the fifth most commonly cited reason (5%). Other reasons included the distance of ART centers compounded with severe illness, which prevented travel for the participants who probably needed ART most. In a few cases participants were waiting to complete their tuberculosis treatment prior to registering at ART clinics.

Study findings show that younger clients, single clients and clients working as unskilled manual labour were more likely to not register at ART centers. Further non-disclosure of HIV status and knowledge of HIV-positive people in the community were also associated with a higher probability of not registering at ART centers; highlighting the continuing role of stigma in the community. Additionally, indicators suggestive of financial incapacity (e.g. working as manual labour, not owning household goods such as pressure cookers or pans, fans, a sewing machine or a vehicle for transport) were significantly more likely not to register for ART services. Similar factors also emerged from the analysis of secondary data from ART centers in Phase 1 of this study. Further, these issues were also mentioned by clients who had registered at ART centers but continued to face difficulties while accessing services. If not addressed, these may be the very factors that contribute to non-adherence at a later stage.

Disclosure and stigma continue to be important barriers to accessing services. Intensive counselling and support to address and facilitate disclosure of HIV status and manage fears related to loss of confidentiality are urgently needed.

The study also provides an assessment of the quality of counselling at ICTCs from interviews with HIV-positive people undertaken immediately after post-test counselling; and of the quality of counselling at ART centers from interviews conducted after registration at the ART centers. Overall clients were satisfied with counselling services at ICTCs. However, counselling at ICTCs and ART centers had some deficiencies. Topics that were inadequately covered included emphasis on partner testing, condom demonstration, explanation on the window period and information on PLHIV networks. Counselling at ART centers suffered from similar weaknesses, including insufficient information on the need for regular follow-ups and adherence to treatment, CD4 tests, and HIV testing of spouse and children. Health system issues, such as the shortage of HIV testing kits in ICTCs and health worker strikes also contributed to impeding registration at ART centers.

In conclusion, the majority of newly diagnosed HIV-positive people do register at ART centers. While barriers that deter HIV-positive people from accessing treatment services do exist, they are not insurmountable. Addressing client and health system barriers would serve to increase uptake of services.

Recommendations

- The study has demonstrated that programs can successfully track HIV positive persons in the community. Attempts must be made to track all newly diagnosed HIV positive people in the community. A two way process between the counsellor and HIV positive client is envisaged
 - a) Counsellors should routinely follow newly diagnosed positive people over two months after the HIV test, to determine whether they have registered at an ART center and reasons for not doing so, if they have not registered. This could be done through phone calls or outreach workers. ICTC registers would need to be modified to include additional information on registration at ART centers.
 - b) HIV positive clients must be asked to visit the ICTC or call the counsellor after they register at ART centers. While this is being done at some centers, implementation at a wider level may be considered.
- Enlisting support from PLHA networks for clients to reach ART centers is an important additional resource for health providers. This is not being implemented across all sites; this link can be strengthened to improve enrollment and follow-up in the community.
- ICTC counsellor's scope of work could be expanded to undertake an assessment of health and social status of newly diagnosed HIV positive people. The objective would be to identify persons who may be sick with advanced disease and in need of urgent medication; or having characteristics that may predict delayed registration or non-registration at ART centers – e.g. manual labourers, clients from a poor economic status, and illiterate clients who may require additional support to reach ART centers. Counsellors may be trained to initiate a more aggressive follow up plan for these clients.
- Healthy clients, on the other hand, would benefit from more focussed counselling on the importance of registering and assessing eligibility for ART even if they are in good health.

- Several clients found travelling a long distance to ART centers burdensome for a variety of reasons – e.g. ill health, financial difficulties, lack of transport arrangements, not having people to accompany them etc. This is not only a barrier to uptake of ART services but also to long term adherence to treatment.
 - a) In low prevalence states, where ART centers receive clients from several districts or neighbouring states (as in the case of Varanasi), Link ART centers need to be established quickly. At present Link centers only provide delivery of ART medications, all checkups are done at referral ART centers. Weekly visits by specialists from the ART center and arrangements to collect and transport blood for CD4 cell counts could be considered.
 - b) Enlisting support of PLHA networks to accompany clients to ART centers should be encouraged.
 - c) Travel concessions on public transport could be provided.
- Fear of inadvertent disclosure of status and resulting stigma is an important barrier to seeking ART services. The program may consider offering choice of ART centers to newly diagnosed HIV positive people for the initial evaluation and registration, and long-term follow up. This would allow clients to register safely and without fear. Clients could move to center closer to their home once they felt comfortable with their HIV positive status and treatment.
- Closer monitoring of counselling at ICTCs and ART centers is required at the state and district level. Routine monitoring visits should be planned that include a review of service data as well as some exit interviews with clients and/or observation of counselling sessions where possible.
- Data quality issues were noted at both ICTC and ART centers.
 - a) Rigorous and regular monitoring of data quality at ICTCs and ART centers is urgently needed. Monitoring visits should include a review of registers.
 - b) Harmonization of data collection at ICTC and ART centers is required. Coding of key variables should be similar at both sites.
 - c) Linking of ICTC and ART center data is urgently needed for program monitoring. Client PID numbers (unique ID) should be recorded in ART registers to link the two data bases. A joint monthly review of linked data by ICTC counsellors and ART counsellors could ascertain the number of clients who registered successfully and those who did not register and therefore need to be tracked in the community.

1.0 Introduction

India had an estimated 2.31 million (1.8 - 2.9) people living with HIV at the end of 2007, with a HIV prevalence of 0.34 per cent (NACO Annual Report, 2008-09). Despite the low HIV prevalence, these statistics place India among countries with a large number of people living with HIV (PLHIV). Providing treatment, care and support services for this population is a challenging task for the public health care system both as a national program and at the state level.

India has a large network of public health facilities distributed across rural and urban areas that provide free health care to the population. HIV testing is available at Integrated Counselling and Testing Centers (ICTCs) located in government health facilities in almost all districts across the country. At the end of March 2009, there were 2487 ICTCs in India, and 10,200,000 people had been tested for HIV at the centers in 2008-09 (NACO Annual Report, 2008-09). India also has large and active private health care system where HIV testing and antiretroviral therapy (ART) is available for a fee. Anecdotal information suggests that HIV testing is undertaken prior to most surgical and gynaecological procedures including deliveries.

To address the care and support needs of PLHIV, the Ministry of Health and Family Welfare (MOH FW), Government of India, initiated a national programme in 2004 to provide free ART for PLHIV. The model for delivery of ART adopted by the National AIDS Control Organisation (NACO) is a centralized institutional model supported by Non Government Organisations (NGOs) and Community Based Organisations (CBOs). The programme

envisages community involvement for tracking HIV-positive people receiving treatment with the help of trained paramedical personnel, community workers and people living with HIV/AIDS. Community Care Centers (CCCs) were set up to support services. All HIV-positive people are required to be tested at a government ICTC prior to being registered at the ART centers (ARTC); thus clients tested in the private sector are required to undergo a repeat HIV test at the ICTC in order to receive ART. To expand the geographic reach of treatment services, ART centers covering large geographical areas have associated Link ART centers placed at ICTCs or CCCs; especially in the low prevalence northern states that have a smaller network of ART centers. Link ART centers have the potential to be upgraded into functioning ART centers. At the end of March 2009, there were 211 functioning ARTCs and 254 CCCs across the country, and to date 2,17,781 are receiving ART. NACO aims to reach 300,000 adult PLHIV and 40,000 children living with HIV through 250 ARTCs and 650 Link ARTC by 2012 (NACO Annual report 2008-09).

A major challenge for the health system with its network of ART centers has been to increase utilization of ART services and enrolment into the program. Counsellors at ICTCs are expected to advise all newly diagnosed HIV-positive people to register at ART centers for further care including an evaluation of eligibility to initiate ART. However, anecdotal information suggests that less than 20 per cent of HIV-positive individuals who need treatment access it at ART centers. Barriers may include financial, social and organizational factors. Financial barrier is the largest obstacle

in both public and private healthcare sectors. Despite the provision of free antiretroviral (ARV) medications and CD4 tests, patients have to spend out of pocket on other laboratory investigations (e.g. radiological, blood tests, etc), nutritional supplements and transport costs (Sarna et al 2006, 2008). Additionally, families often have multiple HIV infected members (parents and children) who need treatment, increasing the financial burden on families with limited resources (Sarna et al, 2007). Social barriers such as stigma, discrimination, gender inequality, and lack of education also represent great challenges to HIV-positive individuals and their further access to treatment.

India's thriving private health sector delivers around three-fourths of all health care services and

comprises 74 per cent of the total health expenditure in the country (World Bank, 2007). The widespread utilisation of the private sector and traditional practitioners in the country suggests that they are trusted, accessible, and affordable practitioners. Furthermore, HIV/AIDS is still associated with significant stigma/taboo which may prevent people from accessing care from designated ART centers and draw patients to the private sector for reasons of confidentiality (Sarna et al 2006). Additionally, people also carry negative perceptions of government healthcare centers for reasons such as improper behaviour of health staff, staff shortages, a lack of supplies and drugs, and long waiting times to see a doctor (Bhat et al, 2004).

2.0 The Project

As NACO expands the network of ART centers it is important to understand the factors that contribute to utilization of ART services by HIV infected individuals. The Population Council, with support from NACO, undertook a multi-site study from April 2009 to March 2010 in four high HIV prevalence and three low HIV prevalence states to understand the context and factors that influence the uptake of ART services. The study was designed to provide guidance to the national HIV/AIDS control program on developing programmatic strategies to promote enrolment of HIV-positive individuals at ART centers aimed at increased service utilization and better care for HIV infected individuals. The study was conducted in two phases.

In the first phase we undertook analysis of secondary data collected from ICTCs and ARTCs in the study districts. A qualitative component was included to provide insights for designing the Phase 2 cohort study. We conducted focus group discussions with HIV positive persons from PLHA networks and with health workers. In-depth interviews were also conducted with PLHIV receiving services at ARTCs.

In the second phase, we conducted a prospective observational cohort study among newly diagnosed HIV-positive people tested at ICTCs. Individuals who tested positive at selected ICTCs were recruited into the study and followed till their registration at the referral ART center. Those who did not register at the referral ART center were tracked in the community for a follow-up interview.

This report is structured to follow the study format. Part One describes the study methodology,

site selection and results for Phase 1 dealing with the collection and analysis of secondary data from ICTCs and ARTCs while Part Two describes the cohort study.

2.1 Objectives

The global objective of this study was to understand the barriers that prevent HIV-positive people from accessing ART services to inform programmatic strategies to improve uptake of ART services.

The specific objectives of the project were to:

1. Understand the profile and characteristics of individuals who test HIV-positive at ICTCs.
2. Understand the profile and characteristics of HIV-positive people registered at ART centers for HIV care and treatment.
3. Compare the socio-demographic characteristics of people diagnosed HIV-positive at ICTCs with those accessing ART services to determine profiles or sub-groups of PLHIV who may not reach ART centers.
4. Assess the individual, familial, socio-cultural and structural barriers that affect enrolment of newly diagnosed HIV-positive individuals at ART centers.

2.2 Selection of study districts and study sites

To obtain a broad view of the ART program across the country, the study was conducted in four high prevalence and three low prevalence states in India. States and study districts were selected in consultation with NACO at a technical resource group meeting that included representatives from five Centers of

Excellence for ART services and NACO senior staff. Study districts and corresponding ART centers were selected based on HIV prevalence in the state (category A and B districts), client load at the ART centers and the network of ICTCs in the catchment area of ART centers.

Two districts were selected in the high prevalence states of Maharashtra, Karnataka and Andhra Pradesh. In Manipur only one district was selected due to the overall size of the state, logistical concerns and the presence of two ART centers in Imphal where most clients were referred. One district was selected in each of the low prevalence states of Uttar Pradesh, Rajasthan and Gujarat. Selection criteria for ART centers included a minimum of 1000 cumulative HIV-positive clients registered at the ART center in the district and monthly rate of at least 30 new registrations per month.

In the high prevalence states, three large volume ICTCs that referred clients to the ART center were selected in each district. In the low prevalence states each ART center has a wider geographical coverage and usually receives clients from ICTCs from surrounding districts. For Phase 1, the committee selected one ICTC from within the district and two ICTCs from outside districts in the three low HIV prevalence states; the aim was to utilise the wider geographical coverage to identify barriers faced by clients accessing services at ICTCs and ART centers. In all states one ICTC was located in the same hospital as the ART center.

A mapping exercise was conducted to select high volume feeder ICTCs. The research team gathered information on the ICTCs referring HIV-positive people to each of the selected ART centers, specifically

focussing on the number of clients tested per month, average number of HIV-positive people diagnosed per month, geographical coverage of the ICTCs and closest ART center. Geographical coverage extended to neighbouring states for some ART centers. A final selection was made in consultation with District State AIDS Control officials, Senior Medical Officers in-charge of the ART centers and health care staff at the clinics.

For the cohort study (Phase 2), based on feedback from health workers in the field, it was decided not to select the ICTCs located within the same hospital as the ART centers, since almost all the newly diagnosed HIV-positive people reached ART centers quite easily. Therefore, in Phase 2, three high volume ICTCs outside the hospital were selected for each ART center. In the low prevalence states these ICTCs were located in different districts.

Thus in each district one ARTC and three corresponding feeder ICTCs were selected: a total of 30 ICTCs across 10 districts in seven states were included in Phase 1 of the study. Manipur was not included in Phase 2 due to administrative and logistical reasons. Phase 2 was conducted in six states with a total of 9 ART centers and 27 ICTCs. Selected districts and sites are shown in Table 1.

2.3 Ethical Approval

Ethical approval for the study was obtained from the Institutional Review Board of the Population Council and from the Technical Resource Group on Research and Development, NACO and the NACO Ethics Committee for Research at NACO. Data collection instruments and informed consent forms were approved by both bodies.

Table 1: State-wise list of participating ART Centers and ICTCs

State	District	ARTC	ICTC
Andhra Pradesh	Krishna	District Hospital, Vijawada	Vijawada ¹ Gudivada Nandigama Mylavaram ²
	East Godavari	District Hospital, Rajamundhry	Rajamundhry ¹ Mandapeta Gokavaram Kadium ²
Maharashtra	Kolhapur	District Hospital, Kolhapur	Kolhapur ¹ Ichalkaranji Gandigal Kagal ²
	Satara	District Hospital, Satara	Satara ¹ Phaltan Karad Patan ²
Karnataka	Bijapur	District Hospital, Bijapur	Bijapur ¹ Bagewadi Indi Muddebihal ²
	Bagalkot	District Hospital, Bagalkot	Bagalkot ¹ Jamalkhandi Mudhol Badami ²
Manipur ^c	Imphal	Rajiv Gandhi Institute of Medical Sciences, Imphal	RIMS MLSS Bishenpur
Rajasthan	Jaipur	SM Singh Medical College, Jaipur	Jaipur (SMC) ¹ Alwar Sikar Ajmer ¹
Uttar Pradesh	Varanasi	Banaras Hindu University, Varanasi	Varanasi (BHU) ¹ Azamgarh Jaunpur Bhadoi ²
Gujarat	Mahesana	District Hospital, Mahesana	Mahesana ¹ Palanpur Patan Kadi ²

1 ICTCs not included in phase 2 cohort study

2 ICTCs not included in phase 1

3 Manipur was dropped from phase 2 due to administrative difficulties

3.0 Secondary Data from ICTC and ART centers

3.1 Methods

A cross-sectional study design was used for secondary data analysis of existing information from ICTC and ART centers. At ICTC, data were collected from the locator register (PID Register for general clients, ICTC register for general clients) and the HIV test register for all clients over 15 years of age who tested positive at participating ICTCs between October 1, 2008 and March 31, 2009. Information collected included: socio-demographic information (age, sex, education, employment, and marital status), referred from, referred to, and residential district. Route of infection, partner testing and partner HIV test results were also recorded. HIV testing facilities located at PPTCT centers **were not included** in this study.

At ART centers data were collected from the Pre ART Registration records (register), ART cards (white cards) and Laboratory registers for all HIV-positive people over 15 years of age who registered at participating ARTCs between October 1, 2008 and March 31, 2009.

Results from the secondary data analysis are presented in three parts: first for data collected from ICTCs, followed by data collected from ARTCs and then comparisons between ICTCs and ARTCs. Data is presented by state and, where essential, gender comparisons have been made.

3.2 Limitations and challenges

NACO instituted a standardized data collection system across all ICTCs and ART centers in the country through centrally printed and distributed registers. However, transition to new registers took place at different time periods resulting in data variability across sites prior to the end of 2008, for example, missing variables or differently coded variables. Quality of data was also variable across centers and there was significant missing information on key variables. Further, similar variables were coded differently at ICTCs and ART centers preventing comparisons. The findings presented in this report are based on existing data collected from the registers at selected centers.

4.0 Integrated Counselling and Testing Centers

A total of 7814 people tested HIV-positive between October 1, 2008 and March 31, 2009 across the 30 participating ICTCs. Table 2 shows the distribution of clients recruited by state and district, and the proportion of clients who resided in the same district as the ICTC.

Table 2: Distribution of HIV-positive people by state, district and ICTCs

State	District	HIV positive Clients (n)	ICTC	HIV positive Clients (n)	Clients from within same district (%)
Andhra Pradesh	Krishna	993	Vijayawada*	633	95.4
			Gudivada	223	
			Nandigama	137	
	East Godavari	817	Rajahmundry*	696	94.4
			Mandapeta	82	
			Gokavaram	39	
Maharashtra	Kolhapur	981	Kolhapur*	878	95.9
			Ichalkaranji	46	
			Gadingal	57	
	Satara	704	Satara*	479	97.3
			Phaltan	71	
			Karad	154	
Karnataka	Bijapur	918	Bijapur*	812	93.8
			Bagewadi	57	
			Indi	49	
	Bagalkot	959	Bagalkot*	391	100
			Jamakhandi	289	
			Mudhol	279	
Manipur	Imphal and Bishenpur	354	RIMS Imphal*	285	41.1
			MLSS Imphal	14	11.8
			Bishenpur	55	
Uttar Pradesh	Varanasi, Azamgarh and Jaunpur	1035	Varanasi*	829	12.3
			Azamgarh	75	92.0
			Jaunpur	131	93.9
Rajasthan	Jaipur, Alwar and Sikar	685	Jaipur*	585	19.0
			Alwar	31	87.1
			Sikar	69	63.8
Gujarat	Mehasana, Palanpur and Patan	368	Mehasana*	191	55.5
			Palanpur	119	92.4
			Patan	58	89.7
TOTAL		7814		7814	

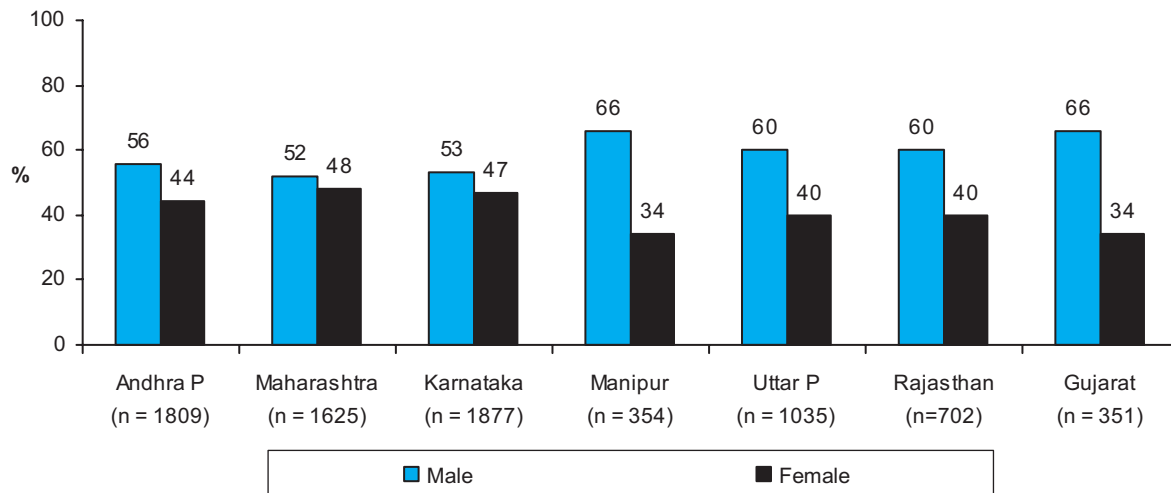
* ICTCs located in same referral hospital as the ART center

As expected, high HIV prevalence states had a larger number of newly diagnosed HIV-positive clients compared to the low prevalence states with the exception of Manipur and Uttar Pradesh (UP) (Table 1). UP, a low prevalence state, reported the largest number of newly diagnosed HIV-positive clients (n = 1035) for the six month reference period. The ICTC in Varanasi received clients from a large geographical area including some districts of neighbouring Bihar, Jharkhand and Madhya Pradesh. Despite being a high prevalence state, Manipur had the lowest number of newly registered HIV-positive clients in the preceding six months (n = 354). Most participants coming from districts outside Imphal were referred directly to the ARTC at RIMS by NGOs, lowering the numbers tested at other ICTCs located in Manipur. In all states the highest number of HIV-positive clients came from ICTCs located in the same hospital as the ARTCs. These ICTCs serve as an entry point for several clients from outside districts and a wider geographical area that have been referred from the private sector or NGOs.

4.1 Gender

Overall 56 per cent were males and 44 per cent females. One client self-identified as a transgender and was considered a male for the purpose of analysis. The mean age for all clients was 35.4 years (SD 9.1) and the median age was 35 (IQR 30, 40). Males were significantly older than female clients (mean age males: 37.1 years (SD 9.1) vs. females 33.3 years (SD 8.6); p <0.001 T test). The age of clients ranged from 15 to 83 years for males and 15 to 73 years for females. There were substantial differences in the distribution of males and females across states. Low prevalence states of Uttar Pradesh, Rajasthan and Gujarat had a substantially higher proportion of male clients compared to female clients (Figure 1). In the high prevalence states there were also more male clients, however, the differences between the sexes was smaller; women formed between 44 to 47 per cent of clients tested HIV-positive.

Figure 1: Gender distribution of HIV positive clients by state (ICTC)

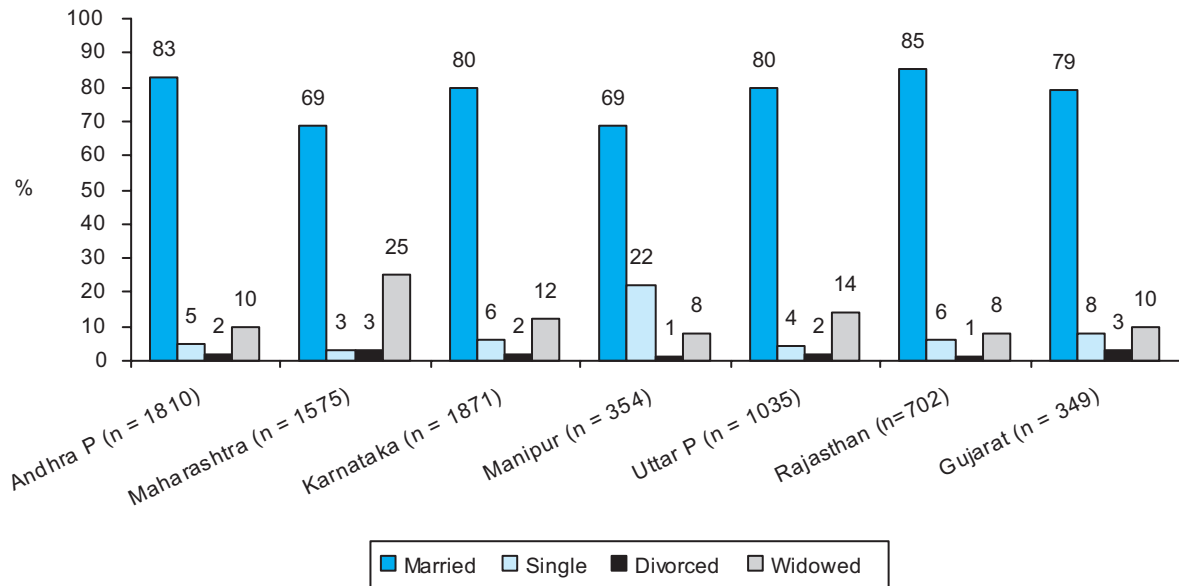


4.2 Marital status

Overall, the majority of clients, 78.4 per cent, across all states were currently married; 5.7 per cent were single (never married), 1.8 per cent were separated or divorced and 14 per cent were widowed. Maharashtra and Manipur had the lowest proportion of married clients (69%). In Maharashtra a quarter (25%) of all clients were widowed and in Manipur a fifth of all clients were single. Significant gender differences were observed. Males clients were more likely to be

married compared to female clients (86.3% vs. 68.3%; $p < 0.001$) while female clients were more likely to be widowed compared to males (26.5% vs. 4.3%; $p < 0.001$). Data on HIV testing for spouses was available only for 53 per cent ($n = 3259$) of married participants ($n = 6037$). Among the married clients, 54.8 per cent ($n = 1787$) of spouses had undertaken HIV tests; 80.5 per cent spouses were HIV-positive and 19.5 per cent were HIV-negative.

Figure 2: Marital status of HIV positive clients by state (ICTCs)

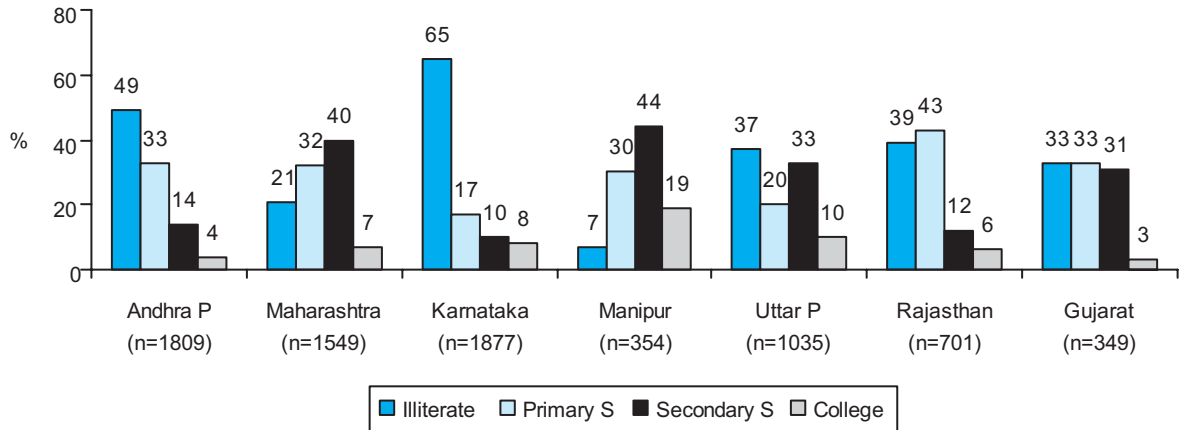


4.3 Education level

Information on the educational level of clients accessing services at ICTCs is collected routinely. Overall 41.9 per cent of the newly diagnosed HIV-positive clients were illiterate, 28 per cent of the clients had completed primary schooling, 22.7 per cent had completed secondary school and only 7.4 per cent had

a college education, per ICTC registers. Karnataka had the highest proportion of illiterate clients (65%), possibly due to the large rural population accessing services. Both Bijapur and Bagalkot are small towns in rural areas. Manipur recorded the highest proportion of clients with a secondary education (44%) and college level education (19%).

