PALS

PLHIV-ART LINKAGE SYSTEM

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The Information system to enhance access and continuum of care for PLHIV

NACO

National AIDS Control Organisation

India's voice against AIDS
Ministry of Health & Family Welfare, Government of India
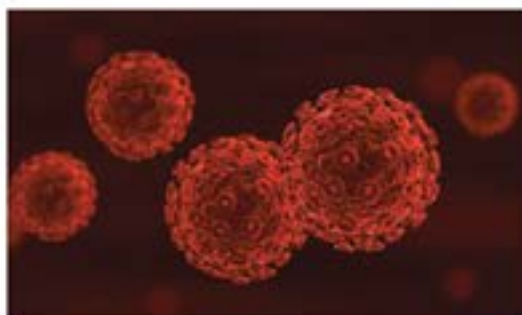
25 Years of India's AIDS Control Programme

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

Foreword

India aims to reduce annual new HIV infections by 50 percent through the National AIDS Control Program (NACP) – IV. The country is also committed to achieving the global 90-90-90 target to end the AIDS epidemic by 2020. Key to achieving these targets is the tracking of PLHIVs and their access to care and treatment. The PLHIV-ART Linkage System (PALS), developed by NACO, with technical assistance from PEPFAR Centers for Disease Control and Prevention with implementing partner Voluntary Health Services, WHO and other key stakeholders enables this. PALS is a case-based tracking system of all the People Living with HIV, and specifically pregnant women and infants.

Hosted on the 'Meghraj' cloud server of the GOI, PALS is a web-based system that enables capture of information for each PLHIV at every service delivery interface through a unique ID. It enables real-time linkage between ICTC and ART, across facilities, districts and states in the country. The system captures a range of information from HIV diagnosis to ART initiation including demographics, details of spouse/ partner HIV testing and infant testing details, in the case of pregnant women. The dashboard feature enables analytics at the facility, district, state and national levels. Work-plans for follow ups for each ICTC and ART are also generated. Thus, through a case-based tracking, PALS enables better program monitoring and epidemic surveillance. This document provides an overview of PALS, how it was conceptualized and developed, its features, implementation, benefits and challenges, and best practices on how it has helped facilities, districts and states to track and monitor individual cases and the epidemic. It also situates PLAS in the global context, as a unique Electronic Health Record innovation for PLHIV in India.

I hope that PALS would enable India to strengthen program monitoring to effectively track and monitor the HIV epidemic.

(Sanjeeva Kumar)

Preface

Government of India is committed to reducing new HIV infections in India; and eliminating new HIV infections among children is a key focus. To enable this, guidelines for Prevention of Parent to Child Transmission of HIV (PPTCT) were developed in 2014. With the modifications in interventions following the change in guidelines, there was a need for a comprehensive information system to track and follow up on HIV positive pregnant women during ANC, delivery, PNC, and to track their newborn child for more than 24 months. This was the genesis of PALS, which was first developed to track the PPTCT cohort. Following its successful implementation in 22 states, PALS was extended to capture information of all general PLHIV including Men, Women, children, orphan babies etc., in 2016. It has since been implemented in 33 states and union territories in India.

Prior to PALS, all information for pregnant women and other PLHIV was being maintained in excel sheets. The process of compiling the excel sheets at the district, state and national levels; and data aggregation was a challenge for several states. With PALS, this process has become much easier. At a glance, we now know the status of the epidemic, with data disaggregated by cohorts of PLHIV, sex and geographies. The system enables generation of reports at all levels and lists for follow up for facility level staff. Going forward, the implementation of PALS across states needs to be strengthened, for it to facilitate epidemic monitoring. It is also envisaged that PALS would be linked to other information systems such as the MCTS and IMS to enable a seamless flow of information across the care continuum.

Globally, PALS is a one of kind system. There are few systems in the world that enable a case- based tracking, similar to an EHR for PLHIV. Thus, there is significant potential for other high prevalence countries to learn from the best practices and challenges of PALS.

(ALOK SAXENA)

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अपनी एचआईवी अवस्था जानें, निकटतम सरकारी अस्पताल में मुफ्त सलाह व जाँच पाएँ
Know your HIV status, go to the nearest Government Hospital for free Voluntary Counselling and Testing

▌ A Table of Contents

Executive summary

The PLHIV-ART Linkage System (PALS) is a web based, real time, case-based information system for People Living with HIV. It enables information capture for each individual, and data linkages across facilities, districts and states in India. Aggregated information at each level, helps identify trends and monitor the epidemic. PALS was Developed by the National AIDS Control Organization (NACO), with technical assistance from the Presidents Emergency Plan for AIDS Relief (PEPFAR) - US Centers for Disease Control and Prevention (CDC) and implementation partners including the Voluntary Health Services (VHS), FHI360, WHO and others.

The key features of PALS:

- Individual case-based tracking of PLHIV
- Captures range of information from HIV diagnosis to ART Initiation
- Information can be entered at each level of service delivery interface
- Enables recording of demographic information including contact details for follow up
- Unique PID (Patient Identification) for each PLHIV
- Enables recording of the HIV test details of spouse / partner, to ensure partner management
- Ensures linkage between ICTC and ART Centers to which the PLHIV has been referred
- Enables workplan generation for follow up on each ICTC and ART
- Dashboard for analytics – at the facility, district, state and national levels
- Secured login facility to ensure confidentiality of information

PALS is a Unique Case Based tracking and surveillance System. Before the introduction of PALS, the HIV program monitoring and reporting systems had three significant limitations. First, lack of national electronic data system for capturing individual PLHIV data, helping in reducing data duplication. Second data from persons diagnosed in HIV testing programs was not linked to data in the HIV care and treatment program monitoring systems. Hence, it was not possible to measure actual linkage to care, understand populations least likely to be linked to care, or intervene to locate and engage these persons in care. In other words, it was not possible to accurately measure or identify persons who were diagnosed but had not entered care or to measure the timeliness of entry into care. Third, beyond the facility level, monitoring and reporting systems used aggregate data which can overestimate the number of persons in care and the number of patients lost to follow-up.

PALS provides significant lessons and pointers for developing individual case-based tracking / surveillance for other health programs in the country.

PALS is hosted on the 'Meghraj' cloud server of National Informatics Center, Government of India. 'Meghraj', is an initiative to accelerate delivery of e-services in the country while optimizing Information and Communication Technology (ICT) spending of the Government of India. PALS is accessible to all establishments of National AIDS Control Organization at National, State, District level and diagnostic (Integrated Counseling and Testing Centers) and treatment centers (ART Centers) in India.

PALS was initially developed to track and facilitate continuum of care to all the PLHIV women and their babies for more than 24 months under the Prevention of Parent to Child Transmission of HIV (PPTCT) program (Option B+) across India named as "PPTCT module". Based on the successful implementation of this module NACO decided to extend PALS to track all the other PLHIV General Clients include PLHIV men, women, spouses/partners, children and orphan babies and this module is currently named as "Integrated PALS" which includes both PPTCT and General clients. PALS is at present implemented in 33 states and union territories of

India. To document the process, challenges and lessons on development and implementation of PALS and to identify and document best practices, success stories and impact by PALS a review was done in three states – Tamil Nadu, Odisha and Telangana. The choice of these states was dictated by the fact that the implementation of PALS is at various levels. It was felt that the varying levels would offer lessons on how the roll out is occurring, the bottlenecks and how it could be addressed. Detailed case studies are presented in the report for each selected states.

PALS has helped the states to

- Track and manage cases across geographies, this is specifically useful in the case of border districts, where there is significant movement of PLHIV
- Enable data management by eliminating duplication and redundancies
- Identification and tracking of Loss to follow up (LFU) cases
- Data management for the PPTCT and Early Infant Diagnosis cohort

Issues of infrastructure, human resource challenges and capacity building were some of the issues mentioned as bottlenecks. All the stakeholders have highlighted the need for capacity building for the personnel from the state to the facility level, to effectively use the features of PALS. The need for an offline version, which could be used in locations that do not have access to internet; and for linkage of PALS to other information systems such as Inventory Management System, National Health Mission's Mother and Child Tracking System was also articulated. Based on users request the offline version of PALS is developed and is ready for launch.

Review of literature globally, indicates that there are few systems such as PALS, which enable client-based tracking of people living with HIV. PALS is an Electronic Health Records innovation that facilitates continuum of care for PLHIV by capturing demographic and service access data; while enabling real-time linkage across geographies, service delivery points and cohorts of PLHIV.

Abbreviations

AD	Additional Director
APD	Additional Project Director
AIDS	Acquired Immuno-Deficiency Syndrome
ANC	Antenatal Care
APSACS	Andhra Pradesh State AIDS Control Society
ART	Anti-retroviral Therapy
ARV	Anti-retroviral Drug
BP	Bridge Population
BSD	Basic Services Division
CD4	Cluster of differentiation 4
C-DAC	Center for Development of Advanced Computing
CDC	Centers for Disease Control and Prevention
CPT	Co-trimoxazole preventive therapy
CST	Care Support and Treatment (Division)
DAPCU	District AIDS Prevention and Control Unit
DDG	Deputy Director General
DGHT	Division of Global HIV & TB - CDC
DIS	District ICTC Supervisor
DOB	Date of Birth
EHR	Electronic Health Records
EID	Early Infant Diagnosis
FHI	Family Health International
FSW	Female Sex Worker
GC	General Client
GOI	Government of India
HIV	Human Immuno-Virus
HSS	HIV Sentinel Surveillance
HSSP	HIV Sensitive Social Protection Portal
IAS	Indian Administrative Service
IBBS	Integrated Biological and Behavioral Surveillance
ICTC	Integrated Counselling and Testing Center
IHRC	India HIV AIDS Resource Center
IITF	India International Trade Fair
IMS	Inventory Management System
IOG	Institute of Obstetrics and Gynaecology and Government Hospital, Chennai
ITM	IyyamThavir Mobile App
ITPO	Indian Trade Promotion Organization
KP	Key Population
LFU	Lost to Follow up
M&E	Monitoring and Evaluation
MCTS	Mother and Child Tracking System
MEO	Monitoring and Evaluation Officer
MES	Monitoring, Evaluation and Surveillance
MIS	Management Information Systems
MoHFW	Ministry of Health and Family Welfare
MSDS	Migrant Service Delivery System
MSM	Men who have Sex with Men
NACO	National AIDS Control Organization
NACP	National AIDS Control Program
NFHS	National Family Health Survey
NGO	Non-Government Organizations
NPO	National Program Officer
OBG	Obstetrics and Gynecology
OSACS	Odisha State AIDS Control Society
PALS	PLHIV-ART Linkage System
PD	Project Director
PEPFAR	United States President Emergency Plan for AIDS Relief
PID	Patient Identification
PLHIV	People Living with HIV/AIDS
PNC	Postnatal Care
PPP	Public Private Partnership
PPTCT	Prevention of Parent to Child Transmission
PW	Pregnant Woman
RNTCP	Revised National Tuberculosis Control Program
SACS	State AIDS Control Society
SCMS	Supply Chain Management System
SI	Strategic Information
SIMS	Strategic Information Management System
SMS	Short Message Service
STI	Sexually Transmitted Infection
TB	Tuberculosis
TG	Trans-Gender
TI	Targeted Intervention
TNSACS	Tamil Nadu State AIDS Control Society
TOT	Training of Trainers
TSACS	Telangana State AIDS Control Society
UNAIDS	United Nations program on HIV and AIDS
UNICEF	United Nations Children's Fund
UT	Union Territory
VHND	Village Health and Nutrition Day
VHS	Voluntary Health Services
VHS-CDC	Voluntary Health Services - Centers for Disease Control and Prevention
WHO	World Health Organization

▌Introduction

India has the third largest HIV epidemic in the world. As per the India HIV Estimation Report, NACO (2015), National adult (15–49 years) HIV prevalence was estimated at 0.26 percent (0.22 percent–0.32 percent) in 2015. The adult HIV prevalence was estimated at 0.30 percent among males and at 0.22 percent among females. The UNAIDS (2016) estimates HIV prevalence in India (among all age groups) at 0.3 percent (UNAIDS Data Book, 2017). Though this proportion is small compared to many other middle-income countries; however, given India's population, this equates to 2.1 million people living with HIV[1] For the same year, an estimated 62,000 people died from AIDS-related illnesses in India[2]. Among states, in 2015, Manipur had the highest estimated adult HIV prevalence of 1.15 percent[3].

