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COMMUNITY MONITORING OF ART DRUGS AND HIV/AIDS SERVICES: A REPORT

ANDHRA PRADESH, KARNATAKA,
MAHARASHTRA, TAMIL NADU, TELANGANA

MAY 2015-APRIL 2016



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Abbreviations

AIDS - Acquired Immuno Deficiency Syndrome

ART - Anti Retroviral Treatment

CBO - Community-based Organization

CD4 - Cluster of Differentiation 4

CLHIV - Children Living with HIV/AIDS

CSO - Civil Society Organization

DAPCU - District AIDS Prevention and Control Unit

DNP - Delhi Network of Positive People

FSW - Female Sex Workers

GH - Government Hospital

Hb - Haemoglobin

HSV - Herpes Simplex Virus

HIV - Human Immunodeficiency Virus

ICTC - Integrated Counseling and Testing Centre

ICDS - Integrated Child Development Scheme

MSM - Men who have Sex with Men

MARP - Most At Risk Population

NGO - Non Governmental Organization

NACO - National AIDS Control Organization

NACP - National AIDS Control Program

NHM - National Health Mission

OIs - Opportunistic Infections

PLHIV - People Living with HIV/AIDS

PPTCT - Prevention of Parent to Child Transmission

PCR - Polymerase Chain Reaction

PWN - Positive Women's Network

RTI - Reproductive Tract Infections RFT - Renal Function Test

STI - Sexually Transmitted Infections

TG - Transgender

TLE - Tenofovir Lamivudine Efavirenz

TB - Tuberculosis

TI - Targeted Intervention

VCAN - We Community Action Network

WHO - World Health Organization

ZLN - Zidovudine Lamivudine Nevirapin

Executive Summary

Community-based monitoring enables local communities to evaluate the health services available to them and generate appropriate information regarding bottlenecks that come in the way of quality service delivery.

The idea of engaging community members as potential monitors was drawn from the experience of the Community Action for Health driven by the Advisory Group of Community Action (AGCA). This pilot effort by CFAR was focused on people living with and affected by HIV, including Most at Risk Populations (MARPs) who are experiencing the same set of issues and concerns that public health service users across different parts of the country have faced over many years.

BACKGROUND

The National AIDS Control Program (NACP) is a program that is premised and founded on a high level of community involvement, participation and engagement. In 2014, when funding for AIDS control was drastically reduced, we found that there was a growing disquiet among People Living with HIV (PLHIVs) across the country regarding stock-out or shortage of drugs, the uneven quality of services, lack of equipment and inadequate staff in ART Centers and sub-centers. We realized that the resilience and morale of the treatment seeker and patient was as vital as an efficient supply chain to ensure both unflinching treatment adherence as well as effective management of HIV.

On October 15, 2014, a meeting was held between senior officials of National AIDS Control Organization (NACO) led by Mr. K B Agarwal, Joint Secretary, NACO and representatives of civil society organizations (CSOs), where it was decided that CSOs would monitor the services on the ground and inform NACO about the actual situation on stock-outs and erratic supplies on a real time basis. On 28 November 2014, at a second meeting held at NACO, it was decided that a more structured framework on community monitoring should be developed, which was done with the help of the experts including those involved in community monitoring under the National Rural Health Mission.

OBJECTIVES

1. To document the experiences of ART users and their assessment of the extent of shortage of drugs and diagnostics.
2. To assess its effect on treatment adherence and the health seeking behavior of users.
3. To facilitate remedial action on the ground to strengthen ART adherence and reduce any types of discontinuation of ART use.
4. To evolve ways of institutionalizing an internal mechanism and process to make community-led feedback integral to care, support and treatment services.

METHODOLOGY

Three community representatives were selected from each of the three districts in Andhra Pradesh, Karnataka, Maharashtra and Tamil Nadu, and one district in Telangana. They

represented female sex workers (FSW), transgenders, MSM (men who have sex with men), and PLHIV. They were trained by experts for over 1½ months on how to roll out the program, how to conduct interviews and so on.

Questionnaires to assess availability of and convenience in securing ART, medication for opportunistic infections (OI), diagnostics and to identify related concerns were created for five categories — sex workers, MSM, transgender, adult, antenatal and postnatal women, and children. The five formats were almost similar in design and included two components. One documented the respondents' feedback on the line of treatment, the availability or difficulty they faced in getting ART drugs and access to diagnostics and services. The second component looked at the effects in terms of economic and psycho-social stress and the management of HIV.

The structured exercise of community monitoring was piloted in Maharashtra in April 2015 and initiated in the same month in five states: Tamil Nadu, Karnataka, Maharashtra, Andhra Pradesh and Telangana.

Over a period of twelve months, the community monitors reached out to a total of 2925 respondents. They administered the questionnaires through purposive sampling (exit interviews at ART centers as well as CBOs). They were able to collect information from users registered at 35 ART centers. The data collected was analyzed using the SPSS software and the findings were systematically processed.

KEY FINDINGS

The findings from the pilot study showed that the shortages and erratic supply of ART drugs were impacting ART users differently and what was common to all was the growing uncertainty.

The one-year study showed clearly that the stock-outs, erratic supply and the side effects often caused by the subsequent regimen change, concurrent with the lack of adequate counseling services, had forced many of the respondents to discontinue ART use.

Of the ART users, 97 percent of the adult population were on first line regimens and three percent on second line regimens.

Drug shortages and access to medicines and tests

Experiencing acute shortage and erratic supply of ART drugs

Sixteen percent respondents across all categories had experienced acute shortage of ART drugs to the extent of returning home empty-handed after at least one visit to the ART center. The number of visits ranged from twice to five times a month. Many received reduced amounts of drugs during a visit. Sixty percent of the respondents were women, who had to suffer a significant loss in wages and 14 percent of them were children who had to rely on their grandparents and other adults to collect the drugs.

A total of seven percent of respondents did not receive the same drugs that they were taking before, though 71 percent of them were told it was the same drug.

Access to medication for opportunistic infections

Sixteen percent of people had opportunistic infections over the last one year and 53 percent respondents accessed OI medication.

CD4 Test

Of the respondents, 83 percent have done CD4 test twice and more times and 16 percent of respondents have done CD4 once in the last one year. Only one percent of respondents have not done CD4 tests.

Viral Load test

Eleven percent of respondents had heard of Viral Load test and only six percent were referred for the tests.

Pap Smear/ Vivali Test

Out of 757 women who were eligible for Pap Smear only 173 were referred for the test.

To assess the effect of shortages on treatment adherence and health-seeking behaviour of users

Side effects

Almost 30 percent of the total respondents suffered from side effects of the ART drugs.

Discontinuation

Thirteen percent of respondents discontinued ART for different lengths of time.

A key finding was that almost all of those who had discontinued treatment were counseled and facilitated by the community monitors to start treatment again.

RECOMMENDATIONS

- Restore adequate funding for HIV/AIDS programmes, especially to ensure that there are no stock-outs or shortages of drugs and tests, as well as resource persons including counselors to prevent uncertainty, confusion and discontinuation of ART use among the PLHIV.
- Facilitate remedial actions to be carried out in consonance with the service providers to strengthen ART adherence and reduce any types of discontinuation of ART use.

Community Monitoring of ART Drugs and HIV/AIDS Services

INTRODUCTION

Community-based monitoring (CBM) enables local communities to evaluate the health services available to them and generate appropriate information regarding bottlenecks that come in the way of quality service delivery. If the monitoring mechanism is institutionalized, it can, in the long run, also strengthen local decision-making that can solve problems at a district/sub-district level, improve community capacity and effective participation in local governance and help government health facilities to improve the health outcomes in their area.

The idea of engaging community members as potential monitors was drawn from the experience of the Community Action for Health driven by the Advisory Group of Community Action (AGCA), constituted under the National Health Mission (NHM) to provide technical and other inputs on how to implement NHM programs wherever community action was envisaged. While there are many case studies and community participation projects to learn from, this pilot effort by CFAR was focused on people living with and affected by HIV, including Most at Risk Populations (MARPs) who are experiencing the same set of issues and concerns that public health service users have faced over

It is not enough to only ask people to take ART and do a mere follow up of the people who have stopped taking ART. This will not make a difference unless the real factors forcing them to discontinue ART are addressed. The community monitoring is an important and serious work which requires not only understanding about the subject but the will to ensure all those who need ART are on the treatment and are able to access all the services as per the NACO treatment guidelines.

- Ms. Kousalya, President, Positive Womens Network

many years and across different parts of the country.

In a major path breaking move that is considered as a milestone in ART in India, NACO, on 1st April 2004, started disseminating free ART at six centers in high prevalence states. The initiative proved to be a vital step in clearing a major hurdle in availability and accessibility to the treatment. Since then the program has been scaled up and operational guidelines for ART services have undergone several changes as per the requirement. Various stakeholders have put in tremendous efforts to make ART a success. Targeted Interventions (TI), Positive People's Network, NGOs, doctors and counselors at District AIDS Prevention and Control

Unit (DAPSUs) and the State AIDS Control Societies (SACS) have made it possible to disperse ART in all parts of India. In last 12 years free ART has been accessed by over 768,000 PLHIV through 1,251 ART and Link ART centers. Today, a majority of PLHIVs are registered for preART and they are accessing free ART and related services in government hospitals.

However, recent years have seen a regression. Donor funding for the HIV response in low- and middle-income countries declined by almost 13% between 2014 and 2015¹. In India, this decline in funding, compounded by delays in issuing tenders and notification of awards, has resulted in stock-outs and erratic supply of drugs, diagnostic kits, and basic commodities like condoms, which have hindered access to effective prevention and treatment. In such situations, community monitoring can act as an early warning mechanism to provide data on areas that require immediate attention and follow-through.

Ultimately, community-based monitoring is a tool to facilitate more inclusive decision-making on issues that are important to members of a community, and can be expanded beyond health to other issues such as education, women's safety, nutrition, and so on.

BACKGROUND

In view of the many reports coming in from different parts of the country about stock-outs and erratic supply of ART medicines, the uneven quality of services, lack of equipment and inadequate staff in ART centers and sub-centers, a meeting was held on 15 October 2014 between senior officials of the National AIDS Control Organization (NACO) led by Mr. KB Agarwal, Joint Secretary, NACO and representatives of civil society organizations (CSOs). At the meeting it was decided that CSOs would monitor the services on the ground and inform NACO about the actual situation on stock-outs and erratic supply on a real time basis.

¹ UNAIDS and the Henry J Kaiser Family Foundation (2016) "Financing the Response to HIV in low- and middle- income countries: International Assistance from Donor Governments in 2015"

THE KEY PILLARS OF COMMUNITY MONITORING

Community monitoring is an integral part of the public healthcare system not only in moments of crisis, disaster and stock-outs but also in ensuring convergence and cohesion between the provider and users.

Recognize that the intent of community monitoring is preventive. In the case of chronic disease management where adherence to regimen and compliance with the due procedures is at the core of any public health investment, even minor disruptions can prove deleterious.

If the monitoring is done with the understanding that the feedback can be used to do timely course correction then enabling community monitors to do remedial action becomes integral to the exercise.

In the last week of November, we informed NACO of the concern around stock-outs of ART and furnished a list of 106 ART users from nine states who faced stock-outs. We also presented a memorandum. A copy of the memorandum was submitted to Prime Minister's Office.

It was decided at the November meeting that a more structured framework on community monitoring should be developed. As a first step, around 40 community members representing various networks and organizations of people living with and most vulnerable to HIV came together on 27-28 November 2014, to deliberate on the various dimensions of the issue and clarify the scope and content of the initiative.

While this required a shared understanding of treatment regimens, prophylaxis and diagnostics that were being made available by NACO to those living with HIV, it was equally important to understand the anxieties about drug 'stock-outs' and shortages being expressed by PLHIVs (directly and indirectly through the media).

The feedback from PLHIVs across states made it clear that to develop any meaningful strategy to mitigate or address such crisis we needed to go beyond an anecdotal and case study approach and do a more systematic community monitoring study to understand the happenings on the ground and how the shortages of ART medicines and services were affecting users in different ways.

We realized that the resilience and morale of the treatment seeker and respondent were as vital as an efficient supply chain to ensure both unflinching treatment adherence as well effective management of HIV.

We felt the need for an internal mechanism and process to monitor both the quality of service provisioning and its uptake and our joint ability to handle the crisis, unexpected developments and even disasters.

OBJECTIVES OF COMMUNITY MONITORING

1. To document the experience and the ART users assessment of the extent of the shortage of ART medicines and diagnostics.
2. To assess its effect on treatment adherence and the health seeking behaviour of users.
3. To facilitate remedial action on the ground to strengthen ART adherence and reduce any types of discontinuation of ART use.



Community monitors being trained at Bangalore

The community monitors explain what motivated them to undertake this rigorous exercise for a year and at a time when their peers were in despair and their overall morale was low.

According to Udaya Kumari, Bengaluru, “As we all know, the focus on HIV program is declining. It is evident in all ART centers. Earlier ART counsellors used to give individual counselling to all ART users. But, nowadays in our experience the majority of ART counsellors don’t have time to counsel as all centers in Bengaluru get nearly 200 to 300 PLHIVs daily. There is a need to educate the ART users on regular basis. Children do not get child-friendly counseling in the ART centres.”