Figure 3: Educational level of clients by state (ICTC)

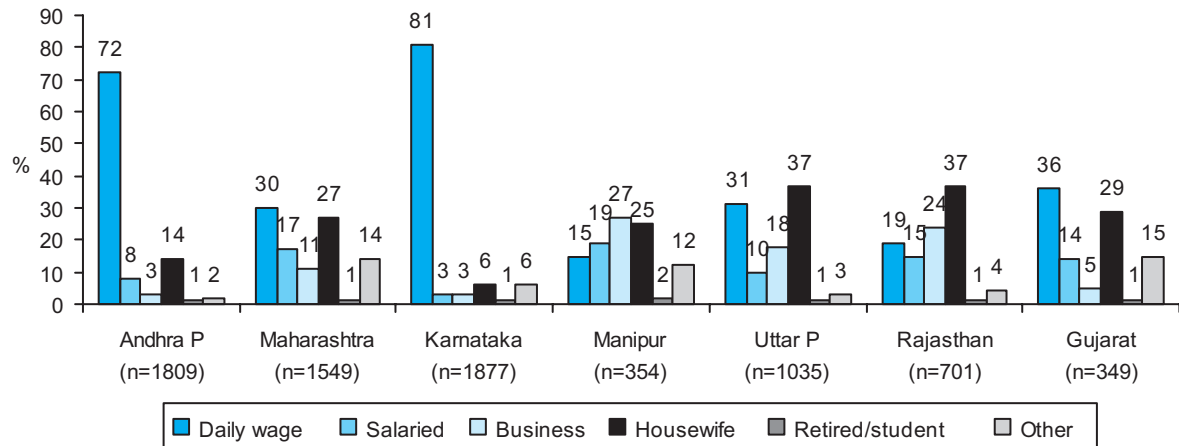


4.4 Occupational status

Overall 51.5 per cent of all clients (n = 7631) across all states were working as daily wage or unskilled labourers, 10.2 per cent were salaried employees, 9.6 per cent ran businesses, 0.3 per cent were retired and 0.7 per cent were students. Additionally, 21.1 per cent of clients are recorded as being house-wives, these included 44 male clients; and 6.6 per cent were categorized as

‘other’. ICTC registers do not record unemployment data and occupational data collected at ICTCs does not allow us to make this distinction. It is possible that unemployed clients may be coded under housewives and others. It is interesting to note that Karnataka and Andhra Pradesh with the highest proportion of illiterate clients also reported the highest proportion of clients working as unskilled manual labour.

Figure 4: Occupational status of clients by state (ICTC)



4.5 Route of Infection

The overall route of infection for the majority of clients (90%) was recorded as heterosexual exposure in ICTC registers. All other routes of infection were mentioned for less than 3.5 per cent of clients. Differences were observed across states. In Manipur clients infected as a result of injecting drug use constituted 26.6 per cent. The route of infection for 22.5 per cent of clients was not specified in Uttar Pradesh and for 9.3 per cent clients in Rajasthan, suggesting that clients may be hesitant to provide information in

low HIV prevalence states where the HIV is not as widespread.

The majority of HIV-positive clients were referred to ART centers. The proportion of HIV-positive clients referred to ART centers was the lowest in Manipur (60.7%). As injecting drug use is a common source of HIV infection in this population, counsellors at ICTCs often refer HIV infected injection drug users (IDUs) to NGOs for social support and assistance guiding these people to the ART center.

Table 3: Routes of HIV infection and ARTC referral for clients by state (ICTC)

	Andhra Pradesh % (n=1804)	Maharashtra % (n=1493)	Karnataka % (n=1877)	Manipur % (n=354)	Uttar Pradesh % (n=1034)	Rajasthan % (n=701)	Gujarat % (n=351)	Total % (n=7614) ¹
Route of HIV Infection								
Heterosexual	96.4	95.1	92.1	70.3	75.1	88.7	89.2	90.0
Homosexual	2.3	0.5	0.5	0.3	0.1	0.6	2.8	1.0
Blood transfusion	0	1.3	0.2	1.7	1.6	0.1	0.3	0.6
Exposure at health facility	0.4	0.5	0.5	0	0.4	0.1	0	0.4
Parent to child	0.2	0.3	0.2	0.6	0	1.0	1.4	0.3
IDU	0.6	0.1	0.1	26.6	0.2	0.1	0.3	1.5
Not specified	0.1	2.2	6.4	0.6	22.5	9.3	6.0	6.2
Referred to ART center by counsellor								
	n=1808	n=1166	n=1373	n=354	n=1035	n=621	n=347	n=67041
Referred to ARTC	100	90.2	95.2	60.7	90.2	98.2	99.1	70.8

¹ denominators vary due to missing data

5.0 ART Centers

A total of 11568 HIV-positive people registered for treatment between October 1, 2008 and March 31, 2009 across the 10 participating ART centers. Table 4 shows the distribution of clients recruited by state and district, and the proportion of clients who resided in the same district as the ART center. As expected, the ART centers in high prevalence states registered more clients during the reference period

compared to centers in low prevalence states. In high prevalence states, the majority of clients registering at ART centers resided in the same district as the ART centers. By contrast, in the low prevalence states, the majority of clients came from outside districts, or as in the case of the ART center at Varanasi, UP, from districts in neighbouring states such as Bihar, Jharkhand and Madhya Pradesh.

Table 4: Distribution of HIV-positive people registering at ART centers by state and district

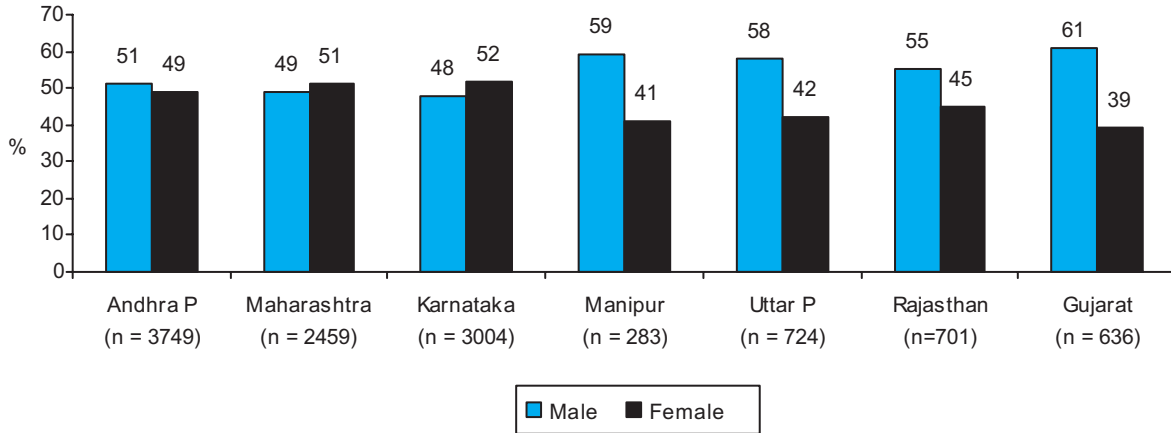
State	District	Clients registered (n)	Clients from within same district (%)
Andhra Pradesh	Krishna	2620	96.8
	East Godavari	1129	94.1
Maharashtra	Kolhapur	1185	96.3
	Satara	1274	99.6
Karnataka	Bijapur	1479	83.9
	Bagalkot	1536	94.7
Manipur	Imphal	283	56.5
Uttar Pradesh	Varanasi	724	10.4
Rajasthan	Jaipur	701	17.5
Gujarat	Mehasana	637	32.3
TOTAL		11568	

5.1 Gender

Overall 51.1 per cent of clients registering at ART centers across all states were male. There were gender differences across states. (Figure 5) The high prevalence states of Maharashtra (51%) and Karnataka (52%) registered more females than males, while Andhra

Pradesh had marginally more male than female clients. Despite being a high prevalence state, Manipur had significantly more male clients; possibly due to the fact that injecting drug use is more common among men, leading to more HIV infections among men. The low prevalence states had substantially fewer female clients.

Figure 5: Gender distribution of clients by state (ARTC)

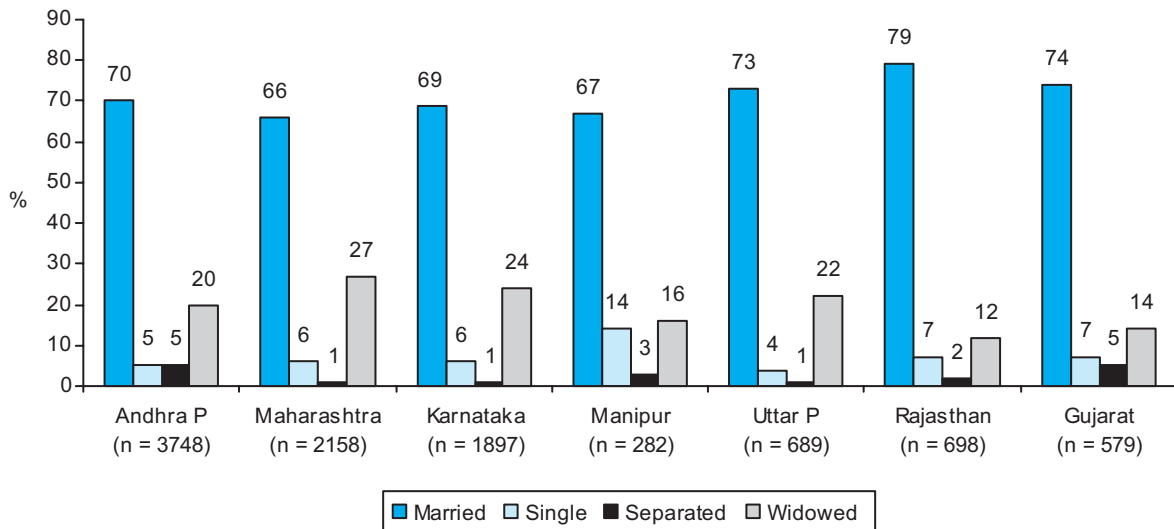


5.2 Marital status

Across all states the majority of clients, 70.7 per cent, were currently married, 20.6 per cent were widowed, 5.8 per cent were single (never married) and 2.0 per cent divorced or separated. Around a quarter of the clients registering in Maharashtra (27%), Karnataka

(24%) and Uttar Pradesh (23%) were widowed. (Figure 6). There were significant gender differences; males were more likely to be currently married compared to female clients (82.6% vs. 57.9%; $p < 0.001$) while females were more likely to be widowed compared to male clients (35.3% vs. 6.8%; $p < 0.001$).

Figure 6: Marital status of clients by state (ARTC)

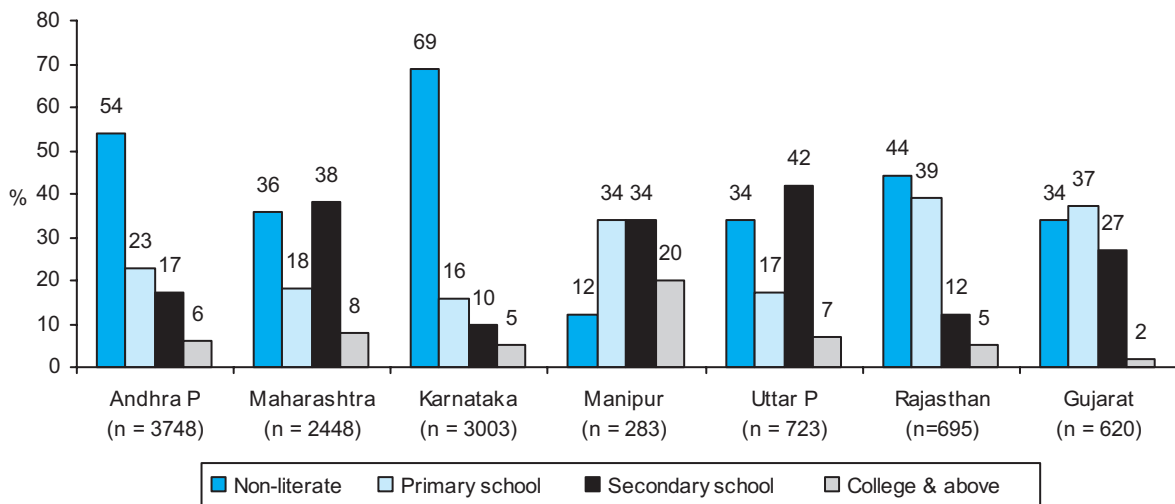


5.3 Education level

Overall, 50 per cent of the clients registering at ART centers during the reference period were illiterate, 21.8 per cent had completed primary school, 21.7 per cent had completed secondary school and only 6.4 per cent had a college education. Karnataka had the highest proportion of illiterate clients (69%)

followed by Andhra Pradesh (54%) (Figure 7). A third of the clients in Manipur had completed secondary school and 21 per cent a college education. There were gender differences in education level among clients; female clients were more likely to be illiterate compared to male clients (59.2% vs.41.2%; $p < 0.01$).

Figure 7: Educational level of clients by state (ARTC)

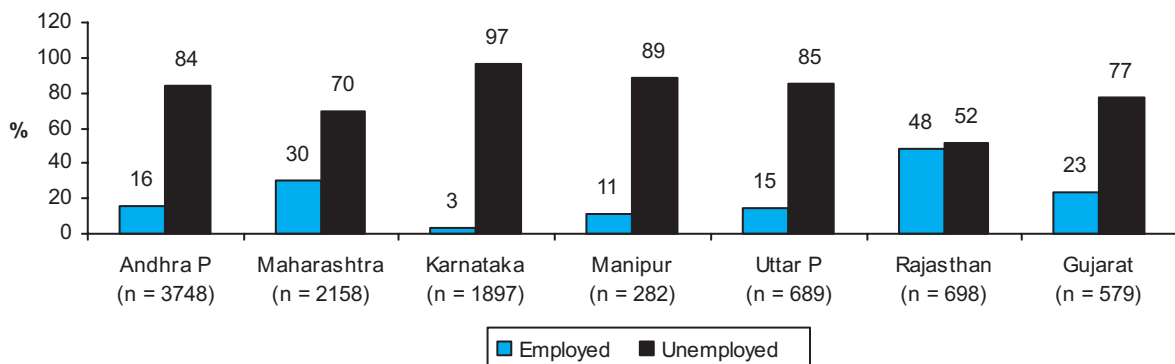


5.4 Employment status

Overall, the majority of clients, 81.2 per cent, registering at ART centers were unemployed. The states of

Maharashtra and Rajasthan had a higher proportion of employed clients (Figure 8).

Figure 8: Employment status of clients by state (ARTC)

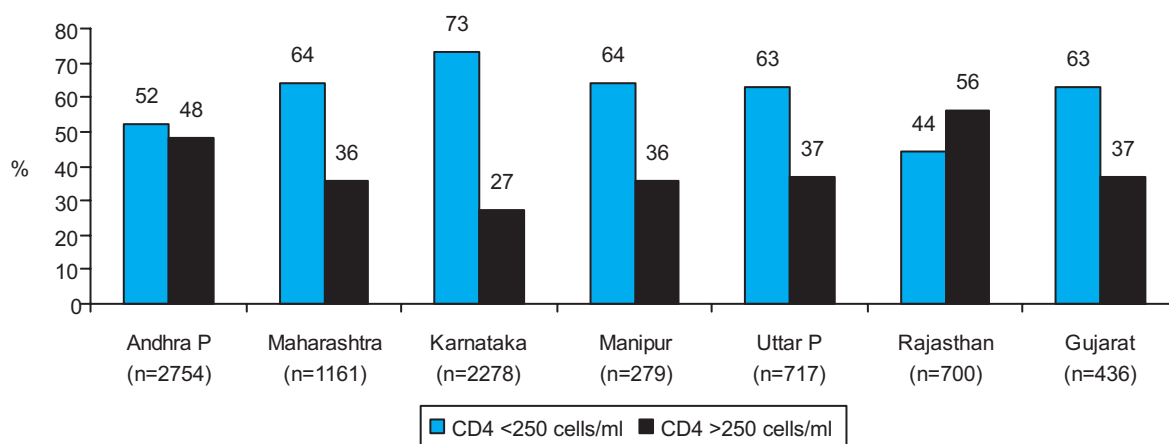


5.5 Immune status: CD4 cell counts

The hallmark of HIV disease is the gradual destruction of the body's immune system allowing opportunistic infections and causing weakness. HIV-positive clients with advanced disease are often too sick to work. To assess eligibility for initiating ART, newly diagnosed HIV-positive clients are asked to undertake a CD4 count test. Figure 9 presents the distribution of CD4 cell counts for newly diagnosed HIV-positive

clients registering at ART centers. It is interesting to note that states like Karnataka, Manipur and Uttar Pradesh with higher rates of unemployment also had a higher proportion of clients with CD4 cell counts < 250 cells/ml. [Note: data on CD4 counts from laboratory and ART registers was available for 8325 clients (missing data for clients who did not undertake the test, did not collect the result or in some cases where report was handed over to the client)].

Figure 9: Immune status of HIV positive clients by state (ARTC)



5.6 Registration at ART centers

Data collected from new registrations at ART centers revealed that almost two-thirds of newly diagnosed clients registered at the ART center within 1 month (30 days) and a further 11 per cent registered within three months. Thus the majority of clients reached ART centers within three months of their HIV test. Almost a fifth of all clients took more than six months

to register at an ART center, of which 12 per cent took more than a year. Bivariate analysis shows that younger people; females; widowed or separated people; illiterate individuals or those with only a primary education; and unemployed persons were more likely to take longer to reach ART centers, and to register after two months (Table 5).

Table 5: Time taken for registration at ART centers (ARTC)

Time to registration		% (n=10864)		
1 month or less (0-30 days)		63.4		
Three months (31 to 90 days)		11.4		
Six months (91-180 days)		6.5		
One year (181-365 days)		6.2		
More than a year (> 365 days)		12.4		
Socio demographic variables related to time taken to register				
		Less than 60 days	More than 60 days	Significance ¹
Age	30 years or less (n=4358)	68.7	31.3	p<0.001
	31 to 45 years(n=5432)	72.7	27.3	
	46 or more years(n=1072)	76.0	24.0	
Sex	Male (n=5518)	74.4	25.6	p<0.001
	Female (n= 5335)	68.5	31.5	
Marital status	Married (n=4961)	70.5	29.5	p<0.001
	Single (n=398)	73.4	26.6	
	Widowed (n=1472)	61.6	38.4	
	Separated (n=199)	55.8	44.2	
Educational status	Illiterate (n=5481)	70.2	29.8	p<0.001
	Primary education (n=2301)	68.6	31.4	
	Secondary education (n=2326)	75.9	24.1	
	College education (n=723)	74.8	25.2	
Employment	Employed (n=1765)	76.0	24.0	p<0.001
	Unemployed (n=7702)	69.7	30.3	
CD 4 cell count	<250 cells /ml (n=4731)	71.0	29.0	p=0.440
	>250 cells/ml (n=3094)	71.8	28.2	

¹ Chi square test

5.7 Comparison of clients from ICTCs and ART centers

An objective of the study was to compare the socio-demographic characteristics of newly diagnosed HIV-positive people from ICTCs and ART centers to determine characteristics that identify clients who may not reach or register at ART centers. Comparisons were made by age, gender, education and marital status where

data collected at ICTCs and ART centers were similarly coded (Figures 10-13). The age profile of HIV-positive clients (n = 19310) at ICTC and ART centers showed minor differences between the two centers; the proportion of HIV-positive clients older than 30 years of age was marginally lower at ART centers. Differences were observed on the gender profile (n = 19310): the proportion of males was lower at ART centers. On

the educational profile (n = 19183) the proportion of illiterate clients was higher at ART centers compared to all other educational categories. With regard to marital

status, (n = 15333) ART centers had a lower proportion of married clients but a higher proportion of widowed clients.

Figure 10: Age profile of clients from ICTC and ART centres

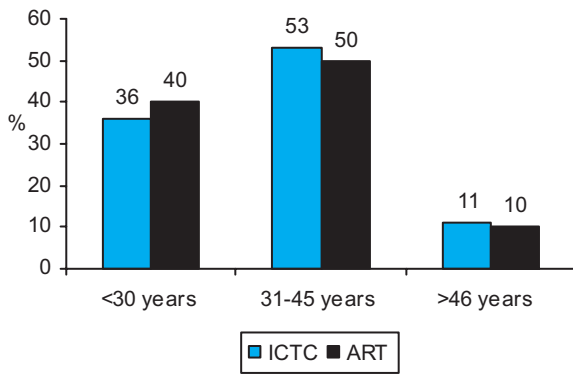


Figure 11: Gender profile of clients from ICTC and ART centres

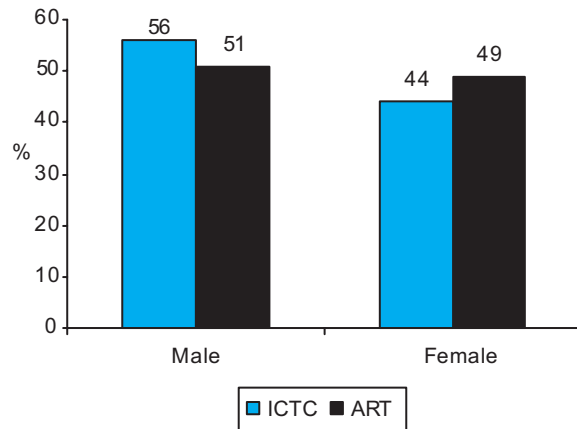


Figure 12: Educational level of clients from ICTC and ART centres

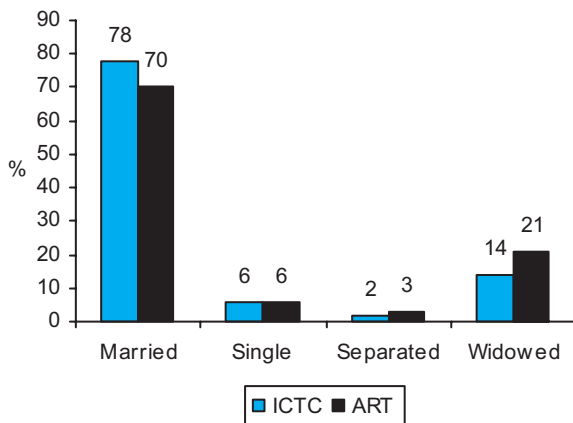
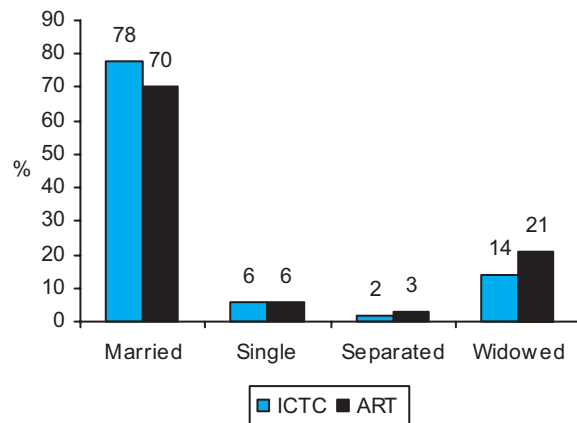


Figure 13: Marital status of clients from ICTC and ART centres



6.0 Conclusions (Secondary data analysis)

Information collected from ICTC and ART centers provides important insights into the HIV program of NACO and the profile of its clients.

Overall program services reach more men than women. However, important regional differences emerge indicating that women were under-represented to a larger extent in the low prevalence states. At both ICTCs and ARTCs, around three-fourths of HIV-positive clients were currently married and more than a tenth widowed. Women were less likely to be married and more likely to be widows at both ICTCs and ARTCs, highlighting their vulnerability. It is important to note that only half the spouses of HIV-positive married clients had been tested for HIV. At both ICTCs and ARTCs a substantial proportion of clients were illiterate (between 40-50 %), there again women were more likely to be illiterate. At ICTCs more than half the newly diagnosed HIV-positive people were working as daily wage manual labour while at ARTCs more than three-quarters of newly registered clients were unemployed, highlighting the economic vulnerability of the population accessing public sector HIV services.

It is encouraging that 63 per cent of HIV-positive clients registered at ART centers within one month of their HIV test. However, the fact that 19 per cent of HIV-positive people registered at ART centers after six months or more of their HIV test including more than a tenth who registered after a year of their HIV test, requires evaluation. Further analysis of data collected from HIV-positive clients registering at ART centers suggests that younger people (less than 30 years of age), women, widowed or separated clients,

clients with lower educational levels, and unemployed clients were more likely to register late at ART centers. Health care personnel at ICTCs would do well to focus on these sub-groups to provide additional support and counselling to assist these clients to reach ART centers for timely evaluation of eligibility for initiating treatment.

While information above obtained from clients registering at ART centers identifies groups at risk of registering late, the comparison of the socio-demographic characteristics of HIV-positive people from ICTC and ARTC provides important information on certain groups of HIV-positive individuals who may not access ART services. The proportion of HIV-positive men (while comparing data on gender), married (while comparing marital status) and older clients (while comparing age groups) was lower at ART centers compared to ICTCs suggesting that these groups may not be reaching ART centers. Similarly while comparing education, the proportion of clients with primary and higher education was lower at ART centers compared to ICTCs. It is important to understand that while there may be several factors that influence access to treatment, this comparison provides directions to the program on areas for further research.

The client load was variable across ICTCs and ART centers. ICTCs located in referral hospitals, where ART centers are located, have a substantially higher client load than other ICTCs. Similarly ART centers receive HIV-positive clients from several districts; and in low prevalence states from other states as well. High client load would impact the quality of service provided and the long distance travelled for

out-of-district or out-of-state clients pose a barrier to accessing services. This may be especially relevant for the large proportion of HIV clients who were illiterate or clients working as daily wage labour or unemployed clients. Expanding the network by establishing ART Link centers in low prevalence states may serve to speed up enrolment.

A high client load also influences the quality of programmatic data collected. Data quality was variable across sites. There was substantial missing data on critical variables such as marital status, testing for spouses and HIV status of spouses at ICTCs and missing information on CD4 cell counts and family members at

ART centers. This impedes monitoring and programmatic evaluation. Closer monitoring of data quality is required and monitoring systems need strengthening. Further, on some variables, coding categories differed between ICTC and ART centers records preventing comparisons. Harmonisation of data collection at both points may be considered. Lastly, clients testing HIV-positive at ICTCs and clients registering at ART centers are presently not linked in any way apart from the date of HIV test and address of the ICTC; ART centers do not record PID numbers from ICTCs. This link would provide a measure of the proportion of HIV-positive clients from ICTCs who register at ART centers.

7.0 Cohort Study

7.1 Methods

Study methods are described below.

7.2 Study design

A prospective observational cohort study design was used. Clients testing HIV-positive at government ICTCs were recruited into the study and followed till they registered at ART centers in a two-month time frame.

All newly diagnosed HIV-positive people from selected ICTCs were invited to participate in the research study. Willing participants were interviewed immediately after their post-test counselling session. Participants were then followed and interviewed a second time when they registered at the referred ARTCs. Refusals were carefully documented.

Clients who did not register at ARTCs within two months after their HIV test and first interview at the ICTC were contacted in the community for an interview to ascertain reasons for not visiting or registering at the ARTC. Clients willing to undertake a face-to-face interview were invited to the ICTC or a place of their choice for the interview. Participants, who were not willing to participate in a face-to-face interview, underwent a telephone interview. Community health workers and PLHA network members working with or and engaged by the ICTCs helped to trace participants in the community. Careful documentation of the number of people contacted, people interviewed face-to-face, people interviewed by telephone and those not found was maintained.

7.3 Study sites

The cohort study was implemented in six states: Andhra Pradesh, Maharashtra, Karnataka, Rajasthan, Uttar Pradesh and Gujarat. In each of the three high HIV prevalence states two districts were included and within each district one ARTC and three high volume feeder ICTCs were included. In each of the three low HIV prevalence states one district with its main ARTC and three high volume ICTCs from outside the district (different districts) were included. Thus a total of 9 ART centers and 27 ICTCs were included in the cohort study.