In 2016, India had 80,000 (62,000 - 1,00,000) new HIV infections and 62,000 (43,000 – 91,000) AIDS-related deaths. There were estimated 2,100,000 (1,700,000 – 2,600,000) people living with HIV in 2016, among whom 49% (40% - 61%) were accessing antiretroviral therapy.

The key populations most affected by HIV in India are: Sex workers, with an HIV prevalence of 2.2 percent; Gay men and other men who have sex with men, with an HIV prevalence of 4.3 percent; people who inject drugs, with an HIV prevalence of 9.9 percent; Transgender people, with an HIV prevalence of 7.2 percent.Since 2010, new HIV infections have decreased by 46 percent and AIDS-related deaths have decreased by 22%.

http://www.unaids.org/en/regionscountries/countries/india/

Overall, India's HIV epidemic is steadily declining, from 0.38 percent adult HIV prevalence in 2001-03 to 0.26 percent in 2015. The incidence of new infections has also declined by 66 percent from 2000 (as compared to a global average decline of 35 percent), and AIDS-related deaths have declined by 54 percent between 2007-15[4]. Through its evidence-informed, comprehensive programs, India managed to achieve the 6th Millennium Development Goal of halting and reversing the HIV epidemic. However, there remain several challenges ahead; while the rate of reduction of new HIV infections has decreased; there is a rising trend seen in some states/UTs[5]. In its most recent program, the National AIDS Control Program (NACP) - IV (2012-17), India aimed to reduce annual new HIV infections by 50 percent through the provision of comprehensive HIV treatment, education, care and support for the general population and build on Targeted Interventions for key affected groups and those at high risk of HIV transmission[6]. A key component to achieve this target was to eliminate new HIV infection among children, along with focused efforts on high-risk groups. On April 28, 2017; India also committed to achieving the global 90-90-90 target to end the AIDS epidemic; *i.e. By 2020, 90 percent of all people living with HIV will know their HIV status and 90 percent of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90 percent of all people receiving antiretroviral therapy will have viral suppression.*

To achieve the NACP IV targets and reach the goal of the UNAIDS "90-90-90", tracking and follow up of all the People Living with HIV (PLHIV) is vital. To increase access and facilitate continuum of prevention, care and treatment services to all the PLHIV, a web based, real time, case based information system named as "PLHIV ART Linkage System (PALS)" was developed by National AIDS Control Organization (NACO) at national level with technical assistance from Presidents Emergency Plan for AIDS Relief (PEPFAR)- US Centers for Disease Control and prevention (CDC) along with implementing partners Voluntary Health Services (VHS), FHI360, WHO and other key stakeholders.

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[1]UNAIDS 2017 (Data Book)

[2]UNAIDS 2017 (Data Book)

[3]The details of other states are as follows. Mizoram (0.80 percent), Nagaland (0.78 percent), Andhra Pradesh & Telangana (0.66 percent), Karnataka (0.45 percent), Gujarat (0.42 percent) and Goa (0.40 percent). Maharashtra, Chandigarh, Tripura and Tamil Nadu have shown estimated adult HIV prevalence greater than the national prevalence (0.26 percent), while Odisha, Bihar, Sikkim, Delhi, Rajasthan and West Bengal have shown an estimated adult HIV prevalence in the range of 0.21– 0.25 percent; see India HIV Estimation Report, 2015, NACO

[4]India HIV Estimation Report, 2015, NACO

[5]India HIV Estimation Report, 2015, NACO

[6]NACO (2013) 'Statement Containing Brief Activities of the Department of AIDS Control in 2013'

PALS was initially developed to track and facilitate the continuum of care for all the PLHIV women and their babies for more than 24 months under the Prevention of Parent to Child Transmission of HIV (PPTCT) program (Option B+) across India named as "PPTCT module". Based on the successful implementation of this module NACO decided to extend PALS to track all the other PLHIV General Clients include PLHIV men, women, spouses/partners, orphan babies and children and this module is named as "Integrated PALS" which includes both PPTCT and General clients.

HIV case-based surveillance or tracking is an approach that involves the reporting of individual-level information from each person diagnosed with HIV at the ICTC. Information along the course of disease from diagnosis to entry into care, initiation of antiretroviral therapy (ART), viral suppression, and death are necessary to measure progress towards epidemic control. Hence it is important that these events are collected and maintained longitudinally.

Objectives of the Assignment

At present, NACO is successfully implementing PALS in 33/36 states and Union Territories. This assignment is to develop a knowledge product on PALS for larger dissemination; by documenting its key features and its success stories and lessonslearned. The key objectives are:

• To document the process, challenges and lessons on development and implementation of PALS

• To identify and document best practices, success stories and impact by PALS.

• Situate PALS in the global context - to review global systems of HIV data management to understand the process in which PALS could benefit from such systems simultaneously draw lessons or inform global practice

Methods Used for Documenting PALS

Given the objectives of the assignment, interactions with the key stakeholders, desk review of documents including analysis of secondary data was undertaken. The details from the interactions, field observations and desk review formed the basis for this document.

Desk Review	• Documents on PALS; training manuals; presentations and progress reports on PALS
	• Internet-based search; specifically, on global systems of HIV record keeping
Key Stakeholder Interactions	• NACO, New Delhi
	• US CDC, DGHT India
	• VHS, Chennai
Field visits in 3 states • Odisha • Tamil Nadu • Telangana	**State level officials**
	• Project Director,
	• Additional Project Director
	• Joint Director (BSD)
	• Joint Director (CST)
	• M&E Officer
	District level officials / DAPCU
	• District AIDS Control Officer
	• District Program Manager
	• District ICTC Supervisor
	• M&E Assistant
	Facility Level stakeholders
	• ICTC/PPTCT Counsellors
	• ART Data Managers

Report Structure

The report is structured as follows. The first section details how PALS enables the individual case-based tracking of PLHIVs, which is consolidated at the level of the facility, district, state and national levels also enables monitoring of the PLHIV linkages and their access to ART. The data, apart from enabling tracking of the individual and monitoring of the program also enables generation of work plans for the counselors for follow up. The system of both client data management and the process flow of information enables a comprehensive framework. The tracking of the individual and the monitoring of the consolidated data at each level helps to reduce the loss to follow up, thus leading to the realization of the 90-90-90 goals. While the first section, outlines what PALS could do; the next section is more a reality check of what PALS has been able to achieve or what is the status of PALS implementation. This section is based on the field visits in 3 states of Odisha, Tamil Nadu and Telangana. It provides an overview of the status and perspectives of key stakeholders. The next section places PALS in the context of the global and national data management systems. The conclusion and recommendations emerging from the sections above are outlined.

Chapter - 1

PALS - Enabling ART Linkages for PLHIVs: Development and Process

1.1 PALS – a Case-Based Tracking System for PLHIV

Based on WHO new guidelines of December 2013, NACO as part of the PPTCT program, initiated a lifelong ART (triple drug regimen) for all pregnant and breastfeeding women living with HIV, regardless of CD4 count or WHO clinical stage, both for their health and prevention of vertical HIV transmission, including additional HIV prevention benefits. In addition, it was decided to provide treatment for a minimum of 6 weeks to children born to HIV positive mothers.

Launch of PALS

The PALS was launched on World AIDS Day, 1st December 2015, by **Shri Jagat Prakash Nadda, Health Minister, Government of India.**

As mentioned above, PALS, a web-based software was developed with "PPTCT module"

1. To track and facilitate the continuum of care to all the PLHIV women and their babies for more than 24 months,

2. To standardize PPTCT-ART linkage mechanism,

3. To strengthen routine monitoring and evaluation system for capturing PLHIV pregnant and breastfeeding women, their exposed baby's cohort and services delivered to them across India.

PALS was initially developed to track the HIV positive PPTCT cohort. PALS was pre-tested in Andhra Pradesh, Telangana, Maharashtra and Delhi. After incorporating inputs from these states, the system was launched in December 2015. Following its launch and successful implementation in 22 states[7]; NACO decided to extend it to track all PLHIVs; an issue described later in the report. When introduced it was initially referred to as the PPTCT-ART Linkage System. When extended to track all the PLHIVs, the software was restructured to capture individual details of all HIV positive men, women, children including orphaned children, in addition to the pregnant and breastfeeding women and their infants. The integrated software tracking tool was referred to as "PLHIV ART Linkage System (PALS)".

Iterative process of system development

The process of development of PALS was one that went through several changes and iterations. While initially designed for just PPTCT, it was extended to general PLHIVs. Several features and functionalities have also been added after the pilot testing and at the request of the NACO.

Some of the major iterations made in PALS include -
• Changes in the report and output formats
• Practical scenarios of client flow and linkages highlighted during pre-testing – such as provision of entering details of multiple pregnancies;
• Linkages of spouse/ partner testing

"For pregnant women and infants, documentation was a challenge. While the MCTS has a mapping of services given to pregnant women, we had no record of HIV services provided. Hence, we started the process of maintaining excel line-listing (an extensive excel sheet with 124 fields/columns). However, women move from place to place, while ANC services may be availed in one location, delivery may happen at another place. This was not possible to track in an excel file and details were duplicated at every service delivery point.

Further, compiling facility level excel sheets at the district and state levels every month was a challenge - information had to be carefully copy pasted. Except for one state which has mastered this, other states often found it challenging.

Hence there was need for software to capture details of and track pregnant women - one that enabled capture of information from multiple data entry points. There was also a need to ensure EID and follow up for 18 months.

PALS is an important source of data for documenting EMTCT. It is a longitudinal cohort data of all HIV positive pregnant women; it documents all the services given during PPTCT and EID continuum of care. This is only source of data which will lead to calculating impact indicator or transmission rate in validation of EMTCT. This system documents the services irrespective of where the pregnant women and HIV exposed child has accessed service in the country."

Dr. Asha Hegde, NPO-BSD, NACO

Integrated PALS (with PPTCT module and General clients Module) was first pre-tested in Bihar and Meghalaya, in the months of September - October 2016[8]. The pre-test helped to fine tune the software and the revamped software was initially implemented in 4 states -Bihar, Meghalaya, Rajasthan and West Bengal. Subsequently, this was extended to other states and at present, it is implemented in 33/36 states and union territories across India[9].

The key features of PALS

• Individual case-based tracking of PLHIV
• Captures range of information from HIV diagnosis to ART Initiation
• Information can be entered at each level of service delivery interface
• Enables recording of demographic information including contact details for follow up
• Unique PID (Patient Identification) for each PLHIV
• Enables recording of the HIV test details of spouse / partner, to ensure partner management
• Ensures linkage between ICTC and ART Centers to which the PLHIV has been referred
• Enables workplan generation for follow up on each ICTC and ART
• Dashboard for analytics – at the facility, district, state and national levels
• Secured login facility to ensure confidentiality of information

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[7]The states are Andhra Pradesh, Chandigarh, Chhattisgarh, Dadra and Nagar Haveli, Delhi, Gujarat, Jammu & Kashmir, Jharkhand, Karnataka, Kerala, Madhya Pradesh, Uttar Pradesh, Maharashtra, Manipur, Mizoram, Odisha, Puducherry, Punjab, Goa, Tamil Nadu, Daman & DIU & Uttarakhand.

[8]See NACO (ND); Pre-Pilot Testing cum Training - PLHIV-ART Linkages System-Bihar & Meghalaya State (mimeo); Basic Services Division; New Delhi, India

[9]NACO has included a specific chapter on PALS in the National HIV Counseling and Testing Services (HTS) Guidelines, December 2016.

The software, thus, apart from tracking an individual PLHIV along the continuum of service from the ICTC to the ART center; also enables partner management and workflow assignment for the counselors to follow up, ensuring that the loss to follow up is minimized. The entire process is kept confidential by using a unique PID for each PLHIV.