Ayesha, a sex worker who is also living with HIV stated, “ART treatment is our right. We are asking the government to ensure that the treatment education reaches each and every PLHIV of the most vulnerable groups”

Sangita, a sex worker from Kolhapur, mobilizes positive sex workers for monthly meetings and takes them to the CPR, government hospital. She said, “doctors deny surgeries, delivery, even dental treatment once they realize that patient is HIV positive, they are not even providing ART drugs on time. We will have to stop this as a break in treatment has a very serious effect on women’s lives.”

4. Evolve ways of institutionalizing an internal mechanism and process to make community-led feedback integral to care, support and treatment services.

METHODOLOGY

Recognizing the importance of the issue, a group of people representing different networks volunteered to systematically work on the framework and the format of the questionnaire. Questionnaires to assess the availability and convenience in securing ART, OI medication, diagnostics and to identify related concerns were created in five formats — for sex workers, MSM and transgenders, adults, antenatal and postnatal women and children living with HIV (Annexure I).

All the five formats included two components: the first documented the respondent’s feedback on the line of treatment, the availability or difficulty they faced in getting ART medicines and access to diagnostics and services like counseling and the provisional arrangements that had been made, if any. This meant recalling the period when ART medicines were given for shorter periods of time; respondents were given less dosage and asked to come more frequently to collect ART, the delays or interruptions in diagnostic tests and of being advised to procure referrals to other facilities on their own. The second component looked at the effects in terms of economic and psycho-social stress and the management of HIV. This included their feedback on any regimen change they had gone through, of being advised on the side effects that they faced, the decision they took to



Capacity building of community monitors at Bangalore

The findings from the pilot study showed that the shortages of ART drugs was impacting ART users differently and what was common to all was the growing uncertainty.

discontinue, for what reasons and for how long. The formats differed slightly when it came to recording queries on reproductive tract infections (RTI) and sexually transmitted infections (STI) depending on the typology, i.e. women, men and transgender, the services under PPTCT and pediatric ART medicines and services. The formats were then translated into Tamil, Marathi, Kannada and Telugu.

The first set of community researchers, drawn from People living with HIV and MARPs, gave their consent to the process and through them we reached out to others in the five states of Tamil Nadu, Andhra Pradesh, Telangana, Karnataka and Maharashtra. A total of 39 representatives who had experience of working with the community and advocating their rights were selected from each of the three districts of Andhra Pradesh, Tamil Nadu, Maharashtra and Karnataka, and one district of Telangana. They represented FSWs, MSM, TG and PLHIV. More than half of them were ART users themselves.

Facilitating recipients of ART programs to become monitors

We found that in all the five states, the community monitors had six to twelve years' experience of working with the community. This experience ranged from being senior

field or outreach workers to holding administrative posts in organizations. In Karnataka Chandrika, who herself has been living with HIV for last 18 years, is part of Milana family support network since 2004. Gajalaxmi is a treasurer of VCAN, a state-level network of sex workers and transgenders in Tamil Nadu. Kasturi of Belagavi is working with Spandana, an organization that works with positive people and also runs an orphanage for CLHIV. Shahnaz, Sangita and several other sex workers are dedicated workers managing registered CBOs and Targeted Interventions (TIs) for last three to six years.

The community monitors were trained on how to administer the questionnaire and how to strengthen treatment education or literacy among ART users in order to prevent drop outs due to lack of knowledge or not knowing how to manage side effects.

Experts and community representatives together agreed on a basic framework to monitor HIV services from the lens of users and affected people. This meant trying to understand the effects of the many shifts and departures that were taking place — from change of ART medicines and reduced quantum of medicines given on each visit to ART centers to variations in dosage, denial of any medication or not having timely access to essential diagnostic tests.

This was followed by state-level preparatory processes that included sessions on treatment literacy, finalizing the formats, pre-testing the survey formats and finally getting the ground ready for the roll out.

The final training on how to impart education on treatment literacy and monitor services was facilitated in each state by a team of state-level experts.

Community monitoring was initiated in April and May 2015. Once the format of the questionnaires was completed, the community monitors administered them through random sampling (exit interviews at ART centers as well as CBOs) to understand the following:

- line of treatment they were on — first line, second line and pediatric;
- whether they had experienced any stock-out in the past or present (in the last one year);
- and if they had received timely and necessary access to diagnostic services — CD4 tests, PCR kits, viral load tests, Pap Smear test — and HIV prevention services — treatment for OI, tests for STIs and counseling.

Stock-outs and irregular supply and availability of ART drugs result in ART users getting either no medication or reduced quantum of medication or even a different combination of medicines, which can cause serious side effects.

The community monitoring initiative was rolled out from 22nd April to 2nd May 2015. The tools and the process were first piloted in Maharashtra. Twenty five respondents were enlisted, of whom 12 were FSW, six were PLHIV, four women were accessing PPTCT services, two were MSM and one was transgender. A total of 10 respondents were from Kolhapur, eight from Solapur and seven were from Ahmednagar. All of them were on first line ART. They were interviewed across three civil hospitals located in the respective districts by a team of nine community workers.

While antenatal women did not experience any ART drugs or commodity stock-outs, all the 25 respondents had difficulty in either accessing the drugs or from side effects because of erratic supply.

- Ten respondents had to visit the ART centers more than once to get the drugs; the number of visits ranged from two to five.
- Shortage of OI medicines was also experienced and three respondents were told to buy the medicines from outside.
- Six respondents had side effects due to change in regimen; only four were informed of the change. None of the respondents received any counselling or information on management of side effects.
- Three respondents had discontinued their medications because they could not manage the side effects of regimen change.
- Ten respondents had stopped eating during the period of shortages, and were depressed.

Significantly, the monitors from Karnataka, Telangana and Andhra Pradesh were also sharing similar feedback on the effect of shortages of ART medicines.

Fig. 1. Districts selected for community monitoring in Maharashtra, Karnataka, Tamil Nadu, Andhra Pradesh and Telangana

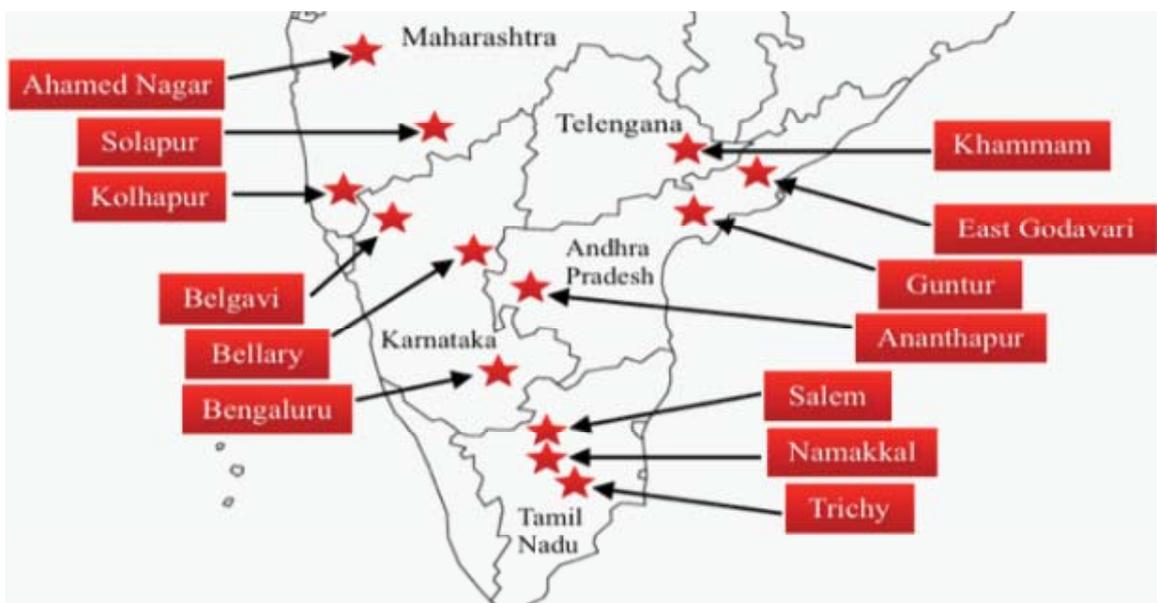


Table 1: Selected ART centres in the five states

State	No. of hospitals	Names
Maharashtra	4	Civil Hospital, Solapur, Civil Hospital, Ahmednagar, CPR, Savithiribai Phule Hospital, Kolhapur
Karnataka	11	Bowring Hospital, Victoria Hospital, Indira Gandhi Hospital, VIMS, GH Siraguppa, Hospet ART centre, BIMS, Belagavi, Gokak ART centre, ART Centre, Chikkodi, Link ART centre, Baihangol
Tamil Nadu	7	Trichy GH, Manaparai GH, Pullambadi GH, Salem GH, Namakkal District HQ Hospital, Paramathi, Vellore, Tiruchengodu GH
Andhra Pradesh	10	Government General Hospital- Ananthapuram, ART Centre - Kadiri, RDT – Bathalapalli, Government General Hospital - Kakinada, Rajamundry Government General, Hospital, Guntur GH, Sattenapalli GH, Bellamkonda GH, Tenali GH, Repalle GH
Telangana	3	Government General Hospital, Khammam, Bhadrachalam Area Hospital, Link ART Kothagudem

Following the initiation of the pilot, community monitoring started in the other 10 districts selected (Fig. 1). The information was collected from 35 ART centers (Table 1).

Data collected between May 2015 and April 2016 was analyzed using the SPSS software and the findings were systematically processed.

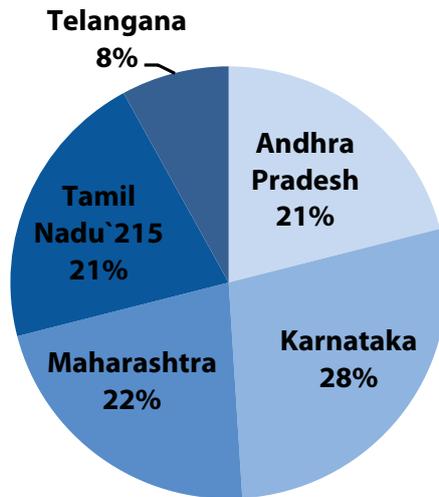
Firstly, all responses on the questionnaire administered and filled by community monitors were entered into excel sheets and inspected and checked for any anomalies and discrepancies. We ensured that queries not applicable to the respondent such as a Pap smear test in the context of male respondents were entered as N/A and not as 'NO', which may have given erroneous results.

The data was also checked for its logical correlation. For example, in case of queries around Opportunistic Infections, if the respondent denied any instance of OI, then the response to the subsequent query on whether a treatment was received, was N/A and not a variable like 'Yes' or 'No'.

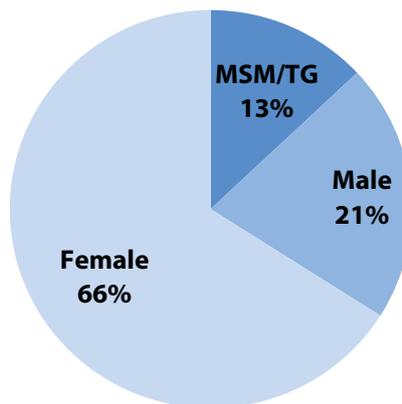
Again, we ensured that a common terminology was used to describe similar types of diseases as in the case of dysentery, diarrhoea or loose motions.

Some variables that were open ended, for which the response varied from a low numeral to a high one, were further split for easy interpretation. This was particularly so in the context of recording the responses on the distance required to travel to reach the ART Center for which the response was anything between half kilometers to 300 kilometers. These were split into three variables — up to 10 km, above 10 to 20 km, and above 20 km.

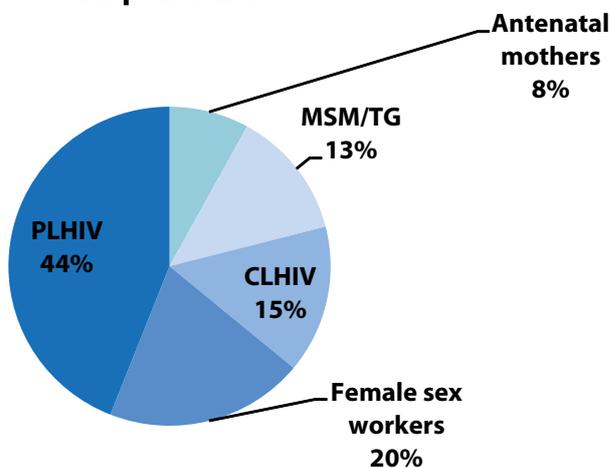
Graph No. 1: State-wise distribution of respondents



Graph No. 2: Genderwise distribution of respondents



Graph No. 3: Population-wise distribution of respondents



All the quantitative and qualitative data was converted into codes. For example - Yes to 1, No to 2 and NA to 3, and so on.

All the excel sheets that were prepared state-wise, were then exported into the SPSS software and the data was again checked for logical discrepancies if any. Any data clubbed or split was also run for each variable to get the frequency percentage.