7.4 Study population and recruitment

Newly diagnosed HIV-positive people undergoing post-test counselling were informed about the study by ICTC counsellors. Willing candidates were then approached by the study interviewer. Interviews were conducted after obtaining written informed consent from each participant. Informed consent was obtained twice; separately for the baseline interview and for the follow-up interview. Inclusion criteria for the study were: a) 18 years or more of age; b) HIV-positive test result; c) willingness to participate, to provide contact information and be contacted in the community; and d) residing at the same address for the past 6 months and not planning to move in the next three months (non-migrant).

Ethical approval for the study was obtained from the Institutional Review Board of the Population Council and from the Technical Resource Group on

Research and Development, NACO and the NACO Ethics Committee for Research at NACO. Data collection instruments and informed consent forms were approved by both bodies.

7.5 Data collection and management

Data collection for the cohort study was done between September 2009 and March 2010. Baseline and follow-up interviews were conducted by trained research interviewers using semi-structured data collection instruments. Baseline interviews were conducted at ICTCs. Follow-up interviews were conducted at ARTCs for participants who registered at the clinic; for others who did not register follow-up interviews were done at mutually convenient locations such as participant's homes, ICTCs where they were tested, or NGO centers providing services for HIV-positive people.

Data collection instruments were transported to the Population Council office in Delhi and data were entered in a database using SPSS version 11.0. Quality checks were implemented to identify and rectify any

discrepancies between the interview schedules and data base. Data was analysed at Population Council, Delhi.

7.6 Limitations and challenges

The research team faced several challenges during the data collection period due to political unrest and natural calamities. In Maharashtra a 5-week strike by ICTC staff in December 2009 impacted the number of tests undertaken and recruitment into the cohort. This was preceded by a month (August 2009) during which there was a shortage of HIV testing kits; kits were available only for emergency cases. During this period no HIV testing or limited testing took place and participants had to make multiple trips to obtain reports and receive referrals. In Andhra Pradesh recruitment went slow as a result of devastating floods in the project area in October 2009 and political disturbances in September 2009 and January 2010. In Gujarat, the ICTC at Palanpur was in the process of starting an ART center as a result of which some clients delayed registration so that they could register at the new ART center.

8.0 Results

8.1 Recruitment and retention of cohort

Between September 1, 2009 and January 7, 2010 a total 1600 people tested positive at the 27 participating ICTCs. Of these 543 HIV-positive people were not included in the study: 79 (4.9%) were children below 18 years of age and therefore ineligible; 191 (11.9%) refused to be interviewed, 194 (12.1%) did not come back to the ICTC to collect their HIV test result; 14 (0.8%) were too sick to be interviewed (seriously ill people/hospital admissions); 63 (3.9%) were not interviewed by study researchers for various reasons (e.g. counsellors did not inform HIV-positive people about the study, HIV-positive

people could not wait for the interviews, strike by clinic staff, etc.); one participant did not complete the interview and one participant was interviewed twice. Thus, a total of 1057 (66%), newly diagnosed HIV-positive people participated in the study as part of the study cohort.

A total of 777 participants (73.5%) from the baseline cohort registered at ARTCs within 2 months and were interviewed at their respective ARTCs. An additional 11 participants were interviewed at ARTCs, however, these 11 participants were not interviewed at baseline for reasons mentioned above and were excluded from the follow-up cohort.

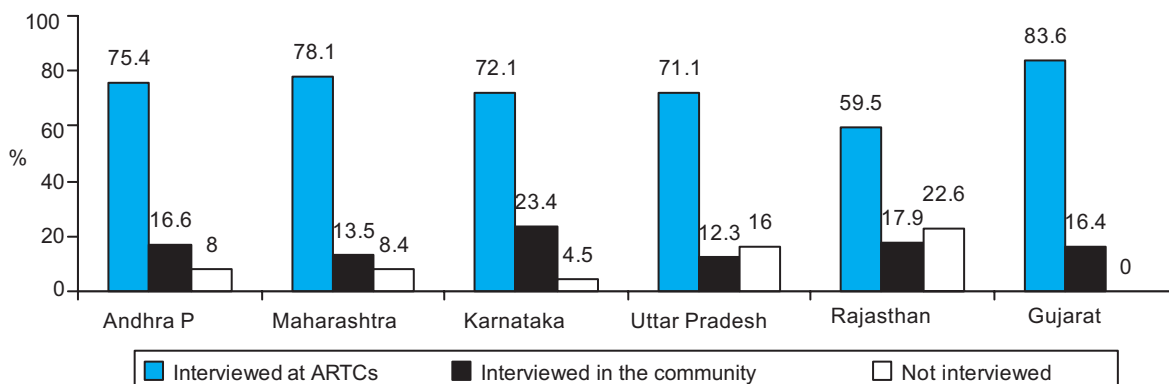
Table 6: Recruitment and retention of the study cohort

Baseline cohort after HIV test (Interviewed at ICTC)	Registered at ARTC <2 months of HIV test (Interviewed at ARTC)	Not registered at ARTC (Interviewed in the community)	Lost to follow-up (Not interviewed)
n=1057	73.5% (n=777)	17.9% (n= 189)	8.6% (n=91)

Of the baseline cohort (n = 1057) 280 participants did not register at their referral ARTC within two months of their HIV test. Study researchers traced these participants in the community with assistance from ICTC

counsellors and PLHIV network members linked to the ICTCs. Locator information was obtained from ICTC registers and study locator forms stored at ICTCs. The research team successfully contacted and interviewed

Figure 14: Retention of cohort by state



189 participants in the community (at their homes, at the ICTC where they were tested or at health centers). Thus a total of 966 participants were interviewed at follow up (777 at ARTCs and 189 in the community).

A total of 91 participants (8.6%) could not be interviewed: 32 died within two months of their HIV test, 14 migrated out of the district, 5 refused to be interviewed, one participant moved to another ARTC, 8 participants were not available for interviews despite accurate locator information (not at home, not free) and 31 participants (3.4%) could not be traced as they provided incorrect contact

addresses and were considered lost to follow-up.

Figure 14 shows the distribution of the proportion of clients who registered at ARTCs within 2 months, those who did not register and were interviewed in the community and those who were not interviewed. Uttar Pradesh and Rajasthan had the highest proportion of participants who were not interviewed. Table 7 shows the distribution of those who were not interviewed at follow-up. Thus the final sample of study participants included for analysis was 1057 participant interviews at baseline and 966 participants with follow-up interviews.

Table 7: Distribution of participants not interviewed at follow-up

	Andhra Pradesh (n=22)	Maharashtra (n=13)	Karnataka (n=15)	Uttar Pradesh (n=22)	Rajasthan (n=16)	Gujarat (n=0)	Total (n=91)
Refused	0	0	1	0	4	0	5
Died	12	2	6	9	3	0	32
Migrated/moved out of district	1	0	0	8	5	0	14
Address incorrect/untraced	7	7	7	4	6	0	31
Registered elsewhere	0	0	0	1	0	0	1
Not available for interview	2	4	1	0	1	0	8

8.2 Profile of study participants

8.2.1 Socio-demographic profile of study participants

Table 8 provides information on the demographic profile of study participants by state. Overall 51.7 per cent (n = 546) of the participants were female. The gender distribution varied across states. In Gujarat and Rajasthan women constituted a smaller majority at 34.3 per cent and 40.5 per cent respectively. Maharashtra had the highest proportion of women participants at 60.6 per cent.

The mean age for all clients was 34.7 years (SD 8.9) and the median age 35 years (IQR: 29, 40). Males were marginally older than female clients. The mean age for males was 36 years, SD 8.9 and females was 33.4 years, SD 8.7 ($p < 0.001$ T test). Age ranged between 18 to 70 years for both males and females. More than a third (38.8%) of the participants were under 30 years of age; in Karnataka nearly half were under 30 years. A tenth of the clients were over 45 years of age (Table 8). Interestingly, 14 participants were over 60 years of age.

Across all states the majority of clients were married (65.3%). Rajasthan had the highest proportion of

married participants at 77.4 per cent (Table 8). Over a fifth of clients reported being widowed (21.7%). Men were more likely to be married compared to female participants (m: 80% vs. f: 51.5%; $p < 0.001$). More female participants reported being widowed compared to male participants (f: 34.8% vs. m: 7.6%; $p < 0.001$). Among married participants, 44 per cent of the participants had spouses who had not yet tested for HIV (m: 48.2% vs. f: 37.3%). Of those tested, women were more likely to report a HIV-positive spouse (f: 49.8% vs. m: 27.8%; $p < 0.001$). Death of a spouse due to HIV was reported by 58.6 per cent of all widowed participants; female participants were more likely to report death of the spouse due to HIV (f: 64.6% vs. m: 30.8%; $p < 0.001$).

Overall, 56.2 per cent of participants across all states were illiterate, 15 per cent had a primary education and 28 per cent had secondary or higher education. Maharashtra had the highest proportion of participants with secondary or higher education (52.9%) while Karnataka had the highest proportion of illiterate participants.

The majority of participants were Hindu (Table 8). Almost two-thirds of all participants lived with their spouse and/or children (65.9%; $n = 695$) and their extended family (23.7 %; $n = 250$). Almost a tenth lived alone (9.9%; $n = 104$) and less than one per cent shared living quarters with room-mates or friends or co-workers [data not shown].

Table 8: Socio-demographic profile of study participants by state

		Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=337)	Uttar Pradesh % (n=138)	Rajasthan % (n=84)	Gujarat % (n=67)	Total % (n=1057)
Gender	Males	49.6(137)	39.4(61)	45.1(152)	48.6(67)	59.5(50)	65.7(44)	48.3(511)
	Females	50.4(139)	60.6(94)	54.9(185)	51.4(71)	40.5(34)	34.3(23)	51.7(546)
Age	≤30 yrs	40.2(111)	27.7(43)	48.1(162)	29.7(41)	32.1(27)	38.9(26)	38.8(410)
	31-45 yrs	48.2(133)	60.0(93)	43.0(145)	64.5(89)	54.8(46)	50.7(34)	51.1(540)
	≥46 yrs	11.6(32)	12.3(19)	8.9(30)	5.8(8)	13.1(11)	10.4(7)	10.1(107)
Marital status								
	Currently married	62.7(173)	60.6(94)	66.5(224)	66.7(92)	77.4(65)	62.7(42)	65.3(690)
Living together, not married		1.8(5)	0.6(1)	1.7(6)	0.7(1)	0.0(0)	0.0(0)	1.2(13)
	Single	4.3(12)	8.4(13)	9.5(32)	0.7(1)	4.7(4)	14.9(10)	6.8(72)
	Divorced/separated	8.7(24)	8.4(13)	3.3(11)	0.7(1)	1.2(1)	4.5(3)	5.0(53)
	Widowed	22.5(62)	22(34)	19.0(64)	31.2(43)	16.7(14)	17.9(12)	21.7(229)
Education	Illiterate	55.1(152)	27.1(42)	75.7(255)	52.2(72)	53.5(45)	41.8(28)	56.2(594)
	Primary	19.2(53)	20.0(31)	9.5(32)	14.5(20)	15.5(13)	20.9(14)	15.4(163)
	Secondary or higher	25.7(71)	52.9(82)	14.8(50)	33.3(46)	31.0(26)	37.3(25)	28.4(300)
Religion	Hindu	72.5(200)	90.3(140)	96.1(324)	99.3(137)	91.7(77)	91.0(61)	88.8(939)
	Muslim	2.5(7)	4.5(7)	3.6(12)	0.7(1)	7.1(6)	7.5(5)	3.6(38)
	Christians	25.0(69)	0.0(0)	0.0(0)	0.0(0)	0.0(0)	1.5(1)	6.6(70)
	Other	0.0(0)	5.2(8)	0.3(1)	0.0(0)	1.2(1)	0.0(0)	1.0(10)

8.2.2 Employment and income

Across all states more than three-fourths (78.8%, n = 833) of participants were employed. However, employment status varied across states (Table 9). Andhra Pradesh had the highest proportion of unemployed participants (32.2%). Overall men were more likely to be employed compared to female participants (m: 87.3% vs. f: 70.9%; $p < 0.001$). The main reason provided for not working was: (i) being too sick: 39.5 per cent; (ii) not wanting to work: 29 per cent; (iii) never worked: 21.8 per cent; (iv) lost job due to HIV: 1 per cent; and (v) other reasons: 8.6 per cent. More female participants reported never having worked (f: 28.2% vs. m: 6.3%) and not wanting to work (f: 38.4% vs. m: 6.2%); while more

male participants reported not working due to illness (m: 79.7% vs. f: 23.1%).

Two-thirds (68%) of employed participants were working as agricultural or other manual labour. Three-quarters of the participants were working in their residential villages (Table 9). Uttar Pradesh and Rajasthan had the highest proportion of employed participants who worked outside their residential district (40% and 28% respectively). The study participant was the main earning member for half the families (52%); of those male participants were the main earning member in most households (69%). Self-reported median household income for all states was Rs 2000 (IQR: 1350-3000); there were no significant differences between states.

Table 9: Employment and income profile of study participants

	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=337)	Uttar Pradesh % (n=138)	Rajasthan % (n=84)	Gujarat % (n=67)	Total % (n=1057)
Employment							
Employed	67.8 (187)	82.6 (128)	84.6(285)	84.8 (117)	73.8 (62)	80.6 (54)	78.8 (833)
Unemployed	32.2 (89)	17.4 (27)	15.4 (52)	15.2 (21)	26.2 (22)	19.4 (13)	21.2 (224)
Location of workplace	(n=173)	(n=127)	(n=282)	(n=684)	(n=575)	(n=547)	(n=771)¹
Same village	63.4 (116)	82.7 (105)	89.4 (252)	4.1 (30)	4.4 (31)	9.6 (43)	74.8 (577)
Within district	26.2 (48)	12.6 (16)	7.8 (22)	16.2 (11)	17.5 (10)	13.0 (7)	14.8 (114)
Outside district	10.4 (9)	4.7 (6)	2.8 (8)	39.7 (27)	28.1(16)	7.4 (4)	10.4 (80)
Main earning member	(n=275)	(n=155)	(n=336)	(n=137)	(n=84)	(n=67)	(n=1057)²
Self	55.6 (153)	60.0 (93)	43.2 (145)	45.3(62)	60.7(51)	65.7(44)	51.9(548)
Males	74.6 (114)	52.6 (49)	61.3 (89)	79.0 (49)	80.3 (41)	81.8 (36)	68.9 (378)
Females	25.4 (39)	47.4 (44)	38.7 (56)	21.0 (13)	19.7 (10)	18.2 (8)	31.1 (170)
Spouse	24.8(68)	22.6 (35)	35.4 (119)	21.9(30)	29.8 (25)	20.8 (14)	27.6 (291)
Parents	7.6 (21)	6.5 (10)	9.8 (33)	16.8 (23)	3.6 (3)	9.0 (6)	9.2 (96)
Siblings	1.5 (4)	3.9 (6)	6.3 (21)	3.6 (5)	1.2 (1)	–	3.5 (37)
Others	10.5 (29)	7.0 (11)	5.3 (18)	12.4 (17)	4.7(4)	4.5 (3)	7.8 (82)
Household monthly income	(n=275)	(n=155)	(n=322)	(n=138)	(n=84)	(n=67)	(n=1040)²
Median (IQR)	Rs. 3000 (2000-4000)	Rs. 2500 (1500-4000)	Rs. 1500 (1000-3000)	Rs. 1500 (1000-3000)	Rs. 3000 (2000-4000)	Rs. 2500 (1500-3000)	Rs 2000 (1350-3000)

¹ of those employed

² denominators vary due to missing information

8.2.3 Poverty

The Quick Poverty Score (QPS) India was used to assess the economic status of study participants. The QPS is a simple, easy-to-use tool that health service programs can use to assess the prevalence of poverty among their clients. The QPS provides a snapshot of uptake of program services by those living below the national poverty line and below US \$1 per day. The index utilizes 10 questions on housing conditions,

household assets and household amenities to form a score that is used to provide the distribution of the study population against probability scores of falling below the national poverty line and below US \$1/day. Questions are listed in Annex 1. Data for the QPS was collected only at the follow-up interview and is available only for participants who were interviewed at ART centers or in the community (n = 966).

Table 10: Quick Poverty Score card for study participants

National poverty likelihoods (%)	Likelihood of falling below US \$1/day (%)	Andhra Pradesh % (n=254)	Maharashtra % (n=142)	Karnataka % (n=322)	Uttar Pradesh % (n=116)	Rajasthan % (n=65)	Gujarat % (n=65)	Total % (n=964) ¹
National 62.4	81.9	–	–	–	–	–	–	–
National 43.2	63.1	0.4 (1)	0.7 (1)	5.2 (16)	34.8 (32)	2.5 (1)	3.8 (2)	6.1 (53)
National 24.4	44.1	6.9 (16)	3.6 (5)	16.9 (52)	25.0 (23)	22.5 (9)	3.8 (2)	12.4 (107)
National 16.8	26.3	14.3 (33)	15.9 (22)	26.0 (80)	21.7 (20)	17.5 (7)	11.3 (6)	19.5 (168)
National 7.8	11.2	25.1 (58)	18.1 (25)	25.3 (78)	10.9 (10)	27.5(11)	18.9(10)	22.3 (192)
National 5.4	4.1	20.8 (48)	17.4 (24)	15.9 (49)	7.6 (7)	20.0 (8)	30.2(16)	17.6 (152)
National 4.9	2.1	16.9 (39)	23.2 (32)	6.8 (21)	–	2.5 (1)	5.7 (3)	11.1 (96)
National 1.6	0.7	10.8 (25)	14.5 (20)	2.9 (9)	–	–	17.0 (9)	7.3 (63)
National 0.9	0.1	3.5 (8)	5.1 (7)	1.0 (3)	–	5.0 (2)	9.4 (5)	2.9 (25)
National 0.0	0.0	1.3 (3)	1.4 (2)	–	–	2.5 (1)	–	0.7 (6)

Note: Column 1 and 2 refer to the Quick Poverty Score for India. See reference for details on calculation.

Table 10 provides the distribution of the scores by state. Overall 38 per cent of the participants fell into the categories with higher probability of falling Below Poverty Line (BPL): 6 per cent with 43.2 per cent likelihood of being BPL (63.1% likelihood of being < \$1/day), 12.4 per cent with 24.4 per cent likelihood of being BPL (44.1% likelihood of being < \$1/day)

and 19.5 per cent with 16.8 per cent likelihood of being BPL (26.3% likelihood of being < \$1/day). Twenty-two per cent of all participants belonged to categories with less than 5 per cent probability of being BPL (last four categories).

In Uttar Pradesh, participants were distributed in categories with higher probability of being BPL;

34.8 per cent of the participants were placed in the category with 43.2 per cent likelihood of being BPL (63.1% likelihood of being < \$1/day). By contrast in Maharashtra and Andhra Pradesh the distribution edged toward lower likelihood of being BPL with 0.7 per cent per cent and 0.4 per cent respectively with 43.2 per cent likelihood of being BPL.

8.3 HIV testing

8.3.1 Referrals

During their interviews at the ICTC, participants were asked about how they had been referred. The majority (41%) had been referred from government sector

facilities. These included referrals made by Auxiliary Nurse and Midwives (ANMs), Accredited Social Health Activists (ASHAs) and Anganwadi workers (5.9%; n = 62). Self referrals constituted almost a fifth of the referrals (19%), largely taking place in the low HIV prevalence states (Table 11). Referrals from the private sector were highest in UP, Gujarat and Andhra Pradesh. In Karnataka more than half of the referrals and in Rajasthan more than two-thirds of the referrals were from government facilities. Almost a tenth (11.5%) of the participants were referred to the ICTC by family members, relatives and friends; the highest proportion in Andhra Pradesh.

Table 11: Participant referral to ICTCs by state

	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=336)	Uttar Pradesh % (n=138)	Rajasthan % (n=84)	Gujarat % (n=67)	Total % (n=1056)
Government sector	31.9(88)	40.7(63)	50.8(171)	23.9(33)	66.7(56)	31.4(21)	40.9(432)
Private sector	23.9(66)	18.7(29)	8.9(30)	23.9(33)	2.4(2)	26.8(18)	16.9(178)
Self referral	16.3(45)	11.0(17)	22.6(76)	20.3(28)	21.4(18)	22.4(15)	18.8(199)
Relatives and friends	19.2(53)	14.8(23)	5.7(19)	12.3(17)	2.4(2)	10.4(7)	11.5(121)
NGO	8.7(24)	14.8(23)	12.0(40)	19.6(27)	7.1(6)	9.0(6)	11.9(126)

Note: Private sector includes private doctors, RMP, hospitals, laboratories. Government sector includes government hospitals, PHC, CHCs, TB program.

8.3.2 Reasons for undertaking HIV test

Participants were asked about their reason(s) for seeking a HIV test at the ICTC. Multiple responses were allowed (Table 12). The most frequently cited reason for seeking a HIV test across all states was frequent illness (68%). Almost a fifth said they requested a HIV test because of their own risky

sexual behaviour while, a fifth requested it after their spouse or partner tested HIV-positive, and just over a tenth did so after the death of their spouse or intimate partner. More female participants reported undertaking a test after the death of a spouse than male participants (f: 20.9% vs. m: 2.2 %; $p < 0.001$). Interestingly, just over a fifth of the participants also

reported undertaking HIV test on their partner's request or because of their partner's high risk behaviour. More female participants reported testing for HIV due to their partner's high risk behaviour than males (m: 17.4% vs. f: 2.4 %; $p < 0.001$). Overall 13.4 per cent of participants reported testing at the ICTC to confirm a previous positive result.

Number of HIV tests

Although two-thirds of the participants reported only one HIV test including the current test (67.8 %; $n = 712$),

multiple testing was commonly reported. Overall more than a quarter (26.5%; $n = 278$) reported two HIV tests, 4.3 per cent ($n = 45$) reported three tests and 1.6 per cent ($n = 16$) reported four or more tests. Figure 15 shows the distribution by state. Around a third of the participants in UP, Gujarat, Maharashtra and Andhra had come in for second HIV tests.

Among those who had two or more tests, the median duration of time since the first HIV test was 6.5 months (IQR: 2, 24). Significantly more men reported multiple tests than female participants. Nearly

Table 12: Reasons for seeking HIV testing at ICTCs

	Andhra Pradesh % (n=276)	Maharashtra % (n=141) ⁵	Karnataka % (n=336)	Uttar Pradesh % (n=138)	Rajasthan % (n=84)	Gujarat % (n=67)	Total ¹ % (n=1042)
Frequent illness	73.2(202)	57.4(89)	75.9(255)	68.8(95)	54.8(46)	52.2(35)	68.4(722)
Partner HIV-positive	21.4(59)	23.2(36)	13.7(46)	20.3(28)	27.4(23)	19.4(13)	20.0(211)
Wanted a second opinion	20.7(57)	18.1(28)	8.0(27)	2.9(4)	10.7(9)	23.9(16)	13.4(141)
Own risky behaviour/ unprotected sex	13.8(38)	24.5(38)	27.4(92)	3.6(5)	21.4(18)	22.4(15)	19.7(206)
Partner's behaviour/request	18.1(50)	33.9(37)	27.4(92)	10.2(14)	26.2(22)	9.0(6)	21.2(221)
Death of spouse/partner	11.3(113)	14.8(23)	9.8(330)	18.1(25)	13.1(11)	3.0(2)	11.8(125)
Family member HIV-positive/death ²	3.6(10)	14.9(23)	2.7(9)	2.1(3)	4.8(4)	1.5(1)	4.7(50)
Exposure to blood ³	9.0(25)	22.6(35)	2.7(9)	0.7(1)	2.4(2)	12.0(8)	7.6(80)
Others ⁴	29.3(81)	21.3(30)	9.5(32)	22.5(31)	11.9(10)	37.3(25)	20.1(209)

¹ Multiple responses possible; total may not add up to 100%

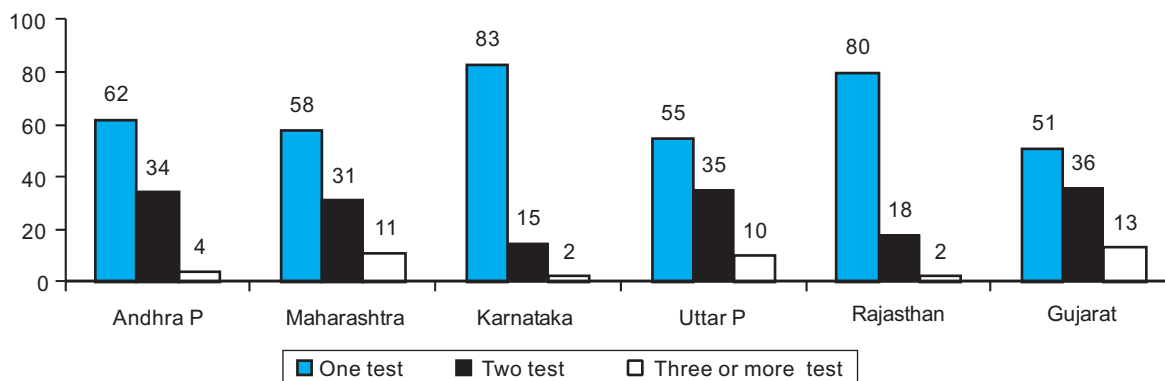
² Includes death of a child

³ Includes work related exposure, blood transfusion, fear of unsafe injections and injecting drug use

⁴ Includes pregnancy, accidents/injuries, medical/dental checkups, blood donation, because of access to free ART and

⁵ 15 cases with missing information from Maharashtra

Figure 15: Number of HIV tests undertaken by study participants by state (including current HIV test)



a third of male participants reported having undertaken two HIV tests: (m: 30.7% vs. f: 22.5%; $p < 0.001$) and less than a tenth reported three or more tests (m: 7.5% vs. f: 4.2%; $p < 0.001$). Among those who came in for a repeat HIV test, 75.8 per cent of participants reported that their first HIV test was done in the private sector. In the high HIV prevalence states the proportion of participants testing in the private sector was higher (Andhra Pradesh: 74.8%; Maharashtra: 83.1%; Karnataka: 86.5%) than in the low HIV prevalence states (Rajasthan: 41.2% and Gujarat: 60.6%) with the exception of Uttar Pradesh: 77.6 per cent.

8.3.3 HIV testing and counselling services

Number of visits made to the ICTC

The majority of participants reported a single visit to the ICTC for their HIV test (92%, $n = 974$). Around

4 per cent ($n = 42$) participants reported a second visit and 2 per cent ($n = 20$) reported three or more visits. The main reasons for repeat visits were the absence of the counsellor ($n = 23$) mostly reported from Andhra Pradesh ($n = 15$); lack of testing kits ($n = 16$; almost all reported from Maharashtra); reaching the center after working hours ($n = 8$); and non-availability of the lab technician ($n = 3$). Twelve participants provided no reason ($n = 12$).

Although attempts are made to provide HIV results the same day in the evening at most ICTCs, more than a tenth of the participants reported having to undertake multiple visits for collecting test results (13.2%; $n = 138$). Thirty per cent of participants in Andhra Pradesh ($n = 39$), 16.1 per cent in Maharashtra and 9.8 per cent in UP reported multiple visits to collect their test results. The main reasons cited for these visits were the absence of the counsellor (13.2%; $n = 16$); test results not ready/

available (26.1%; n = 36); counsellors asking HIV-positive clients to first visit the TB department for a chest x-ray (28.2%; n = 39); reaching the clinic after working hours (14.9%; n = 18); having to meet the doctor (3.3%; n = 4) and other reasons (5.7%; n = 8). In Andhra Pradesh counsellors asked participants to visit the TB department and obtain chest x-rays prior to releasing their HIV test result.

Waiting time at ICTCs

Overall, the majority of participants (84.8%) waited less than 30 minutes to see the counsellor. Over 90 per cent of participants were seen within 30 minutes in Gujarat (95.5%), Karnataka (94.6%), Rajasthan (93.9%), and Uttar Pradesh (93.3%). The proportion of participants seen within 30 minutes was lower in Andhra Pradesh (74.3%) and lowest in Maharashtra (65.3%). Counsellors spent a median of 10 minutes (IQR: 5, 15) with participants to provide pre-test counselling and a median of 20 minutes (IQR: 15, 30) for post-test counselling. Counselling sessions went on for up to an hour in a few cases.