Technical Features of PALS Software: PALS is hosted on the 'Meghraj' cloud server which is SSL enabled. 'Meghraj', is an initiative to accelerate delivery of e-services in the country while optimizing ICT spending of the Government. This ensures optimum utilization of infrastructure to speed up the development and deployment of eGov applications. Meghraj is one of the ambitious initiatives of Government of India to utilize and harness the benefits of Cloud Computing, "GI Cloud". The technical details of the PALS software are given in the box below.

Technical Details of PALS Software

• Software	• NetBeans8.0
• Frame Work	• Struts 1.3.8 MVC
• Web server	• Apache-Tomcat 8.0
• User interface	• J-query
• Database	• PostgreSQL 9.2
• Scalability and Testing	• J-meter

PALS software can be used in the latest versions of most browsers such as Chrome, Internet Explorer, Mozilla Firefox or Edge. The minimum internet speed required for the operation of the software is 512 Kbps.

Figure 1: Login Page for PALS

1.2 The Key Stakeholders

The Table below, provides details of the various stakeholders involved in the development of the PALS software, its rollout and subsequent management, at various levels. The development of the PALS software was done based on the suggestion and guidance of the Basic Services Division of the NACO. Their request was supported by CDC, Atlanta, who provided the financial support to FHI360 and subsequently to VHS for the development of the software,and to support its roll out and handholding to ensure that all the states adopt it. The capacity building for the use of the software was provided by NACO and was facilitated by VHS. The roll out, monitoring and handholding support was done by NACO, supported by VHS.

In few states, UNICEF, had placed consultants to ensure that the software, especially for the PPTCT, was adopted by the state. The consultants had provided support to ensure that the counsellors adopted it and provided them backup support to address issues that arose in the use of the software.

PALS - a Unique Case Based tracking and surveillance System.

Before the introduction of PALS, the HIV program monitoring and reporting systems had two significant limitations. First, data from persons diagnosed in HIV testing programs was not linked to data in the HIV care and treatment program monitoring systems. Hence, it was not possible to measure actual linkage to care, understand populations least likely to be linked to care, or intervene to locate and engage these persons in care. In other words, it was not possible to accurately measure or identify persons who were diagnosed but had not entered care or to measure the timeliness of entry into care. Second, beyond the facility level, monitoring and reporting systems used aggregate data which can overestimate the number of persons in care and the number of patients lost to follow-up.

	Development of PALS	Implementation of PALS		
		Capacity Building	**Roll-out & monitoring**	**Data entry**
National Level	• BSD, NACO • CDC • VHS • WHO • FHI 360	• BSD, NACO • Facilitation support by CDC/VHS	• BSD, NACO • Technical & facilitation support by CDC/VHS	
State Level		• BSD, SACS • UNICEF - through consultants placed in SACS	• BSD, SACS • M&E Officer, SACS	
District Level		• District Program Manager (DAPCU)/ District M&E officer, who have attended state level orientation build capacity/ provide handholding support to facilities	• District Program Manager (DAPCU)/ District M&E officer	
Facility Level				• ICTC Counsellor • ART Data Manager

Table 1: Stakeholders in the development and implementation of PALS

1.3 Data flow and Management in PALS

Client Data Management

Data is entered into PALS at the ICTC and ART centers by using the Add/Search Patient module. When tested positive at the ICTC; PLHIV details are entered in PALS by the ICTC counsellor. Prior to adding a new client, all ICTC counsellors are expected to "search" to ensure same client has not already been registered in any another facility. For instance, there is a likelihood that a person tested for HIV in one facility may visit another facility for reconfirmation and may not reveal his pervious test. Or, a PLHIV may not be carrying the records of the previous visits to the ICTC/ ART centers. In such instances, the search feature enables the counsellor to check if the PLHIV has a prior history and has been recorded elsewhere. This helps to weed out the duplication in recording of the PLHIVs[10]. As mentioned above each PLHIV could be categorized as **PPTCT** (which would also include infant details), **General Client, Spouse/ partner** or **Orphan baby**. This enables tracking of each cohort.

At registration in the ICTC, the following details of each PLHIV are recorded in the software.

- Demographic and Testing details– includes name, Aadhar number (optional), phone number, address, age, gender, marital status, education, occupation and PID number, in addition to HIV, TB and Syphilis test details
- Referral details– includes name of the ART center referred to and referral date.The referral details enable real-time linkage of the ICTC with the ART. Once an ICTC counsellor enters details of ART center; the ART center (to which the PLHIV has been referred) can see details of the client(s) on their screens, thus making it easier to follow up. For instance, if a referred PLHIV does not show up, the ART counsellor can either follow up or inform the ICTC counsellor to further follow up during outreach. ICTC counsellor too can follow up with a client if she/he linked to the ART center.
- Spouse/ partner details–includes demographic and testing details of the spouse/ partner. If the spouse/ partner has already been tested and the details are available on PALS, the system would search for the record and enable a linkage. If the spouse/ partner tests negative, details of the same would be entered, for the system to enable follow ups at three and six months, for subsequent testing.
- If there is an instance of death of PLHIV, that is also recorded.
- For the PLHIV pregnant woman, apart from the details above, information on MCTS mother ID, ANC, delivery, PNC, infant test records from 6 weeks, to 6 months, 12 months and 18 months are also recorded.

At ART, the following details are recorded.

- ART registration details - includes pre - ART registration number, ART registration number, baseline CD4 and WHO HIV clinical staging
  - Reasons, if not initiated on ART
  - If initiated– regimen and CPT details and status of the client at 6 and 12 months
- TB test details
- Death, if any of the PLHIV.

Unique PALS PID Number

Assigning a PID (patient ID) to each PLHIV is a key aspect of the PALS. When a PLHIV is registered at the ICTC, s/he is assigned a PID as part of this anonymous and reliable system for tracking a client in treatment, and care services. PID helps in –

- Creating a confidential service recognition system that uniquely identifies each PLHIV without disclosing their personal information.
- Avoiding duplication in the counting of PLHIV in service provision.
- Enabling analysis of treatment cascades through continuum of care indicator data
- Assessing the mobility of PLHIV through other ICTCs and ART centers
- Support in program management by enabling reorientation of services to meet the changing needs and attendance patterns of PLHIVs.

The PALS system uses the existing PID (given by the ICTC) to generate a unique identification for each client:

This is built on the PID that the ICTC has been following. Each ICTC, at the beginning of the year, starts with new numbering. In other words, in each ICTC across the country, on January 1 each year, the PLHIV numbering starts with 1. This is closed at the end of the year. As the ICTC counsellors were familiar with this; the PALS adapted this numbering by adding additional 18 digits to the numbering systems at ICTCs. These 18 digits are auto-generated by the system, and the last 5 digits are entered by the ICTC. This also ensures comparability between the registers maintained by the ICTC and the system.

The unique 23-digit PID number given to each PLHIV indicates the following. The first two digits indicate the type of case; PW indicates pregnant woman and GC indicates General Client. The next 6 digits indicate the type of facility; the next 2 digits stand for the state, followed by 3 for district. Digits 14-16 form a unique code, followed by 2 digits for the year. The last 5 digits stand for the PID number given to the client by the ICTC. The Figure below provides a view of the PID generated by PALS.

23 digits Unique - PID

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23

GCSAICTCAPGTR0011500002 - PID given to Patient registered in Bapatla ICTC of Guntur District of Andhra Pradesh state

GC	First Two Digits-Types of Client GC/PW
SAICTC	6 Digits - Type of Facility
AP	2 Digits - State Code
GTR	3 Digits - ICTC Code
15	2 Digits - Year of detction
00002	Last 5 Digits - Serial number given to Patient

While the PALS software enables real time data entry using the Add/ Search patient feature; the data in almost all the ICTCs and ART centers are first recorded in registers and subsequently entered in PALS. In some facilities entry is done at the end of the day, while in others, by the end of the week. The reasons for this is taken up in the subsequent section.

The information recorded for each PLHIV is available individually and as a consolidated data at the level of the facility, district and state. This consolidated information is displayed in a **dashboard.** The dashboard displays details both in numbers and graphs. An overview of the dashboard is given in the figure below. For instance, Figure 2 given below provides a representation of an ICTC dashboard. The first tile in the dashboard indicates the total number of general PLHIV disaggregated by sex. The second tile is for pregnant women; the third is infant children and the last is for the ART linkages. It indicatesthe total number of PLHIV, in group tested and referred by the ICTC, who have been linked to the ART center. The view details button provides details for each client. Similar dashboard is also visible in the ART centers.

"Tracking the PLHIV from the point of detection till the point of successful ART linkage has been the major challenge in the HIV program. The spillages across the program have always been a threat to the UNAIDS 90-90-90 goal. An ideal technology-driven approach called PLHIV ART Linkage System (PALS) has found a solution to address the above. PALS has been a unique system that is designed, developed and implemented across the country by VHS-CDC project under the guidance of National AIDS Control Society with the support of Centers for Disease Control and Prevention (CDC). Its distinctive feature of individual tracking enables the service providers like ICTC and ART centers vigorously follow-up PLHIV who have not been linked with ART center. District and State Administrators effectively use it for planning and decision making. PALS allows NACO to use the National data productively for policymaking".

(Dr. Joseph D Williams, Director Projects, VHS, Chennai)

General Individual		
Male	21	(58%)
Female	15	(42%)
TG	0	(0%)
Total	36	
View Details		→

Pregnant Women		
New Case	2	(100%)
Known	0	(0%)
Multi Preg	0	
Total	2	
View Details		→

Infant/Children		
Orphan	0	(0%)
PPTCT	2	(100%)
Total	2	
View Details		→

ART Linkages	
GC	25
PPTCT	2
Infant	0
Orphan	0
Total	27
View Details	→

Figure 2: Representation of Client Details on an ICTC dashboard

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The figures below provide an overview and indication of the graphs that could be generated by the PALS software. The first figure refers to the details of the different ART regimen provided to the PLHIVs, the second provides disaggregated data for PLHIV by their education levels. The third figure provides details of the PPTCT-ART cascade, it indicates the number of the pregnant women tested HIV positive, numbers referred to ART center, numbers initiated on ART, numbers aborted, numbers delivered, still births and live births, details of ARV prophylaxis initiated and EID details of the infants. The last graph provides details of the linkage of general PLHIVs to the ART centers and includes details of the CD4 counts and the initiation of ART.