RESULTS AND DISCUSSION

From May 2015 to April 2016, 39 community monitors from 13 districts across the five states reached out to a total of 2925 respondents.

State, gender and population profile

A total of 2925 respondents were contacted during this period, of which 815 were from Karnataka, 645 from Maharashtra, 613 from Andhra Pradesh, 602 from Tamil Nadu and 250 from Telangana (Graph No. 1). They included 1927 women, 618 men and 380 MSM/ TG (Graph No. 2). Population-wise breakup of the respondents were as follows: FSWs — 593, MSM/TG from Most At Risk Population — 380, PLHIV Adult — 1270, CLHIVs — 449, ante/postnatal mothers — 233 (Graph No. 3).

Respondents and their ART regimen

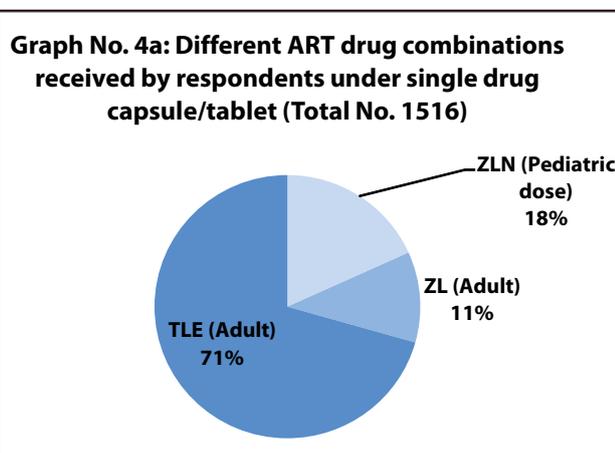
A total of 2402 respondents are on first line ART; among them, 16 children above the age of 14 years are getting adult ART medicines, 231 ante/postnatal women are getting first line ART medicines and 461 are getting paediatric ART. Only 63 (2.1 percent) respondents are on second line ART. Also 1516 (51.8 percent) respondents are getting one drug (mixture of two or more ART medicines in one capsule/tablet); 1407 (48.1 percent) are getting two; and two are getting three ART medicines (two or three different capsules/tablets with single or a mixture of ART medicines).

Combination of regimen received by number of respondents

A total of 1516 adults, CLHIV, CLHIVs on adult dose and ante/postnatal women received different ART medicines combination as first line single drug capsule/tablet. The majority of them received following ART medicines (Graph No. 4a).

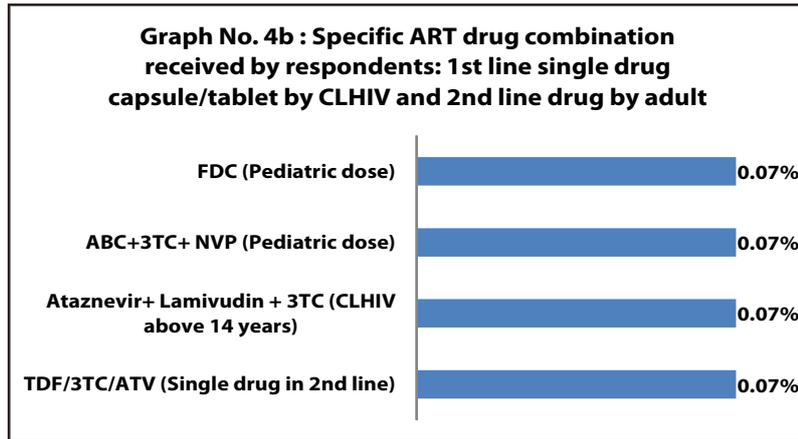
- Tenofovir 300mg + Lamivudine 300mg + Efavirenz 600mg — 1067 respondents
- Zidovudine 300mg + Lamivudine 150mg — 169 respondents
- Zidovudine 300mg + Lamivudine 150mg + Nevirapine 200mg — 276 respondents

Three CLHIV respondents received



different specific ART drug combinations under first line single drug and one adult received single drug in second line (Graph No. 4b)

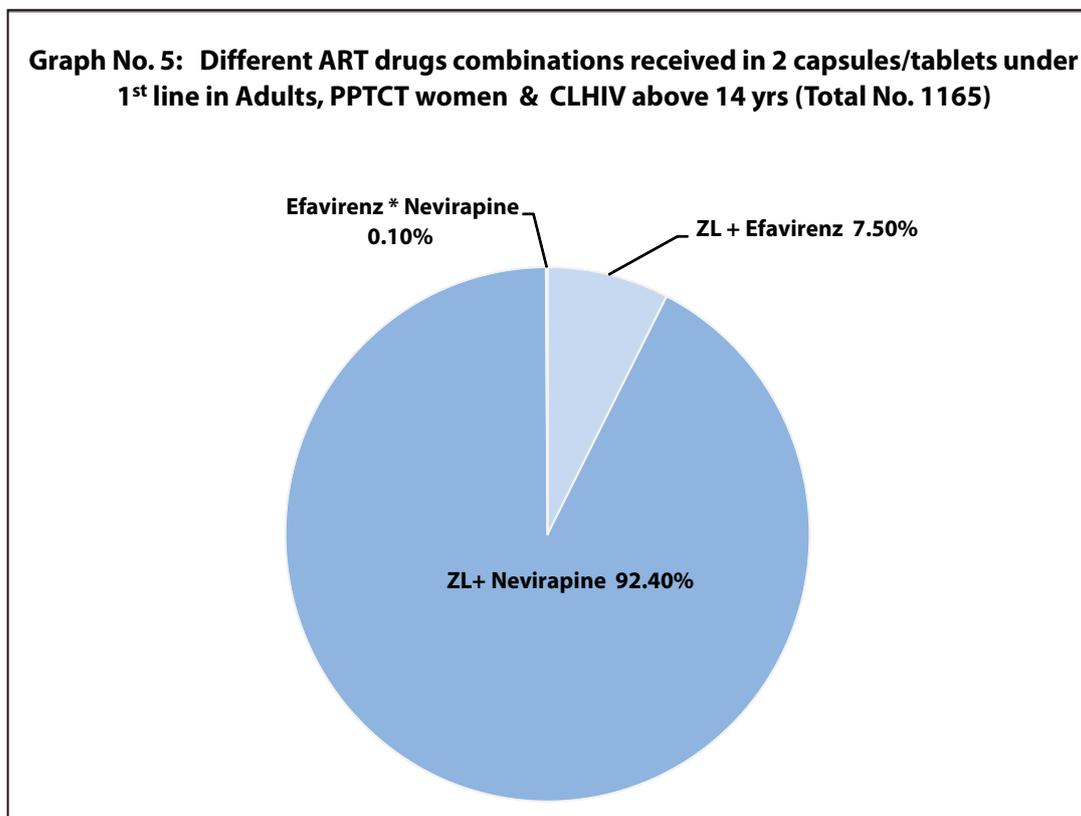
- Zidovudine 300mg + Lamivudine 300mg + Nevirapin 200mg + Efavirenz 60mg — 1 respondent (paediatric dose to CLHIV)

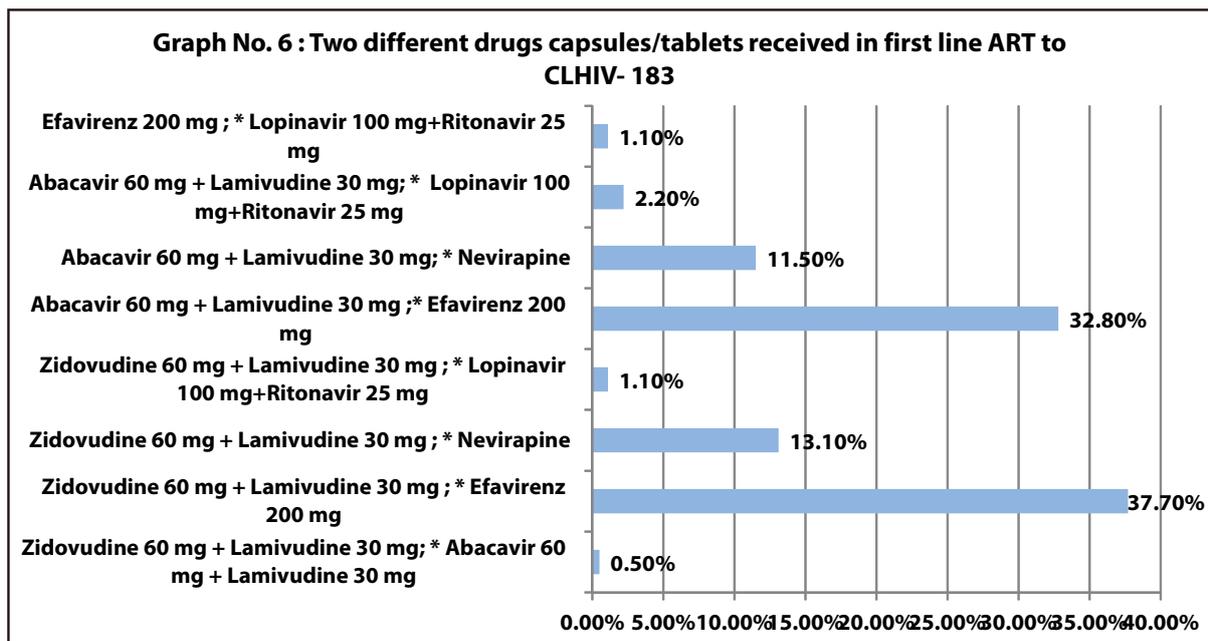


- ABC+ 3TC + Neverapin — 1 respondent (paediatric dose to CLHIV)
- Atazanavir + Lamivudine+3TC — 1 respondent (CLHIV above 14 yrs)
- TDF/3TC/Atazanavir — 1 respondent (second line drug to adult)

A total of 1165 respondents received two different ART medicines capsules/tablets in first line ART (Graph No. 5).

- Zidovudine 300 mg +Lamivudine 150mg ;* Efavirenz 600 mg — 87 respondents
- Zidovudine 300 mg +Lamivudine 150mg;*Nevirapine 200mg — 1077 respondents
- Efavirenz 600 mg + Nevirapine 200mg — 1 respondent





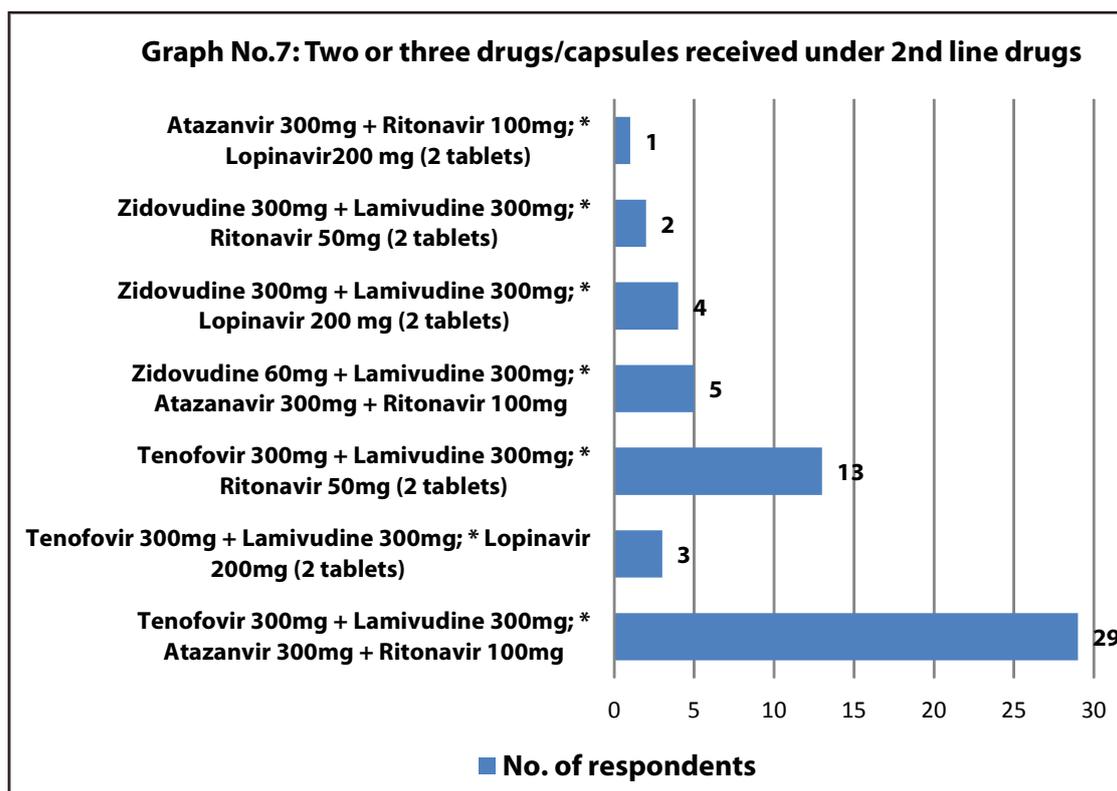
Two different pediatric ART medicines capsules/tablets received in first line ART to CLHIV- 183 (Graph No. 6)