Pre-test Counselling

Participants were asked several questions to assess the quality of the counselling they received at ICTCs. These interviews were conducted immediately after the post-test counselling after the participants received their HIV-positive results; therefore, recall is expected

to be good. Table 13 shows the distribution of participant responses by state. The quality of counselling was variable across the states.

During pre-test counselling only 70 per cent of participants were told about how the HIV test works and only 36 per cent of participants were told about the window period (Table 13). Routes of HIV transmission were discussed with 80 per cent of the participants and prevention of transmission with 78 per cent of participants. Only 62 per cent participants reported that they were able to ask questions. Confidentiality of the results was mentioned to less than three-fourths of participants.

Post-test counselling

During post-test counselling the majority of participants were told about the meaning of the test result (Table 14). However, testing of sexual partners was mentioned to 72 per cent of participants and testing of children to 67 per cent of participants. Although ways to prevent HIV were discussed with 88 per cent of participants, condom demonstration was reported by only just over half the participants.

With regard to ART services the majority of participants received an explanation on antiretroviral therapy (86.5%), were provided referral slips for ART centers (86.5%) and given information on the availability of free ART (91.5%). Directions to the nearest ART center were provided to around three-fourths of

Table 13: Topics covered by counsellors during pre-test counselling

	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=329)	Uttar Pradesh % (n=135)	Rajasthan % (n=83)	Gujarat % (n=67)	Total % (n=1045)
Explain how HIV is transmitted	60.5(167)	84.5(131)	94.5(311)	91.9(124)	54.2(45)	92.5(62)	80.4(840)
Explain client's right to accept or refuse HIV test	67.8(187)	67.1(104)	96.7(318)	51.9(70)	43.4(36)	22.4(15)	69.9(730)
Tell you that your results would not be shared	54.0(149)	64.5(100)	97.0(319)	63.7(86)	56.6(47)	89.6(60)	72.8(761)
Explain how the test works	48.2(133)	65.8(102)	85.1(280)	90.4(122)	65.1(54)	59.7(40)	70.0(731)
Explain about window period	30.1(83)	54.2(84)	24.0(79)	40.0(54)	42.2(35)	61.2(41)	36.0(376)
Give you advice on preventing the spread of HIV	55.4(153)	86.5(134)	93.6(308)	88.9(120)	54.2(45)	94.0(63)	78.8(823)
Give you time to ask questions	37.7(104)	63.2(98)	93.6(308)	37.8(51)	54.2(45)	67.2(45)	62.3(651)

Note: All respondents were asked all options.

participants. CD4 testing to determine eligibility for initiating treatment was discussed with just over three-fourths of participants (Table 14).

Travel concessions for PLHIV are available in some states, especially in the three low prevalence states; the availability of travel concessions was mentioned to just over a third of participants overall. In Rajasthan and Karnataka over 60 per cent of participants were informed of the availability of travel concessions (Table 14). All ART centers require proof of identity and contact address for

participants prior to registration for treatment.

Counsellors are required to inform clients to carry these documents with them to the ART center, in order to avoid multiple trips to complete the registration process. Only 68.4 per cent of participants were provided this information.

Most ICTCs are now linked to local community PLHIV networks and have outreach workers. However, less than a third of the participants (30.2%) were introduced to a member of a PLHIV network (Table 14).

Table 14: Topics covered by counsellors during post-test counselling

	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=329)	Uttar Pradesh % (n=135)	Rajasthan % (n=88)	Gujarat % (n=67)	Total % (n=1044)
Explain the meaning of the test result	98.9(273)	94.2(146)	97.9(322)	94.0(126)	94.0(126)	92.5(62)	96.5(1007)
Inform about availability of free ART treatment	89.1(246)	95.5(148)	97.6(321)	82.8(111)	79.5(66)	94.0(63)	91.5(955)
Discuss ARV treatment	90.6(250)	77.4(120)	97.6(321)	75.4(101)	67.5(56)	82.1(55)	86.5(903)
Discuss the prevention of HIV transmission	88.0(243)	85.8(133)	94.8(312)	89.6(120)	61.4(51)	95.5(64)	88.4(923)
Provide referral slip for the ARTC	74.6(206)	67.7(105)	98.2(323)	94.8(127)	95.2(79)	94.0(63)	86.5(903)
Discuss CD4 test	82.6(228)	69.0(107)	97.0(319)	61.2(82)	65.1(54)	56.7(38)	79.3(828)
Ask to revisit ICTC after registration at ARTC	67.4(186)	69.0(107)	97.6(321)	44.0(59)	69.9(58)	89.6(60)	75.8(791)
Provide directions to the ARTC	56.2(155)	77.4(120)	79.3(261)	76.9(103)	74.7(62)	95.5(64)	73.3(765)
Advice on disclosure of HIV status	65.9(182)	59.1(91)	96.4(317)	79.7(106)	39.8(33)	53.7(36)	73.4(765)
Recommend that sexual partner(s) be tested HIV	68.8(190)	61.3(95)	72.0(237)	82.8(111)	77.1(64)	80.6(54)	71.9(751)
Recommend that children should be tested	44.2(122)	65.2(101)	74.5(245)	91.8(123)	80.7(67)	68.7(46)	67.4(704)
Inform that proof of identity required at ARTC	74.6(206)	27.1(42)	96.7(318)	51.5(69)	34.9(29)	74.6(50)	68.4(714)
Condom demonstration	38.0(105)	32.9(51)	80.5(265)	22.4(30)	54.2(45)	83.6(56)	52.9(552)
Inform about travel concession to reach ARTC	16.3(45)	14.8(23)	63.5(209)	9.0(12)	60.2(50)	26.9(18)	34.2(357)
Introduce to PLHA network	9.1(25)	15.5(24)	38.9(128)	64.9(87)	26.5(22)	43.3(29)	30.2(315)

Counselling guidelines require counselling to be done in a private space for reasons of confidentiality. Over three-fourths (77.4%) of participants reported that they had been counselled in a room with the door closed (Table 15). Counselling guidelines mandate that counselling be done in a place where no other person can overhear the discussion and no other person can see or observe the person being counselled. Although

only 40.7 per cent reported that counselling was done out of earshot of others (auditory privacy), and 30.5 per cent reported that counselling was done where the participant could not be seen by others (visual privacy), the vast majority of participants perceived that they had been counselled in private, as reported by 91.6 per cent of participants.

Table 15: Counselling services: Spatial arrangements

Counselling Room	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=329)	Uttar Pradesh % (n=134)	Rajasthan % (n=82)	Gujarat % (n=67)	Total % (n=1043)
Room with closed door	95.3(263)	76.8(119)	90.9(299)	42.5(57)	22.0(18)	77.6(52)	77.5(808)
Cabin room separated by cloth or wooden wall	29.3(81)	45.8(71)	69.9(230)	47.0(63)	32.9(27)	83.6(56)	50.6(528)
Auditory Privacy ¹	87.3(241)	38.7(60)	5.5(18)	26.9(36)	24.4(20)	70.1(47)	40.5(422)
Visual privacy ²	29.0(80)	35.4(55)	12.5(41)	31.3(42)	61.2(51)	74.6(50)	30.6(319)
Client perception that they were counselled in privacy ³	91.3(252)	87.7(136)	96.4(317)	88.8(119)	84.1(69)	92.5(62)	91.6(955)
No interruption during counselling	75.4(208)	74.2(115)	98.2(323)	45.5(61)	46.3(38)	73.1(49)	76.1(794)

¹Auditory privacy - counselling conducted in a space where others could not hear the discussion

² Visual privacy – client counselled in a space where others could not see the client nor the counsellor

³ Participant felt comfortable that they s/he had been counselled privately

High levels of satisfaction with counselling services were reported by the majority (86.8%) of participants (Table 16). Counsellors appeared to be sympathetic (88.3%) and attentive (94.1%). Overall

15.9 per cent participants felt that counsellors were in hurry and rushed through the session and only two-thirds of the participants felt that counsellors encouraged or allowed participants to ask questions.

Table 16: Counselling services: Counsellor's performance

	Andhra Pradesh % (n=276)	Maharashtra % (n=155)	Karnataka % (n=328)	Uttar Pradesh % (n=132)	Rajasthan % (n=82)	Gujarat % (n=67)	Total % (n=1040)
Found counsellor attentive	95.7(264)	93.5(145)	97.3(319)	56.1(74)	90.2(74)	91.0(61)	94.1(979)
Found counsellor in hurry to end session	18.1(50)	21.3(33)	7.3(24)	31.8(42)	15.8(13)	5.9(4)	16.0(166)
Counsellor encouraged questions	15.5(43)	60.0(93)	90.4(297)	29.5(39)	52.4(43)	61.2(41)	67.9(706)
Counsellor sympathetic and friendly	78.3(216)	80.0(124)	98.2(322)	89.4(118)	89.0(73)	97.0(65)	88.3(918)
Found counsellor critical of past risk behaviours	8.3(23)	1.9(3)	3.4(11)	6.0(8)	39.0(32)	7.5(5)	7.9(82)
Satisfied/very satisfied with counselling	81.8(226)	90.3(140)	89.3(293)	84.8(112)	84.1(69)	94.0(63)	86.8(903)

8.4 Disclosure of HIV status

It is well recognised that HIV is a highly stigmatised disease and HIV-positive people are careful about disclosing their HIV status freely. Participants were asked whether they had disclosed their HIV status to anyone at their follow-up interview. Therefore data is only available for clients who were interviewed at ART centers (n = 777) and those interviewed in the community (n = 189).

Overall, nearly 70 per cent of participants had disclosed their HIV status to at least one person

(Table 17). Disclosure rates were lower among participants from low prevalence states highlighting to some extent the anxiety and fear in these communities. The lowest disclosure rates were reported from UP (47%) and Rajasthan (51%). Even in high prevalence states only around three-fourths of participants had disclosed their HIV status to someone. Disclosure was significantly lower among participants who were interviewed in the community compared to those who had registered at ART centers (54.8% vs. 72.9%; $p < 0.001$).

Table 17: Disclosure of HIV status

	Andhra Pradesh % (n=254)	Maharashtra % (n=142)	Karnataka % (n=320)	Uttar Pradesh % (n=116)	Rajasthan % (n=65)	Gujarat % (n=65)	Total % (n=962)
Disclosed to any one	77.6(197)	71.8(102)	74.1(237)	46.6(54)	50.8(33)	67.7(44)	69.3(667)
Disclosed to spouse/ sexual partner ^{1,2}	52.4(133)	60.8(62)	63.7(151)	72.2(39)	72.7(24)	63.6(28)	65.5(437)
Disclosed to a parent ^{1,2}	39.1(77)	30.4 (31)	43.0 (102)	61.1 (33)	45.5 (15)	6.8 (3)	39.1(261)
Disclosed to a sibling ^{1,2}	28.4 (56)	16.7 (17)	58.6 (139)	68.5 (37)	63.6 (21)	31.8 (14)	42.86(284)
Disclosed to other relative ^{1,2}	29.0 (57)	35.3 (36)	8.9 (21)	24.1 (13)	21.2 (7)	75.0 (33)	25.0 (167)
Disclosed to a friend ^{1,2}	10.7 (21)	13.7 (14)	6.4 (15)	14.8 (8)	12.1 (4)	27.3 (12)	11.1 (74)

¹ Among those who had disclosed to someone

² Multiple responses allowed

Disclosure to sexual partners/spouse was low even among those who disclosed their HIV status to someone. Only 65 per cent had disclosed their HIV status to their spouse (Table 17). Interestingly, highest disclosure to sexual partners/spouses was reported in UP and Rajasthan where overall disclosure was the lowest.

Participants who had disclosed their status were asked if they regretted their decision to disclose. Overall only 42 per cent of all participants did not regret their decision to disclose. Nearly a fifth (18%) of all participants reported that they were discriminated by their friends, while 8.5 per cent were discriminated by their extended family and several by their immediate family after disclosing their HIV status.

A young HIV-positive male patient from Varanasi told interviewers:

“I was working in Bombay. I was tested because I was very ill and was not getting well. So my friend told me to get tested for HIV since Bombay is full of HIV. So in Bombay people knew my status. They stopped

talking to me. When I came to Varanasi I did not tell anyone. Here nobody knows other than my family. My family is very supportive.”

A young female participant from Rajasthan narrated:

“My husband was very ill and was tested for HIV. My brother-in-law got to know about my husband’s status. Everyone’s behaviour towards me changed. I was thrown out along with my kids after his death. I was blamed for my husband’s illness. I had never worked and now I did not know how to fend for my children. A widow’s life is hard; there is no support from family even.”

Another young widow from Rajasthan narrated:

“My husband did not tell me about his HIV status, while my sisters-in-law and father-in-law knew he was ill because of HIV. I did not get any support from in-laws or my own family after husband’s death. By myself I went for tests. I was very ill and admitted in hospital and a friend helped me. I was referred from Bhilwara to Jaipur since I was HIV-positive”.

Table 18: Reason for regretting disclosure of HIV status¹

Reasons for regretting disclosure	Andhra Pradesh % (n=197)	Maharashtra % (n=102)	Karnataka % (n=237)	Uttar Pradesh % (n=59)	Rajasthan % (n=42)	Gujarat % (n=44)	All % (n=681) ³
No regrets	87.8(173)	65.7(67)	9.7(23)	0	0	54.5(24)	42.1(287)
Friends excluded me	2.5(5)	9.8(10)	25.7(61)	62.7(37)	26.2(11)	11.4(5)	18.9(129)
Family secluded me	5.6(11)	13.7(14)	5.5(13)	8.5(5)	16.7(7)	15.9(7)	8.4(57)
Lost my job	0	2(2)	14.8(35)	1.7(1)	0	15.9(7)	6.6(45)
Had to move residence	0.5(1)	0	2.5(6)	3.4(2)	7.1(3)	0	1.8(12)
Others ²	3.6(7)	8.8(9)	41.8(99)	23.7(14)	50(21)	2.3(1)	22.2(151)

¹ Among those who disclosed

² The major reasons specified under the category 'others' were various experiences of discrimination by the immediate family, spouse or children.

³ Includes 14 additional participants from UP (5) and Rajasthan (9) who had earlier reported not disclosing their HIV status

These three narratives highlight the challenge HIV-positive people face with regard to disclosure of their HIV status to spouses, family and friends. Disclosure at one end could bring support and at the other end discrimination. Counsellors need to be sufficiently skilled to understand the nuances of each HIV-positive person's context in order to guide them on disclosure. Disclosure to spouses, especially wives, is important not only from the point of view of HIV prevention but also to prepare families to cope in case the husband, who is often the breadwinner in these families, passes away.

Once they got to know about their HIV status, the greatest worry for the majority of interviewees was death (53%), not being around to take care of their family (35%) or not being able to earn a living (32%) (Table 19). People worried about not being able to meet medical expenses related to their illness (29%) and about HIV infection in their children (28%). As disclosure to spouses/partners was limited (see above), many clients also worried about their spouses learning of their HIV status.

Table 19: Greatest worry or fear after knowing HIV status¹

Greatest worry	Andhra Pradesh % (n=254)	Maharashtra % (n=142)	Karnataka % (n=317)	Uttar Pradesh % (n=116)	Rajasthan % (n=65)	Gujarat % (n=65)	All % (n=959)
Death	42.9(109)	50.7(72)	58.3(185)	62.9(73)	58.5(38)	43.1(28)	52.7(505)
Not being around to take care of family	44.9(114)	9.2(13)	42.0(133)	44.8(52)	13.8(9)	24.6(16)	35.1(337)
Ability to make money/work	31.5(80)	4.9(7)	45.1(143)	32.8(38)	16.9(11)	47.7(31)	32.3(310)
Medical expenses	22.4(57)	2.1(3)	49.2(156)	27.6(32)	21.5(14)	27.7(18)	29.2(280)
Children getting HIV	15(38)	43.7(62)	34.1(108)	20.7(24)	41.5(27)	21.5(14)	28.5(273)
Spouse getting to know	7.9(20)	27.5(39)	20.2(64)	7.8(9)	23.1(15)	33.8(22)	17.6(169)
No worry	9.8(25)	22.5(32)	11.7(37)	13.8(16)	26.2(17)	1.5(1)	13.3(128)
Others	0.8(2)	2.8(4)	2.8(9)	9.5(11)	10.8(7)	9.2(6)	4.1(39)

¹ Multiple Responses allowed, percentage may not add to a 100

Interviewers asked participants if they knew of other HIV-positive people in their community. The majority (67%) of participants did not know of any other HIV-positive person or household (Table 20).

However, a fifth of all participants knew between one to three households with HIV-positive people. Even in low prevalence states participants knew of households with HIV infected individuals.

Table 20: Number of households in community with HIV-positive member(s) known to study participants

	Andhra Pradesh % (n=254)	Maharashtra % (n=142)	Karnataka % (n=317)	Uttar Pradesh % (n=116)	Rajasthan % (n=65)	Gujarat % (n=65)	All % (n=959)
None	48.4(123)	85.9(122)	68.8(218)	63.8(74)	84.6(55)	78.5(51)	67.0(643)
1-3	39.0(99)	8.5(12)	8.5(27)	32.8(38)	15.4(10)	13.8(9)	20.3(195)
4 or more	12.6(32)	5.6(8)	22.7(72)	3.5(4)	0	7.7(5)	12.7(121)

8.5 HIV-positive participants interviewed at ART Centers

ICTC counsellors routinely refer newly diagnosed HIV-positive people to ART centers with referral slips and directions to register as soon as possible. Follow-up interviews were conducted with study participants as soon as they registered at ART centers. A total of 777 (73.5%) HIV-positive participants interviewed at ICTCs (baseline: n = 1057) reached their referral ART centers within two months of their HIV test at the ICTC. Interviews were conducted in ART centers.

8.5.1 Time taken to reach ART center

The majority (92.6%; 709/766) of the participants had returned to the ICTC and collected their HIV test results within one week; 5.5 per cent (42/766) of participants had collected the result within a month and

the remainder after a month (1.9%, 15/766). Eleven participants had inaccurate dates recorded for the date of collection of result and so were excluded from this analysis; most of these participants had tested in the private sector and were required to undertake a repeat HIV test at a public sector ICTC.

Participants reached ART centers after a median of 7 days (IQR: 3, 18 days) after collecting their HIV test result and post-test counselling at the ICTC. Overall, nearly 60 per cent of participants reported at referral ART centers within a week, and nearly 30 per cent within a month (Table 21). Twenty participants across all states were registered on the basis of HIV test results from private physicians; they were then referred back to a government ICTC for a repeat test before initiating CD4 testing and evaluation of eligibility for ART; these participants had negative time periods and were not included in the table below.

Table 21: Time taken to register at ART center

Time between collecting HIV test and registration at ART Center	Andhra Pradesh % (n=205)	Maharashtra % (n=112)	Karnataka % (n=232)	Uttar Pradesh % (n=92)	Rajasthan % (n=48)	Gujarat % (n=54)	Total % (n=743) ¹
0-7 days	66.3(136)	66.1(74)	66.4(154)	12.0(11)	62.5(30)	72.2(39)	59.8(444)
8-30 days	26.8(55)	23.2(26)	25.9(60)	60.9(56)	29.2(14)	20.4(11)	29.9(222)
31- 60 days	4.4(9)	10.7(12)	6.5(15)	21.7(20)	4.2(2)	7.4(4)	8.3(62)
61 or more days ²	2.4(5)	0	1.3(3)	5.4(5)	4.2(2)	0	2.0(15)

¹ Excludes 20 participants who were registered based on HIV test done in the private sector and were then sent for retesting at government ICTC showing reverse dates. Missing data: 14 participants.

² Longer time period between collecting their test result and coming back for post test counselling; e.g. in cases where family members collected the test result.

Reasons for registering at ART center after 30 days of collecting HIV test result

Participants who registered after a month (30 days) of their HIV test were asked for the reasons for the delay in reaching ARTCs (n = 77). Open ended qualitative responses were collected. Forty-five participants provided reasons; others did not comment. The most commonly cited reasons were: health worker strike (n = 8); being busy with work and family commitments e.g. crop season, death in family etc. (n = 6); financial difficulties to travel long distance to ART center (n = 6) and not having someone to accompany them (n = 5). Other reasons included: repeating HIV test to confirm HIV status (n = 4); feeling well (n = 4); pregnancy or recent delivery (n = 3); family opposition (n = 3); waiting to test spouse and children (n = 2), completing TB treatment (n = 1) or just fear of being diagnosed HIV-positive (n = 1). Support offered by outreach workers was mentioned positively by several participants. Selected quotes are given below:

“My husband wanted to test outside [in private laboratory], he also took me with him when he went for the test but only he underwent the test, only he tested. He made me delay even coming here.” – 18-year-old woman from Gudivada.

“I have agricultural land so for the last 4 or 5 months I was busy with harvesting and I was not able to come to the center, now I am free so I came here now...”
38-year-old man from Bagewadi

“...my husband died from TB. After his death I was very sick, that's why I went to Government hospital...”
“Till today, I did not know about my health problem. Nobody told me what is the problem – the counsellor at that time only said there is a problem in your blood,

that's all. I took my report today, after one and a half months after my blood test. My family members had misconceptions about my illness and so they took me to all the temples and swamiji, they thought it happened by black magic....when counsellor told me about my HIV status I was shocked. 30-year-old woman from Bagewadi who came back to collect her test result and post-test counselling after 18 months.

8.5.2 Health care services accessed

Researchers asked about health care services that participants may have utilised or accessed prior to registering at the ART.

Prior use of ART

About four per cent (n = 31) of participants were receiving ARV medications prior to registering at the ART center (Table 22). More than half of these participants had procured ARVs on advice from private physicians and purchased medications from chemists (18/31); three participants received ART from NGOs and one accessed ART from another government ART center; and seven participants did not provide a response. These participants had been taking ART for a median of 4.5 months (IQR: 2, 12).

Thirty-four participants (4.4%) reported that they were concurrently registered at other facilities for ART services (Table 22). Among these participants, the majority (79.4%, n = 27/34) were registered at other government centers, 44.1 per cent (15/34) were registered with private physicians, and 5.9 per cent (2/34) were registered with NGOs. Multiple responses were permitted on this question; responses show that some participants were accessing services from multiple services providers (eight participants were

accessing services from both government and private providers, while one participant was accessing services from both the private sector and NGO providers).

Three per cent (n = 25) of participants had consulted a private allopathic physician after their

HIV test result. Interestingly, less than one per cent (n = 7) had consulted a traditional practitioner (ayurvedic, unani or vaidh) but 1.4 per cent (n = 11) of participants reported that they were taking traditional medicines.

Table 22: ART health services utilised by clients prior to registration at ART centers

	Andhra Pradesh % (n)	Maharashtra % (n)	Karnataka % (n)	Uttar Pradesh % (n)	Rajasthan % (n)	Gujarat % (n)	Total % (n) ¹
Used ART previously	(n=207) 3.9(8)	(n=121) 2.5(3)	(n=241) 4.6(11)	(n=99) 6.1(6)	(n=50) 0	(n=55) 5.5(3)	(n=773) 4.0(31)
Registered elsewhere for ART	(n=207) 3.4(7)	(n=121) 4.1(5)	(n=242) 5.4(13)	(n=99) 2.0(2)	(n=50) 4.0(2)	(n=56) 8.5(5)	(n=775) 4.4(34)
Consulted private allopathic physician after HIV test at ICTC	(n=206) 8.3(17)	(n=121) 1.7(2)	(n=243) 0.8(2)	(n=98) 0	(n=50) 2.0(1)	(n=56) 5.4(3)	(n=774) 3.2(25)

¹ Denominators vary due to missing information

CD4 tests

The vast majority of participants had undertaken CD4 count tests to assess eligibility for the initiation of ART (96.4 %; 730/757) and of those most of the participants (96.8%) had undertaken CD4 tests at government ART centers. CD4 test results were not available for 49 participants. Overall, 55 per cent of participants had CD4 cell counts less than 250 cells/ml making them eligible to start ART immediately. A higher proportion of participants in low HIV prevalence states

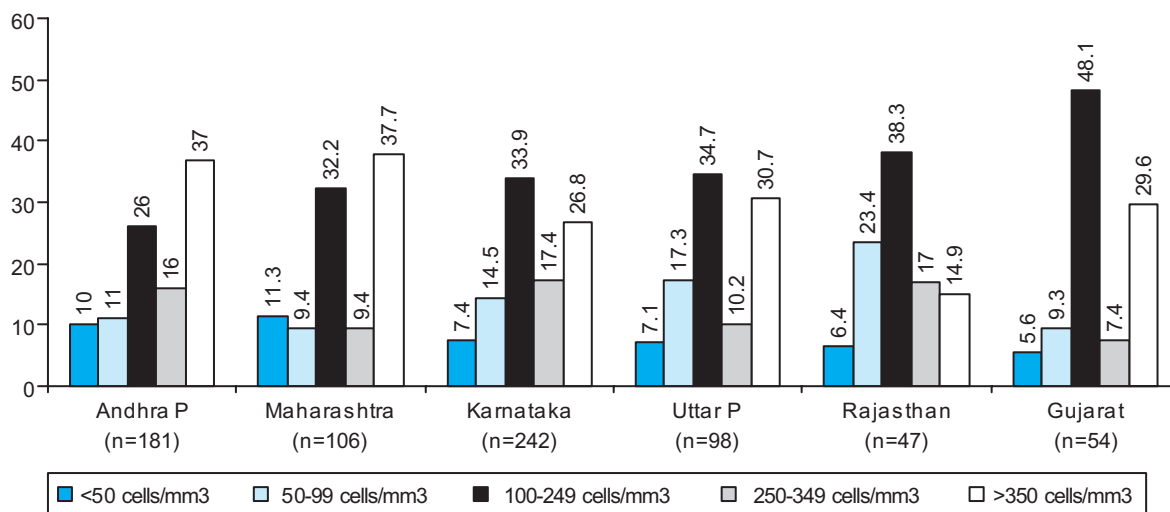
of UP (61%), Rajasthan (68%) and Gujarat (63%) had advanced immune-suppression (< 250 cells/ml), suggesting that people undertook HIV tests when already symptomatic (Figure 16). Of the high prevalence states, Karnataka had a higher proportion of participants with advanced immune-suppression (55%) compared to Andhra Pradesh and Maharashtra. In Andhra Pradesh and Maharashtra, over a third of the participants had cell counts higher than 350 cells/ml.

Table 23: CD4 testing

	Andhra Pradesh % (n=200)	Maharashtra % (n=111)	Karnataka % (n=242)	Uttar Pradesh % (n=99)	Rajasthan % (n=50)	Gujarat % (n=55)	Total % (n=757)
CD4 test done	93.5(187)	97.3(108)	97.5(236)	100(99)	100(50)	90.9(50)	96.4(730)
CD4 test done at government ART center ¹	98.4(184)	91.7(99)	98.9(232)	97.0(96)	98.0(49)	92.0(46)	96.9(706)

¹ Of those who had undertaken a CD4 test

Figure 16: Immune-status of participants who registered at ART centers by state: CD4 cell counts



8.5.3 Access to ART centers

ICTCs are the first point of contact for HIV-positive people, from where they are then referred to ART centers. Therefore, it is important to understand and assess the process of referrals from the ICTC. The large majority of participants (89.7%; n = 680) who registered at ART centers within 2 months had been informed about the availability of free ART at government centers by the counsellors at the ICTC.