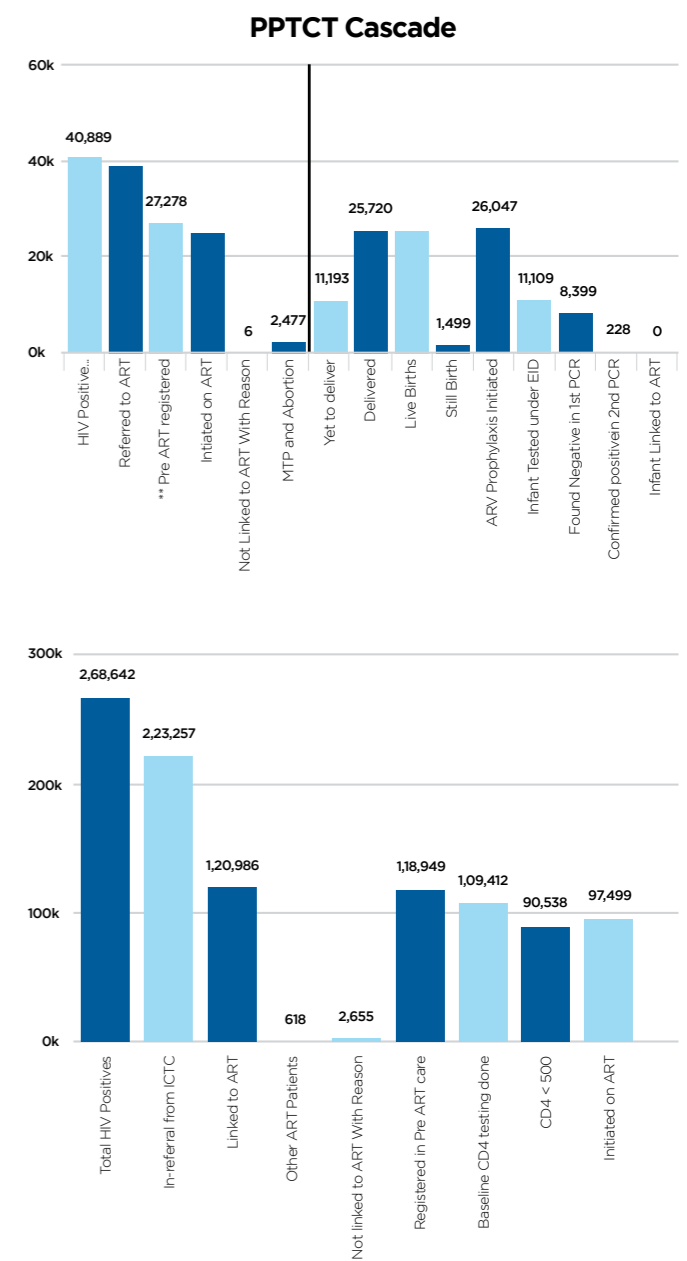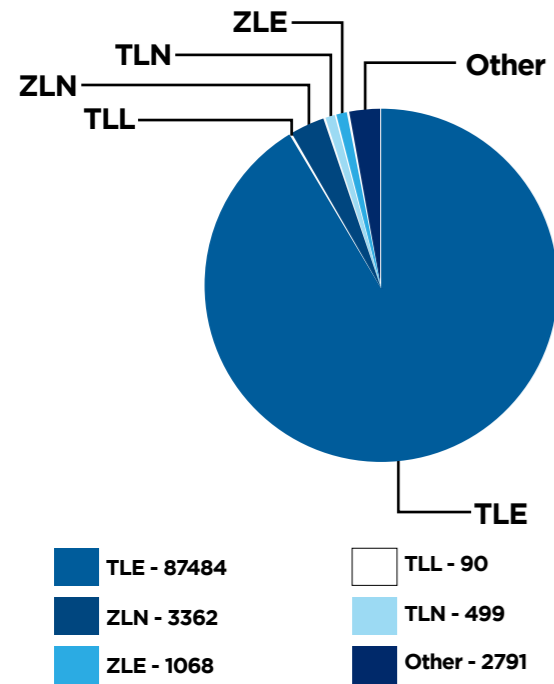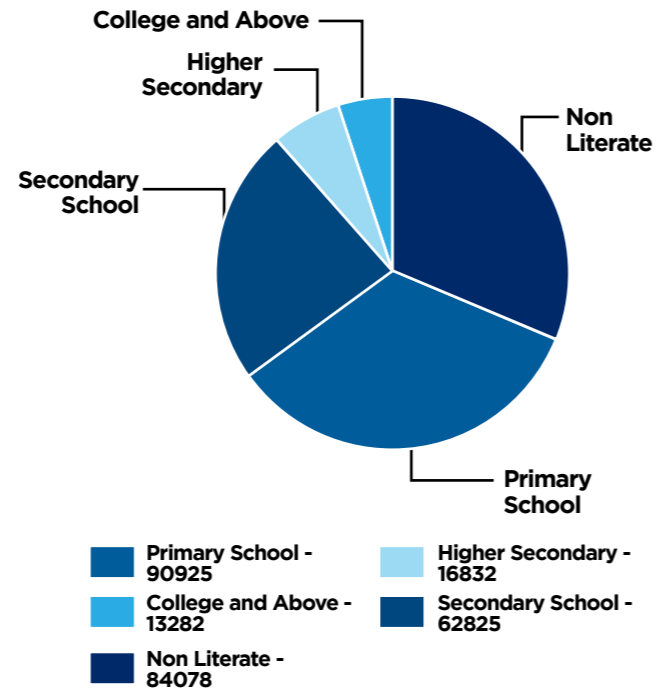### PPTCT – ART Cascade General client cascade

PPTCT Cascade

Figure 3: Examples of Dashboard Graphs

Details of ART regimen for general client

TLE - 87484
ZLN - 3362
ZLE - 1068
TLL - 90
TLN - 499
Other - 2791

Education Status of PLHIV Clients

Primary School - 90925
College and Above - 13282
Non Literate - 84078
Higher Secondary - 16832
Secondary School - 62825

Color coding indicating status of data entry of each client

As mentioned above, PALS enables tracking of each PLHIV and the data is consolidated to provide a cohort level overview for each group, segregated by sex, age and other aspects. However, for that to happen, the entry of data at the ICTC or at the ART centers is imperative. To enable an assessment or review of the status of data entry for PLHIV, the software uses a color code to indicate the extent to which the data uploading is complete. The figure (4) below provides an overview of the color codes and the corresponding status of data entry for each PLHIV. The status of data entry at each stage of the service delivery is reflected in the figure below the color codes.

Not Entered
Partially Entered
Fully Entered
Data Frozen
Fully entered by other ICTC
Partially entered by other ICTC
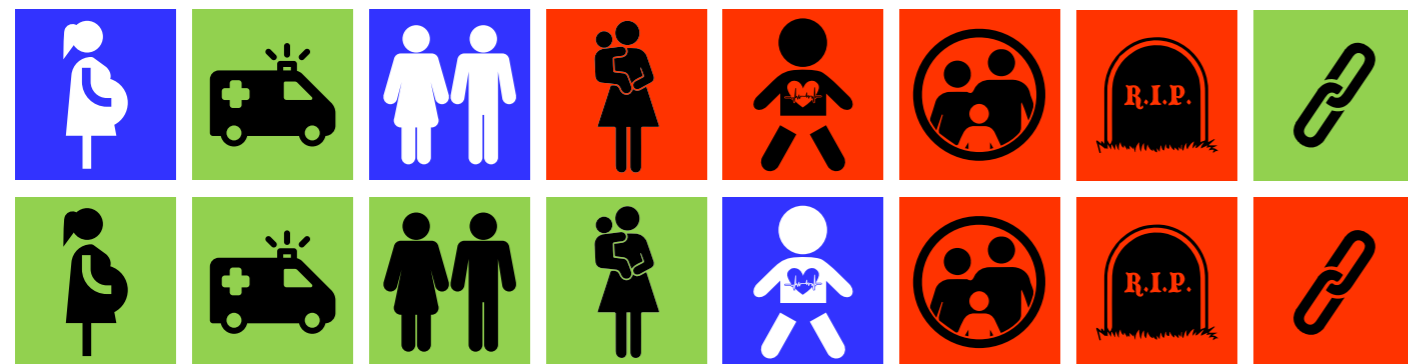
Figure 4: Color Code Pattern

Figure 5: Status of Data Entry at Each Stage of Service Delivery for Two PLHIVs

In the figure (5), for the first PLHIV (1st Row), ANC and spouse testing details are partially entered, details of delivery, and EID are yet to be entered. The client has been linked to ART (frozen in green color). In the case of the second PLHIV (2nd Row)details of ANC, spouse testing, and delivery are filled and frozen; linkage to ART is colored violet (partially entered by other ICTC), indicating multiple points of service access. The color coding serves two functions - reminds the concerned persons of the pending data entry and indicates pending stages of service delivery for each client.

Work-plans

Derived from the client data base, PALS enables, the generation of workplan for the ICTC and ART personnel by generating due lists for follow ups and list of PLHIV who have missed the scheduled visits. Basis this, the ICTC and ART counsellors may develop the plan for follow up with the concerned PLHIV and share the details with field level personnel and organizations for further follow up to ensure adherence to treatment.

Reports

PALS, also generates various reports based on the PLHIV data, which are useful for both monitoring the activities and to inform the planning of the interventions. The details of the reports that could be generated by PALS are given below.

National	State	District	ART	ICTC
Abstracts	Abstracts	Abstracts	ART Line list	ICTC Line list
ICTC-ART Linkage	ICTC-ART Linkage	ICTC-ART Linkage	ART Case report	Beneficiary Card
Spouse Partner test	Spouse Partner test	Spouse Partner testing	ART Analytical report	ICTC analytical report
Data entry status	Data entry status	Data entry status		Work plans
Drill down report	Drill down report	Drill down report		
ICTC line list	ICTC Line list	ICTC Line list		
Orphan children line list	Monthly Report	Monthly Report		
Monthly Report	ART report	ART reports		
ART report	ART analytical report	ART analytical report		
ART analytical report	ART Line list	Work plans		
ART Line list	Work plans			

Table 2: Reports Generated at Different Levels

For each PLHIV cohort - General, Pregnant women, Spouse/partner and Infants, the ICTC counsellor can generate an excel download for already known and newly detected positive cases. This downloaded report resembles the NACO line listing in excel format. This reduces the burden on the counsellors to maintain the line-listing. Similarly, the ART counsellor can download line list in excel for those who are linked with ART, which is the same as the ART line-listing.

While the report module enables users to generate reports for varying time periods, each of the PLHIV cohort- both aggregate and individual level information, two kinds of report- data entry status report and monthly report (up to the facility level) are generated that assist in regular monitoring of data entry at the facility/ district and state levels.

The 'add/search patient' module primarily facilitates entry of information, 'dashboard' reports and 'work-plans' modules use already entered information to enable client tracking, monitoring and surveillance. Beneficiary card allows access to complete details for each client in 4 different formats - General Beneficiary Card, Discordant Couple Card, PPTCT Card and EID Card. Further analytical reports can be generated by all users from the ART and ICTC facility to national level.

At National and State levels, drill-down reports allow program managers and officials to view beneficiary level information. Administrator modules at the state and national level enable management of the system - registration of new users, resetting passwords, data management and resolving technical issues, if any.

PPTCT - Beneficiary Card

PID No			Pre ART No.	
Type of HIV Case	☐ Newly detected HIV Positive		☐ Already known HIV Positive	

HIV testing details (Section A3)			
Date of HIV Confirmatory test		Date of Posttest Counselling	
Route of Transmission of HIV	☐ 1 a. Heterosexual: Commercial Partner ☐ 1 b. Heterosexual: Casual/non- commercial, non-regular Partner ☐ 1 c. Heterosexual: Regular Partner/Spouse ☐ 2. Homosexual/Bisexual ☐ 3. Through Blood and Blood products ☐ 4. Through infected Syringe and Needles ☐ 5. Parent to Child (for children) ☐ 6. Not specified/unknown		

If already known HIV positive (History of HIV testing)		
Whether detected as	☐ Pregnant Women	☐ General Client
State		District	
ICTC Name		On ART No.	

Demographic Details of AN/DIL/PN Mother (Sec A1)			
Name		Age	
Order of Pregnancy		Mobile Number	
Aadhaar Number (UID)		Voter ID Card No	
MCTS ID		Ration Card No.	
Marital Status	☐ Married ☐ Divorced ☐ Separated ☐ Unmarried ☐ Widowed ☐ Live in relationship		
Education	☐ Non-Literate ☐ Primary School ☐ Secondary School ☐ College and above		
Occupation	☐ Agricultural Laborer ☐ Non- Agricultural Laborer ☐ Domestic Servant ☐ Housemaid ☐ Skilled Worker ☐ Semi- skilled Worker ☐ Petty Business/Large Business/small Shop/self-employed ☐ Service (Govt./Pvt.) ☐ Student ☐ Truck Driver/helper ☐ Local Transport Worker (Auto/ Taxi Driver) ☐ Handcraft Pullers, Rickshaw Pullers, etc.)		

Figure 6: Template of the beneficiary card

The **distinctive characteristic of PALS** as Case Based tracking / reporting system and which distinguishes it from aggregate reporting are

- Accurately add new information pertaining to an existing case record, and to determine duplication of records, if any; (i.e. two or more records for the same individual), PALS is designed to enable matching to identify if the information of the PLHIV is already available.

- It enables timely longitudinal population-based data collected at a facility aggregated to the facility, district, state and national levels. This can help to determine and describe the geographic, demographic and risk factor distributions of HIV. This in turn ensures that quality information is provided to NACO or SACS for program planning and evaluation.