- Zidovudine 60mg + Lamivudine 30mg + Abacavir 60mg + Lamivudine 30mg — 1 respondent
- Zidovudine 60mg + Lamivudine 30mg + Efavirenz 200mg — 69 respondents
- Zidovudine 60mg + Lamivudine 30mg + Nevirapine — 24 respondents
- Zidovudine 60mg + Lamivudine 30mg + Lopinavir 100mg + Ritonavir 25mg — 2 respondents
- Abacavir 60mg + Lamivudine 30mg + Efavirenz 200mg — 60 respondents
- Abacavir 60mg + Lamivudine 30mg + Nevirapine — 21 respondents
- Abacavir 60mg + Lamivudine 30mg + lopinavir 100mg + Ritonavir 25mg — 4 respondents
- Efavirenz 200mg + Lopinavir 100mg *+ Ritonavir 25mg — 2 respondents

Two or three different ART medicines capsules/tablets received under second line drug - 61 respondents

Of the 63 respondents on 2nd line treatment, all except two received two capsules/tablets of different combinations of ART medicines as follows (Graph No. 7):

- Tenofovir 300mg + Lamivudine 300mg; * Atazanvir 300mg + Ritonavir 100mg — 29 respondents
- Tenofovir 300mg + Lamivudine 300mg; * Lopinavir 200mg (2 tablets) — 3 respondents
- Tenofovir 300mg + Lamivudine 300mg; * Ritonavir 50mg (2 tablets) — 13



respondents

- Zidovudine 60mg + Lamivudine 300mg; * Atazanvir 300mg + Ritonavir 100mg — 5 respondents
- Zidovudine 300mg + Lamivudine 300mg; * Lopinavir 200 mg (2 tablets) — 4 respondents
- Zidovudine 300mg + Lamivudine 300mg; * Ritonavir 50mg (2 tablets) — 2 respondents
- Atazanvir 300mg + Ritonavir 100mg; * Lopinavir 200 mg (2 tablets) — 1 respondent

Out of the total 61 respondents, one CLHIV and one respondent received specific ART drug combination in two capsules/tablets under 2nd line and one adult received a combination of three capsules/tablets.

- Abacavir 60mg + Lamivudine 30mg (tablet/syrup); * Nevirapine (Syrup) — 1 respondent (1st line ART 2 ART medicines combination received to paediatric respondent on 2nd line drug)
- Atazanvir 300mg + Ritonavir 100mg; * Abacavir — 1 respondent

One respondent received three capsules/tables of different combinations of ART medicines

- Atazanvir 300mg + Ritonavir 100mg; * lopinavir 200mg (2 tablets); * Ritonavir 50mg (2 tablets) — 2 respondents

Status of pre/postnatal mothers

153 (65.7 percent) out of 233 HIV positive pregnant women respondents were experiencing their first pregnancy, 67 their second pregnancy, 11 their third and one each were in their fifth and sixth pregnancy. Of the total, 116 (49.8 percent) of pregnant women were put on ART after pregnancy was established. Of the 176 who delivered babies, 49 (29 percent) women said that they took ART till delivery (five percent) and 23 percent took the drugs while breastfeeding though ideally, a woman on ART should continue it lifelong. All of them started their ART during pregnancy under PPTCT program. Among the babies born to these women, 168 (95.5 percent) received Nevirapine syrup and 128 (72.7 percent) received Septran, 151 (85.8 percent) children underwent PCR test.

KEY FINDINGS

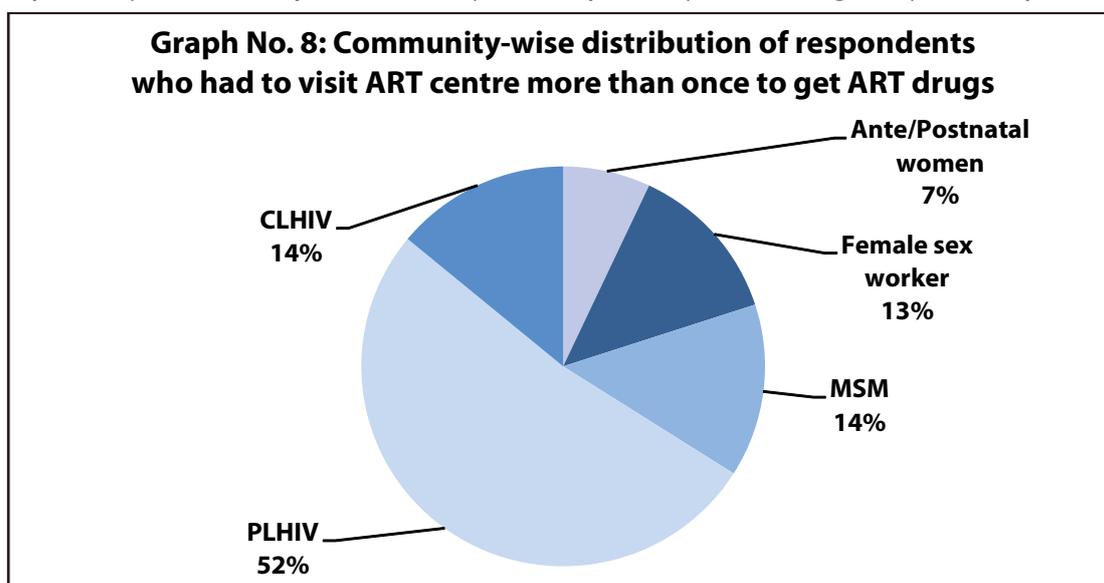
Stock-outs and irregular supply and availability of ART drugs results in ART users getting either no medication or reduced quantum of medication or even different combination of medicines, which can result in serious side effects.

The extent of disruption that the shortage and in some cases outright stock-outs of ART drugs and other commodities were caused by diverse factors.

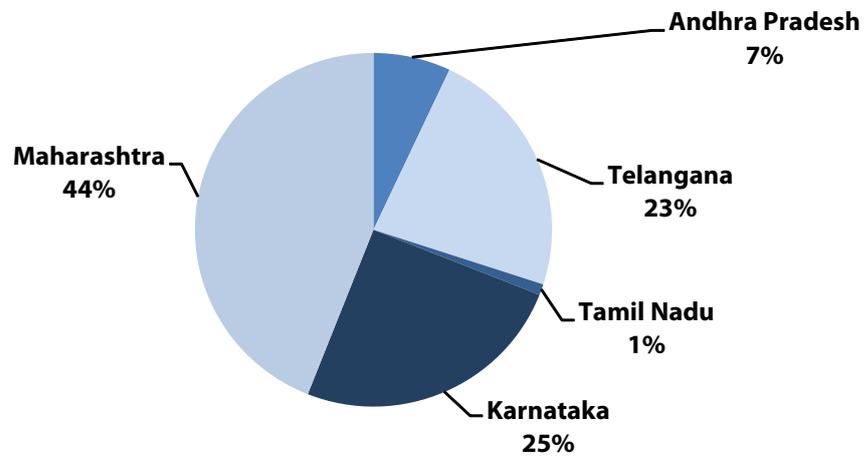
Many of those who suffer from side effects cannot manage it because of lack of adequate counselling services

The diagnostic services are inadequate at best.

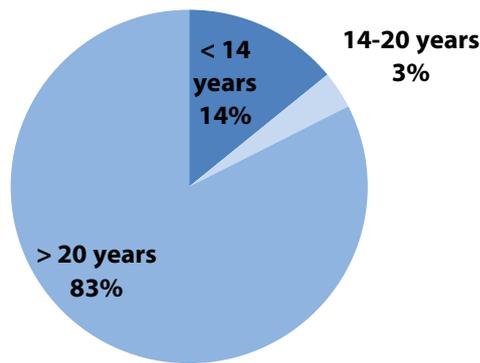
Ideally, a person living with HIV should get ART drugs quota of a month in one visit. However 470 (16 percent) respondents said that they had to pay more than one visit to collect their monthly dose of ART; of these 427 went twice, 24 three times, 15 four times and four had to visit five times in a month. (Graphs 8,9,10,11). Maximum respondents who had to visit ART center more than once in a month were from Maharashtra (205, 44 percent) followed by Karnataka (117, 25 percent) and Telangana (109, 23 percent).



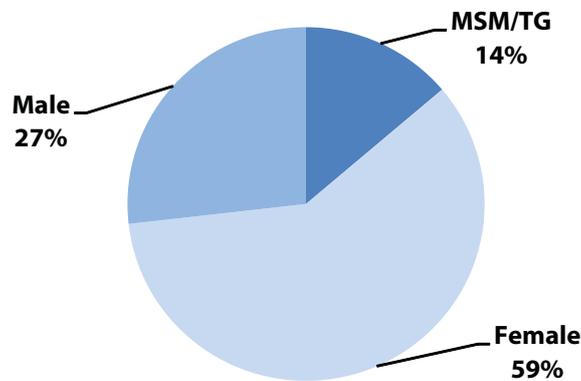
Graph No. 9: Statewise distribution of respondents who had to come to ART centre more than once to get ART drugs



Graph No. 10: Age-wise distribution of respondents who had to visit ART centre more than once to get ART drugs



Graph No. 11: Gender-wise distribution of respondents who had to visit ART centre more than once to get ART drugs



A total of 71 (2.5 percent) respondents did not get the ART medicines for some time, in spite of visiting the ART centre more than once.

Frequency of more than one visit goes up to 20 percent (463) of total 2323 respondents if we exclude Tamil Nadu where stock-out was not experienced.

For people who are living with HIV and/or are on ART for longer time, getting small dosages and additional number of visits to the ART center impact both access and adherence to drugs adversely.

Among the PLHIV who had to visit more than once in a month around 279 or 60 percent were women who had to sacrifice their wages for the number of days they visit ART center, but also had to face lot of challenges. The majority of women cannot move out without permission, there is a risk of getting identified at the hospital. This may amount to the risk of breaking confidentiality of their HIV status.

Sixty six or 14 percent were children below fourteen who were dependent on their aged grandparents and adults to collect their dose of ART drugs.

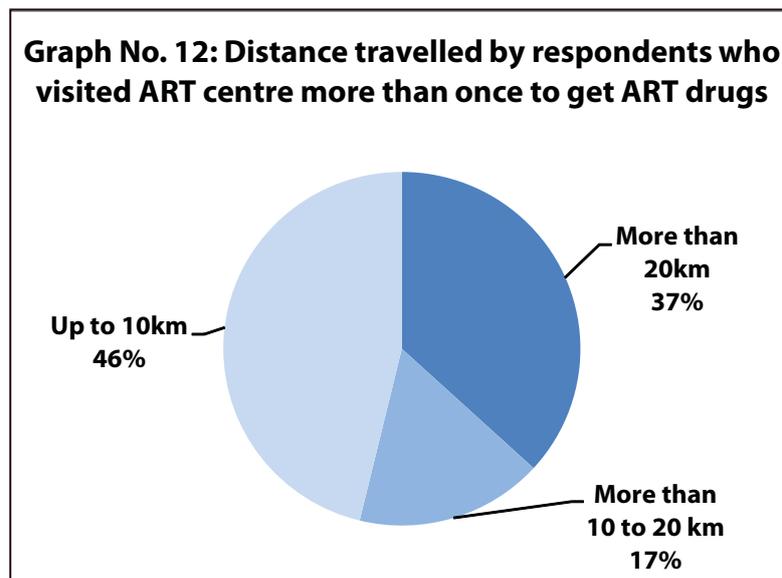
Out of those who had to visit the ART center more than once, 470 (13 percent) were sex workers and MSM/TG (14%) for whom sacrificing a day's income to collect medicines itself is a big challenge and stigma and discrimination they face in public may push them to discontinue the dosage rather than visit the ART center several times in a month.

Among the people who had to visit more than once, 80 percent were more than 30 years old. The cost was felt most by people who had to travel long distances to collect their monthly quota of ART drugs. These people had been living with HIV and been on ART for a long time, and an additional number of visits to the ART center to get drugs could impact

both access to drugs and adherence to treatment adversely.

Out of 470 respondents who had to visit the ART center more than once, almost 253 live beyond the 10 km periphery from ART center, of which 173 respondents have to travel more than 20 kilometers to collect their monthly dose of ART medicines (Graph

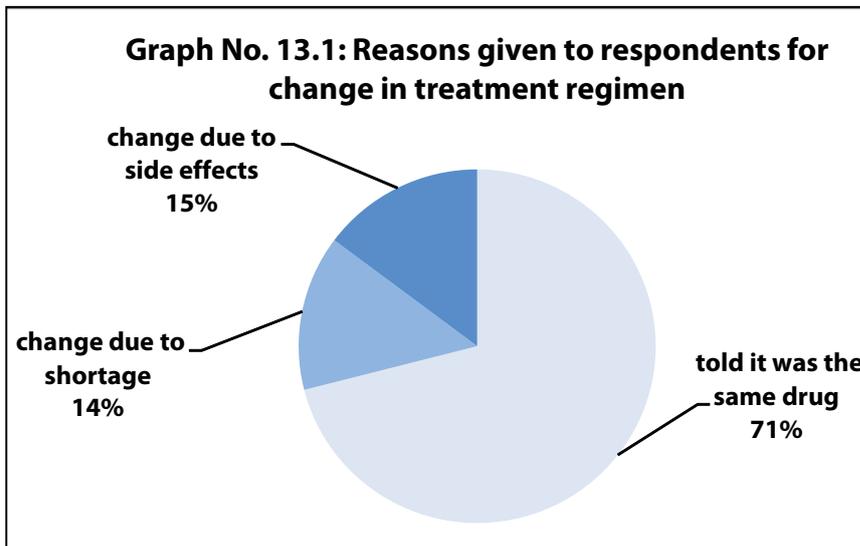
Graph No. 12: Distance travelled by respondents who visited ART centre more than once to get ART drugs



12). For example, in Maharashtra where the maximum respondents had to visit more than once in a month, many had to travel distances ranging from 40 to 100 km. on each trip from the village to the district hospital, which cost them 200 to 400 rupees and a total of three to five hours of time in travel, leading to loss of wages for the day. The frequent travel can have a serious impact in terms of economic burden on the lives of PLHIV.