Referral slips and directions

ICTC centers are required to provide HIV-positive clients a referral slip that includes key information

on the date of HIV test, contact details and address of ICTC, PID number, and key socio-demographic information of the client: age and gender. Overall 81.7 per cent of participants reported that they had received referral slips by the counsellor at the ICTC. As ART centers are mostly located in district hospitals, clients benefit from directions to these centers. Almost three-fourths (73%) of the participants reported receiving directions to the ART centers. In Andhra Pradesh, however, less than half of the participants received referral slips (45%) and directions to ART centers (40%). (Table 24)

Table 24: Referral slips and directions given to HIV-positive clients at ICTCs

	Andhra Pradesh % (n=208)	Maharashtra % (n=121)	Karnataka % (n=243)	Uttar Pradesh % (n=99)	Rajasthan % (n=50)	Gujarat % (n=56)	Total % (n=777)
Provided referral slip by counsellor at ICTC	45.2(94)	95.0(115)	98.4(239)	82.7(81)	100(50)	100(56)	81.7(635)
Provided directions to ART centers by counsellor at ICTC	40.4(84)	94.2(114)	74.5(181)	93.8(91)	94.0(47)	91.1(51)	73.1(568)

Locating ART centers in the hospital

Finding ART centers within hospitals is often challenging for sick, unaccompanied or low literacy patients. Thus clinics need to be well marked with clear directions for clients to find the center easily. The majority of participants reported that centers were well marked (90%) with clear and visible sign boards (83%) directing patients to the center (Table 23). Difficulty in locating ART centers was reported variably from different states. In Rajasthan, only about a quarter of the participants from Rajasthan felt that the ART center in the SMS Hospital was well marked (26%) with clear signboards (22%) to direct clients; and more

importantly, only half the participants (54%) reported that staff at the main reception/inquiry desk were aware of the location of the center and therefore able to assist. Across all states, the majority of participants felt that other hospital staff were generally helpful in assisting clients to locate the ART center, often enquiring on their behalf or accompanying them. Qualitative responses illustrate the difficulties clients faced, as this 35-year-old woman from Mandapeta, Andhra Pradesh reported:

“Searching for ART center is very difficult in Rajamundry. It is very difficult to reach ART center. Only after consulting many hospital staff, we reached it.”

Table 25: Location of ART center

	Andhra Pradesh % (n=208)	Maharashtra % (n=121)	Karnataka % (n=241)	Uttar Pradesh % (n=98)	Rajasthan % (n=50)	Gujarat % (n=56)	Total % (n=774)
ART Center well marked	88.0(183)	95.0(115)	100(241)	93.9(92)	26.0(13)	100(56)	90.4(700)
Clear and visible signboards with directions to ARTC	86.1(179)	71.9(87)	95.0(229)	86.7(85)	22.0(11)	91.1(51)	82.9(642)
Staff at hospital Inquiry Desk know location of ART center	58.0(120)	67.8(82)	90.9(219)	92.9(91)	54.0(27)	89.3(50)	76.1(589)
Other hospital staff assisted clients to locate the ART center	73.1(152)	78.5(95)	87.6(211)	77.6(76)	76.0(38)	98.2(55)	81.0(627)

People accompanying HIV-positive individuals

HIV is a highly stigmatized disease and PLHIV are careful about disclosing their positive status. At the same time PLHIV may be feeble and ill from advanced HIV disease or illiterate and dependent, and therefore, need help to reach ART centers and navigate hospital departments. Women are particularly vulnerable

as many are not used to travelling alone. Participants were asked who accompanied them to the ART center. Across all sites family members accompanied participants to ART centers (66%). A small number of participants were accompanied by friends (Table 26). Less than fifth of the participants reached ART centers unaccompanied by anyone (16.8%).

“My in-law’s house is very far from Jaipur....as the hospital is far away I cannot go alone, there is no one to accompany me so I have brought my brother...” said this 34-year-old woman from Alwar, Rajasthan.

Another 30-year-old woman from Nandigama, Andhra Pradesh said,

“I am very sick; it has been very difficult for me to come to ART center. My friends accompany me and they give me money also for the travelling....”

In many centers as a part of community engagement PLHIV network members are enlisted to support newly diagnosed HIV-positive people who are willing

to use this assistance. Overall less than a tenth (7.2%) reported that they were accompanied by a PLHIV network member. Those who were accompanied by PLHIV outreach workers appreciated the assistance greatly. Interestingly 40 per cent of the participants from UP reported that they were accompanied by a member of the PLHIV network; this supports anecdotal reports that these networks are very active in UP.

“I was ill when I went to Jaunpur for the test. At the ICTC, PLHIV met me and I came here accompanied by him.....it was very helpful....I had no difficulty in finding the ART center.” 45-year-old man from Jaunpur, UP.

Table 26: Person accompanying the participant to the ART center

	Andhra Pradesh % (n=208)	Maharashtra % (n=121)	Karnataka % (n=240)	Uttar Pradesh % (n=97)	Rajasthan % (n=50)	Gujarat % (n=56)	Total % (n=772)
No one	16.3(34)	12.4(15)	24.6(59)	2.1(2)	16.0(8)	21.4(12)	16.8(130)
Family member	64.9(135)	73.6(89)	64.6(155)	54.6(53)	78.0(39)	73.2(41)	66.3(512)
Friend	11.5(24)	6.6(8)	2.9(7)	3.1(3)	0	3.62)	5.7(44)
PLHA network	2.4(5)	4.1(5)	2.0(5)	40.2(39)	4.0(2)	0	7.3(56)
Out-reach worker	4.8(10)	3.3(4)	5.8(14)	0	2.0(1)	1.8(1)	3.9(30)

Travel to ART centers

ART centers in this study were mostly located in district hospitals. In low prevalence states ICTCs were located in CHCs or PHCs in other districts; and in the high prevalence states ICTCs were located in CHCs and PHCs within the same district. In India, districts can be fairly large and can cover a wide geographical area. Therefore, HIV-positive people may need to travel a fair distance to access ART services. In Rajasthan the ICTC at Alwar district hospital was 169 km from Jaipur

while the ICTC at Azamgarh , UP was 87 km from the ART center in Varanasi. ICTCs in Gujarat were comparatively closer to the corresponding ART center in Mahesana district. In Rajamundhry, Andhra Pradesh the ART center was atleast 40 km from Kadium and 35 km from Mandapeta. Transportation costs and travel time may pose a barrier to seeking ART services. Participants spent a median of 2 hours (IQR: 1.3, 3 hours) to reach their respective ART Center. Each trip cost a median of Rs 90 (IQR: 50, 150) equivalent

of \$ 2.00. The majority of participants (83.4%, n = 646) travelled by bus to reach ART centers; there was no significant variation between states. At some ICTCs in Gujarat, the medical superintendent and district authorities had organized a monthly trip for the ambulance to carry PLHIV to the ART center in Mahesana on a prefixed monthly schedule. In Rajasthan, HIV-positive people were provided travel concessions and given passes.

Problems faced in reaching ART centers

Participants were asked about the difficulties they faced in reaching the ART centers; open ended qualitative responses were collected. A total of 756 (97%) participants provided responses. It was encouraging to note that 75.5 per cent of the participants faced no problems in reaching their respective ART centers.

The most frequently cited difficulty was transportation and distance to the ART centers (11.3%; n = 84) linked with financial constraints and loss of wages (5.7%; n = 36) each time they travelled to the center. Thirteen per cent of participants from Andhra Pradesh; 22 per cent from UP and 20 per cent from Gujarat reported travel costs led to financial difficulties.

“I had financial problems.... for that reason...the day I visited the center I did not eat food that day.”
32-year-old female from Azamgarh, UP.

“Two times to come to ART center means lot of expenses that I spent for travelling and loss of work on that day.” 30-year-old woman from Kadiam, Andhra Pradesh.

HIV-positive people initiating ART are often sick with advanced immune-suppression. Participants

found travelling to distant ART centers challenging due to ill health, fatigue and weakness (5.3%; n = 40). This was mostly reported from Andhra Pradesh (7.5%), Karnataka (8%) and UP (6%).

“I came to the ART center in a bus, I faced breathing problems, I have TB and I am not able to stand or travel.” 33-year-old woman from Bagewadi.

“I am suffering from paralysis so I am not able to walk properly, that’s why my mother came along with me. She is also facing health problems. I suffered a lot travelling.” 30-year-old man from Bagewadi, Karnataka.

A 27-year-old pregnant woman explained, *“From my village to ART center is very far, there is no direct bus. Roads are not good. As I am pregnant it is very difficult to travel such a distance.”*

Several clients (3%; n = 22) found it difficult to locate the ART center in the hospital, mostly reported from Andhra Pradesh and Rajasthan.

“I am an illiterate person, I was confused and found it difficult to search and locate the ART center. I had trouble to reach the center properly.” 65-year-old woman from Mudhol, Karnataka.

“...identifying the ART center is very critical – [I spent] a lot of time to search the ART center, I was there many hours.” 38-year-old male from Mandapeta, Andhra Pradesh.

Some participants (1.0%; n = 8) from Maharashtra reported health worker strike as a reason for multiple visits to the ICTC to obtain their test result and referral slips that interfered with reaching the ART center. Other problems included waiting time at ART centers, multiple visits to the center, and

childcare. To accommodate the problem of childcare while parents seek services, the ART center in Mahesana has established a play room with an attendant for children.

8.5.4 Quality of services at ART centers

To assess the quality of services at ART centers participants were asked about their experience at these centers.

Number of visits required for registration at ART Centers

To register for treatment services, ART centers require participants to bring the following: a HIV test

report from a government ICTC; a referral slip from the ICTC; a ration card or election card as proof of identity, contact address and photographs. Participants may require more than one visit to complete these formalities.

Less than two-thirds (60.0%) of all participants were registered on their first visit to the ART center (Table 27). The ART centers in Karnataka were the most efficient in registering clients on their first visit (91.6%). Registration on the first visit was less frequently reported in the low prevalence northern states. Participants in UP reported the most number of visits to the ART center in Varanasi: 16.5 reported three visits while 77.3 per cent reported four or

Table 27: Number of visits required for registration at ART center

	Andhra Pradesh % (n=208)	Maharashtra % (n=121)	Karnataka % (n=239)	Uttar Pradesh % (n=97)	Rajasthan % (n=50)	Gujarat % (n=56)	Total % (n=771)
Number of visits made to ART center for registration							
One visit	73.1 (152)	67.8 (82)	91.7 (219)	2.1 (2)	16.0 (8)	1.8(1)	60.2(464)
Two visits	20.7 (43)	24.0 (29)	7.5 (18)	4.1 (4)	78.0 (39)	87.5(49)	23.6(182)
Three visits	4.8 (10)	5.0 (6)	0.8 (2)	16.5 (16)	4.0 (2)	10.7 (6)	5.4(42)
Four or more visits	1.4 (3)	3.2 (4)	0.0	77.3 (75)	2.0 (1)	0	10.8 (83)

more visits before they were registered into the ART program.

Interaction with counsellors at ART centers

On registration at the ART center, HIV-positive participants receive extensive counselling on ART, on eligibility for treatment, on the lifelong nature

of treatment and the importance of adherence to treatment. Patients are also provided counselling for positive prevention and the need for testing the spouse and/or sexual partners and any children. The quality of interaction was assessed.

ART centers cater to a large number of clients referred from several ICTCs across the district and

clients have to wait to be seen by health workers.

Overall, waiting time for clients to be seen by a counsellor at the ART center was short; nearly 60 per cent of participants met the counsellor within 30 minutes (Table 28). A third of clients waited between half to one hour to meet the counsellor, while less than a tenth waited longer than an hour. The initial counselling sessions are important as HIV positive clients receive information on the assessment of eligibility for treatment, interpretation of CD4 tests, ART and adherence. Counsellors at ART centers spent less than 10 minutes with a third of the clients, between 10-20 minutes with nearly sixty per cent of clients and more than 20 minutes with less than a tenth of the clients (Table 28).

Counsellors covered the essential topics listed above to a variable degree and seemed to focus less on some issues. While counsellors did cover the topic of prevention of HIV transmission with the majority of participants (80%), HIV testing of spouse/sexual partner and children was not discussed with nearly a third of the participants (30.5%). Counsellors discussed treatment with antiretroviral medications during counselling with the majority of participants (80%); however, almost half the participants (46%) were not told about CD4 test to assess eligibility for treatment. Nearly a third of the participants were not informed about the need for regular follow-up after starting ART (37%) or treatment adherence – the

need to take all medications correctly, consistently and continuously to prevent treatment failure (33%) (Table 28). Although, it is possible that the topics of regular follow-up visits and adherence are discussed in greater detail when ART is initiated, an introduction to the issues should be a part of the initial counselling process.

Although there is an active effort in many states to utilize PLHIV network members to provide community outreach and support services, this is happening variably in different states. Overall, counsellors told less than a quarter of participants about PLHIV support services. Information about PLHA networks and linking participants with its members was mostly reported in UP and Gujarat, where 55 per cent and 88 per cent of participants, respectively, were told about these services (Table 28).

Participants were asked their impression about the counsellors' attitude and their satisfaction with the counselling interaction. The majority of participants found the counsellors sympathetic (84%) and their respective sessions with the counsellors conducted in private (75%). An area of weakness in the counselling was the opportunity to ask questions and clarify doubts. A third of the participants felt that they were not encouraged to ask questions (30%) and that their doubts were not clarified to their satisfaction (33%). Just over half (56%) of the participants reported being satisfied with their interaction with counsellors (Table 28).

Table 28: ART counselling services at ART Centers by state

	Andhra Pradesh % (n)	Maharashtra % (n)	Karnataka % (n)	Uttar Pradesh % (n)	Rajasthan % (n)	Gujarat % (n)	Total % (n)
Waiting time to meet							
ART counsellor	(n=208)	(n=117)	(n=241)	(n=98)	(n=50)	(n=56)	(n=770)¹
30 mins or less	33.2(69)	71.8(84)	58.2(140)	55.1(54)	86.0(43)	96.4(54)	57.7(444)
31-60 mins	46.6(97)	23.9(28)	37.3(90)	27.6(27)	12.0(6)	3.6(2)	32.5(250)
60 mins or more	20.2(42)	4.3(5)	4.5(11)	17.3(17)	2.0(1)	0	9.8(76)
Time spent by counsellor	(n=208)	(n=117)	(n=241)	(n=99)	(n=50)	(n=56)	(n=771)²
10 mins or less	24.5(51)	47.0(55)	31.1(75)	42.4(42)	38.0(19)	16.1(9)	32.6(251)
10-20 mins	72.1(150)	47.8(56)	60.6(146)	41.4(41)	56.0(28)	58.9(33)	58.9(454)
20 mins or more	3.4(7)	5.2(6)	8.3(20)	16.2(16)	6.0(3)	25.0(14)	8.6(566)
Topics discussed by ART counsellor	(n=208)	(n=116)	(n=241)	(n=99)	(n=50)	(n=53)	(n=767)³
Prevention of HIV transmission	76.0(158)	74.1(86)	81.3(196)	90.9(90)	74.0(37)	100(53)	80.8(620)
HIV Testing for partner/children	64.9(135)	61.2(71)	60.2(145)	94.9(94)	84.0(42)	86.8(46)	69.5(533)
ARV treatment	73.6(153)	58.6(68)	85.9(207)	98.0(97)	86.0(43)	98.1(52)	80.8(620)
ARV treatment is lifelong	67.3(140)	41.4(48)	77.2(186)	91.9(91)	92.0(46)	96.2(51)	73.23562
Need for regular follow-up	54.8(114)	25.0(29)	72.2(174)	75.8(75)	80.0(40)	96.2(51)	63.0(483)
Treatment adherence	45.2(94)	51.7(60)	73.4(177)	92.9(92)	90.0(45)	92.5(49)	67.4(517)
CD4 test to assess ART eligibility	55.3(115)	25.0(29)	54.8(132)	85.9(85)	24.0(12)	77.4(41)	54.0(414)
Nutrition	70.2(146)	87.1(101)	85.9(207)	93.9(93)	88.0(44)	96.2(51)	83.7(642)
PLHA networks/social support	10.1(21)	44.0(51)	5.4(13)	55.6(55)	4.0(2)	83.0(44)	24.3(186)
Counsellor's attitude sympathetic	(n=208)	(n=117)	(n=240)	(n=99)	(n=50)	(n=56)	(n=770)¹
	55.8(116)	94.0(110)	97.9(235)	94.9(94)	92.0(46)	87.5(49)	84.04(650)
Privacy during ART counselling	(n=208)	(n=115)	(n=240)	(n=99)	(n=50)	(n=56)	(n=768)⁴
	61.1(127)	64.3(74)	93.8(225)	57.6(57)	70.0(35)	94.6(53)	74.3(571)
ART Counsellor encouraged questions	(n=208)	(n=115)	(n=240)	(n=99)	(n=50)	(n=56)	(n=768)⁴
	48.6(101)	80.0(92)	73.8(177)	82.8(82)	82.0(41)	76.8(43)	69.8(536)
ART Counsellor clarified doubts satisfactorily	(n=208)	(n=115)	(n=240)	(n=99)	(n=50)	(n=56)	(n=768)⁴
	42.8(89)	78.3(90)	37.5(90)	77.8(77)	82.0(41)	76.8(43)	66.6(511)
Satisfaction with counselling session	(n=208)	(n=115)	(n=240)	(n=99)	(n=50)	(n=56)	(n=768)⁴
Fully satisfied	59.2 (123)	64.4 (74)	35.8 (86)	76.8 (76)	70.0 (35)	73.2 (41)	56.6 (435)
Somewhat satisfied	34.1 (71)	30.4 (35)	57.5 (138)	19.2 (19)	28.0 (14)	23.2 (13)	37.8 (290)
Not satisfied	6.7 (14)	5.2 (6)	6.7 (16)	4.0 (4)	2.0 (1)	3.6 (2)	5.6 (43)

¹⁻⁴ Note: denominators vary due to missing information

Interaction with physicians at ART center

Doctors' consultations usually follow those of the counsellor. Doctors are expected to emphasize and reinforce key messages on treatment and HIV prevention, while also providing specific treatment related information, as their word carries weight. Overall, waiting time to be seen by the physicians was short; 60 per cent of the participants waited less than 30 minutes to meet the physician. However, 44 per cent of participants reported that their doctor spent less than 5 minutes with them and a further 41 per cent of participants reported that the doctors spent between 5-10 minutes with them. Only 15 per cent of participants reported a meeting of more than 10 minutes with their treating physician.

It appears doctors did not focus on HIV prevention during their interaction with participants. Prevention of HIV transmission was not mentioned to 40 per cent of participants, importance of condom use with partners was mentioned to 60 per cent of the participants, and doctors did not recommend testing for partners and children to 47 per cent of study participants (Table 29). Similarly, treatment adherence and CD4 testing to assess eligibility was discussed with less than half the participants. While over three-fourths of participants (77%) found the doctor's attitude sympathetic, almost half of the participants felt that questions were not encouraged (41%) and that their doubts were not clarified (46%). Just over half of the participants reported satisfaction with their interactions with doctors (52.8%).

Table 29: Interaction with Physicians at ART Centers

	Andhra Pradesh % (n)	Maharashtra % (n)	Karnataka % (n)	Uttar Pradesh % (n)	Rajasthan % (n)	Gujarat % (n)	Total % (n)*
Waiting time to meet Doctor at ART Center	(n=195)	(n=94)	(n=146)	(n=99)	(n=50)	(n=55)	(n=639)
30 mins or less	59.0 (115)	56.3 (53)	76.0 (111)	44.5 (44)	50.0 (25)	80.0 (44)	61.4(392)
31-60 mins	32.8 (64)	36.2 (34)	10.3 (15)	34.3 (34)	50.0 (25)	16.4 (9)	28.3 (181)
60 mins or more	8.2 (16)	7.5 (7)	13.7 (20)	21.2 (21)	0	3.6 (2)	10.3 (66)
Time spent by doctor	(n=195)	(n=94)	(n=146)	(n=99)	(n=50)	(n=55)	(n=639)
5 mins or less	30.3(59)	47.9 (45)	74.0 (108)	40.4 (40)	18.0 (9)	38.2 (21)	44.1 (282)
5-10 mins	51.8 (101)	30.8 (29)	23.3(34)	39.4 (39)	80.0(40)	30.9 (17)	40.7 (260)
10 mins or more	17.9 (35)	21.3 (20)	2.7 (4)	20.2 (20)	2.0 (1)	30.9 (17)	15.2 (97)
Topics discussed by ART counsellor	(n=195)	(n=94)	(n=146)	(n=99)	(n=50)	(n=53)	(n=637)
Prevention of HIV transmission	79.5 (155)	46.8 (44)	55.5 (81)	46.5 (46)	56.0 (28)	60.4 (32)	60.6 (386)
Condom use	34.9 (68)	33.0 (31)	41.1 (60)	33.3 (33)	56.0 (28)	60.4 (32)	39.6 (252)
HIV Testing for partner/children	55.4 (108)	62.8 (59)	37.7 (55)	52.5 (52)	72.0 (36)	56.6 (30)	53.4 (340)
ARV treatment is lifelong	66.2(129)	69.1 (65)	43.8 (64)	70.7 (70)	82.0 (41)	62.3 (33)	63.1 (402)
Treatment adherence	39.0 (76)	38.3 (36)	35.6 (52)	69.7 (69)	76.0 (38)	52.8 (28)	46.9 (299)
CD4 test to assess ART eligibility	55.9 (109)	53.2 (50)	42.5 (62)	54.5 (54)	24.0 (12)	58.5 (31)	49.9 (318)
Nutrition	69.2 (135)	73.4 (69)	45.9 (67)	57.6 (57)	74.0 (37)	54.7 (29)	61.9 (394)
Doctor's attitude sympathetic	(n=195)	(n=94)	(n=145)	(n=99)	(n=50)	(n=55)	(n=638)
	55.4 (108)	95.7 (90)	89.0 (129)	92.9 (92)	78.0 (39)	65.5 (36)	77.4 (494)
Doctor encouraged questions	(n=195)	(n=94)	(n=146)	(n=99)	(n=50)	(n=55)	(n=639)
	49.2 (96)	67.0 (63)	57.5 (84)	57.6 (57)	86.0 (43)	56.4 (31)	58.5 (374)
Doctor clarified doubts satisfactorily							
	43.6 (85)	69.1 (65)	47.3 (69)	54.5 (54)	84.0 (42)	52.7 (29)	53.8 (344)
Satisfaction with Doctor's interaction	(n=195)	(n=94)	(n=147)	(n=99)	(n=50)	(n=55)	(n=640)
Fully satisfied	62.65(122)	46.8 (44)	22.45(33)	68.7 (68)	84.0 (42)	52.7 (29)	52.8 (338)
Somewhat satisfied	31.3 (61)	51.1 (48)	43.5 (64)	24.2 (24)	12.0 (6)	47.3 (26)	35.8(229)
Not satisfied	6.2 (12)	2.1 (2)	34.0 (50)	7.1 (7)	4.0 (2)	0	11.4 (73)

* Participants were reluctant to provide responses assessing physicians. 139 participants did not provide responses on this section.

8.6 Clients interviewed in the community (did not register at ART Centers)

Counsellors at ICTCs refer all people who test HIV-positive to specific ART centers. These ART centers are usually located within the district in high prevalence states. In low prevalence states these centers may be located outside the district as there are fewer ART centers servicing several ICTCs.

The research team tracked participants who did not register at the referred ARTC within two months of their HIV test. Participants were tracked in the community with assistance from ICTC counsellors and PLHIV network members linked to the ICTCs. Locator information was obtained from ICTC

registers and study locator forms stored at ICTCs.

The research team was successful in contacting and interviewing 189 participants; three of these interviews were done by telephone as clients were unable to meet research interviewers (all in Rajasthan). This section presents results from the interview with these participants.

8.6.1 Health care services accessed

Researchers enquired about health care services that participants may have utilised or accessed after their HIV test. Participants were asked whether they had consulted other health care providers and whether they had undertaken further HIV testing (Table 30).

Table 30: Health care services obtained by participants who did not register at referred ART centers

	Participants interviewed in the community % (n/N)
Additional HIV tests undertaken after testing at ICTC	4.9 (9/184)
Consulted another physician outside referred ARTC after HIV test	13.3 (25/188)
Private allopathic physician	24 (6/25)
Government allopathic physician	52 (13/25)
Ayurvedic/Unani/Vaidh	24 (6/25)
Registered for ART services with other providers	9.6 (18/187)
Where registered:	
Other Government ARTC	44.4 (8/18)
Private doctor	16.7 (3/18)
Other/NGO	11.0 (2/18)
No response provided	27.8 (5/18)
Taking traditional medications	4.3 (8/185)
Taking ARV medications	4.3 (8/186)

Further HIV testing

A small number of participants (n = 9) had undertaken further HIV testing to confirm their HIV status. Five of these nine participants undertook one additional HIV test while four participants undertook two additional HIV tests. All additional tests were done at private laboratories.

Twenty-five participants had consulted a health care practitioner after their HIV test. Over half of these (52%) consulted a government physician (Table 30). A quarter (24%) of the participants consulted a traditional healer (ayurvedic/unani/vaidh). Eight participants were currently taking traditional medications (Karnataka: 5, Rajasthan: 2 and Gujarat: 1).

8.6.2 Registration at other ART Centers

A small proportion (9.6%; 18/187) of participants had registered for ART services at other clinics or ART centers. The majority of these participants (44.4%; 8/18) had registered at government ART Centers in other districts, for a variety of reasons that included stigma, distance and travel concerns, and financial difficulties. Five of the 18 participants were taking ARV medications from other centers: three from private physicians and two from NGOs. Five respondents did not provide responses. Qualitative responses were obtained to provide deeper insight into reasons for why these clients did not register at referral ART centers. A 40-year-old male participant from Gokavaram, Rajamundhry explained why he had registered for treatment at the ART center in Kakinada:

“If we went to the Rajamundhry ART centre for treatment our neighbours or relatives may find out about us. My daughter lives in Kakinada and so we decided to go there.”

Another young participant said, *“Vijayawada center is too far, I do not have sufficient money for travel so I visited Machbilipatnam ART center which is cheaper for me to reach.”*

A few participants were seeking ART from private sector physicians and NGOs (Table 29). A 25-year-old male from Vijayawada district explained why he was seeking treatment in the private sector:

“As I said, my relative is working in the government hospital and someone can identify me in there. My relative then will disclose to others. So I have this fear....I will go to a private hospital for taking treatment, I will not go to government hospital.”

8.6.3 Reasons for not registering at ARTC

The vast majority (90.4%; 171/189) of those who did not register at the referred ARTC had not registered at any other ART center and were not getting ART. These participants were asked reasons for not seeking ARV treatment. Quantitative data and qualitative responses were analysed in this section. Several participants reported multiple reasons for not registering at the referral ART center or seeking treatment. Table 31 provides the main reason (one key reason) cited per participant.

Table 31: Reasons for not registering at ART centers

	% (n=171)
Felt fine, did not want to start ART (includes 3 with high CD4 counts)	29.8 (51)
Busy so could not visit ARTC (includes death in family [3] and 6 could not take time off from work for fear of losing their job)	22.2 (38)
Fear of disclosure	8.8 (15)
Financial difficulties	8.8 (15)
Opposition by family members	5.3 (9)
No one to accompany them to the ART center	3.5 (6)
Wanted to confirm diagnosis with another HIV test	3.5 (6)
ARTC very far (6)/too sick to travel to reach ART (2)	4.7 (8)
Strike at ART center	2.3 (4)
Taking TB treatment	2.9 (5)
Multiple visits required before registration	1.2 (2)
Does not have ration card or address proof/temple pujari advised 21 day fast/taking traditional ayurvedic medication	2.3 (4)
No response provided	4.7 (8)

The most commonly cited reason was that participants were well and did not feel the need to start treatment (29.8%); this included a few participants who did consult doctors and had high CD4 counts. A 31-year-old married female from Muddebihal, Karnataka said:

“I tested in private hospital and I do not have any health problem now – I am fine so why should I go for ART treatment? And my husband is also opposed to me going to the ART center.”