1.4 Process Flows in PALS

Client Data Flow

When an individual (General client, Pregnant woman or Infant) is first referred to an ICTC (either by field level service providers/ Medical Officers/ or through the PPTCT during ANC), S/he undergoes a pre-test counseling before undergoing HIV test. If s/he is found positive, then s/he undergoes post-test counselling and gets registered as PLHIV. The registration, as described above, is then done by the ICTC counsellor by using the add/search feature of PALS. The counsellor then, refers the PLHIV to an ART center. After this, at every stage of service access, such as registration, referral, ART treatment, ANC, Delivery, PNC and Infant follow up in the case of pregnant women and in case of any death, the details are to be entered in PALS. An overview of the process flow of PLHIV, both pregnant women and general clients is outlined in Figure7, below. The figure also depicts the process of client flow and the data entry that occurs at each stage in PALS.
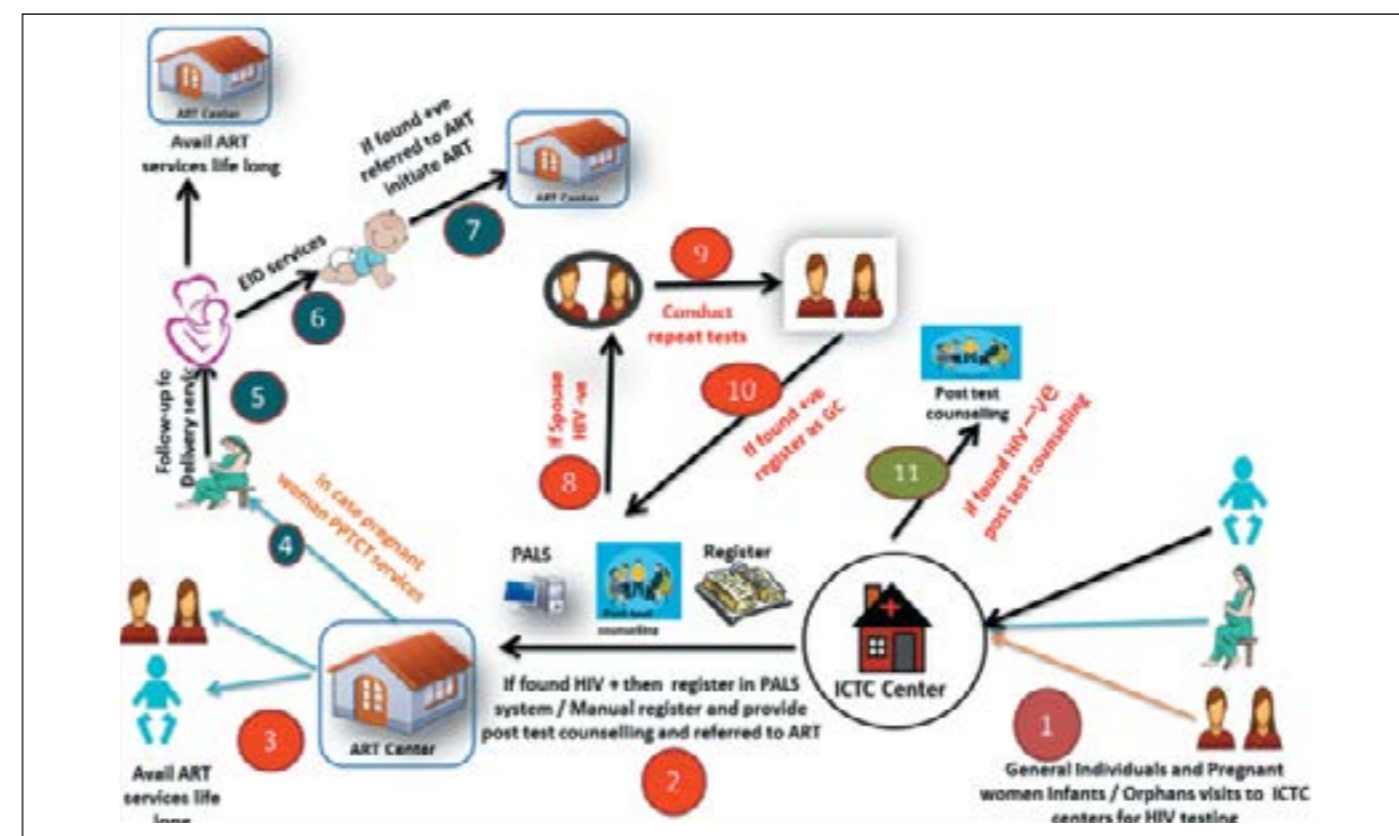
Figure 7: Client Flow in HIV Treatment Cascade and Recording Process in PALS

The responsibility of data entry for each PLHIV is primarily with the ICTC counselors, especially the ICTC in which the PLHIV was first tested and found positive. The ICTC counsellor is expected to enter initial demographic and testing details of PLHIV for smooth referral to ART center. It is important to note that the demographic, testing and referral details can only be entered by the 'mother ICTC'; or the ICTC where the PLHIV was first registered; while ART data manager is expected to enter only ART details. Other details of spouse testing, ANC, delivery, infant follow up and death can be entered by any of the other ICTCs where the client may access care.

The above process of client flow in a treatment cascade of PLHIV is broken down by the General PLHIV and pregnant women PLHIV in the figures (8 and 9) below.

Figure 8: PALS Process Flow for General PLHIV
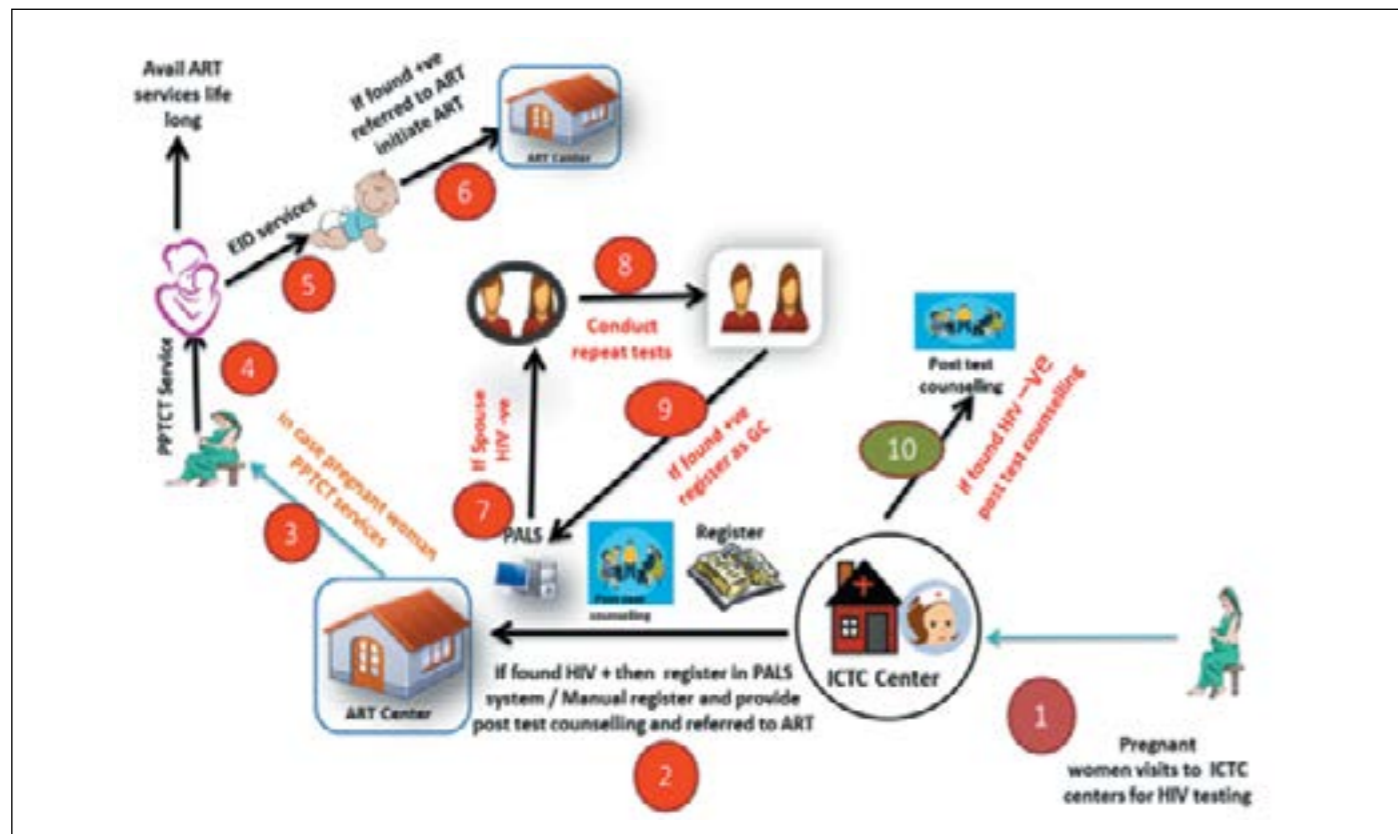
Figure 9: PALS Process Flow for Pregnant Women

- All children born to PLHIV pregnant women are linked to the mother and are followed up for 18 months.
- After 18 months, if child is diagnosed as HIV positive, then child will be registered automatically as a General Client. All mothers are tracked in PALS for a period of 24 months, from ANC to EID. All ANC details would be maintained in the PPTCT module and they would subsequently be treated as General Clients.
- Similarly, spouse/ partner details for all General and PPTCT PLHIV are also linked through the system. Once the spouse/partner found HIV positive he/she will be registered automatically as general client.
- Thus, while the system tracks specific cohorts of PLHIV, it also allows transfer of PLHIV from one cohort to another and linkage across cohorts. This ensures tracking across the care continuum.

Information Flow

As mentioned above, based on the PLHIV data, PALS generates reports and these reports are generated at various levels. The data is first entered in the PALS by the ICTC counsellors and ART data managers at the facility level. Facility level information is then reviewed and analyzed at the district by the District Program Manager and M&E officer, DAPCU (if available). SACS M&E officer and officials of the BSD review information at the state level. Further, the BSD at NACO reviews state level aggregated data at the national level.

Based on information entered at the facility level, officials at the district, state and national levels, can generate consolidated MIS reports, including the ICTC line-list for general clients, PPTCT line-list and ART line-list; they can also access facility level information. Reports to review status of data entry by ICTC and ART centers, are also available.

Thus, the process of information going upwards is consolidated at each level, and the monitoring at each level and the feedback ensures that the service provision is efficient and the lost to follow up of PLHIVs is minimized. An overview of how the information flows is provided in the figure given below.
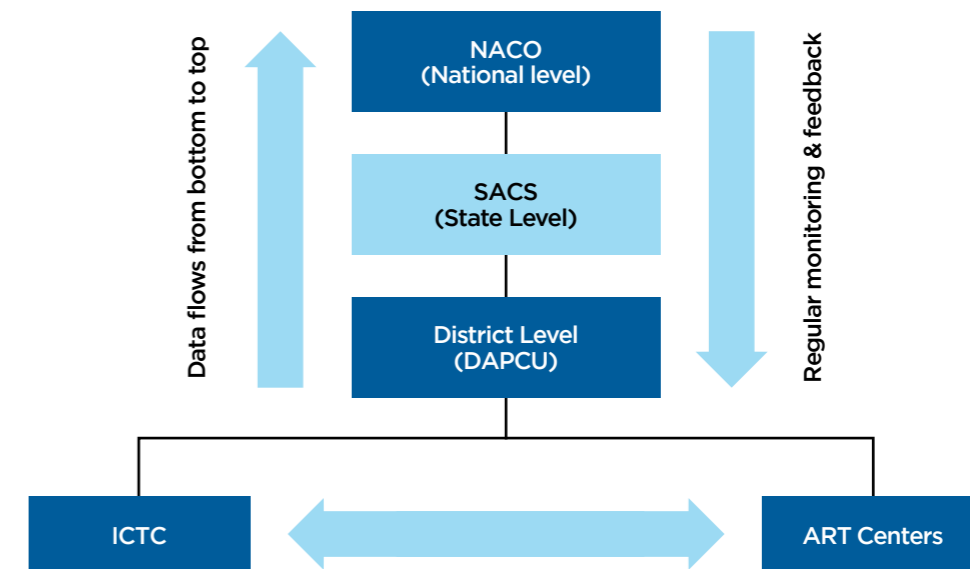
Figure 10: PALS Information Flow

Thus, PALS is a comprehensive client-based tracking system for people living with HIV. The system enables capture of individual demographic, service access and treatment data, which compiled at facility, district, state and national levels, enables program monitoring and epidemic surveillance. Critically, it enables tracking of the first two 90's of the UNAIDS global goals - (1) 90 percent of all people living with HIV will know their HIV status (through capture of all case detection and HIV positive clients) and (2) 90 percent of all people with diagnosed HIV infection will receive sustained antiretroviral therapy (through tracking and follow up between ICTC and ART).