Change in the drug regimen can cause confusion, and destroy the respondent's trust in the credibility of the service provider. This has both short term and long term repercussions, especially in the case of chronic illnesses like HIV/AIDS.

In the place of medication that had been long used, substitute medicines were provided to the patient, causing confusion and unexpected acute side effects. A total 195 (seven percent)



respondents did not receive the same drug that they were taking before. Of these 177 (90 percent) respondents consulted a doctor or a counsellor. Among them, 25 were told that the drug was changed due to a shortage of previously taken drug (Graph 13.1). Though

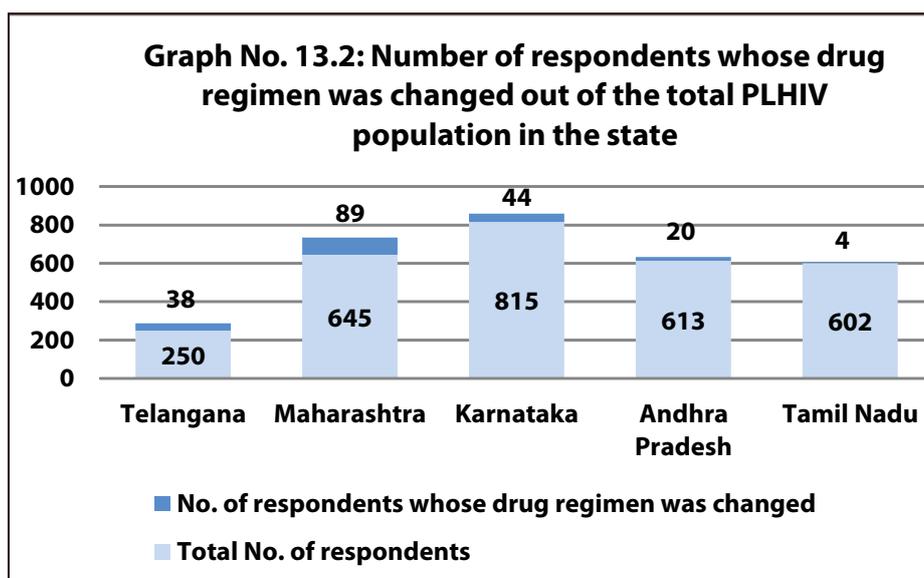
almost half the respondents had suffered acute side effects, only 26 were told that the drug was changed due to side effects. The majority were told that the drug was the same. So the possibility of change in drug due to stock-out is much higher.

The majority of the respondents whose drug regimen was changed were in Maharashtra (46 percent), followed by Karnataka (23 percent) and then Telangana (20 percent). However, as a percentage of the state's total number of respondents, in Telangana 15.2 percent of the population received different ART drugs, followed by Maharashtra (14 percent), Karnataka (five percent), Andhra Pradesh (3.3 percent) and Tamil Nadu (0.4 percent) (Graph 13.2).

Two hundred and sixty two (8.9 percent) respondents did not receive ART drugs sufficient for one month at some time or another. Of these, 192 (7 percent) were told by the doctor that ART medicines are not available due to stock-out and others were not informed.

Respondents were without drugs for varying

The study clearly points out that in the midst of severe disruption, stock-outs were also experienced by a significant section of respondents. The impact of shortages and stock outs was further compounded by side effects and opportunistic infections.



periods. One hundred and thirteen respondents (43.3 percent) said that they did not receive the ART drugs for the period of 15 days to one month and 10 (3.8 percent) respondents did not get medicines for one to three months (Graphs 13.1 and 13.2). One hundred and seventeen respondents (44.8 percent) had to collect ART medicines every 15 days and 22 respondents (8.4 percent) had to visit again in less than 15 days to get the monthly stock.

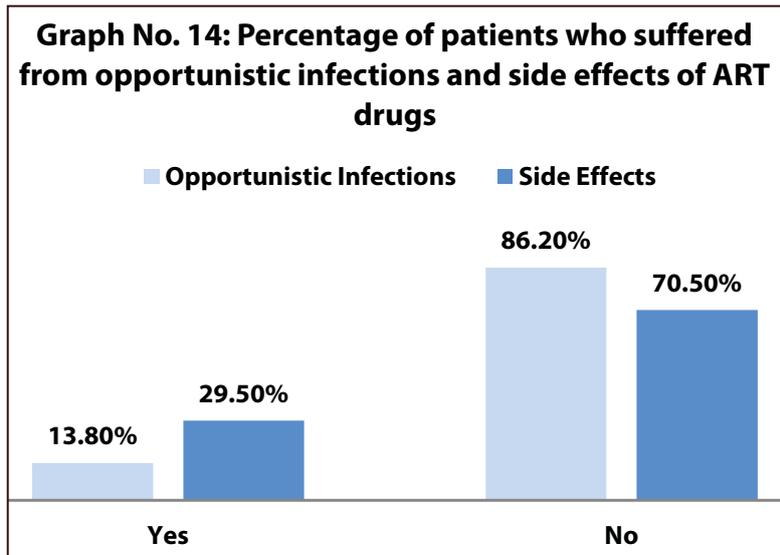
Among all five states, Tamil Nadu is the only state where respondents did not experience ART stock-outs at all (Table 2). In Karnataka, 117 (44.8 percent) respondents received 15 days' stock at a time, forcing them to return once a fortnight for medication. At the same time, there was no time when the respondents did not receive any drug at all. However this is not the case for other states. Maharashtra, Telangana and Andhra Pradesh faced the issues of stock-out, especially Telangana where 17.6 percent of the respondents from the state had to go without drugs for a significant length of time.

Table 2: Statewise break up of stock-out

State	Total respondents	Not received drugs	Visited > once	Change in drug
Karnataka	815	117 - 14.4%	121 - 14.8%	44 - 5.4%
Maharashtra	645	67 - 10.4%	205 - 31.8%	89 - 13.8%
Andhra Pradesh	613	32 - 5.2%	32 - 5.2%	20 - 3.3%
Telangana	250	44 - 17.6%	109 - 43.6%	38 - 15.2%
Tamil Nadu	602	0 - 0%	7 - 1.2%	4 - 0.7%

As shown in Graph No. 14, almost a third of the respondents (862) experienced side effects. They included 198 (23 percent) FSW, 109 (13 percent) MSM, 369 (43 percent) Adult PLHIV, 131 (15 percent) CLHIV and 55 (six percent) ante/postnatal women.

Around 30 types of symptoms of side effects were narrated by respondents, many of whom suffered from more than one at a time. The most common symptoms were nausea and vomiting (220; 26 percent) tiredness/weakness (213; 25 percent), giddiness (177; 21



percent), skin rashes (117; 14 percent), headache/migraine (101; 12 percent) and fever (97; 11 percent). Apart from these, sleep disorders and problems related to the digestive system were also mentioned by 4-9 percent of respondents.

Opportunistic infection

Around 404 or 14 percent respondents (Graph 14) developed opportunistic infections in the last one year — 81 (20 percent) FSW, 39 (10 percent) MSM, 199 (50 percent) other adult PLHIV, 67 (17 percent) CLHIV and 18 (6 percent) ante/postnatal women. Around 23 types of one or more symptoms of opportunistic infections were reported by respondents. The most common symptoms were fever (111; 28 percent), TB (82; 21 percent), cough (69; 17 percent), fungal infection (40; 10 percent), STI symptoms (39; 10 percent), tiredness (38; percent). Apart from these loose motions, pneumonia and loss of weight were also mentioned by 4-8 percent of respondents. Of the total, 272 (67 percent) respondents received the treatment for OI; 57 percent respondents did not receive the treatment for OI due to shortage/non availability of medicines.

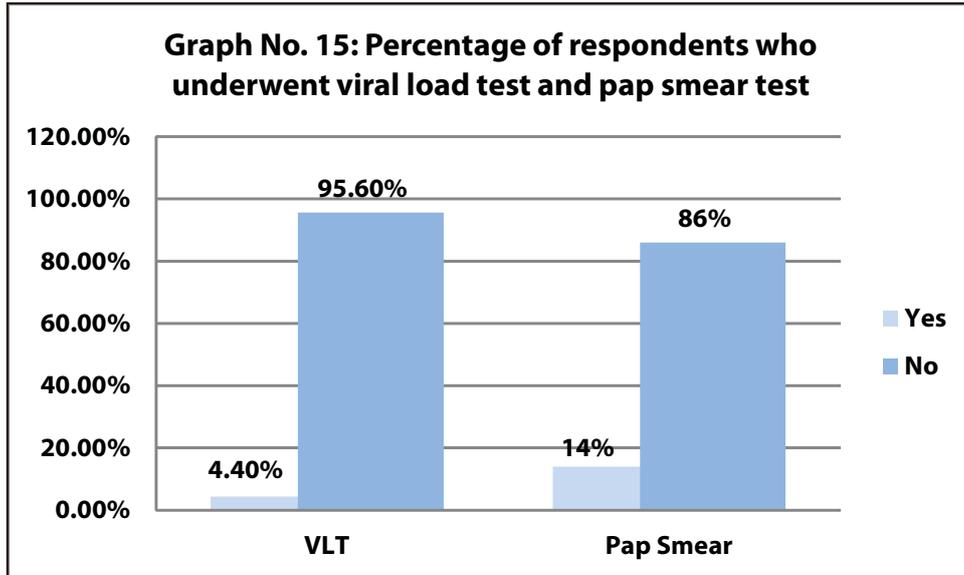
DIAGNOSTIC SERVICES

1) Blood tests

Almost 86 percent (2471) of the respondents had been tested for Haemogram, Blood sugar or RFT/LFT in the preceding year; 2886 respondents (98.7 percent) tested for CD4 count.

2) Viral load test

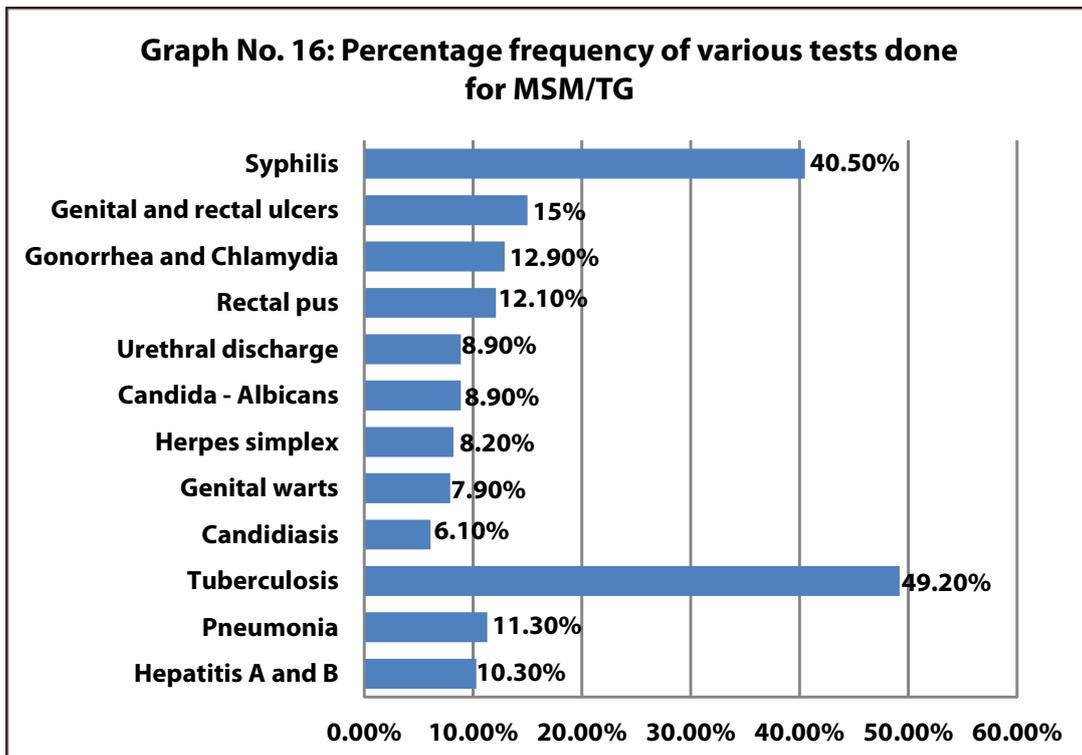
Only 10 percent (296) of the respondents were aware of the viral load test and of that, only 130 (4.4 percent) were referred for it. (Graph 15) All respondents who were referred for second line drug ideally should have undergone viral load test. Of the 78 (2.7 percent) respondents who were referred for second line drugs only 50 (64 percent) respondents had done viral load test; the rest could not avail of this test.