Another 30-year-old female from Jaunpur, UP said, *“My CD4 report is good, so the doctor told me that you come in March.”*

Many participants (22 per cent) did not register at ARTCs because they were occupied with work or family responsibilities and work often overlapped with

financial concerns as illustrated in the following quote from a 26-year-old female from Indi, Karnataka:

“My husband and I are going to work; if I took leave one day then we will lose our job. I cannot go to ART alone because I do not know anything in Bijapur...”

Another young male participant reported, *“I am a lorry driver and so when I go on a trip it takes minimum one month time [for me to return]”*

Another 25-year-old man said, *“I do coconut business, this is its season. So I did not go to Vijayawada as I was busy. Need to earn when we have work. If we do not earn it is difficult to survive.”*

Several participants (8.9%) cited fear of disclosure of their HIV status in their communities as the

main reason for not seeking treatment, as illustrated by this 45-year-old male from Karnataka:

“...I did not visit ART center for taking treatment because in Bijapur [Government ART center] my relative is working...so I did not disclose my status to anybody – it is a matter of prestige. If they come to know about this then they will disclose my status to all my relatives then it will create a problem for the family.”

Even though treatment is provided free of cost at government ART centers, participants found the cost of travel burdensome.

“I do not have money to travel to this district hospital. We are poor, I am widowed person. If I am not doing any work, there is no income for my family. I have two children. I am struggling to feed my family daily....” narrated a 35-year-old female from Mudhol, Karnataka.

Several participants felt that ART centers were too far away for them to access services both due to cost of travel as well as the logistics of travel especially for sick participants as mentioned by this 55-year-old male from Jamakhandi, Karnataka:

“I am becoming very weak. I do not have the capacity to go to ART center.... last time I was admitted in government hospital Jamakhandi. So I did not get time to go to Bagalkot ART center.”

Some participants also consulted traditional healers and priests, as this 28-year-old female stated:

“I will take ayurvedic medicine for 6 months, if I am not recovering [from HIV infection], then I will take ART medicine.”

Another 43-year-old lady from Muddebihal explained:

“I believe in God. I do not want to go to ART center. Without treatment my HIV will cure. The pujari of temple has told me to fast for 21 days for my cure.”

Around four participants could not register at the ARTC due to a strike by health workers across ICTCs and ARTCs in Maharashtra in the month of December 2009. Other reported barriers were family objection, ill-health, and not having documents such as ration cards or election ID cards as proof of address for registration purposes. A 40-year-old female participant from Bijapur in Karnataka lamented:

“When I received my test report the counsellor told me that you go to ART center along with HIV report and also election ID card or ration card. But I do not have these cards. He told me if you go to ART center without this they will not give medicines -- that is why I did not visit ART.”

Several women reported opposition by their husbands and family as this 26-year-old female participant from Kadiam, Andhra Pradesh reported:

“My husband has not given me permission to go get ART, otherwise I would go.... Now I am feeling comfortable but I know that after some days without ART treatment I will become weak...”

Several participants reported that they had been asked by physicians to first complete their TB treatment prior to registering at the ARTC. In other cases participants felt strained by the number of visits required to complete formalities such as blood tests, chest x-rays prior to receiving their HIV test result and

referral to the ARTC. This was particularly evident in Andhra Pradesh.

“ICTC counsellor did not give me the HIV report so I visited the ICTC two times; x-ray report also they did not give me. I visited the hospital seven times. I have no energy. Local Gudivada hospital I visited many times. Vijayawada city I do not know. I do not know how many times I [will need to] visit the ART center. I [am] scared with no one ready to come with me.” 37-year-old male

A few participants were not convinced that they were HIV-positive and wanted to confirm the result by testing again. Others wanted to repeat the HIV test at a private laboratory for better quality of testing. A 25-year-old female reported:

“I do not believe this ICTC result and I did not tell my husband also about my status. I will not take treatment in government hospital, I will go to a private hospital for another HIV test. If this is also found positive then I will take treatment in private hospital only. I will pay for it, I do not care about money. I think private treatment is good.”

Another 45-year-old female participant said:

“I have decided to take another HIV test privately, that’s why I did not go anywhere.”

8.6.4 Awareness about the availability of free ART and CD4 test

Most participants (82.9%; 155/187) had received information about the availability of free ARV medications at government ART centers and had been given referral slips for designated ART centers by the counsellors at ICTCs (77.5%). There was variability

across states. Over a quarter of the participants from Andhra Pradesh (29.2%) and a quarter from UP (25%) reported not having been informed about the availability of free ART. And about half the participants in Andhra Pradesh (44%) and a third in Maharashtra (33%) did not receive referral slips (Table 32).

A small proportion of participants had undertaken a CD4 test to assess eligibility for ART. Eighteen participants (9.6%) had undertaken a CD4 count test. Of these 77.7% (14/18) of the participants did so at government ART centers. Three participants (16.6%) had CD4 tests done at private clinics. One participant was unaware of where the CD4 test was done.

Rajasthan government offers PLHIV travel concessions on bus and rail transport. Participants were asked whether they had been informed about travel concessions on public transport. In Rajasthan 24 per cent (12/50) reported that they had received this information from counsellors at ICTCs. Participants from other states did not respond to this question; this facility is not offered in other states.

As a part of community engagement and support for HIV-positive people, many State AIDS Control Organizations are engaging PLHIV from networks to support clients and help with out-reach activities. Participants were asked whether they had received any support from PLHIV support groups. Overall, less than a fifth (17.1%) reported that they had been introduced to PLHIV network members by ICTC counsellors and staff. This appeared to be mainly taking place in UP (56%) and Gujarat (63.6%) and to a lesser extent in Maharashtra (33.3%) (Table 32). Interestingly, participants in high prevalence states appeared to be more comfortable about PLHIV or out-reach workers visiting them at home than participants

Table 32: Referral slips and information on services provided

	Andhra Pradesh % (n=46)	Maharashtra % (n=21)	Karnataka % (n=78)	Uttar Pradesh % (n=17)	Rajasthan % (n=15)	Gujarat % (n=11)	Total % (n=187)
Informed about availability of free ART	71.7(33)	95.2(20)	83.3(65)	70.6(12)	93.3(14)	100(11)	82.9(155)
Provided a referral slip at ICTC	56.5(26)	66.7(14)	80.8(63)	100(17)	93.3(14)	100(11)	77.5(145)
Provided directions to ARTC at ICTC	23.9(11)	81.0(17)	92.3(72)	87.4(14)	80.0(12)	100(11)	73.3(137)
Told HIV is curable	8.7(4)	4.8(1)	3.8(3)	17.6(3/16)	6.7(1)	0	6.4(12)
Taken CD4 test to assess disease stage	10.9(5)	23.8(5)	2.5(2)	25.0(4/16)	6.7(1)	9.1(1)	9.6(18)
Introduced to a PLHA network member at ICTC	4.3(2)	33.3(7)	9.0(7)	52.9(9/16)	0	63.6(7)	17.1(32)
Comfortable with PLHA or ORW visiting at home	50.0(23)	61.9(13)	64.1(50)	5.9(1)	26.7(4)	54.5(6)	51.9(97)

in low HIV prevalence states except Gujarat. In UP where nine participants had been put in touch with PLHIV network members, only one reported that he was comfortable in meeting them at home.

8.7 Registration at ART centers

To better understand factors that influence patient registration at ART centers further analysis was

undertaken. Table 33 presents differences on key socio-demographic and economic variables on bivariate analysis between clients who registered at ART centers within two months of their HIV test (n = 777) and clients who did not register but were interviewed in the community (n = 189).

Table 33: Differences between registered and non-registered clients on socio-demographic and economic variables (Bivariate analysis)

		Registered at ART Centers % (n=777)	Not registered at ART Centers % (n=189)	Sig ²
Gender (n=966)	Males	48.3 (375)	43.9 (83)	p=0.283
	Females	51.7 (402)	56.1 (106)	
Age (n=966)	Mean (SD)	34.8 (8.9)	33.2 (8.2)	p=0.017
Marital status (n=966)				
	Currently married/Cohabiting	68.0 (528)	61.9 (117)	p=0.040
	Single	5.7 (44)	10.6 (20)	
	Divorced/separated/Widowed	26.3 (205)	27.5 (52)	
Educational level (n=966)				
	Illiterate	54.0 (420)	65.1 (123)	p=0.022
	Primary	16.5 (128)	11.6 (22)	
	Secondary or higher	29.5(229)	23.3 (44)	
Employed (n=966)		78.4 (609)	82.5 (156)	p=0.206
Number of HIV tests¹ (n=962)				
	One	66.6 (515)	72.5 (137)	p=0.122
	Two or more tests	33.4 (258)	27.5 (52)	
Given referral slip for ART by counsellor at ICTC (n=957)				
		87.0 (670)	88.7 (160)	p=0.600
Satisfied with counsellor at ICTC				
		86.4 (666)	88.7 (165)	p=0.528
Disclosed HIV status to someone (n=961)				
	Yes	72.9 (565)	54.8 (102)	p<0.001
Family member receiving ART (n=857)				
	Yes	14.8 (104)	15.8 (27)	p=0.749
Know HIV-positive people in the community (n=961)				
	Yes	34.7 (268)	51.1 (94)	p<0.001
Principal occupation (n=958)				
	Labourer	52.5 (407)	66.1 (121)	p=0.003
	Other	40.3 (312)	30.1 (55)	
	Professional	7.2 (56)	3.8 (7)	
Own agricultural land (n=961)	Yes	39.6 (307)	44.1 (82)	p=0.264
Live in Pucca house (n=963)	Yes	64.5 (501)	57.0 (106)	p=0.057
Primary source of cooking energy (n=964)				
	None	0.8 (6)	1.6 (3)	p=0.388
	Firewood/charcoal	74.4 (578)	77.8 (147)	
	LPG	22.9 (178)	18.5 (35)	
	Others	1.9 (15)	2.1 (4)	
Owning household items (n=961) (television, bicycle/scooter or motorcycle, almirah/dressing table, sewing machine, one/two or more pressure cookers/pans, one/two or more electric fans (0-8))				
	0	20.3 (158)	27.5 (52)	p=0.001
	1-2	35.8 (278)	33.3 (63)	
	3-5	37.6 (292)	31.2 (59)	
	6-8	6.3 (49))	7.9 (15)	

¹ when visiting ICTC ² T test

On bivariate analysis, significant differences ($p < 0.05$) were observed between the two groups: participants who registered at ART centers within 2 months of their HIV test and participants who did not register, on several variables shown in Table 33. Comparisons between the two groups were drawn on the following variables:

Gender: There were no significant gender differences between the two groups ($p = 0.283$).

Age: Mean age was significantly lower for clients who did not register at ART centers compared to those who registered ($p = 0.017$) suggesting that younger clients are more likely to delay registering at ART centers.

Marital status: There were significant differences on marital status between the two groups. The largest difference was observed among single (never married) participants, where the proportion of single participants who did not register at ART centers was twice the proportion of single participants who did register. A marginally higher proportion of divorced or widowed participants did not register at ART centers. By contrast, a higher proportion of married or cohabiting participants registered at ART centers.

Educational level: Significant differences were observed between the two groups on educational level. A higher proportion of illiterate clients did not register at ART centers compared to those who registered. Literate participants with any primary, secondary or higher education were more likely to register at ART centers.

Employment: There were no significant differences between groups.

Number of HIV tests undertaken: There were no significant differences between groups on this variable.

Participants received referral slip for the ART center from the ICTC: There were no significant differences

between both groups with regard to receiving referral slips from the ICTC.

Satisfaction with ICTC counsellors: Participant's satisfaction with their interaction with the ICTC counsellor was explored. No significant differences emerged between groups.

Disclosure of HIV status to someone: There were significant differences between the two groups on disclosure of HIV status. Among those who did not register at ART centers, the proportion of persons who had disclosed their HIV status to someone was significantly lower compared to those who had registered.

Have a family member receiving ART: There were no significant differences between the two groups with regard to having a family member receiving ART.

Knowledge of HIV-positive persons in the community: Significant differences were observed between the two groups. A significantly higher proportion of participants who did not register knew HIV-positive persons in the community.

Economic variables were explored. There were differences on certain economic indicators suggesting that participants with lower incomes or those who were economically weak were less likely to register for treatment. A higher proportion of participants who lived in pucca houses, owned a higher number of household goods such as a pressure cooker, sewing machine, fans, television or a vehicle registered at ART centers compared to those who did not register. Participants with households where the principal occupation was labour were significantly more likely not to register at ART centers. Ownership of agricultural land was not significantly different between the two groups.

CD4 cell counts were not included in this comparison as the majority of clients interviewed in the community had not undertaken this test.

9.0 Conclusions

The study was designed to document the uptake of ART services in the public sector and to determine the reasons why some people do not access these services even when these are available for free in the public sector. A cohort of 1057 newly diagnosed HIV-positive people were followed over 2 months. Almost three-fourths (73.5%; $n = 777$) of the cohort registered at ART centers within two months of collecting their HIV test result. Of those who did not register at ART centers, 17.9 per cent ($n = 189$) were successfully interviewed in the community and 5.6 per cent ($n = 60$) were tracked but not interviewed and only around 3 per cent ($n = 31$) participants were untraced and lost to follow-up. This provides evidence to the program that clients can be successfully tracked in the community.

The majority of the HIV-positive participants, who did not register at ART centers and were interviewed in the community, were not accessing ART nor had undertaken CD4 tests to assess their eligibility for treatment. This places these clients at risk of delaying treatment. A small number of HIV-positive clients ($n = 18$) had registered at government ART centers in other districts for reasons of confidentiality, financial constraints and centers being close to their place of residence. And a very small proportion of participants were accessing the private sector, suggesting that the public sector is still the main provider of services for this population. Procedures need to be in place for clients to inform ICTC or ART centers that they have registered for treatment at other centers. Linking client information in ICTC registers to the registers at ART centers by recording PID numbers could provide

the necessary link. Revisiting ICTC by clients after registration at ART centers may be emphasized; this is being done at some centers. Formalising the inclusion of follow-up information in the ICTC register may direct counsellors to collect this information routinely through phone calls or outreach activities. The proposed central national registry for ART services will be very useful.

HIV-positive clients interviewed in the community did not register at referral ART centers for a variety of reasons. A perception of relatively good health removed the urgency to register immediately for several clients (30%), while work and family engagements kept others away from the ART center (22%). The fear of disclosure of their HIV status, being recognised by villagers or relatives and resulting stigma was the overriding concern for many others (9%). Although ART is offered free at government centers, financial difficulties and travel expenses were deterrents for several participants (9%). Family opposition comprised the fifth most commonly cited reason (5%). Other reasons included the distance of ART centers compounded with severe illness, which prevented travel for the participants who probably needed ART most. In a few cases, participants were waiting to complete their tuberculosis treatment prior to registering at ART clinics.

Bivariate analysis indicated that younger clients, single clients and those working as unskilled manual labour were significantly more likely to not register at ART centers. Further, non-disclosure of HIV status and knowledge of HIV-positive people in the community were also associated with a higher probability of

not registering at ART centers; highlighting the continuing role of stigma in the community. Additionally, indicators suggestive of financial incapacity (e.g. working as manual labour, not owning household items such a pressure cooker, fans, vehicle or a sewing machine) were significantly associated with a higher probability of not registering for ART services. Similar factors emerged from the analysis of secondary data from ART centers in Phase 1 of this study. Further, these issues were also mentioned by clients who had registered at ART centers but continued to face difficulties while accessing services. If not addressed, these may be the very factors that contribute to non-adherence at a later stage.

Counsellors at ICTCs and health workers at hospital departments such as TB and ANC clinics from where clients are routinely sent for HIV testing should be cognisant of these factors and quick to identify clients at risk of disappearing into the community. Identification of an at-risk client should trigger a closer follow-up and community outreach intervention. It is of concern that 32 newly diagnosed HIV-positive people who did not register at ART centers had died within 2 months of their HIV test. These participants, with presumably advanced HIV disease, did not receive the benefit of the free ART program. These participants could have benefitted from a more aggressive follow-up and tracking in the community.

Disclosure and stigma continue to be important barriers to accessing services. Intensive counselling and support to address and facilitate disclosure of HIV status and manage fears related to loss of confidentiality are urgently needed. There should be provision for HIV-positive participants to be offered a choice of government ART centers to choose from, especially

in states where a wider network of ART centers exists. Giving people a choice would go a long way in addressing some of the confidentiality issues confronting newly diagnosed HIV-positive people as well as addressing the barrier of distance to ART centers. Fast tracking the opening of link ART centers would further serve to reduce the travel and related costs thereby facilitating uptake of services. Best practices that could be emulated include the provision travel concessions on public transport for PLHIV, as is being provided in Rajasthan; and the organisation of transport services (hospital ambulance) from ICTCs to referral ART centers on a fixed monthly schedule, as is being done in Mahesana, Gujarat.

The study also provides an assessment of the quality of counselling at ICTCs from interviews with HIV-positive people undertaken immediately after post-test counselling; and of the quality of counselling at ART centers from interviews conducted after registration at the ART centers. Overall, clients were satisfied with counselling services at ICTCs. Topics that were inadequately covered included emphasis on partner testing, condom demonstration, explanation on the window period and information on PLHIV networks. Counselling at ART centers suffered from similar weaknesses, including insufficient information on the need for regular follow-ups and adherence to treatment, CD4 tests, and HIV testing of spouse and children. Doctors appeared to rush through appointments with clients. These weaknesses could be addressed through a more rigorous monitoring of services including periodic low cost state level evaluations through exit interviews and client satisfaction surveys. Health system issues, such as the shortage of HIV testing kits in ICTCs and health worker strikes

also contributed to impeding registration at ART centers. In addition, certain local policies requiring chest x-rays and other checkups to be done before referring clients to ART centers entail multiple trips for clients. Although designed to facilitate uptake, this practice may be having a negative impact, as multiple trips prove onerous and financially burdensome for sick and economically weak clients. A review of these policies may be considered.

In conclusion, the majority of newly diagnosed HIV-positive people do register at ART centers. While barriers that deter HIV-positive people from accessing treatment services do exist, they are not insurmountable. Addressing client and health system barriers would serve to increase uptake of services.

Recommendations:

- The study has demonstrated that programs can successfully track HIV positive persons in the community. Attempts must be made to track all newly diagnosed HIV positive people in the community. Efforts can be made by both clients and health providers.
 - a) Counsellors should routinely follow newly diagnosed positive people over two to three months after the HIV test, to determine whether they have registered at any ART center and if not reasons for not doing so. This could be done through phone calls or outreach workers. ICTC registers could be modified to include additional information on registration at ART centers.
 - b) Clients must be asked to visit the ICTC or call the counsellor after they register at ART centers.

While this is being done at some centers, implementation at a wider level may be considered.

- Enlisting support from PLHIV networks for clients to reach ART centers is an important additional resource for health providers. This is not being implemented across all sites; this link can be strengthened to improve enrolment and follow-up in the community.
- ICTC counsellor's scope of work could be expanded to undertake an assessment of health and social status of newly diagnosed HIV positive people. The objective would be to identify persons who may be sick with advanced disease and in need of urgent medication; or having characteristics that may predict delayed registration or non-registration at ART centers — e.g. manual labourers, clients from a poor economic status, and illiterate clients who may require additional support to reach ART centers. Counsellors may be trained to initiate a more aggressive follow-up plan for these clients.
- Healthy clients would benefit from more focussed counselling on the importance of registering and assessing eligibility for ART even if they are in good health.
- Several clients found travelling a long distance to ART centers burdensome for several reasons — e.g. ill health, financial difficulties, lack of transport arrangements, not having people to accompany them, etc. This is not only a barrier to uptake of services but also for long-term adherence to treatment for patients on treatment.
 - a) In low prevalence states where ART centers receive clients from several districts, and in

- some cases neighbouring states (as in the case of Varanasi), Link ART centers need to be established quickly. At present Link ART centers only provide delivery of ART medications. Weekly visits by specialists from the ART center and arrangements to collect and transport blood for CD4 cell counts could be considered.
- b) Enlisting support of PLHIV networks to accompany clients to ART centers should be encouraged.
 - c) Travel concessions on public transport can be provided.
- Fear of inadvertent disclosure of status and resulting stigma is an important barrier to seeking ART services. The program may consider offering choice of ART centers to newly diagnosed HIV positive people for the initial evaluation and registration, and long-term follow up. This would allow clients to register safely and without fear. Clients could move to a center closer to their home once they felt comfortable with their HIV positive status and treatment.
 - Closer monitoring of counselling at ICTCs and ART centers is required at the state and district level. Routine monitoring visits should be planned that include a review of service data as well as some exit interviews with clients and/or observation of counselling sessions where possible.
 - Data quality issues were noted at both ICTC and ART centers.
 - a) Rigorous and regular monitoring of data quality at ICTCs and ART centers is urgently needed. Monitoring visits should include a review of registers.
 - b) Harmonization of data collection at ICTC and ART centers is required. Coding of key variables should be similar at both sites.
 - c) Linking of ICTC and ART center data is urgently needed for program monitoring. Client PID numbers (unique ID) should be recorded in ART registers to link the two data bases. A joint monthly review of linked data by ICTC counsellors and ART counsellors could ascertain the number of clients who registered successfully and those who did not register and therefore need to be tracked in the community.

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Annex 1. Quick Poverty Score for India

1. How many people aged 0-17 are in this household?
Enter '00' if None, Enter '05' if 5 and so on
2. What is the household's principal occupation?
Labourers – 01
Others – 02
Professional – 03
3. Is the residence all pucca (burnt bricks, stone, cement, tiles and jack board/cement plastered reeds, timber, galvanized tin or asbestos cement sheets)?
Yes – 01
No – 02
4. What is the household's primary source of energy for cooking?
Fire wood chips / charcoal – 01
None – 02
Others – 03
LPG – 04
5. Does the household own a television?
Yes – 01
No – 02
6. Does the household own a bicycle, scooter or motor cycle?
Yes – 01
No -02
7. Does the household own an almirah/dressing table?
Yes – 01
No – 02
8. Does the household own a sewing machine?
Yes – 01
No – 02
9. How many pressure cookers or pressure pans does the household own?
None – 01
One – 02
Two or more – 03
10. How many electric fans does the household own?
None – 01
One – 02
Two or more – 03

Annex 2. Informed consent for people testing positive for HIV/AIDS at ICTC centers (Consent for Baseline survey)

Purpose of the study

(Greet the man/woman). My name is _____.
..... The Population Council is conducting a study to learn more about the problems HIV-positive persons face in receiving care and treatment. This study is being sponsored by the NACO (National AIDS Control Organization), MOH&FW of the Government of India. NACO will use this information to improve HIV testing and treatment services for HIV positive persons. Your participation in this study will help NACO to improve the quality of services for you and other people who need treatment for HIV infection.

Procedure

You will be asked to participate in two interviews at an interval of 2 months. The first interview will be done today. The second interview will be done in the next 2-3 months. Today, you will be asked questions on what you know about HIV, treatment with ART, social support available for PLHAs, quality of services at ICTCs, difficulties people face in getting treatment for illnesses and for HIV infection. After the interview you will receive a referral number/card to show at the ART treatment centers.

We will need your contact information to contact you for your second interview. We understand that you may want to keep your HIV status secret. Please give us an address and telephone number, that you are comfortable with, where we can reach you. Please tell

us how you would like the research staff to identify or introduce him/her self, a convenient time when you would be available and the form of greeting the research staff can use. Your contact information will be stored carefully under lock and key. The research staff will arrange to meet you at a convenient time and location for the second interview.

We would like to ask for your consent to be interviewed today, in private by one of our trained interviewers.

Benefits and Risks

If you agree, your participation will help organizations like the ICTCs and its staff in addressing PLHA's needs more efficiently. Some of the questions that you will be asked may be sensitive or personal in nature and perhaps make you uncomfortable. The interviewer will not insist on answers to all questions. Your participation in the study may not benefit you directly. Whether you agree or not, both you and your family will receive all of the health care services that are normally provided through the government health system.

There is a minimal risk of someone learning of your HIV status when the research team contacts you for the second interview. We are giving you the contact information of our research officer. If you need our assistance, you can contact us on this phone number. We will assist you to get counselling support from a counsellor, PLHA support group or NGOs. We will also be able to offer counselling to family members.

Compensation

You will receive Rs 100 towards reimbursement of transport costs for each of the two interviews.

Offer to answer questions and freedom to withdraw from the study

You can refuse to respond to any question and can stop the interview at any time. You or your family will not be deprived of any services, if you decide to drop out of the study. The interview will take approximately 20 minutes. Participation is completely voluntary.

Confidentiality

Everything that you report during the interview will be kept strictly confidential and your name will not be recorded on the questionnaire. The contact information that we collect is kept separate from the questionnaire and will be kept under lock and key. This information

will only be used by the researchers and will be used only for contacting for the study's follow-up interview. All records of your interviews and data collected from medical records will be kept in a safe place under lock and key. These will be destroyed after the completion of the study.

Subject's Statement

I have read the consent document regarding my participation in the study / the consent document regarding my participation in the study has been read out to me. I have been given a chance to ask questions and my questions have been answered to my satisfaction.

I understand that all records will be kept private, will be destroyed after the study and that I can leave the study at any time. I have also understood that my decision not to be in this study or to leave the study will not affect the services I will receive.

I agree to be in this study as a volunteer.

Name of the subject_____

Signature of the subject:_____

Signature of a witness:_____

Date:_____

Date:_____

[Tear Here]

Contact information:

Name:

Address:

Telephone:

Any contact telephone, if not of self: (name of person and number)

ART referral card no:

Information and salutation to be used when contacting subject:

Annex 3. Understanding the factors affecting enrollment of PLHAs into ART services in India

Baseline Survey

Interview to be conducted at the ICTC

Subject ID

Interview site/ICTC code [__ __]	1. Nandigama 2. Gudivada 3. Mylavaram 4. Gokavaram 5. Mandapeta 6. Kadium 7. Gadingal 8. Ichalkarauji 9. Kagal 10. Karad	11. Phaltan 12. Patan, Satara 13. Indi 14. Bagewadi 15. Muddebihal 16. Jamakhandi 17. Badami 18. Mudhol 19. RIMS, Imphal 20. MLSS, Imphal	21. Bishenpur 22. Azamgarh 23. Bhadoi 24. Jaunpur 25. Sikar 26. Ajmer 27. Alwar 28. Palanpur 29. Patan, Gujarat 30. Kadi
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ART Center [__ __]	1. Vijayawada 2. Rajahmundry 3. Kolhapur	4. Satara 5. Bijapur 6. Bagalkot	7. Imphal 8. Varanasi 9. Jaipur 10. Mehasana
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State [__ __]	1. Andhra Pradesh 2. Maharashtra	3. Karnataka 4. Manipur	5. Uttar Pradesh 6. Rajasthan 7. Gujarat
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Informed consent obtained	Yes 01 No 02	[__ __]
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Date of informed consent	DD/MM/YY	[__ __ __ __ __ __]
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Reference slip number	[__ __ __ __ __ __]
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Screening

1. 18 years of age	2. HIV-positive status: received proof, confirmed
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Research Interviewer	Name:	Signature:
Status of Data Collection [__ __]	1. Completed	2. Refused
		3. Incomplete

Start time: .../.....