This section is based on desk review of documents and field visits to three states. The field visit was done to see the implementation on ground and understand the issues. The three states are Tamil Nadu, Odisha and Telangana. The choice of these states was dictated by the fact that the implementation of PALS is at various levels of implementation. It was felt that the varying levels would offer lessons on how the roll out is occurring, the bottlenecks and how it could be addressed. In Tamil Nadu and Odisha, the system has been successfully implemented across districts and facilities in the state.

2.1 Roll-out of PALS

Following the launch of the PALS by the Health Minister, Government of India, a one-day orientation meeting for all states was convened in Delhi. Officials from each state, including the APD, PPTCT consultants and M&E persons attended the orientation conducted by NACO, supported by CDC and VHS. Officials were provided an overview on PALS, its features, and use.

Following this, a letter was sent out by NACO to all states to implement the software across facilities. Further, all facilities were directed to enter data for all PPTCT cases starting from 2012. In other words, it was expected that all data from the start of the NACP IV program (2012) would be entered in PALS; and ICTC counsellors were expected to enter this data for the 3-year time period - 2012 - 15, in addition to concurrent entries.

Integrated PALS was demonstrated to all the officials of NACO, chaired by Dr. C. V Dharma Rao, Joint Secretary NACO on 19th Oct 2016 NACO, wherein, DDG (BSD), DDG (CST), DDG (TI), Director Finance and other NACO officials and representatives from CDC, WHO and VHS were present. The system was well received and appreciated and potential for its integration with IMS and SIMS was discussed.

During this meeting, the JS, NACO suggested that the PALS be demonstrated as a unique system developed by NACO at the India International Trade Fair (IITF) organized by India Trade Promotion Organization (ITPO) between November 14-27, 2016. The theme of the trade fair was Digital India.

A short video film was developed in Hindi and English and PALS was showcased at the IITF.

Ms. Anupriya Patel, Hon'ble MoS Health was briefed on PALS at IITF on 19 Nov 2016

Mr. K. B Agarwal, IAS, MoHFW was briefed on PALS at IITF on 19 Nov 2016

NACO official was briefed on PALS at IITF, Pragati Maidan, New Delhi

Chapter - 2
PALS in Operation - Best Practices, Issues and Impact

A National Level orientation was undertaken for all the states & UTs on both the PPTCT and Integrated modules of PALS. Subsequently, the NACO, VHS and WHO teams visited 17 states to further supplement the capacity building activities on PPTCT module of PALS. Similarly, NACO has trained state level ToTs on integrated module of PALS. In PEPFAR-CDC focused cluster districts in the states of Andhra Pradesh and Maharashtra, VHS has trained all the ICTC counselors, ART Data Managers, district and state officials.

At the state level, to enable implementation of PALS orientation meetings were conducted by NACO, following which states have trained ICTC and ART staff. Training modules were developed including - (a) A handbook for Integrated PALS, (b) Data dictionary; (c) presentations and (d) User manuals for both ICTC counsellors and ART data managers were developed by VHS with support from PEPFAR-CDC.

Training Materials for PALS

1. **Data Dictionary:** The Data Dictionary essentially serves the role of a ready reckoner that could be used by anyone who is using PALS. The dictionary has four columns. These are Serial Number; Indicator; Definition and Source. The indicators denote the various details that must be entered in the PALS. These include the name of the PLHIV; their mobile number, age, marital status and order of pregnancy etc. The column on definitions, details the indicators such as what details should be entered in the slot on name of the PLHIV. The last column provides the details of where the details could be sourced; such as the line list register, counselling register etc. The dictionary is divided into following sections
   1. ANC Details Tab (Newly detected HIV+ve Woman)
   2. ANC Details Tab (Already known HIV+ve Woman)
   3. Referral Details
   4. Spouse and Family Details
   5. Delivery details
   6. EID Details
   7. Antibody testing details
   8. Deaths reported

   The dictionary is structured as per the sequence of the data entry in PALS.

2. **User Manual** (both for ICTC and ART Centers) – provides details of the sequence of steps that must be followed for data entry both in ICTC and ART centers. The manual has a grab of the screen that opens at each aspect of data entry.

3. **The handbook** provides a detailed step by step process for entering the data.

An overview of the implementation of PALS in three states is as follows:

Tamil Nadu
A three-day orientation at the state level was provided by NACO in October/November 2015. Representatives from each district/ DAPCU team were part of the training, along with state officials. The district officials in-turn have provided on-site training to ICTC counsellors and ART data managers on PALS.

Odisha
A one-day training was organized for ICTC counsellors in November 2015, with support from UNICEF. In a duration of 5 days, all ICTC counsellors and ART data managers, across the state, and some ART counsellors were trained on PALS. A total 205 ICTC counsellors, 17 ART data managers and 25 ART counsellors were trained. A detailed orientation on all fields and process of data entry on PALS was provided by the UNICEF PPTCT consultant.

Telangana
A two-day training, in close collaboration with SACS, VHS and UNICEF was undertaken in Telangana for ICTC and ART counsellors, district ICTC supervisors, M&E assistants, data managers and staff of BSD and CST departments. Three batches of trainings were organized in April 2017. The two-day training involved theory and practical sessions, where ICTC and ART counsellors were made to enter data for General and PPTCT clients. A total 160 members from 10 districts have been trained on PALS. The training was facilitated by representatives of NACO, VHS-CDC and TSACS.

The process of training and the trainees trained differs slightly across the states. In Tamil Nadu and Odisha, following the training, all facilities were directed to start using PALS and enter data for all clients, beginning 2012.

"The idea of NACO to have a line list of all PLHIV in the country is a novel thought. I am very happy to lead this marvellous application PLHIV ART Linkage System (PALS) from the Information technology front through VHS, where I had an opportunity to work with NACO, CDC and various stakeholders in designing, development and implementation of PALS. PALS is a complex but user- friendly application, that uses open source technologies like JAVA, Postgress and Apache Tomcat 8.0. PALS is totally secured site, hosted on Government of India's Meghraj cloud server maintained by NIC. PALS addresses complicated functionalities like follow up of partners of PLHIV, follow up of children of HIV Positive mothers, Orphan babies etc., PALS provides a perfect connect between ICTC and ART linkage of all PLHIV registered thus directly supporting the UNAIDS 90-90-90 goal. PALS also has an offline version to address internet issues in the field"

(K. Laxman Das, Programme Specialist, (Information Systems), VHS, Chennai)

2.2 Status of implementation of PALS

As mentioned above, the data is first entered manually by the ICTC counselors in registers, and then in PALS. It takes a day or two for the transfer of information from physical records to the computer-based system. States have adopted cut off dates for entry of legacy PLHIV data. For instance, in Odisha it was decided that all data of PPTCT clients since 2012 would be entered and for general clients, the cut off year was kept at 2015. Present status of client details reflects both current and the backlog. Table 3, given below provides an overview of the present status (as on 31st March 2018) of data entry for each PLHIV cohort, across states. At present, a total of 21,17,000 PLHIV are estimated in India, of which entry in PALS has been done for 3,46,984 PLHIV.

S. No	Name of the State	Data entry details for PALS			
		*No. of PPTCT clients	No. of GC	Total No. PLHIV Registered	**No. of Infants born under PPTCT
1	ANDAMAN AND NICOBAR ISLANDS	0	0	0	0
2	ANDHRA PRADESH	5926	26311	32237	2231
3	ARUNACHAL PRADESH	12	33	45	4
4	ASSAM	478	2473	2951	131
5	BIHAR	765	11285	12050	33
6	CHANDIGARH	151	1056	1207	59
7	CHATTISGARH	812	1197	2009	65
8	DADRA AND NAGAR HAVELI	53	137	190	2
9	DAMAN AND DIU	13	97	110	4
10	DELHI	858	6173	7031	243
11	GOA	44	406	450	0
12	GUJARAT	4090	12077	16167	2506
13	HARYANA	373	2248	2621	79
14	HIMACHAL PRADESH	41	1151	1192	0
15	JAMMU & KASHMIR	46	83	129	0
16	JHARKHAND	477	4090	4567	162
17	KARNATAKA	4241	38917	43158	2707
18	KERALA	208	1975	2183	92
19	LAKSHADWEEP	0	0	0	0
20	MADHYA PRADESH	1776	7280	9056	690
21	MAHARASHTRA	8094	55332	63426	4174
22	MANIPUR	314	1311	1625	139
23	MEGHALAYA	195	1099	1294	2
24	MIZORAM	414	2022	2436	74
25	NAGALAND	558	2699	3257	111
26	ODISHA	1528	4811	6339	865
27	PUDUCHERRY	44	1372	1416	14
28	PUNJAB	1602	12176	13778	632
29	RAJASTHAN	2058	13429	15487	532
30	SIKKIM	0	43	43	0
31	TAMIL NADU	3675	57881	61556	1535
32	TELANGANA	190	94	284	49
33	TRIPURA	33	453	486	0
34	UTTAR PRADESH	2282	25875	28157	803
35	UTTRAKHAND	82	880	962	14
36	WEST BENGAL	625	8460	9085	204
	Total	**42058**	**304926**	**346984**	**18156**

GC-General Clients
PPTCT-Prevention of Parent to Child Transmission of HIV

Table 3: PLHIV Data Captured in PALS, as on 31st March 2018

* PPTCT data captured from 1st April 2012 onwards
** Number shown under Infants are children born to HIV Positive Mothers (exposed babies) under PPTCT cascade. HIV status of these children is yet to be confirmed.

States are in the process of entering the data from 2012, while also enabling concurrent entries. However, it is important to note that there has been significant progress in data entry into PALS as depicted in Figure 11.
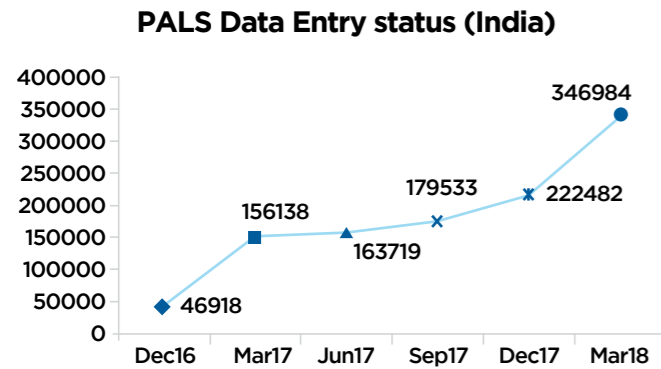
PALS Data Entry status (India)

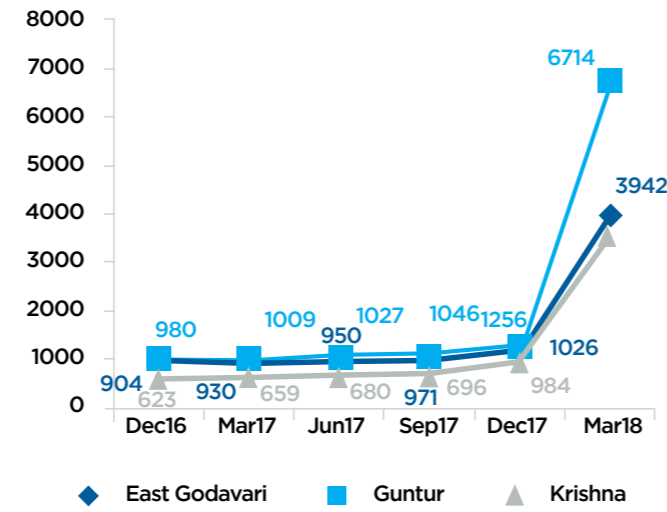Figure 11: PALS Data Capture Status – India

Figure 11, given above indicates the progress made on data entry into PALS. It may be observed that there is nearly a 6-fold increase in data entry compared to December 2016.