3) Pap smear/ Vivali test

Cervical cancer is leading cancer among Indian women. One woman dies every eight minutes of cervical cancer in the country; sex workers and women living with HIV are more vulnerable to this cancer. However, among total 1454 women respondents who were eligible for the Pap smear test, only 204 were screened for cervical cancer (Graph no 15). A total of 131 (15.2 percent) women respondents of adult PLHIV and 73 (12.3 percent) FSWs underwent the Pap smear test. Telangana (37 percent) and Maharashtra (36 percent) offered the Pap smear test to the maximum number of women.

4) MSM/TG screening



As MSM and TGs are prone to higher risk of STIs and opportunistic/co-infections in HIV, they need to be screened for these infections at regular intervals. Out of 380 MSM/TG respondents only 187 (49 percent) were screened for these tests. Graph no. 16 reveals that among these, the test for Syphilis is the most frequent at 154 (41 percent) among STI and the test of Tuberculosis at 187 (49 percent) among opportunistic or co-infections. Other STI tests include genital anorectal ulcers, gonorrhoea and chlamydia, rectal pus, urethral discharge, candida (oral thrush), herpes simplex, genital warts and candidiasis, ranging from 15 percent to six percent in descending order.

Among the tests conducted for other opportunistic/co-infections, 43 (11.3 percent) and 39 (10.3percent) of respondents were tested for pneumonia and hepatitis A and B respectively.

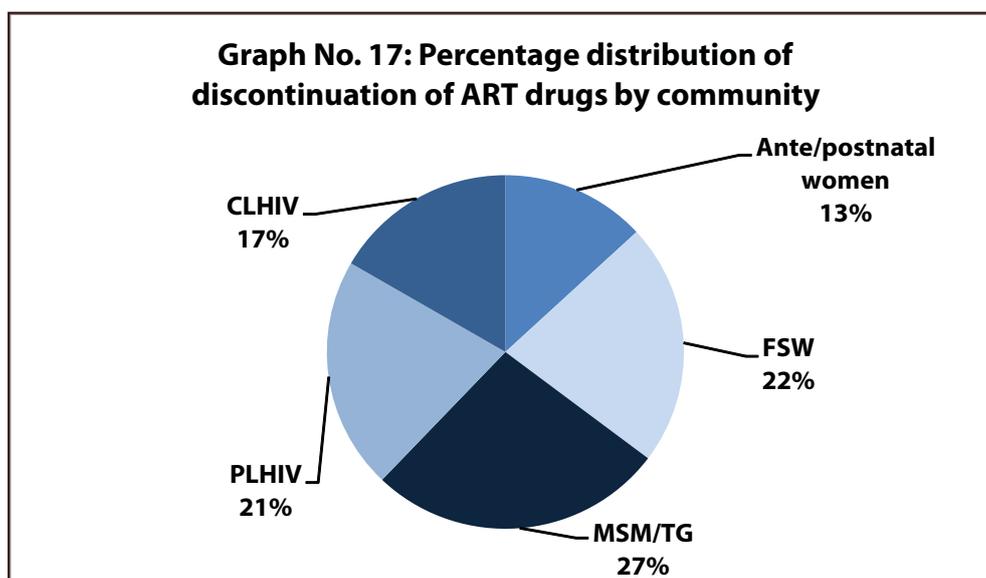
DISCONTINUATION OF TREATMENT

KEY FINDINGS

Given all the debilitating difficulties cited above a sizeable number of respondents, who were earlier adherents to the treatment, discontinued it. The discontinuation was primarily supplier-driven, as the difficulties were caused by inadequacies in the services and drugs provided by the government.

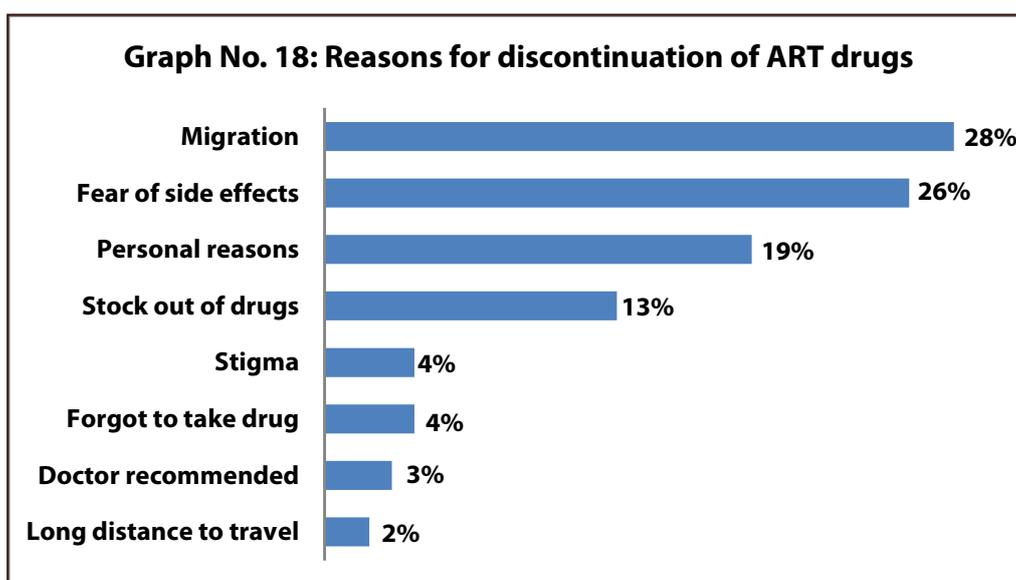
A total of 392 (13.4 per) respondents discontinued ART at some point of time, of which 86 were FSW (22 percent), 67 MSM (17 percent), 170 other PLHIV (43 percent), 49 CLHIV (13 percent) and 20 ante/postnatal mothers (five percent). The maximum number of respondents who discontinued treatment were from the MSM community, followed by FSW for obvious reasons like migration and stigma, and adult PLHIV (Graph no. 17).

The duration of discontinuation of ART medicines varied from 3-4 days to two years. Over all 159 (40 percent) left it for less than a week, 130 (33 percent) discontinued for period of 7-30 days, 77 (20 percent) discontinued it for more than a month to one year and 18 (five percent) for more than a year. Eight (two percent) of the respondents either did not



remember or did not mention the exact period of discontinuation.

The respondents gave various reasons for the discontinuation of ART medicines: migration (111; 28 percent), fear of side effects (101; 26 percent), and stock-out of ART medicines (52; 13 percent) accounted for more discontinuation than the other factors, which include personal issues (73; 19 percent), stigma (17; four percent). Both of the latter can essentially be attributed to discrimination. Besides these eight (two percent) respondents discontinued the ART drugs because of the long distance they needed to travel to collect medicines. In a few cases (10) the doctor recommended discontinuing the ART medicines (Graph 18).



REMEDIAL ACTION

Key findings

There is an urgent need to

- **Recognize that all disruptions from minor to major should be addressed with the same measure of promptness. This is particularly relevant for managing lifelong ailments where adherence to regimen and compliance with the due procedures is at the core of any public health investment.**
- **Recognize that the intent of community monitoring is preventative, and 20 percent of those who restarted treatment, did so because they were motivated by the community monitors.**

The process of remedial follow up started in June 2015, with five cases of respondents restarting treatment. Across the five states, 621 (23 percent) cases were referred to government hospitals for several HIV-related services. This number of cases consists of respondents and their friends and acquaintances recommended by them. By the month of December, the number of remedial follow up cases was 54, which went up to 123 in February and 115 in March 2016. The highest number of cases were referred in Karnataka

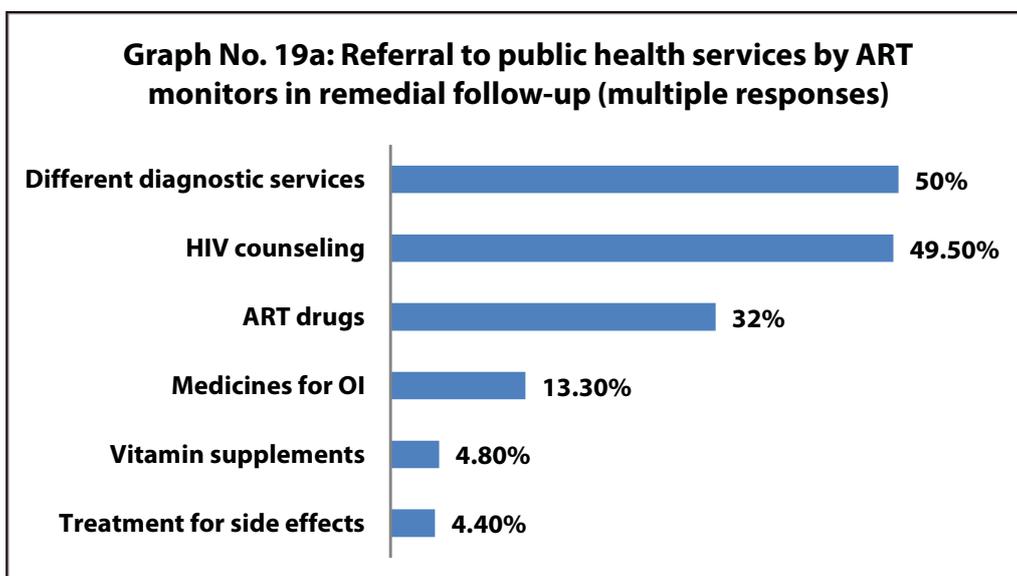
Murali (MSM from Salem, Tamil Nadu): *“As the transgender community is usually not easily reachable, many of our community members were not very open about their status, fearing double discrimination in the society and even within the community at times. The community monitoring process helped us in reaching out to them.*

Many of our community members who were on ART and suffering from certain side effects didn't know whether to discontinue the drug. Today we as community monitors are not only getting people who have dropped out but also play a major role in retaining people on ART by proper referral and linkages based on their need.”

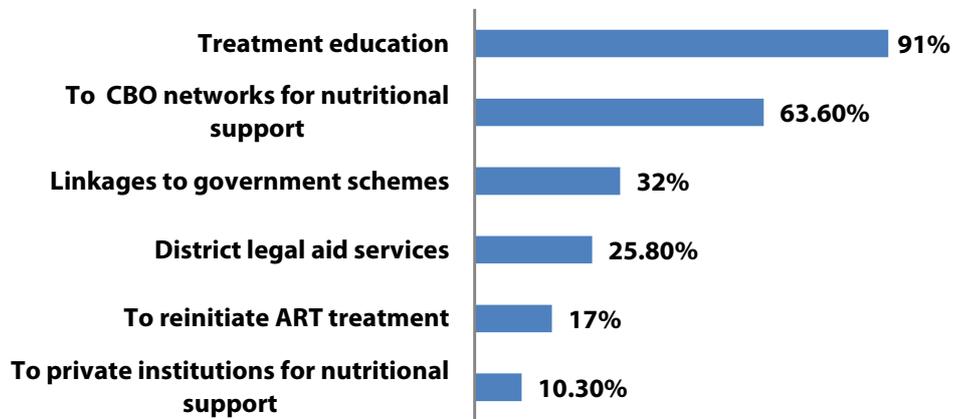
— 253 (40 percent), followed by Maharashtra — 171 (27 percent).

Around 414 (66 percent) women and 217 (24 percent) men were referred for counselling, several tests, medicines and other services and conducted treatment education sessions for them. From four states 543 respondents were referred to different services — 176 (32 percent) referred to public hospital for registration of ART medicines, 269 (49.5 percent) were referred for HIV counselling. Respondents were also sent to public hospitals for getting medicines other than ART of which 72 (13.3 percent) were for opportunistic infections, 26 (4.8 percent) for vitamin supplements and 24 (4.4 percent) were referred for treatment of side effects (Graph 19a and 19b). The least number of cases (23) were referred from East Godavari district of Andhra Pradesh and maximum cases, i.e., 113, were referred in Solapur district of Maharashtra. Among the total 621 cases, 577 (91 percent) were given treatment education. Since services provided in Tamil Nadu were good they conducted treatment education sessions for 87 respondents.