SECTION I: BACKGROUND CHARACTERISTICS

QID	Question	Response options/codes	Coded response	Skip pattern
101	Sex	Female..... 01 Male.....02	[_ _]	
102	Age in Years	Years.....	[_ _]	
103	What is the highest level of education you have had? <i>Instruction:</i> <i>For education enter completed school years from 1 to 12; add one year for each year of university education</i>	Illiterate00 Completed years of education _____ No formal education, but can read and write77	[_ _]	
104	If attended vocational training, years of vocational education.	Years.....	[_ _]	
105	What is your current marital status?	Currently married..... 01 Cohabiting (Not married but living with partner).....02 Single (Never married)03 Divorced or separated.....04 Widowed..... 05	[_ _]	If '03' skip to Q108 If '05' skip to Q107
106	What is the HIV status of your spouse? <i>Instruction:</i> <i>If married or cohabiting refer to current spouse, if widowed refer to dead spouse</i>	HIV negative.....01 HIV positive.....02 Not known.....03	[_ _]	Skip to Q108
107	Was the death of your spouse due to HIV?	Yes..... 01 No.....02 Don't Know.....99	[_ _]	
108	What is your religion?	Hindu01 Muslim.....02 Christian.....03 Sikh.....04 Jain.....05 Buddhist.....06 Other religious groups.....07	[_ _]	
109	Who do you currently live with?	Alone.....01 With spouse and/or children.....02 With extended family.....03 With friends/roommates/workers.....04	[_ _]	

QID	Question	Response options/codes	Coded response	Skip pattern
110	Since how long you have been staying in this location? <i>Instruction:</i> <i>Enter in Months</i>	Months_____	[__ __ __]	
Now I would like to ask you a few questions about your biological children and their HIV status				
Instruction: Check Q105=3, (Single; Never Married) skip to Q114				
111	How many biological children do you have? <i>Instruction: If none write 00</i>	Living sons_____	[__ __]	If 00 skip to Q.113
		Living daughters_____	[__ __]	
		Deceased _____	[__ __]	If 00 deceased skip to Q.113
112	Did any child die due to HIV related illness?	Yes.....01 No.....02	[__ __]	
113	Are any of your children currently infected with HIV? <i>Instruction: If none write 00</i>	Sons..... Daughters.....	[__ __] [__ __]	
114	What is your occupation?	Not working00 Agricultural work.....01 Manual labour.....02 Handicrafts/stitching.....03 Factory worker.....04 Government employee.....05 Shopkeeper.....06 Aganwadi worker.....07 Petty Business.....08 Shops/Business.....09 Health worker.....10 Unskilled labour.....11 Carpenter/Masson.....12 Cycle rickshaw driver.....12 Teacher.....13 Contractor.....14 Truckers/transportation.....15 Other (specify).....88	[__ __]	If 00 skip to Q. 118
115	How far is your place of work from your place of residence? <i>Instruction:</i> <i>If workplace same as place of residence enter 00, if other place, enter distance in kilometers</i>	Same village.....01 Within the district.....02 Outside the district.....03 Distance in kilometers _____	[__ __] [_____]	

Annex 3. Baseline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
116	How many days in a month do you usually stay away from your home, as a part of your job? <i>Instruction:</i> <i>If does not stay away enter '00'</i> <i>If away enter number of days in a month</i>	Days _____	[__ __]	
117	Have you travelled outside the district for work in the past two years?	Yes.....01 No.....02	[__ __]	
INS: CHECK IF Q 114= '00' NOT WORKING, THEN ASK Q 118 to Q 120				
118	If not working, since how long are you not working? <i>Instructions: Enter in months</i>	Months _____ Never worked995	[__ __ __]	
119	What is the reason for not working? <i>Instructions: Do not read out answers</i>	Don't want to work01 Lost job due to HIV.....02 Too sick to carry on working.....03 Don't need to work04 Never worked05 Couldn't find job.....06 Other (specify)88	[__ __]	
120	Did you work prior to your HIV diagnosis?	Yes.....01 No.....02	[__ __]	
121	Who is the prime earning member in your household?	Self.....01 Spouse.....02 Parents.....03 Siblings.....04 Others (specify).....88	[__ __]	
122	What is your average monthly household income?	Amount in Rupees _____	Rs[_____]	
123	What is your spouse/regular partner's age? <i>Instructions:</i> <i>Enter 95 if participant does not have a partner</i>	Age in years _____ N/A95	[__ __]	If 95 skip to Q201
124	Is your current spouse/partner employed/working for pay?	Yes01 No02	[__ __]	
125	What is the highest level of education of your spouse/partner? <i>Instructions: For education enter completed school years from 1 to 12, add one year for each year of university education</i>	Illiterate00 Completed years of education _____ No formal education, but can read and write.....77	[__ __]	

SECTION II: HIV TESTING

Now, I would like to ask you a few questions about why you decided to come in to this clinic for HIV testing and about your experiences in receiving your HIV test results.

QID	Question	Response options/codes	Coded response	Skip pattern
201	Who referred you to this ICTC?	Self-referral.....01 Pvt. Doctor / hospital.....02 Pvt.Laboratory03 Government hospital04 ANM/PHC/CHC05 PMTCT/MCH.....06 NGO07 Others (specify).....88	[_ _]	
202	Why did you want to undertake a HIV test? <i>Instructions:</i> • <i>Mark all that apply</i> • <i>Ask for more reasons, but do not read out</i> • <i>Enter 01 if mentioned</i> • <i>Enter 02 if not mentioned</i> <i>Also record Verbatim below</i>	Own past sexual behaviors.....01 Falling sick very often.....02 For second opinion on earlier test result03 Partner's sexual behaviors04 Partner tested positive.....05 Partner asked me to get tested.....06 Death of spouse/partner.....07 Death of a child.....08 Family member tested positive.....09 Death of family member.....10 Exposure to HIV at work.....11 Had blood transfusion12 Not sure that injected with sterile needle13 Intravenous Drug User.....14 Involved in unprotected sexual behavior15 Others, specify.....88	M=1, NM=2 [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	
	Verbatim account:			
203	How many times have you been tested for HIV including this current test?	Number of HIV tests_____	[_ _]	
204	How long did you think about HIV testing before you decided to be tested for the first time? <i>Instructions:</i> <i>Refer to this test if this is the first, Enter in days</i>	Number of days_____	[_ _]	

Annex 3. Baseline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
205	How long back did you have your first HIV test? <i>Instructions: Enter 00 if this is the first test</i>	Number of months_____	[__ __]	If 00 skip to Q207
206	Where did you undergo your first HIV test? <i>Instructions: Do not read out categories</i>	<u>Govt. sector</u> MCH/ANC/PPTCT clinic01 ICTC/VCT.....02 STI clinic.....03 Pediatric OPD.....04 Hospital in-patient ward.....05 Pvt. sectorPPTCT/NGO06 ICTC /NGO.....07 Diagnostic center/Lab.....08 Pediatric OPD.....09 Hospital in-patient ward.....10 Other (Specify).....88		
207	What was the test result at the first time?	Positive.....01 Negative.....02 Indeterminate.....03	[__ __]	
208	Is today the day of your appointment to collect your test result?	Yes.....01 No.....02 Don't recall.....98	[__ __]	If 'Yes' skip to Q210
209	By how many days did you delay collecting your test results? <i>Instructions: Enter number of days beyond the date of appointment</i>	Number of Days _____ Don't recall.....98	[__ __]	
210	Who accompanied you to this ICTC today?	Came alone.....00 Spouse/partner.....01 Relative.....02 Friend/neighbor.....03 Others(specify).....88	[__ __]	
211	Have you told your spouse/partner about your going for HIV test?	Yes.....01 No.....02 NA.....95	[__ __]	If no/NA skip to next section
212	Was your partner supportive of your getting tested for HIV?	Yes.....01 No.....02 NA.....95	[__ __]	

SECTION III: QUALITY OF COUNSELLING AND SERVICES AT ICTC

Now I am going to ask you questions about the quality of the services that you have received here, at this ICTC, today

QID	Question	Response options/codes	Coded response	Skip pattern
301	How long did you wait to see the counsellor today?	Less than 30 minutes.....01 30-60 minutes.....02 61-90 minutes.....03 91-120 minutes.....04 More than 120 minutes.....05	[_ _]	
302	Did you have a prior appointment?	Yes.....01 No.....02	[_ _]	
303	<u>Before your blood/sample was taken for testing at this ICTC</u> , did a health care provider or counsellor do the following: <i>Instructions:</i> • <i>Read out each option</i> • <i>Enter codes as follows:</i> Yes.....01 No.....02 No response.....97 Don't recall.....98	Explain that you had a choice to agree to the test or refuse the test.....01 Tell you that your results would not be shared with anyone except for the clinic staff responsible for your care.....02 Explain how the test works.....03 Explain that the test does not always detect a very recent HIV infection (window period).....04 Explain how HIV is transmitted.....05 Give you advice on preventing the spread of HIV.....06 Give you time to ask questions.....07	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	
304	How much time did the counsellor spend with you prior to your HIV test? <i>Instruction: Refers to pre-test counselling</i>	Time (in minutes)	[_ _ _ _]	
305	After giving you your test results, did health care provider do the following: <i>Instructions:</i> • <i>Read out each option</i> • <i>Enter codes as follows:</i> Yes.....01 No.....02 No response.....97 Don't recall.....98	Explain the meaning of the test result01 Recommend that your sexual partner(s) be tested for HIV.....02 Recommend that your children to be tested for HIV.....03 Discuss how to prevent the transmission of HIV.....04 Condom demonstration.....05 Explain about ART.....06 CD4 test.....07 Gave referral slip to ART center.....08	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	

Annex 3. Baseline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
		Inform you about travel concession for reaching ART center.....09	[_ _]	
		Explain about free availability of ART treatment.....10	[_ _]	
		Provide directions to reach ART center11	[_ _]	
		Requirement of identification proof such as ration card, voter ID etc. at ART center.....12	[_ _]	
		Introduced to any PLHA network member.....13	[_ _]	
		Inform you to revisit ICTC after visiting ART center.....14	[_ _]	
306	How much time did the counsellor spend with you after your testing? <i>Instruction: Refers to post-test counselling</i>	Time (in minutes)	[_ _]	
307	After giving you your test results, did health worker talk to you about how to share your status with people around you, e.g. your spouse/partner or other family members?	Yes.....01 No.....02 Don't recall.....98	[_ _]	
308	Did the counsellor give you information about NGOs that provide: Nutrition support, Legal assistance, PLHA networks? <i>Instructions:</i> • <i>Read out responses/options</i>	Nutrition support..... Legal assistance..... PLHA networks.....	[_ _] [_ _] [_ _]	Yes=01 No=02
309	Was counselling done in: <i>Instructions:</i> • <i>Read out responses/options</i> • <i>Enter codes as follows:</i> <i>Enter 01 if Yes, enter 02 if No</i>	A room with a closed door.....01 A cabin separated by cloth or wooden wall.....02 A space where the discussion could not be heard by anyone outside.....03 A space where you were not visible to anyone outside.....04	[_ _] [_ _] [_ _] [_ _]	Yes=01 No=02
310	Did you feel that you were counselled in privacy?	Yes.....01 No.....02	[_ _]	
311	What was the level of interruption – did any one enter the room during the counselling session?	No interruption.....01 Some interruption.....02 A lot of interruption03	[_ _]	

Factors Affecting Enrolment of PLHIV into ART Services in India

QID	Question	Response options/codes	Coded response	Skip pattern
312	Did the counsellor listen attentively to what you had to say?	Counsellor was attentive.....01 Counsellor was somewhat attentive....02 Counsellor was not attentive.....03	[_ _]	
313	Was the counsellor in a hurry to end counselling session?	Counsellor was in a hurry.....01 Counsellor was in somewhat of a hurry02 Counsellor was not in a hurry.....03	[_ _]	
314	Did the counsellor encourage you to ask questions?	Counsellor encouraged questions.....01 Counsellor somewhat encouraged questions.....02 Counsellor did not encourage questions03	[_ _]	
315	Did you find the counsellor friendly, sympathetic?	Yes.....01 Somewhat.....02 No.....03	[_ _]	
316	Did the counsellor criticize your or your spouse's sexual or injecting behaviors?	Yes.....01 Somewhat.....02 No.....03	[_ _]	
317	How satisfied are you with the counselling services?	Very dissatisfied.....01 Dissatisfied.....02 Neither satisfied nor dissatisfied.....03 Satisfied.....04 Very satisfied.....05	[_ _]	
318	How many times did you have to come to this testing center to get your HIV test done?	Number of times_____	[_ _]	If only once, skip to Q320
319	What was the reason for making multiple trips for your HIV test?	Counsellor not present.....01 Lab technician on leave.....02 Told to meet doctor.....03 Kits/supplies out of stock.....04 Visited after working hours.....05 Others (specify).....88	[_ _]	
320	Did you have to make many trips to this testing center to collect your test results?	Yes.....01 No.....02	[_ _]	If no skip to Q322

Annex 3. Baseline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
321	Why did you have to make many trips to collect your test result?	Counsellor not present.....01 Test result not reached.....02 Told to meet doctor.....03 Visited after working hours.....04 Others (specify).....88		
322	Did you have to pay anything at ICTC for your tests?	Yes.....01 No.....02	[__ __]	If No skip to Q401
323	If yes, how much did you have to pay?	Amount in Rupees_____	[_____]	
324	Did you face any problems in getting tested for HIV or in getting your test results? If yes, please explain. <i>Instructions: Record verbatim</i>			

SECTION IV: ACCESS TO ICTCs

QID	Question	Response options/codes	Coded response	Skip pattern
401	From whom did you learn about this testing center (ICTC)?	Doctor.....01 Friends.....02 Spouse/partner.....03 Health worker.....04 Anganwadi worker.....05 Hoarding/poster.....06 Other (specify).....88	[__ __]	
402	Approximately, how many kilometers is this testing center (ICTC) from your place of residence? <i>Instruction: Enter distance in kilometers</i>	Distance in Kilometers_____	[_____]	
403	How did you travel to this facility?	Walked.....01 Rickshaw.....02 Taxi.....03 Own car/transport.....04 Bus.....05 Train.....06 Other (specify).....88	[__ __]	
404	Approx. how long did it take you to get here? <i>Instruction: Enter time in minutes</i>	Time in minutes_____	[__ __]	
405	How much did it cost to get here? <i>Instruction: Enter amount in Rupees</i>	Amount in Rupees_____	Rs. [_____]	
406	Do you know where the government ART center, that the counsellor referred you to, is located?	Yes.....01 No.....02 Don't know.....99	[__ __]	If no/DK skip to Q408
407	Approximately, how many kilometers is the ART center from your place of residence? <i>Instruction: Enter distance in kilometers</i> <i>Enter 99 if does not know</i>	Km_____	Do not Know.....99 [__ __]	
408	When do you plan to visit the ART center that the counsellor referred you to? <i>Instructions:</i> <i>If planning to visit within a month, go to Q411</i> <i>If does not want to visit, go to Q410</i> <i>If planning to visit after a month, go to Q409</i>	Within a week.....01 Within a month.....02 After a month.....03 Will not visit.....04 Can't say.....05	[__ __]	If '01 or 02 or 05' skip to Q411 if '04 skip to Q410

Annex 3. Baseline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
409	Why do you want to visit the referral ART center after a month?	Want another HIV test.....01 Feel fine, do not want to start treatment02 ART centre is very far.....03 No money for travel.....04 No money for treatment.....05 Don't know how to reach ART center06 Will lose job if absent often.....07 HIV is not curable.....08 No one to accompanying me.....09 Fear of disclosure of HIV status.....10 Need to collect identification documents11 Others (specify).....88	[__ __]	All codes skip to Q411
410	Why don't you want to visit the referral ART center?	Want another HIV test.....01 Feel fine, do not want to start treatment02 ART centerr is very far.....03 No money for travel.....04 No money for treatment.....05 Don't know how to reach ART center06 Will lose job if absent often.....07 HIV is not curable.....08 No one to accompanying me.....09 Fear of disclosure of HIV status.....10 Need to provide identification details11 Others (specify).....88	[__ __]	
411	Where do you plan to get your ARV treatment, at a government hospital or a private hospital?	Govt. hospital.....01 Private hospital.....02	[__ __]	If '01' skip to Q413
412	Why do you want to go to private hospital for ART treatment?	Can afford it.....01 For confidentiality.....02 Better quality of services.....03 Nearer to my residence.....04 Others (specify).....05	[__ __]	

QID	Question	Response options/codes	Coded response	Skip pattern
413	The last time you were sick and consulted a health worker, where did you go for treatment (general care and not ART)? <i>Instruction:</i> <i>Refers to general medical care – not ART</i>	PHC/CHC.....01 Government hospital.....02 Pvt. Doctor/Hospital.....03 Traditional healer/Vaidh.....04 Homeopathic practitioner.....05 Others (specify).....88	[_ _]	
414	For common illnesses do you usually first try home remedies before consulting an allopathic doctor?	Yes.....01 No.....02	[_ _]	
415	How often do you use traditional treatments from an ayurvedic, unani, homeopathic or vaidhic practitioner when you fall ill – always, sometimes or never?	Always.....01 Sometimes.....02 Never.....03	[_ _]	

End time:

Thank you for participating!

Annex 4. Informed consent for follow-up interview of ICTC patients registering and not registering at ART centers

Purpose of the study

(Greet the man/woman). My name is _____.
..... The Population Council is conducting a study to learn more about the problems HIV- positive persons face in receiving care and treatment. This study is being supported by the NACO (National AIDS Control Organization), MOH &FW, Government of India. NACO will use this information to improve HIV testing and treatment services for HIV positive persons. Your participation in this study will help NACO to improve the quality of services for you and other people who need treatment for HIV infection.

You were asked for consent to interview while you visited ICTC for counseling. At that time we had asked your consent to be interviewed again in another 3 months. I am once again asking your consent to be interviewed, in private by one of our trained interviewers. The questions will be about your experience in getting treatment, the quality of services at ART centers, how you feel with treatment or reasons for not starting treatment.

Benefits and Risks

If you agree, your participation will help organizations like the ART centers and its staff in addressing PLHA's needs more efficiently. Some of the questions that you will be asked may be sensitive or personal in nature and perhaps make you uncomfortable. The interviewer will not insist on answers to all questions. Your

participation in the study may not benefit you directly. You or your family will not be deprived of any services if you withdraw from participation in this study.

A counsellor is available at any time you would like to receive counsellor's services; either during the interview or after the interview or any other time.

In case someone may have learned of your HIV status when the research team contacted you for the second interview, and you need assistance you can contact the ART counsellor.

Compensation

You will receive Rs 100 towards reimbursement of transport costs.

Offer to answer questions and freedom to withdraw from the study

You can refuse to respond to any question and can stop the interview at any time. You and your family will receive all services, if you decide to drop out of the study. The interview will take approximately 15 minutes. Participation is completely voluntary.

Confidentiality

Everything that you report during the interview will be kept strictly confidential and your name will not be recorded on the questionnaire. All records of your interviews and data collected from medical records will be kept in a safe place under lock and key. These will be destroyed after the completion of the study.

Subject's Statement

I have read the consent document regarding my participation in the study / the consent document regarding my participation in the study has been read out to me. I have read or have been read the above considerations regarding my participation in the study. I have been given a chance to ask any questions

I may have and my questions have been answered to my satisfaction.

I understand that all records will be kept private, will be destroyed after the study and that I can leave the study at any time. My decision not to be in this study or to leave the study will not affect the services I will receive.

I agree to be in this study as a volunteer.

Name of the subject _____

Signature of the subject: _____

Signature of a witness: _____

Date: _____

Date: _____

Annex 5. Understanding the factors affecting enrollment of PLHAs into ART services in India

Follow-up Survey

Interview to be conducted at ART center or in the community

Subject ID			
Sex:	1 Male	2. Female	[__ __]
Interview site	1. Vijayawada	4. Satara	7. Imphal
[__ __]	2. Rajahmundry	5. Bijapur	8. Varanasi
	3. Kolhapur	6. Bagalkot	9. Jaipur
			10. Mehasana
District [__ __]	1. Krishna	4. Satara	7. Imphal
	2. East Godavari	5. Bijapur	8. Varanasi
	3. Kolhapur	6. Bagalkot	9. Jaipur
			10. Mehasana
State [__ __]	1. Andhra Pradesh	3. Karnataka	5. Uttar Pradesh
	2. Maharashtra	4. Manipur	6. Rajasthan
			7. Gujarat
Date on the referral slip	DD/MM/YY	[__ __ __ __ __ __]	
Reference slip number		[__ __ __ __ __ __]	
Referred from ICTC code	1. Nandigama	11. Phaltan	21. Bishenpur
[__ __]	2. Gudivada	12. Patan	22. Azamgarh
	3. Mylavaram	13. Indi	23. Bhadoi
	4. Gokavaram	14. Bagewadi	24. Jaunpur
	5. Mandapeta	15. Muddebihal	25. Sikar
	6. Kadium	16. Jamakhandi	26. Ajmer
	7. Gadingal	17. Badami	27. Alwar
	8. Ichalkarauji	18. Mudhol	28. Palanpur
	9. Kagal	19. RIMS, Imphal	29. Patan, Gujarat
	10. Karad	20. MLSS, Imphal	30. Kadi
Research Interviewer	Name:	Signature:	
Status of Data Collection	1. Completed	2. Refused	3. Incomplete
[__ __]			

Start time [___/___]

SECTION I: BACKGROUND CHARACTERISTICS

All participants complete this section

QID	Question	Response options/codes	Coded response	Skip pattern
101	How many people aged 0-17 are in the household	Enter '00' if None. Enter '05' if 5 and above	[__ __]	
102	What is the household's principal occupation?	Labourers.....01 Others.....02 Professional.....03	[__ __]	
103	Is the residence all pucca (burnt bricks, stone, cement, stone, tiles, and jackboard/cement plastered reeds, timber, galvanized tin or asbestos cement sheets)?	Yes.....01 No.....02	[__ __]	
104	What is the household's primary source of energy for cooking?	None.....00 Firewood & chips/charcoal/.....01 LPG.....01 Others (Specify).....88	[__ __]	
105	Does the household own a television?	Yes.....01 No.....02	[__ __]	
106	Does the household own a bicycle, scooter or motorcycle?	Yes.....01 No.....02	[__ __]	
107	Does the household own an almirah/dressing table?	Yes.....01 No.....02	[__ __]	
108	Does the household own a sewing machine?	Yes.....01 No.....02	[__ __]	
109	How many pressure cookers or pressure pans does the household own?	None.....01 One.....02 Two or more.....03	[__ __]	
110	How many electric fans does the household own?	None.....01 One.....02 Two or more.....03	[__ __]	
111	Does the household own agricultural land?	Yes.....01 No.....02	[__ __]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
112	What is your average monthly household income?	Amount.....	Rs...../-	
113	Who is the primary earning member in your household?	Self..... Spouse..... Parents..... Siblings..... Others.....	.01 .02 .03 .04 .88	[_ _]

SECTION II: CLIENTS REGISTERED AT THE ART CENTER
(Interview conducted at ART Center)

QID	Question	Response options/codes	Coded response	Skip pattern
201	When were you tested for HIV at the ICTC? <i>Instruction: Verify from referral slip</i>	Date of test	--/--/--	
202	When did you collect your test results from that ICTC?	Date of collecting result	--/--/--	
203	Did you undertake another HIV test after the test at the ICTC center where we interviewed you?	Yes.....01 No.....02	[__ __]	If No skip to Q205
204	How many additional HIV tests have you undertaken?	Number -----	[__ __]	
205	Has your spouse/partner been tested for HIV?	Yes.....01 No.....02 N/A.....95	[__ __]	If No or N/A skip to Q208
206	When was your spouse/partner tested for HIV — before or after your test result?	Before my result.....01 After my result.....02 Same time along with my test.....03	[__ __]	
207	What is your spouse's/regular partner's HIV status?	HIV positive.....01 HIV negative.....02 Don't know.....99	[__ __]	
208	How many biological children do you have? <i>Instruction: Enter 00 if none; enter 95 if never married/single</i>	Living..... Dead..... N/A.....95	[__ __] [__ __] [__ __]	If N/A skip to Q212
209	How many of your biological children have been tested for HIV? <i>Instruction: Include only living children Enter 00 if none, Enter 95 if child died, Enter 99 if don't know</i>	Number..... DK.....99 N/A.....95	[__ __] [__ __]	If no or DK skip Q212
210	When was the child (were the children) tested for HIV, before or after your test?	Before my result.....01 After my result.....02 Same time along with my test.....03	[__ __]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
211	Please tell me how many of your children are HIV +ve? <i>Instruction:</i> <i>Include only living children</i> <i>Enter 00 if none of the living children are positive</i> <i>Enter 99 if don't know</i>	Number..... Do not know.....99	[_ _] [_ _]	
Now I would like to ask you a few questions related to your visit (s) to the ART center, the treatment you have received and your views about ART services				
212	When was your first visit to this ART Center?	Date of first visit	--/--/--	
213	When did you register at this ART center?	Date of registration	--/--/--	
214	Have you ever received ART prior to registering at this ART center?	Yes.....01 No.....02		If No skip to Q218/219
215	From where did you obtain ART treatment?	Govt. ART center.....01 Pvt. ART center.....02 NGO.....03 Other (specify).....88	[_ _] [_ _] [_ _] [_ _]	
216	How long did you take ART treatment?	Duration in Months	[_ _ _]	
217	On an average, how much money did you spend per month for ART treatment?	Amount in Rupees.....	Rs...../-	
218	<i>[Check Q202. For respondents who registered at the ART center more than one month after collecting HIV test result]</i> What was the main reason for taking more than a month to register at this ART center? <i>Instruction:</i> <i>Do not read out the options</i> <i>Also record verbatim</i>	Wanted to get another HIV test.....01 Felt fine, did not want to start treatment02 Was busy.....03 ART center very far.....04 No money for travel.....05 Loss of work if absent.....06 No one to accompany me.....07 Away from home on work.....08 Was taking other treatment.....09 Others (specify).....88	[_ _] 	
Verbatim account:				

Factors Affecting Enrolment of PLHIV into ART Services in India

QID	Question	Response options/codes	Coded response	Skip pattern
219	<p>[Check Q202, For respondents who registered at the ART center within one month after collecting HIV test result]</p> <p>What prompted you to register at this ART center within one month?</p> <p><i>Instruction:</i> Do not read out the options Enter 1 if mentioned, Enter 2 if not mentioned Also record verbatim</p> <p>Verbatim account:</p>	<p>Counsellor/ Doctor referred.....01</p> <p>Afraid of HIV/AIDS disease.....02</p> <p>PLHA network member accompanied03</p> <p>Was sick/hospitalised.....04</p> <p>Friends suggested.....05</p> <p>Located in the same place where HIV tested.....06</p> <p>Easy accessible.....07</p> <p>Others (specify).....88</p>	<p>M=1 NM=2</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p>	
220	<p>At this time have you registered at any other government or private or NGO ART center?</p>	<p>Yes.....01</p> <p>No.....02</p>		If no skip to Q223
221	<p>Where all have you registered for ART services?</p> <p><i>Instruction:</i> Do not read out the options Enter 1 if mentioned, Enter 2 if not mentioned] Write the name(s) of center(s) on dotted line</p>	<p>Govt. ART center.....01</p> <p>Pvt. ART center.....02</p> <p>NGO.....03</p> <p>Other (specify).....88</p>	<p>M=1 NM=2</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p>	
222	<p>[if more than one ART center]</p> <p>Why have you registered at more than one ART center?</p> <p><i>Instruction:</i> Enter 1 if mentioned, Enter 2 if not mentioned Also record verbatim</p> <p>Verbatim account:</p>	<p>Quality of medicine.....01</p> <p>Quality of services.....02</p> <p>Availability of free medicine.....03</p> <p>Nearer to place of residence.....04</p> <p>Treatment is good.....05</p> <p>No crowd.....06</p> <p>Privacy.....07</p> <p>Belief that confidentiality will be maintained.....08</p> <p>Others (specify).....88</p>	<p>M=1 NM=2</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p> <p>[_][_]</p>	
223	<p>After your HIV test at the ICTC did you consult an ayurvedic/unani or other vaidh?</p>	<p>Yes.....01</p> <p>No.....02</p>	<p>[_][_]</p> <p>[_][_]</p>	If no skip to Q225