In states such as Andhra Pradesh and Maharashtra, where PFPFAR-CDC partner VHS is providing technical support in cluster districts, VHS in consultation with APSACS and MSACS all facility-based staff like ICTC Counsellors, PPTCT Counsellors, ART Data Managers and DAPCU staff were trained on PALS for better implementation of PALS. A total of 588 participants were trained in both Andhra Pradesh and Maharashtra state. Duration of each batch was of two days. By the end of two-day training program, the capacity of all the participants was built on how to do data entry in PALS and on how to generate reports. The training included hands-on-sessions and the participants had access to laptops and internet connection. The hands-on-session helped the participants to clarify the doubts and issues that emerge during the data entry. This provided a significant help to the personnel to begin the entry of the backlog data from 2012, in their respective facilities. The role of the training in enabling an increase in data entry is evident from Figure 12 below, which provides the details for both Andhra Pradesh and Maharashtra districts.

(a) Andhra Pradesh

(b) Maharashtra
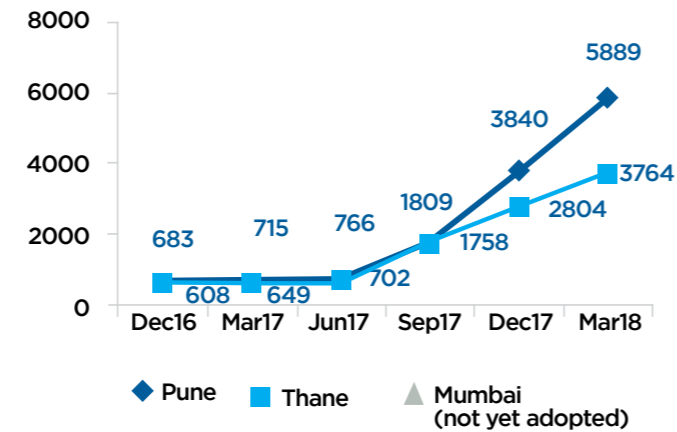
Figure 12: Impact of Training on data entry in PALS in PEPFAR cluster districts in

Group photo with Sh. Parimal Singh, IAS PD, MSACS

PALS for Key populations

Key populations are individuals who are vulnerable and most at risk populations. They include female sex workers (FSW), men who have sex with men (MSM), transgender (TG), and injecting drug users (IDUs), have the highest risk of contracting and transmitting HIV. Due to stigma associated with these KPs, often they have least access to health care services including treatment for HIV.

Programs that provide service for these vulnerable population most often face a challenge in identifying and keeping track of KPs; as mobility is a common with these populations. PALS is a National portal that captures data of all PLHIV including Key Population data. KPs are identified by type of agencies from where they are referred to ICTCs for HIV services. Most of the KPs are being referred from TI-NGOs, TI-ICTCs, TI-NGOs (FSW). PALS captures all this data and consolidates in a single data base, by each ICTC. It certainly provides a way forward for programs to easily access the data of KPs and render them better services. The following table (data as on 31st March 2018) provides an overview of the referral of KPs by various units / institutions to the ICTCs.

Status of PLHIV in-referral to ICTC in India till 31st March 2018

S.No.	Referral unit	No. referred
1	TI-NGO	4863
2	Non-TINGO's	5018
3	OBG/Maternity Homes	1918
4	RNTCP	12773
5	Blood Bank	2215
6	Government health facilities	139588
7	ART Centers	4146
8	STI Clinics	5507
9	Care Support Centres	1468
10	Private health facilities	21245
11	F-ICTC (Fixed/Mobile)	3601
12	PPP-FICTC (Fixed/Mobile)	1486
13	TI-ICTC	162
14	Others	21580
15	Client initiated	41293
16	TI NGO/(FSW)	1646

Dr Rajendra Prasad, APD, APSACS interacting with participants

2.3 Approach to implementing PALS

The status of implementation of PALS varies across states. Table 3 above, provides a glimpse of the differing status across states. Among the three states visited, while Tamil Nadu and Odisha have made significant progress in implementation of PALS, Telangana continues to face challenges. Table 4 given below, provides an overview of the approach to implementation across states, that were visited.

Odisha	Tamil Nadu	Telangana
• One day training of ICTC and ART counsellors – all counsellors across state trained over a 5-day period • Apart from the significant support from the officials of the OSACS, the dedicated PPTCT consultant engaged by UNICEF has been spearheading the entry of data. • The consultant does the data validation twice a month to ensure that any discrepancy in the data between SIMS and PALS	• Implemented across districts after capacity building • There is a significant buy-in for the system at the state level; state level officials understand the merits of the system and hence there is a 'push' towards effective implementation and data entry • The AD In-charge ICTC and State M&E officer closely monitor data entry and provide regular feedback • Monitoring of data entry into PALS at both state and district levels • Comparison of PALS data with SIMS, ART monthly figures to ensure that no case is lost; and entry on all platforms is up-to-date and consistent	• Training of 160 officials and staff on PALS completed • Apart from the training, there has been no significant implementation of PALS in the state, due to hardware challenges

Table 4: Approach to Implementation of PALS in 3 States Visited

Tamil Nadu

PALS was first introduced in Tamil Nadu in July/ August 2015 as the PPTCT module. As mentioned above, a three-day orientation was undertaken by NACO in which few officials from the state and each of the districts were trained. Subsequently, the system has been implemented in all districts and facilities in the state. District level officials who were trained, provided an orientation to the ICTC counsellors and ART data managers during the district monthly review meeting and on-site guidance during visits and clarifications and handholding support over the phone.

> The district M&E officer, Thiruvallur, mentioned that - apart from the training that he had received, he took personal interest to read the NACO guidelines, training manuals and user guides. This helped him to better learn PALS and guide the ICTC counsellors and ART data managers in his district.

All ICTC counsellors were instructed to start entries for all PPTCT clients, beginning 2012. Initially, they faced several challenges while using the system – some mentioned that there were errors, there was a mis-match in PID numbers for the same case across registers, and duplicate entries were also made. However, overtime the counsellors began to better understand how to use the system and have overcome the challenges.

Another challenge faced in the implementation of PALS was the initial reluctance of the ICTC counsellors to enter data into the system. Officials at the state level found that the ICTC counsellor at each service delivery point blamed the other for incomplete data entry. Thus, it was decided that for PALS the responsibility for data entry lies with the counsellor in the 'mother ICTC'. Irrespective of where the client may avail services, the mother ICTC would be responsible for collection and entry and data into PALS.

Having overcome the initial challenges, Tamil Nadu is now one of the states, leading data entry on PALS. Key to this success is the rigorous monitoring and follow up at the state and district levels:

• In the monthly review meetings at the state level, data from PALS and SIMS are compared and matched to ensure consistency across platforms. One of the state officials mentioned that '8 times out of 10, the figures match, however there may be instances of mis-match'. Details of the mis-match are followed up with the respective DAPCUs and rectified.

• On a bi-monthly basis, the BSD and CST division, SACS also compare ICTC and ART data. In-case of any mis-match or gaps, an email is sent to the respective DAPCU, with the discrepancy details and they are given 48 hours to respond/ rectify the same

• At the district level, PALS and ART center monthly reports are compared; and the status of data entry on PALS is reviewed every month (during the monthly review meeting)

Visit of Dr. Asha Hegde, NPO, BSD, NACO during PALS training at Mumbai

Visit of APSACS, CDC & VHS officials during PALS training at Guntur, AP

Case Studies

In Tamil Nadu, implementation of PALS is well-coordinated and closely monitored by the TNSACS. Officials from the BSD, CST Division, M&E Division at the state level and District Program Manager, District ICTC Supervisor and M&E Officer at the district/ DAPCU level are involved in monitoring PALS data entry and data quality.

At the district level
- The DIS and MEO closely scrutinize the line-lists generated from PALS and compare with ART data to identify any discrepancies in data and/or cases that need follow-up. Feedback is then provided to the facility, to rectify/ follow up on the identified cases, in a time bound manner
- The DPM reviews status of data entry on PALS during every review meeting
- Comparison of PALS and SIMS data

At the state level
- The BSD and CST division, jointly review and compare PALS and ART data, twice a month and provide feedback
- Data from PALS is also compared with SIMS
- Performance on PALS data entry for each district is generated by the M&E officer, and feedback provided

General Clients - PALS DATA ENTRY STATUS 2016-2017 - as on 02.06.2017 @ 04.00 PM

Name	Total No. of ICTC's	Gen. Client +ve in SIMS	Total No. of Records in PALS	Data Entry Pending Records	Percent of Data Entry Performance
KANNIYAKUMARI	19	88	92	-4	105
PUDUKKOTTAI	25	202	211	-9	104
THIRUNELVELI	39	391	395	-4	101
RAMANATHPURAM	20	121	122	-1	101
VIRUDHUNAGAR	24	260	262	-2	101
NAMAKKAL	28	421	421	0	100
KARUR	16	177	176	1	99
SIVAGANGA	26	247	242	5	98
NILGIRIS	14	40	39	1	98
TOOTHUKUDI	26	228	222	6	97
ERODE	24	373	363	10	97
SALEM	37	841	818	23	97
KRISHNAGIRI	19	487	471	16	97
CUDDALORE	25	346	328	18	95
ARIYALUR	10	91	82	9	90
PERAMBALUR	8	140	121	19	86
TIRUCHIRAPPALLI	35	641	548	93	85
MADURAI	29	589	474	115	80
NAGAPATTINAM	20	85	68	17	80
COIMBATORE	30	636	507	129	80
DHARMAPURI	17	333	256	77	77
THIRUVALLUR	33	198	147	51	74
THENI	18	299	221	78	74
TIRUVANAMALAI	29	249	170	79	68
VELLORE	37	660	435	225	66
TIRUPUR	21	295	171	124	58

CHENNAI	47	1015	495	520	49
KANCHEEPURAM	30	652	289	363	44
VILLUPURAM	32	375	155	220	41
DINDIGUL	28	463	183	280	40
THIRUVARUR	21	91	34	57	37
THANJAVUR	29	300	99	201	33
TOTAL	**816**	**11334**	**8617**	**2717**	**76**

Table 5: Status of PALS Data Entry Monitored at the State Level in Tamil Nadu

Table 5, given above, provides an overview of how PALS and SIMS data are compared across districts and how the data entry performance for each is quantified and reviewed. Based on this, feedback is provided to each district. This comparison is also done at the district level and feedback provided to each facility.

The focus of the monitoring is two-fold – (a) ensuring data quality – by comparing and matching case details across data sources, to ensure no duplication and loss; and (b) to ensure data entry in PALS across districts.

The efforts of the state have also been appreciated by the NACO, with nearly all districts having reached more than 80 percent reporting in PALS, as compared to SIMS. While the state is successfully implementing PALS, the challenges of using multiple software, and reporting mechanisms were highlighted by facility level staff. In addition to the PALS, Tamil Nadu uses the SIMS, IMS, MSDS, HSSP and IHRC national systems and the SCMS and ITM, which are systems developed by the state for supply chain management and for GPS based tracking of facilities respectively. The facilities also maintain registers for each service delivery point and the excel line-listing for PPTCT and general clients for ICTC and ART.

In addition, almost all facilities continue to use the line list entered in the excel sheets. At the state level too, there are divergent views on this. While one official felt that there is no need for the list; another felt that it should continue, perhaps till the end of the year until PALS is integrated well in the system. Some counsellors too are not keen to give up the line list as they are comfortable with it. For instance, the ART counsellors in one facility at Chennai, have added few more fields to aid them in following up. Many continue to use the line list for reporting purposes and most are unaware that the line list could be generated from PALS. For the ART counsellors and data managers, the focus is largely on IMS and many do not understand the role of PALS in ART.

Field visit in Namakkal, Tamil Nadu

Though there were complaints of having to maintain multiple formats; most ICTC counsellors who were met, felt that PALS was very useful. Some of the examples of how PALS has helped enable follow-ups and linkages are mentioned in the following case studies.

Case 2: Identification of LFU cases

Prabhakaran (name changed), is a 40-year-old male admitted in Ramachandra Medical College, Thiruvallur district with Tuberculosis. He was referred to the ICTC for HIV testing; and was confirmed positive.