A total of 269 (50%) of respondents were referred for one to three different diagnostic services. This included 110 (27 percent) CD4 test, 107 (26 percent) for haemogram, 76 (19 percent) for STI screening, 59 (14 percent) for serological (LFT/RFT, sugar) tests and 38 (nine percent) for sputum test. A few respondents



Graph No. 19b: Various interventions by community monitors in remedial follow-up (multiple responses)

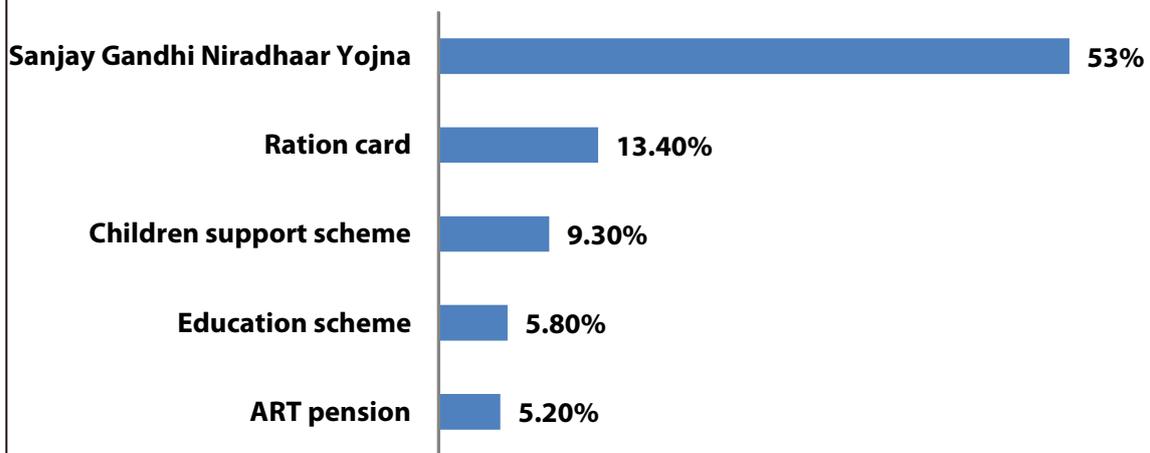


ranging from two to 10 were also referred for PCR, Viral Load test, HIV screening (partner or HIV II). Sixteen (three percent) respondents were referred to private hospitals for diagnostic services, seven (1.3 percent) for treatment of opportunistic infections and 56 (10.3 percent) were provided nutritional support from private institutions.

Sangeeta Patil (FSW, from Kolhapur, Maharashtra): *“Inconsistency of supply was not the only issue when monitoring began as there are other problems which need to be duly addressed like coping with side effects. Once I took a patient to the civil hospital whose CD4 count had dropped. ‘We are doctors, medical experts, we know our work,’ was their answer. They are knowledgeable, who denies that, but it hardly helps us to sort out the problems that a patient faces. Later the patients stop taking medicine or consulting doctors and go in search of other ways to get relief. In the process the patients suffer. This lady has become so weak now that she cannot even walk without support. Thus there is a need for proper medical advice and counselling at the time of change in regimen, which does not happen.*”

“ART adherence of sex workers has increased since we started the monitoring. Irregularity in taking drugs is in control because I personally follow up with the women. I met three women who were not particular about the timing; I made arrangements that someone in their family reminds them. I also visit two of them almost on a daily basis and ask them take proper food and their evening dose in my presence. There was another woman who was in jail for a year, who had stopped her medication. I came to know about it when I met her after she was released from jail. I convinced her to take her medicines properly. She is doing well at present.””

Graph No. 20: Referral to different government schemes by ART monitors under remedial follow-up (multiple responses)



Further, 91 (17 percent) respondents reinitiated ART treatment after the intervention of ART monitors; 345 (63.5 percent) were given nutritional support by attaching them to other CBO networks and 140 (25.8 percent) respondents were referred to District Legal Services Authority.

Syed Ayesha (PLHIV from Guntur, Andhra Pradesh): *“The most important part of three phase monitoring was to bring user and provider together to address the concerns of users. We started referring patients to the respective ART centres in their towns according to their need. Till date we have referred 20 patients who had discontinued ART due to side effects, provided them counselling through ICTC/ART centres and resumed their treatment. They were sent to the outpatient departments and STI centres for clinical tests. Children and pregnant women were referred to the NGOs for nutrition support. We also referred TGs/MSMs to the STI clinics for screening because we found most of them are discriminated. It is an ongoing process to ensure that patients should not relapse; we are monitoring them every three months. Old respondents along with the new ones are followed up either by personal visits or by phone.”*

A total of 172 (32 percent) respondents were provided information and linked with several government schemes — 91 for Sanjay Gandhi Niradhaar Yojna and 23 for ration cards; 16 were referred for children support scheme called Balsangopan, 10 were linked to education schemes and nine to ART pension. Among the other services, less than four percent respondents were provided linkages to get housing loans, ST corporation loans, Aadhar cards, ICPS, bus passes and SHG membership (Graph No. 20).

SHARING SIX MONTH CBM REPORT WITH NACO

The community-based monitoring report of ART and HIV services in five states for duration May 2015 to December 2016 were presented



Sushma Batkadli, community monitor felicitated by DLSA Kolhapur for providing legal support to PLHIV

before Mr N.S. Kang, Additional Secretary, Ministry of Health and Family Welfare and Director General, NACO on 1st February 2016. All senior officials and team leaders were present at the meeting. Nine community monitors — two each from Tamil Nadu, Karnataka, Maharashtra, Andhra Pradesh and one from Telangana — and the CFAR team presented the context, intent, scope and thrust of the community monitoring initiative.

The report indicated that the establishment of the initiative was aimed at enabling communities on the ground to deal individually and collectively with critical situations. Some of these situations could be seen as outside the control of NACO and something that PLHIVs have to deal with immediately, while others were such that NACO would have to at some point to deal with the possible fall outs. Community representatives explained the process of questionnaire preparation, effects of stock-outs and the persisting shortages of ART and shared both the highly disturbing and somewhat less disturbing developments with community insight and experiences on ground. They presented the need to institutionalize community monitoring as an essential step towards creating a community-centered process.

Mr Kang agreed to take all the findings and suggestions on board.

MEETING WITH AGCA

More than twenty community representatives representing sex workers, transgenders, MSM and PLHIV from Karnataka, Maharashtra, Andhra Pradesh, Telangana and Tamil Nadu

participated in the consultation titled "Strengthening Community Action for Health" in New Delhi on the 18th May 2016. They shared the key findings of the monitoring study carried out between May 2015 and April 2016, as well as their efforts, achievements, challenges and struggles in carrying out such an initiative in their district. The officials of AGCA explained how they were carrying out community monitoring of all the health services under NHM. During the presentation they highlighted their role in strengthening awareness among the community about their rights as beneficiaries and simultaneously improved the accountability of the service providers. They also mentioned that CBM is only a way and not the solution for all issues, pointing out that multiple strategies should be used in order to address different concerns.

RECOMMENDATIONS

1. Urgently define a clear roadmap to ensure necessary scale-up of treatment, care, and support services for PLHIV. Many people living with the virus are yet to be enrolled in HIV care. PLHIV need routine and uninterrupted access to CD4 testing to ensure timely initiation of ART and regular monitoring. There is an urgent need to scale up viral load testing, enhance accessibility to second and third line treatment regimens, and increase availability of paediatric formulations.
2. Strengthen community-led education of users and care givers. Given the experience of the HIV programme in evolving a cadre of trained peer educators it would be relatively easier to strengthen peer counselling.
3. Evolve a mechanism to institutionalize community-led feedback for care, support and treatment services (examples include CBGA for NHM service provision). This could be one of the many evolving aspects of HIV prevention and treatment services that NACO can consider as we look to the next phase of AIDS Control program.
4. Build and strengthen treatment literacy into service provision. Organize treatment literacy campaigns; this can be anchored or led by the local networks and CBOs in partnership with doctors and health educators. This campaign can take the form of monthly meetings in each district and can double up both as a support group meeting for people who have started on ART recently and a wider meeting to educate others about the treatment options that are being provided in the districts or state.

ANNEXURE I

QUESTIONNAIRES

FORMAT FOR CHILDREN

Date: _____ District _____ State: _____

1	ART No.	
2	Name of ART/Link ART Center and Place	
3	Child's Name (Optional)	
4	Parents name:	
5	Address : How far is this place from the ART Centre – mention in kms	
6	Contact number	
7	Child's Age	
8	Gender	Male/Female
9	Started ART Age at which ART was initiated _____	At birth
10	Pediatric ART formulation	
	Zidovudine 60 mg + Lamivudine 30 mg +Nevirapine 50 mg tablets (tablet/syrup)	
	Zidovudine 60 mg + Lamivudine 30 mg (tablet/syrup)	
	Abacavir 60 mg + Lamivudine 30 mg (tablet/syrup)	
	Efavirenz 200 mg tablet (tablet/syrup)	
	Nevirapine(Syrup)(in ICTC)	
	Lopinavir 100mg+Ritonavir 25mg (tablet/syrup)	
	Lopinavir+Ritonavir (syrup)	
11	Accessing ART through -	Self/Parent/Guardian/Family members/Friends/Network members
12	Do you recall any instance (time/period) (in the last one year) when ART medicines were not given to you?	Yes/No
12	If Yes mention the month/s and period/s (For instance, in June last year for 15 days or from June last year for two months could be a response)	
13	Was there any information and explanation given to you about the shortage?	Yes/No
14	If Yes, mention what was informed/explained	

15	How many times (in a month) were you required to visit the Centre then? (Frequency of your visit)	
16	Did you receive the same drugs that you were prescribed by the ART center then?	Yes / No
17	If No, what was the change that you noticed?	a. Different size/shape b. Change in color c. Different combination d. Dosage
18	Did you speak to the ART doctor or counselor about the change?	Yes / No
19	If Yes, what explanation did they provide?	
20	Was their explanation useful- were you convinced?	Yes /No
21	If No what was your concern?	
22	Have you experienced any side effects due to ART drugs?	Yes /No
23	If yes, what kind?	
24	What is the advice received from your doctor/ counselor	
25	Did you get relief from following the advice given by the Doctor	Yes /No
26	If No – what is the side effect that you are still experiencing	
27	How many times you have given blood for testing for Hb/blood sugar/WBC/liver functioning (RFT/ LFT) test last year?	
28	How many times you have given blood for CD4 test last year?	
29	Did you encounter any OI while taking ART?	Yes /no
30	If Yes, what?	
31	Do you know about Viral Load Test?	Yes/No
32	Have you been referred to Viral load test?	Yes /no
33	Have you been referred for second line drugs?	Yes /No
34	If yes, mention date of referral	
35	Have you been started on the second line drugs?	Yes /No
36	If yes , mention the date when started	
37	Did you have to wait for second line?	Yes/No
38	If Yes, while waiting for second line did you continue to receive the first line?	Yes /No

39	If Yes, did you have any problems in receiving it?	
40	Have you been referred to any NGO or Medical shop during ART stock out to get ART drugs?	Yes /No
41	If Yes what has been your experience?	
42	Did you receive any reimbursement for ART purchased from medical shop?	
43	Have you ever discontinued ART medication?	Yes/No
44	If yes, how long had you been without ART medication? Mention period	
45	What was the reason for discontinuing?	
46	How did you re-initiate the treatment?	
47	Have you received medicines for opportunistic infection from your Center-	Yes/No
48	If No, what were the reasons?	
49	Are you getting vitamin and other mineral supplements from your center?	Yes/No
50	Any specific observation/feedback? Any recommendation to improve the service?	

FORMAT FOR MARGINALISED WOMEN

Date: _____ District _____ State:

Surveyor: (NAME)

1	ART number	
2	Name(Optional)	
3	Address : How far is this place from the ART centre- mention in km	_____ kms
4	Contact number	
5	Age	
6	Name of ART/Link ART center and location	
7	Accessing ART through -	Self/Parent/Guardian/Family members/Friends/Network members
8	ART (tick the combination/formulation the patient is taking)	1st LINE/2nd LINE
8.1	1st line	
A	TLE (Tenofovir 300 mg + Lamivudine 300 mg + Efavirenz 600 mg)	
B	ZL (Zidovudine 300 mg + Lamivudine 150 mg)	
C	Efavirenz 600 mg	
D	Nevirapine 200 mg	
8.2	2nd line	
E	TL (Tenofovir 300mg + Lamivudine 300 mg)	
F	ZL (Zidovudine 300mg+ Lamivudine 300 mg)	
G	Atazanavir 300mg + Ritonavir 100mg	
H	Lopinavir 200mg (2 tablets)	
I	Ritonavir 50mg (2 tablets)	
9	Do you recall any instance (time/period) (in the last one year) when ART medicines were not given to you?	Yes/No
9.1	If Yes mention the month/s and period/s (For instance, in June last year for 15 days or from June last year for two months could be a response)	

9.2	Was there any information and explanation given to you about the shortage?	Yes/No
9.3	If Yes, mention what was informed/explained	
10	How many times (in a month) were you required to visit the Centre then? (Frequency of your visit)	
11	Did you receive the same drugs that you were prescribed by the ART center then?	Yes / No
12	If No, what was the change that you noticed?	a. Different size/shape b. Change in color c. Different combination d. Dosage
13	Did you speak to the ART doctor or counselor about the change?	Yes / No
14	If Yes, what explanation did they provide?	
15	Was their explanation useful- were you convinced?	Yes /No
16	If No what was your concern?	
17	Have you experienced any side effects due to ART drugs?	Yes /No
18	If yes, what kind?	
19	What is the advice received from your doctor/ counselor	
20	Did you get relief from following the advice given by the Doctor	Yes /No
21	If No – what is the side effect that you are still experiencing	
22	How many times you have given blood for testing for Hb/blood sugar/WBC/liver functioning (RFT/LFT) test last year?	
23	How many times you have given blood for CD4 test last year?	
24	Did you encounter any OI while taking ART?	Yes /no
24.1	If Yes, what?	
25	Do you know about Viral Load Test?	Yes/No
26	Have you been referred to Viral load test?	Yes /no
27	Have you been referred for second line drugs?	Yes /No
27.1	If yes, mention date of referral	
28	Have you been started on the second line drugs?	Yes /No
28.1	If yes , mention the date when started	

29	Did you have to wait for second line?	Yes/No
29.1	If Yes, while waiting for second line did you continue to receive the first line?	Yes /No
29.2	If Yes, did you have any problems in receiving it?	
30	Have you been referred to any NGO or Medical shop during ART stock out to get ART drugs?	Yes /No
30.1	If Yes what has been your experience?	
30.2	Did you receive any reimbursement for ART purchased from medical shop?	
31	Have you ever discontinued ART medication?	Yes/No
31.1	If yes, how long had you been without ART medication? Mention period	
31.2	What was the reason for discontinuing?	
31.3	How did you re-initiate the treatment?	
32	Have you received medicines for opportunistic infection from your Center-	
	Yes/No	
32.1	If No, what were the reasons?	
33	Have you been referred to Pap smear/Viavali test in this year?	Yes /No
34	Are you getting vitamin and other mineral supplements from your center?	Yes/No
35	Any specific observation/feedback? Any recommendation to improve the service?	