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
224	How much did you pay when you consulted ayurvedic/unani or other vaidhs?	Consultation fee..... Medicines..... Blood test including HIV test..... Other	Rs./- Rs./- Rs./- Rs./-	
225	After your HIV test at the ICTC, did you consult a private allopathic practitioner?	Yes.....01 No.....02	[__ __]	If no skip to Q227
226	How much did you pay when you consulted a private allopathic practitioner?	Consultation fee..... Medicines..... Blood test including HIV test..... Other.....	Rs./- Rs./- Rs./- Rs./-	
227	After your HIV test at the ICTC, have you had a CD4 blood test to see if you need to start ART for your HIV infection?	Yes.....01 No.....02 Don't know.....99	[__ __]	If no skip to Q231
228	Where was the CD4 test undertaken?	At ICTC.....01 Private doctor.....02 At ART center.....03 Self referral to pvt lab.....04 Other (specify).....88	[__ __]	
229	How much did you pay for your CD4 test?	Amount.....	Rs...../-	
230	What was your CD4 count? <i>Instruction:</i> <i>Enter 99 if don't know</i>	Count..... Do not know.....99	[__ __ __]	
231	Are you taking ART medications?	Yes.....01 No.....02 Didn't need it (CD4 count high).....98	[__ __]	If no/don't need skip to Q233
232	Where do you get your ART medications? <i>Instruction:</i> <i>Do not read out options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Govt. ART center.....01 Chemist, purchase-out-of pocket.....02 NGO.....03 Sometimes govt., sometimes private.....04 Others (Specify).....88	[__ __] [__ __] [__ __] [__ __] [__ __]	M=1 NM=2

QID	Question	Response options/codes	Coded response	Skip pattern
233	After your HIV test at the ICTC, did anyone advise you to seek HIV treatment/ART from a private practitioner: a. Private allopathic doctor? b. A private non-allopathic doctor like ayurvedic or unani?	No one.....01 Self.....02 PLHA advised.....03 Family members advised.....04 Tout/agent/dalal/middle man advised05 Others (specify).....88	a) [__ __] b) [__ __]	
234	Did any one inform you that HIV is curable?	Yes.....01 No.....02	[__ __]	
235	Are you taking any other treatments like Vaidhic, unani or homeopathic for your HIV infection?	Yes.....01 No.....02	[__ __]	
236	Please tell me how many of your family members are receiving ART treatment? <i>Instruction:</i> <i>Family includes only spouse and biological children</i>	Number..... [IF NONE ENTER '00']	[__ __]	If '00' skip to Q238
237	Do they receive treatment at this ART center?	Yes.....01 No02	[__ __]	
I would now like to ask you some questions about your experience at this center				
238	How many times did you visit this ART center before you were registered?	Number of visits	[__ __]	If only once skip to Q240
239	What was the reason for making more than one trip to this ART center before registration? <i>Instruction:</i> <i>Do not read out options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Counsellor not available.....01 Lab technician not available.....02 Doctor not available.....03 Had to wait for CD4 counts.....04 Asked to repeat HIV test.....05 Medications out of stock.....06 Long queues.....07 Put on a waiting list.....08 Others (specify).....88	M=1 NM=2 [__ __] [__ __] [__ __] [__ __] [__ __] [__ __] [__ __] [__ __]	
240	Did the ICTC counsellor provide the following to reach the ART center? a. Referral Slip b. Directions	Yes.....01 No.....02	a) [__ __] b) [__ __]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
241	Who accompanied you to this ART center?	Came alone.....01 Family member.....02 Friends.....03 PLHA network member.....04 Outreach worker.....05 Others (specify).....88	[__ __]	If PLHA 04 go to Q242, else skip to Q243
242	Were you introduced to the PLHA network member at the ICTC?	Yes.....01 No.....02	[__ __]	
243	Please tell me: <i>Instruction:</i> <i>Enter 01 if Yes, 02 if No</i>	A) Was the ART Center well marked01 B) Were there clear and visible sign boards showing directions to the ART clinic (so that you did not face problem locating ART center).....02 C) Did staff at the reception or enquiry of hospital know about the ART center.....03 D) Were the hospital staff helpful in assisting you.....04	[__ __] [__ __] [__ __] [__ __]	Yes=01 No=02
244	How did you travel to ART center?	Walked.....01 Rickshaw.....02 Taxi.....03 Own Car.....04 Bus.....05 Train.....06 Others (specify).....88 N/A.....95	[__ __]	
245	Approx. how long did it take you to get to ART center today?	Duration in Minutes	[__ __ __]	
246	How much does it cost, on an average, to travel once to the ART center?	Amount in Rupees	Rs...../-	
247	Did anyone inform you about bus or rail travel concession for HIV patients?	Yes, Bus concession.....01 Yes, Rail concession.....02 No.....03	[__ __] [__ __] [__ __]	If no skip to Q249

QID	Question	Response options/codes	Coded response	Skip pattern
248	Who informed about travel concession?	ICTC counsellor.....01 Doctor at ICTC.....02 Health worker.....03 Advertisement in Radio.....04 Newspapers/magazines.....05 Hoarding/poster.....06 PLHA.....07 Friends.....08 Family members.....08 Others.....88	[__ __]	
249	What is the distance to the ART center from your residence?	Distance in Km.....	[__ __]	
250	What were the problems you faced in reaching here? <i>[Record Verbatim]</i>			
251	Did you have to pay anything for your treatment and tests at this ART center?	Yes.....01 No.....02	[__ __]	If no skip to Q253
252	If Yes, how much did you pay for the following services? <i>Instructions: Read out options</i>	A) Registration B) ARV medicines C) OI medicines D) Radiology-X-rays E) Blood tests including HIV test F) Nutritional supplements G) Unani/Ayurveda/homeo medicines	Rupees A. [____] B. [____] C. [____] D. [____] E. [____] F. [____] G. [____]	
253	How much did you spend on HIV related treatment in the last month? <i>Instructions: Read out options Refers to total expense for each category in the last month</i>	A) Registration B) ARV medicines C) OI medicines D) Radiology-X-rays E) Blood tests including HIV test F) Nutritional supplements G) Unani/Ayurveda/homeo medicines	Rupees A. [____] B. [____] C. [____] D. [____] E. [____] F. [____] G. [____]	
Now I would like to ask few questions related to the counselling services you have received at this ART center.				
254	How long did you wait to see counsellor at the ART center?	Less than 30 minutes.....01 30-60 minutes.....02 61-90 minutes.....03 91-120 minutes.....04 More than 120 minutes.....05	[__ __]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
255	How much time did the ART counsellor spend with you?	Less than 10 minutes.....01 10-20 minutes.....02 20-30 minutes.....03 More than 30 minutes.....04	[_ _]	
256	Did the ART counsellor discuss the following with you? <i>Instruction:</i> <i>Read out each topic</i> <i>Enter 1 if Yes, Enter 2 if No</i>	Preventing transmission of HIV.....01 Reduction of risk behaviour.....02 ART treatment.....03 Nutrition.....04 HIV testing for spouse and children05 Follow-ups.....06 Life-long treatment.....07 Treatment adherence.....08 CD4 count eligibility for ART treatment09 Social support & PLHA network.....10 Others (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	Y=1, N=2
257	How did you find the ART counsellor's attitude towards you: sympathetic or not sympathetic?	Sympathetic.....01 Not particularly sympathetic.....02 Negative.....03	[_ _] [_ _] [_ _]	
258	Did you feel that you had enough privacy during your interaction with the counsellor at this ART center?	Yes.....01 No.....02	[_ _] [_ _]	
259	Did the ART counsellor a. Allow you to ask questions b. Answer your question and clarify all your doubts?	Yes.....01 No.....02	a) [_ _] b) [_ _]	
260	How satisfied are you with ART counsellor's counselling session?	Fully Satisfied.....01 Somewhat Satisfied.....02 Not satisfied.....03	[_ _] [_ _] [_ _]	
Now I would like to ask few questions related to the medical services you have received at this ART center				
261	How long did you wait to see doctor at the ART center?	Less than 30 minutes.....01 30-60 minutes.....02 61-90 minutes.....03 91-120 minutes.....04 More than 120 minutes.....05	[_ _] [_ _] [_ _] [_ _] [_ _]	

QID	Question	Response options/codes	Coded response	Skip pattern
262	How much time did the doctor spend with you?	Less than 5 minutes.....01 5-10 minutes.....02 10-20 minutes.....03 20-30 minutes.....04 More than 30 minutes.....05	[_ _]	
263	Did the doctor discuss the following with you? <i>Instruction:</i> <i>Read out each topic</i> <i>Enter 1 if YES, Enter 2 if NO</i>	Preventing transmission of HIV/AIDS0101 Condom use.....02 Reducing risk behaviour.....03 HIV testing for spouse and children04 ART treatment.....05 Life-long treatment.....06 Importance of treatment adherence07 CD4 count eligibility for ART treatment.08 Nutrition.....09 Social support & PLHA Network.....10 Others (specify).....88	Y=1 NO=2 [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	
264	How did you find the doctor's attitude towards you: sympathetic, not sympathetic?	Sympathetic01 Not particularly sympathetic.....02 Negative.....03	[_ _]	
265	Did the doctor a. Allow you to ask questions b. Answer your questions and clarify all your doubts?	Yes.....01 No.....02	a) [_ _] b) [_ _]	
266	How satisfied you are with the doctor's consultation?	Fully satisfied.....01 Partially satisfied.....02 Not satisfied.....03	[_ _]	
267	Did anyone inform you about the availability of free ARV medicines at government ART centers?	Yes.....01 No.....02	[_ _]	If no skip to Q269
268	Who informed about the availability of free ARV medicine at government ART centers?	ICTC counsellor.....01 Member of PLHA Network.....02 ART counsellor/Doctor.....03 Family member.....04 Others (specify).....88	[_ _]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
269	Were you told to go back to ICTC for follow-up visit?	Yes.....01 No.....02	[_ _]	
270	Were you given any referral slip to hand over at the ICTC center at the time of return visit?	Yes.....01 No.....02	[_ _]	
271	Were you told within what time period you have to go for follow-up to ICTC?	Yes.....01 No.....02	[_ _]	
Now, I would like to ask you few questions related to your Identification information to be provided at ART Center				
272	Have you been asked to provide identification information at ART center?	Yes.....01 No.....02	[_ _]	If no skip to Q275
273	What identification information were you asked to provide at this ART center? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Voter identity card.....01 Other photo identity card.....02 Ration card.....03 Permanent address/affidavit/certificate04 Phone number.....05 Contact details of references.....06 Care giver's address and details.....07 Others (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2
274	Do you feel 'uncomfortable' in providing the identification information at the ART center?	Yes.....01 No.....02	[_ _]	If no skip to Q277
275	Providing what identification information made you feel uncomfortable? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Voter identity card.....01 Any other photo identity card.....02 Ration card.....03 Permanent address/affidavit certificate04 Phone number.....05 Contact details of references.....06 Care giver's address and details.....07 Others (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2

QID	Question	Response options/codes	Coded response	Skip pattern
276	Why were you uncomfortable in providing identification information at this ART center? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Fear of disclosure.....01 Don't trust the staff at ART center.....02 Friends would come to know of my status.....03 People would discriminate.....04 Family members will come to know about status.....05 Fear of misuse of identification information.....06 Others (specify).....88	M=1 NM=2 [] [] [] [] [] [] [] [] [] [] [] [] [] []	
277	Are you comfortable with an out-reach worker visiting you at home to verify your identification information, if required by the ART center?	Yes.....01 No.....02	[] [] [] []	

SECTION III: UNREGISTERED CLIENTS

(To be interviewed in the community)

This section does apply to clients who registered at referral ART center

QID	Question	Response options/codes	Coded response	Skip pattern
301	When were you tested for HIV at the ICTC? <i>Instruction:</i> <i>Verify from referral slip</i> <i>If slip not available record month and year</i>	Date of test Month/Year	--/--/-- --/--/--	
302	When did you collect your test results from that ICTC?	Date of collecting result	--/--/--	
303	Did you undertake another HIV test after the test at the ICTC center where we interviewed you?	Yes.....01 No.....02	[__ __]	If No skip to Q305
304	How many additional HIV tests have you undertaken?	Number -----	[__ __]	
305	Has your spouse/partner been tested for HIV?	Yes.....01 No.....02 N/A.....95	[__ __]	If No or N/A skip to Q308
306	When was your spouse/partner tested for HIV — before or after your test result?	Before my result.....01 After my result.....02	[__ __]	
307	What is your spouse's/regular partner's HIV status?	HIV positive.....01 HIV negative.....02 Don't know.....99		
308	How many biological children do you have? <i>Instruction:</i> <i>Enter 00 if none</i> <i>Enter 95 if never married/ single</i>	Living..... Dead..... N/A.....95	[__ __]	If N/A skip to Q312
309	How many of your biological children have been tested for HIV? <i>Instruction: Include only living children</i> <i>Enter 00 if none</i> <i>Enter 95 if child died</i> <i>Enter 99 if don't know</i>	Number..... DK.....99 N/A.....95	[__ __]	
310	When was the child (were the children) tested for HIV, before or after your test?	Before my result.....01 After my result.....02	[__ __]	

QID	Question	Response options/codes	Coded response	Skip pattern
311	Please tell me how many of your children are HIV positive? <i>Instruction:</i> <i>Enter 00 if none are positive</i> <i>Enter 99 if don't know</i>	Number..... Don't know.....99	[__ __] [__ __]	
Now I would like to ask few questions related to HIV treatment (ART Services)				
312	After your HIV test at the ICTC center, have you consulted any doctor about HIV treatment or ART?	Yes.....01 No.....02	[__ __]	If no skip to Q314
313	If yes, who have you consulted	Private allopathic doctor.....01 Government allopathic doctor.....02 Ayurvedic/yunani/vaidh.....03 Others (specify).....88	[__ __]	
314	Have you registered anywhere for ART services?	Yes.....01 No.....02	[__ __]	If YES skip to Q316
315	Why have you not registered any where for ART services and HIV care? <i>Instruction:</i> <i>Also record verbatim</i>	Wanted to get another HIV test.....01 Felt fine, did not want to start treatment.....02 Was busy.....03 ART center very far.....04 No money for travel.....05 Loss of work if absent.....06 No one to accompany me.....07 Fear of disclosure.....08 Family members opposed.....09 Others (specify).....88	[__ __]	Skip to Q320
Verbatim account:				
316	Where all have you registered for ART services? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Govt. ART center.....01 Pvt. ART center.....02 NGO.....03 Other (specify).....88	M=1 NM=2 [__ __] [__ __] [__ __] [__ __]	If only one response skip to Q318
317	Why have you registered at more than one ART center? <i>Instruction: Check if more than one response in the previous question</i> <i>Also record verbatim</i>			

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
318	Where is/are the ART center/s located – where you registered?	Place name:..... Place name:.....		
319	<i>[Check Q316 before asking]</i> If accessing care in a private center, what is the main reason for going to a private practitioner for HIV care and ART? <i>Instruction:</i> <i>Record Verbatim</i>	Quality of care is better.....01 Quality of medicines is better.....02 Closer to my home.....03 Confidentiality.....04 I can afford it.....05 Family pressure.....06 Doctor is good.....07 PLHA suggested.....08 No need to provide identification.....09 Less crowded.....10 Others (Specify).....11	[_ _]	
	Verbatim account:			
320	What was the reason for not registering at the government ART? <i>[(Check Q316 ≠ 1 OR Q316=1 but not the Concerned ART selected for our study, then ask)]</i> <i>[Record Verbatim]</i>	Wanted to get another HIV test.....01 Felt fine, did not want to start treatment02 Was busy.....03 ART center very far.....04 No money for travel.....05 Loss of work if absent.....06 No one to accompany me.....07 No confidentiality.....08 Fear of disclosure as others from my area take treatment there.....09 Family members opposed.....10 Lost the referral slip.....11 No one told me/no referral provided02 Don't want to provide identification details.....13 Too crowded.....14 Others (specify).....88	[_ _]	
	Verbatim account:			
321	After the test at the ICTC did you consult any ayurvedic/unani or other vaidh?	Yes.....01 No.....02	[_ _]	If No skip to Q323
322	How much did you pay when you consulted ayurvedic/unani or other vaidh?	Consultation fee..... Medicines..... Blood test including HIV test..... Other.....	Rs./- Rs./- Rs./- Rs./-	

Factors Affecting Enrolment of PLHIV into ART Services in India

QID	Question	Response options/codes	Coded response	Skip pattern
323	After your HIV test at the ICTC, did you consult a private allopathic practitioner?	Yes.....01 No.....02	[__ __]	If no skip to Q325
324	How much did you pay when you consulted a private allopathic practitioner?	a) Consultation fee.....01 b) Medicines.....02 c) Blood test including HIV test.....03 d) Others (specify).....88	Rs./- Rs./- Rs./- Rs./-	
325	Were you informed about the availability of free ARV medicine at govt ART centers?	Yes.....01 No.....02	[__ __]	
326	Were you given a referral slip for the ART center by the counsellor at ICTC center?	Yes.....01 No.....02	[__ __]	
327	Have you had a CD4 blood test to see if you need to start ART for your HIV infection?	Yes.....01 No.....02 Don't know.....99	[__ __]	If no or DK skip to Q332
328	Where was the CD4 test done?	At ICTC.....01 Private doctor.....02 At ART center.....03 Self referral to pvt lab.....04 Other (specify).....88	[__ __]	
329	What was your CD4 count? <i>Instruction:</i> <i>Enter 999 if don't know</i>	Count..... Do not know.....999	[__ __ __]	
330	How much did you pay for your CD4 test?	Amount.....	Rs...../-	
331	Did the counsellor at the ICTC inform you about the need for taking a CD4 blood test?	Yes.....01 No.....02	[__ __]	
332	Are you taking ART medications?	Yes.....01 No.....02 Don't need it (CD4 count high).....98 N/A, not registered.....95 Don't know.....99	[__ __]	If not 'yes' skip to Q334
333	Where do you obtain your ART medications? <i>Instruction:</i> <i>Do not read out options</i>	Govt. ART center.....01 Chemist, purchase-out-of pocket.....02 NGO.....03 Sometimes govt., sometimes private...04 Others (Specify).....88	[__ __]	

Annex 5. Endline Survey Questionnaire

QID	Question	Response options/codes	Coded response	Skip pattern
334	How much did you spend on HIV related treatment last month? <i>Instruction:</i> <i>Refers to total expense for a month for each category</i>	A) ARV medicines B) OI medicines C) Radiology-X-rays D) Blood tests E) Nutritional supplements F) Consultation fees G) Other (specify)	A. [__ __] B. [__ __] C. [__ __] D. [__ __] E. [__ __] F. [__ __] G. [__ __]	
335	After your HIV test at the ICTC, did anyone advise you to seek HIV treatment/ART from private practitioner? a. Private allopathic doctor? b. A non-allopathic doctor?	No one advised.....01 PLHS advised.....02 Family members advised.....03 Unknown persons advised.....04 Others (specify).....05	a) [__ __] b) [__ __]	
336	Did any one inform you that HIV is curable?	Yes.....01 No.....02	[__ __]	
337	Are you taking any other treatments like Vaidhic, unani or homeopathic for your HIV infection?	Yes.....01 No.....02	[__ __]	
338	Please tell me how many of your family members are receiving ART treatment? <i>Instruction:</i> <i>Family includes only spouse and biological children</i>	Number..... N/A no family.....95 N/A no HIV positive family members95	[__ __]	If '00' skip to Q340
339	Where do they get ART medications? <i>Instruction:</i> <i>Do not read out options</i> <i>Enter '01' if mentioned '02' if not mentioned</i>	Govt. ART center.....01 Chemist, purchase-out-of pocket.....02 NGO.....03 Sometimes govt., sometimes private04 Others (Specify).....88	[__ __] [__ __] [__ __] [__ __] [__ __]	M=1 NM=2
340	After your HIV test, did the ICTC counsellor provide the following? a. Referral Slip for the ART center b. Directions to reach ART center	Yes.....01 No.....02	a) [__ __] b) [__ __]	
341	Were you introduced to a PLHA network member at the ICTC?	Yes.....01 No.....02	[__ __]	

QID	Question	Response options/codes	Coded response	Skip pattern
342	Did anyone in the ICTC inform you about bus or rail travel concession for HIV patients?	Yes, Bus concession.....01 Yes, Rail concession.....02 No.....03	[__ __]	
343	What is the approximate distance to ART center from your residence?	Distance in kms	[__ __ __]	
344	Did you go back to ICTC after testing?	Yes.....01 No.....02	[__ __]	
345	Are you comfortable with an out-reach worker or member of the PLHA network visiting you at home?	Yes.....01 No.....02	[__ __]	

SECTION IV: MESSAGES ON PREVENTION AND TREATMENT SEEKING BEHAVIOUR
All participants complete section IV

QID	Question	Response options/codes	Coded response	Skip pattern
401	What messages on prevention of HIV transmission did you receive at the ICTC center? <i>Instruction:</i> <i>Read out each option</i> <i>Enter 01 if Yes, 02 if No</i>	Preventing of HIV/AIDS.....01 Condom use.....02 Reducing risk behaviour.....03 Recommend that your sexual partner(s) be tested for HIV.....04 Recommend that your children to be tested for HIV.....05 Condom demonstration.....06 Others (specify).....88	Yes=1 No=2 [] [] [] [] [] [] [] [] [] [] [] [] [] []	
402	How useful were these prevention messages? Would you say they were: useful, somewhat useful or not useful?	Useful.....01 Somewhat useful.....02 Not useful.....03 Wasn't in frame of mind to listen.....04 Did not pay attention.....05	[] [] [] [] [] [] [] [] [] []	
403	Were you given any printed materials related to a. Prevention of HIV transmission b. ART treatment	Yes.....01 No.....02	a) [] [] b) [] []	If no to both skip to Q406
404	What messages did the printed materials given to you contain? <i>Instruction:</i> <i>Read out each option</i> <i>Enter 01 if Yes, 02 if No</i>	Preventing of HIV/AIDS transmission01 Condom use.....02 HIV testing for spouse and children...03 ART treatment.....04 CD4 count eligibility for ART treatment.05 Nutrition.....06 Social support & PLHA network.....07 Follow-ups to the ICTC center.....08 Others (specify).....88	Yes= 01 No= 02 [] [] [] [] [] [] [] [] [] [] [] [] [] [] [] []	
405	How useful were these prevention messages on the printed materials? Would you say they were: useful, somewhat useful or not useful?	Useful.....01 Somewhat useful.....02 Not useful.....03	[] [] [] [] [] []	

QID	Question	Response options/codes	Coded response	Skip pattern
406	Would you like to receive some printed material?	Yes.....01 No.....02	[__ __]	
Now I would like to ask few questions related to your treatment seeking behaviour				
407	Where do you go for general illnesses – govt. hospital or private doctor?	Govt. hospital.....01 Private doctor.....02 Sometimes govt., sometimes private...03 Ayurveda doctor.....04 Vaidh/hakim.....05 Others (specify).....88	[__ __]	
408	Why do you use this provider?	Takes time to explain.....01 Understands my situation.....02 Can ask questions.....03 Close to home.....04 Always used this doctor.....05 Others(specify).....88	[__ __]	
409	The last time you consulted a health practitioner did you inform them of about your HIV status?	Yes.....01 No.....02 N/A.....03	[__ __]	

SECTION 5: SOCIAL SUPPORT AND DISCLOSURE

All participants to complete this section

QID	Question	Response options/codes	Coded response	Skip pattern
501	Have you disclosed your HIV status to anyone?	Yes.....01 No.....02	[_ _]	If no skip to Q503
502	If yes, who have you disclosed your status to? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Partner/spouse.....01 Parent.....02 Sibling.....03 Other relatives.....04 Friends.....05 Neighbours/community members.....06 Other (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2
503	Do you regret disclosing your HIV status?	Yes.....01 No.....02	[_ _]	If no skip to Q505
504	Why do you regret disclosing of your HIV status? <i>Instruction:</i> <i>Also record verbatim</i>	Lost job.....01 Had to move residence.....02 Family secluded me.....03 Friends excluded me.....04 Others (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _]	
	Verbatim account:			
505	In general, how satisfied are you with the overall support (help) you get from your family? <i>Instruction:</i> <i>If no family and staying alone, enter N/A</i>	Not satisfied.....01 Moderately satisfied.....02 Very satisfied.....03 N/A.....95	[_ _] [_ _] [_ _] [_ _]	
506	Do you receive support from outside your home or family members?	Yes.....01 No.....02	[_ _]	If no skip to Q508
507	From where do you get support? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Friends.....01 NGO.....02 Community based organization.....03 Religious based organization.....04 Government facility.....05 Workplace programs.....06 Others (specify).....07	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2

Factors Affecting Enrolment of PLHIV into ART Services in India

QID	Question	Response options/codes	Coded response	Skip pattern
508	Are you a member of any PLHA net work?	Yes.....01 No.....02	[_ _]	
509	What is your greatest worry/fear after learning that you are HIV positive? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 1 if mentioned, Enter 2 if not mentioned</i>	Spouse/partner will get to know.....01 Child testing HIV positive.....02 Death.....03 Ability to work and make money.....04 Meeting medical expenses.....05 Not being around to take care of family06 No worries.....07 Others (specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2
510	Do you know any other people in your community who are HIV infected?	Yes.....01 No.....02	[_ _]	If no Skip to Q513
511	How many households in your community do you know where at least one family member is HIV positive? <i>Instruction:</i> <i>Enter 00 if does not know any household</i>	Number.....	[_ _]	If 00 skip to Q601
512	Do you know if all of them are registered at some ART center and taking ART treatment?	Yes, all registered.....01 No, some not registered.....02 Do not know if registered or not.....99 N/A.....95	[_ _] [_ _] [_ _] [_ _]	If 01 skip to Q601
513	What are the reasons, why PLHAs in your community have not registered at ART centers for treatment? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 01 if mentioned, Enter 02 if not mentioned</i>	Do not consider ARTs useful.....01 ART may cause side effects.....02 ART is expensive.....03 Have not heard of treatment.....04 Treatment not available in our community.....05 Fear of stigma.....06 Others(specify).....88	[_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _] [_ _]	M=1 NM=2

SECTION VI: EXPERIENCES AT ART CENTER – STIGMA/DISCRIMINATION

QID	Question	Response options/codes	Coded response	Skip pattern
601	How comfortable are you discussing your health concerns with clinic staff outside ART center, given your HIV status?	Not at all comfortable.....01 Moderately comfortable.....02 Completely comfortable.....03	[__ __]	
602	How satisfied are you with your access to health services given your HIV status, satisfied, somewhat satisfied or not satisfied?	Satisfied.....01 Somewhat satisfied.....02 Not satisfied.....03	[__ __]	
603	Did you or any of your family members have a negative experience with health workers/ medical practitioners because of HIV status?	Yes.....01 No.....02 DK.....99	[__ __]	If not 'yes, skip to Q605
604	If yes, what was the negative experience from health workers/practitioners?	Spoke rudely.....01 Made to wait.....02 Made derogatory comments/remarks.....03 Others (specify).....88	[__ __]	
605	How accepting is your community/village of HIV positive members?	Not at all.....01 Moderately.....02 Completely.....03	[__ __]	
606	Did you or any of your family members have a negative experience in the community because of your/their HIV status?	Yes.....01 No.....02 NA.....95	[__ __]	If no end the interview
607	If yes, what did you/your family member's experience? <i>Instruction:</i> <i>Do not read out the options</i> <i>Enter 01 if mentioned, Enter 02 if not mentioned</i>	Were not invited to social function.....01 Children not allowed to play with other children.....02 People/neighbours stopped talking to us.....03 Refused use of common water resources.....04 Asked to leave the village/community.....05 Others(specify).....88	[__ __] [__ __] [__ __] [__ __] [__ __] [__ __]	M=01 NM=02

End time [-----]

Thank you for participating