FORMAT FOR MSM/TS/TG

Date: _____ District _____

State _____

1	ART number	
2	Name of ART/Link ART Center and Place	
3	Name(Optional)	
4	Address : How far is the place from the ART centre	
5	Contact number	
6	Age	
7	Gender	MSM/TG/TS
8	Accessing ART through	Self/Parent/Guardian/Family members/Friends/Network members
9	ART (tick the combination/formulation the patient is taking)	Ist LINE/2nd LINE
9.1	Ist line	
A	TLE (Tenofovir 300 mg + Lamivudine 300 mg + Efavirenz 600 mg)	
B	ZL (Zidovudine 300 mg + Lamivudine 150 mg)	
C	Efavirenz 600 mg	
D	Nevirapine 200 mg	
9.2	2nd line	
E	TL (Tenofovir 300mg + Lamivudine 300 mg)	
F	ZL (Zidovudine 300mg+ Lamivudine 300 mg)	
G	Atazanavir 300mg + Ritonavir 100mg	
H	Lopinavir 200mg (2 tablets)	
I	Ritonavir 50mg (2 tablets)	
10	Do you recall any instance (time/period) (in the last one year) when ART medicines were not given to you?	Yes/No
10.1	If Yes mention the month/s and period/s (For instance, in June last year for 15 days or from June last year for two months could be a response)	
10.2	Was there any information and explanation given to you about the shortage?	Yes/No

10.3	If Yes, mention what was informed/explained	
11	How many times (in a month) were you required to visit the Centre then? (Frequency of your visit)	
12	Did you receive the same drugs that you were prescribed by the ART center then?	Yes / No
13	If No, what was the change that you noticed?	a. Different size/shape b. Change in color c. Different combination d. Dosage.
14	Did you speak to the ART doctor or counselor about the change?	Yes / No
15	If Yes, what explanation did they provide?	
16	Was their explanation useful- were you convinced?	Yes /No
17	If No what was your concern?	
18	Have you experienced any side effects due to ART drugs?	Yes /No
19	If Yes, what kind?	
20	What is the advice received from your doctor/ counselor	
21	Did you get relief from following the advice given by the Doctor	Yes /No
22	If No – what is the side effect that you are still experiencing	
23	How many times you have given blood for testing for Hb/blood sugar/WBC/liver functioning (RFT/LFT) test last year?	
24	How many times you have given blood for CD4 test last year?	
25	Did you encounter any OI while taking ART?	Yes /No
25.1	If Yes, what?	
26	Do you know about Viral Load Test?	Yes/No
27	Have you been referred to Viral load test?	Yes /No
28	Have you been referred for second line drugs?	Yes /No
28.1	If Yes, mention date of referral	
29	Have you been started on the second line drugs?	Yes /No
29.1	If Yes , mention the date when started	

30	Did you have to wait for second line?	Yes/No
30.1	If Yes, while waiting for second line did you continue to receive the first line?	Yes /No
30.2	If Yes, did you have any problems in receiving it?	
33	Have you been referred for the following test/check up during the routine visit to ART center	Yes/No If yes , specify when
	1. Syphilis test (Every six months) (painless sore on genitals, rectum, anus or mouth)	
	2. Gonorrhea and Chlamydia (3 months) (discharge, pain or burning sensation while urinating)	
	3. Genital/ano rectal ulcers (3 months)	
	4. Rectal Pus (3 months)	
	5. Urethral discharge (3 months)	
	6. Hepatitis A & B (3 months) (fatigue, abdominal pain, loss of appetite, fever, nausea, dark urine, yellowing of skin)	
	7. Herpes Simplex Virus (3 months) (blisters on skin with tingling, itching)	
	8. Tuberculosis (TB) (3 months)	
	9. Pneumonia (PCP)	
	10. Candida - Albicans (Oral Thrush) (itching, burning sensation)	
	11. Candidiasis (Oral) (fungal infection on skin, bloating, constipation)	
	12. Genital warts	
34	If No, what is the reason given by the doctor?	
35	Are you getting vitamin and other mineral supplements from your center?	Yes/No
36	Any specific observation/feedback? Any recommendation to improve the service?	

FORMAT FOR ADULT PLHIV

Date: _____ District _____

State _____

1	ART number	
2	Name (Optional)	
3	Address : How far is this place from the ART Centre	
4	Contact number	
5	Age	
6	Gender	Male /Female
7	Name of ART/Link ART Center and Place	
8	Accessing ART through -	Self/Parent/Guardian/Family members/Friends/Network members
9	ART (tick the combination/formulation the patient is taking)	1st LINE/2nd LINE
9.1	1st line	
A	TLE (Tenofovir 300 mg + Lamivudine 300 mg + Efavirenz 600 mg)	
B	ZL (Zidovudine 300 mg + Lamivudine 150 mg)	
C	Efavirenz 600 mg	
D	Nevirapine 200 mg	
9.2	2nd line	
E	TL (Tenofovir 300mg + Lamivudine 300 mg)	
F	ZL (Zidovudine 300mg+ Lamivudine 300 mg)	
G	Atazanavir 300mg + Ritonavir 100mg	
H	Lopinavir 200mg (2 tablets)	
I	Ritonavir 50mg (2 tablets)	
10	Do you recall any instance (time/period) (in the last one year) when ART medicines were not given to you?	Yes/No
10.1	If Yes mention the month/s and period/s (For instance, in June last year for 15 days or from June last year for two months could be a response)	
10.2	Was there any information and explanation given to you about the shortage?	Yes/No

10.3	If Yes, mention what was informed/explained	
11	How many times (in a month) were you required to visit the Centre then? (Frequency of your visit)	
12	Did you receive the same drugs that you were prescribed by the ART center then?	Yes / No
13	If No, what was the change that you noticed?	a. Different size/shape b. Change in color c. Different combination d. Dosage.
b.	Change in color	
c.	Different combination	
d.	Dosage	
14	Did you speak to the ART doctor or counselor about the change?	Yes / No
15	If Yes, what explanation did they provide?	
16	Was their explanation useful- were you convinced?	Yes /No
17	If No what was your concern?	
18	Have you experienced any side effects due to ART drugs?	Yes /No
19	If Yes, what kind?	
20	What is the advice received from your doctor/ counselor	
21	Did you get relief from following the advice given by the Doctor	Yes /No
22	If No – what is the side effect that you are still experiencing	
23	How many times you have given blood for testing for Hb/blood sugar/WBC/liver functioning (RFT/LFT) test last year?	
24	How many times you have given blood for CD4 test last year?	
25	Did you encounter any OI while taking ART?	Yes /No
25.1	If Yes, what?	
26	Do you know about Viral Load Test?	Yes/No
27	Have you been referred to Viral load test?	Yes /No
28	Have you been referred for second line drugs?	Yes /No
28.1	If Yes, mention date of referral	
29	Have you been started on the second line drugs?	Yes /No

29.1	If Yes , mention the date when started	
30	Did you have to wait for second line?	Yes/No
30.1	If Yes, while waiting for second line did you continue to receive the first line?	Yes /No
30.2	If Yes, did you have any problems in receiving it?	
31	Have you been referred to any NGO or Medical shop during ART stock out to get ART drugs?	Yes /No
31.1	If Yes what has been your experience?	
31.2	Did you receive any reimbursement for ART purchased from medical shop?	
32	Have you ever discontinued ART medication?	Yes/No
32.1	If Yes, how long had you been without ART medication? Mention period	
32.2	What was the reason for discontinuing?	
32.3	How did you re-initiate the treatment?	
33	Have you received medicines for opportunistic infection from your Center?	Yes/No
33.1	If No, what were the reasons?	
34	Have you been referred to Pap smear/Viavali test in this year?	Yes /No
35	Are you getting vitamin and other mineral supplements from your center?	Yes/No
36	Any specific observation/feedback? Any recommendation to improve the service?	

FORMAT FOR PRE AND POSTNATAL WOMEN

Date: _____ District: _____

State: _____

1	ART No.	
2	Name of ART/Link ART Center and Place	
3	Name(Optional)	
4	Address	
5	Contact	
6	Age	
7	Is this your first pregnancy	Yes/No
8	If No, mention the number of this pregnancy?	
9	Have you been referred to HIV and STI test during your visit to PPTCT?	Yes/No
10	Were you on ART before pregnancy?	Yes/No
11	If No, did you start ART during pregnancy?	Yes/No
12	ART (tick the combination/formulation the patient is taking)	1st LINE/2nd LINE
	1st line	
	TLE (Tenofovir 300 mg + Lamivudine 300 mg + Efavirenz 600 mg)	
	ZL (Zidovudine 300 mg + Lamivudine 150 mg)	
	Efavirenz 600 mg	
	Nevirapine 200 mg	
	2nd line	
	TL (Tenofovir 300mg + Lamivudine 300 mg)	
	ZL (Zidovudine 300mg+ Lamivudine 300 mg)	
	Atazanavir 300mg + Ritonavir 100mg	
	Lopinavir 200mg (2 tablets)	
	Ritonavir 50mg (2 tablets)	
13	How long have you continued with ART?	Till delivery/breastfeeding
14	Accessing ART through -	Self/Parent/Guardian/Family members/Friends/Network members
15	Do you recall any instance (time/period) (in the last one year) when ART medicines were not given to you?	Yes/No

16	If Yes mention the month/s and period/s (For instance, in June last year for 15 days or from June last year for two months could be a response)	
17	Was there any information and explanation given to you about the shortage?	Yes/No
18	If Yes, mention what was informed/explained	
19	How many times (in a month) were you required to visit the Centre then? (Frequency of your visit)	
20	Did you receive the same drugs that you were prescribed by the ART center then?	Yes / No
21	If No, what was the change that you noticed?	a. Different size/shape b. Change in color c. Different combination d. Dosage.
22	Did you speak to the ART doctor or counselor about the change?	Yes / No
23	If Yes, what explanation did they provide?	
24	Was their explanation useful- were you convinced?	Yes /No
25	If No what was your concern?	
26	Have you experienced any side effects due to ART drugs?	Yes /No
27	If Yes, what kind?	
28	What is the advice received from your doctor/ counselor	
29	Did you get relief from following the advice given by the Doctor	Yes /No
30	If No – what is the side effect that you are still experiencing	
31	How many times you have given blood for testing for Hb/blood sugar/WBC/liver functioning (RFT/LFT) test last year?	
32	How many times you have given blood for CD4 test last year?	
33	Did you encounter any OI while taking ART?	Yes /No
34	If Yes, what?	
35	Do you know about Viral Load Test?	Yes/No
36	Have you been referred to Viral load test?	Yes /No
37	Have you been referred for second line drugs?	Yes /No
38	If Yes, mention date of referral	

39	Have you been started on the second line drugs?	Yes /No
40	If Yes , mention the date when started	
41	Did you have to wait for second line?	Yes/No
42	If Yes, while waiting for second line did you continue to receive the first line?	Yes /No
43	If Yes, did you have any problems in receiving it?	
44	Have you been referred to any NGO or Medical shop during ART stock out to get ART drugs?	Yes /No
45	If Yes what has been your experience?	
46	Did you receive any reimbursement for ART purchased from medical shop?	
47	Have you ever discontinued ART medication?	Yes/No
48	If Yes, how long had you been without ART medication? Mention period	
49	What was the reason for discontinuing?	
50	How did you re-initiate the treatment?	
51	Have you received medicines for opportunistic infection from your Center-	Yes/No
52	If No, what were the reasons?	
53	Have you been referred to Pap smear/Viavali test in this year?	Yes/No
54	Are you getting vitamin and other mineral supplements from your center?	Yes/No
55	Nevirapine syrup	Received from the center/ bought it from nearest center
56	Has your child been tested for PCR	Within 45 days, 6 months 18 months
57	Has your child received septran (cotrimaxazole- to prevent infections) regularly till HIV confirmation test?	Yes/No
58	Any recommendation to improve the service? Any specific issue during or after pregnancy?	