At the end of the day, when the ICTC counsellor was entering data for all positive cases in PALS, he found Prabhakaran's details were already available on the system, registered by Stanley Medical College, Chennai, in the year 2010. The client had previously tested positive and had been initiated on ART. The Counsellor at Ramachandra Medial College then contacted the ICTC counsellor at Stanley Medical college and was informed that the PLHIV had been lost for over six months. With the discontinuation of ART, the man's health had deteriorated severely, and he was brought to Ramachandra Medial College. Owing to fear of refusal of treatment, the client did not reveal his HIV status.

The ICTC counselor, Ramachandra Medical College, highlighting the importance of PALS said that
- Given that the ICTC counsellor at Stanley Medical College had updated old case details in PALS, this client who had been lost to follow up, was now identified
- While the patient was hesitant to reveal his HIV positive status, this information was critical to his health and further treatment
- Duplication of client details was avoided

A similar case was narrated in Namakkal, where an HIV positive female client, detected by a mobile ICTC in Namakkal in 2008, was referred to the ART center. She did not initiate the ART and was lost to follow up. After nearly 10 years, she came to ICTC Pillanallai and said that she had been availing ART from a private hospital. She was unable to afford the private treatment anymore and hence wanted to continue Government ART services. Though she was unable to provide any PID number or details, the ICTC counsellor searched for her name and found her details on PALS. She was directly linked to ART through PALS. Though considered LFU, through PALS her details were traced and the link between ICTC and ART was enabled.

This case highlights the importance of PALS and the need for its effective implementation
- When PALS data entry is ensured real-time at the facility level – clients can be identified across facilities and geographies
- LFU cases can be tracked
- Duplication of cases is avoided; and
- Appropriate treatment can be provided to HIV positive patients

Case 3: Tracking of cases across geographies

Krishnagiri district in Tamil Nadu, borders Karnataka. There is significant movement of PLHIV between Tamil Nadu and Karnataka, owing to which, there is a loss to follow up among both general and PPTCT cases, for both states.

With PALS having been implemented in both states, Krishnagiri district is now being able to seamlessly provide services to clients who were originally detected and registered in Karnataka. The ICTC counsellors in Krishnagiri now do not have to re-test and re-register the clients.

A case of a HIV positive pregnant woman was highlighted by the state officials, who was tested positive and registered in an ICTC in Karnataka. She however had an Aadhar Card of Tamil Nadu. When she came for delivery to District Hospital Krishnagiri, the ICTC counsellor searched for her details on PALS and her delivery details were updated by Krishnagiri. Thus, even though the case was registered in Karnataka, seamless service provision and data capture was enabled through PALS.

A similar case of a migrant worker was also highlighted, though tested in Krishnagiri, he went to work in Karnataka, where he is continuing his ART treatment. The details have been updated by the respective ICTC counsellor in Karnataka and are visible to the 'mother ICTC' in Krishnagiri.

Case 4: PALS enabling strengthening ICTC to ART linkage and follow up

During the monthly review of PALS data in Namakkal district, workplan for Rasipuram ICTC was generated for the period – 1st April 2017 to 8th March 2018. A total of 126 positive clients were referred to Namakkal ART and 5 to Rasipuram ART. The 5 clients referred to Rasipuram ART had not yet been linked. Following discussions with the respective centers, it was learnt that one of the 5 had already been registered in Namakkal ART, however, the details were not updated.

Having learnt how to generate the workplan, the ICTC counselor, was also able to follow up Rasipuram and other neighboring ART centers on why the client details were not updated. He further found that one of the clients had died and updated the same in the client details; he further urged the ART counsellor to confirm the death details in PALS, after which the system removed the client from the workplan.

Thus, the workplans enable effective coordination and follow up between ICTC and ART to minimize loss between testing and treatment.

While there have been significant gains, evident from the case studies above and these include ensuring data quality, tracking clients and LFU cases across geographies and enabling follow up and reintegration to services; much more could be done. The system could be used more effectively to track clients and monitor the epidemic. of the counsellors, who were met for this documentation, a significant number (more than 2/3) are still unaware of many features of the system. This includes

- Use of dashboard, analysis and report features
- Work plan
- Ability to track clients after referring them to ART
- No counsellor was aware of the significance of color codes and status of data entry

Stakeholders across the state, from the facility to state level, are learning the many features of PALS; often on their own, without significant formal training or support. Following the initial orientation provided in 2015 for the PPTCT – ART system, no further training has been provided for Integrated PALS. The need for training was articulated by nearly all stakeholders.
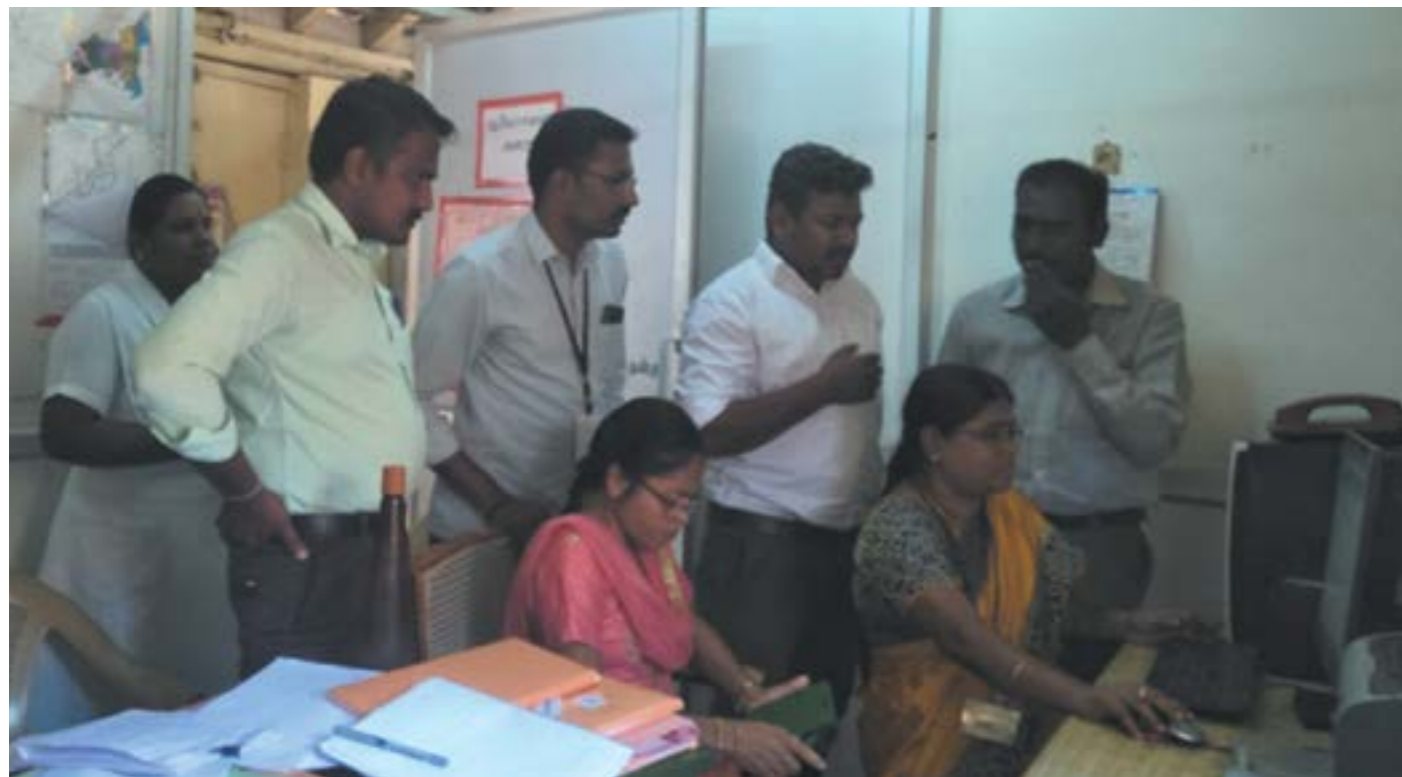
Field visit in Namakkal, Tamil Nadu

Odisha

As of 2018 January, there were 41,641 PLHIVS in the state and out of them 2,351 are pregnant women. Out of the total 41,641 positive cases 14,571 are women. Ganjam district tops the list with 13,778 PLHIVs. In Odisha, according to the SACS officials, the training was managed by the State officials entirely. The training was undertaken in November 2015. The PPTCT consultant had attended the training in Delhi who then, coordinated the training at the state level. UNICEF apart from engaging the consultant and placing her at SACS also supported the capacity building initiatives.

Odisha has done well in the entering of the PPTCT data. PALS has over time become the preferred form of data entry at the ICTC as it has helped to make the process easier for ICTC and ART Data Managers. PALS has helped to reduce discrepancy as it is easy to use, and the logical sequencing enables that errors are eliminated. It was also observed that the UID number has made follow ups much easier.

Initially, the data entry took time. To enter the entire data of PPTCT for one year, it took them 3 months and it took close to two years to have the entire backlog up to 2012 entered in PALS. By November 2017, according to the PPTCT consultant they had entered 100 percent of the client's information in PALS. For some of the older records, there were many issues, such as finding records and hence the process took them two years to complete.

They had also initiated the process for general clients from June 2017. The shift to Integrated PALS however, occurred in June 2017 and the official communication to start the process for general client was received in November 2017. The OSACS officials said that the significant push for entering the General Client data started only in the beginning of 2018.

94 percent of the data for one year has been entered so far. It is anticipated that the back log is expected to be covered in about 6 months.

According to the OSACS, the entry in PALS for a year had identified about 30 percent duplications. Due to regular coordination between SACS and the counsellors and the data managers, they detected duplications. Discrepancies were often observed in cases of pregnant women and about 29 indicators were used and triangulated to weed out the duplication. As mentioned above, this has been significantly achieved due to the efforts of the officials at the state level and due to the PPTCT consultant.

ICTC Counsellor Odisha entering data in PALS

Case Study 5: Reducing Duplication

Significant efforts were made to improve data management through PALS. Several issues surfaced after PALS roll out at the facility and State level. Data duplication has been a constant threat to the data management system.

Since 2015-16, special attention was directed to validate data related to actual number of positive pregnant women every month using different indicators in the SIMS software; such as age, trimester details of pregnant women in each facility. When an error was detected, changes were made.

Prior to PALS, there was limited scope to detect duplication. By comparing the SIMS and PALS, the duplications were identified.

- There was a possibility of manual error while uploading information in SIMS as system only allowed figures, but this error is minimized with PALS as information for each PLHIV needs to be fed against several indicators.

- Since 2016, the PPTCT Consultant at State level has started validating the data by uploading the data from both the software and validating them using Microsoft access.

- By comparing the discrepancies in SIMS and the PALS at the state level for each facility, discussions were held with the counsellors and the managers by using WhatsApp and phone calls and errors were found and addressed and thus over time they were able to identify about 30 percent duplication among pregnant women and this was eliminated. She also shared the validated sheet for each month to enable the discussions. Due to this exercise the gaps were corrected every month at the PPTCT level.

The corrections have also now been made in the registers. According to the OSACS, there is no duplication since December 2017.

To ensure that there is a concurrent data entry occurring in ICTCs and ART centers, the PPTCT consultant gets a list of all the PLHIVs referred to the ART Centers, twice every month. She then shares that list and asks the ART centers to report back if the client has reached and upload the data too, Similarly, if a PLHIV reaches an ART center and the data is not uploaded by the ICTC then, the ART informs her and she in turn ensures that the ICTC uploads the data immediately. This process of monitoring at the state level has ensured that the data is getting uploaded.

The Joint Director sends a letter of appreciation to the individual counsellors if they have done well in data entry. The best among them have been identified as nodal counsellors, who support the other counsellors.

Case Study 6: PALS enabled follow up ensuring EID test of a child

A pregnant lady in Nabarangpur district identified as HIV positive in December 2016, delivered a child in January 2017. The verification of the PALS records at end March 2017 indicated that the EID of the child was not done well past the mandated six weeks. The PPTCT Consultant at the state level contacted the ICTC Counsellor in Nabrangpur, who said that follow up was being done by the ICTC and the HLFPPT outreach worker. However, that both the mother and the child were in her maternal home at Jagadalpur, Chatisgarh and the mother was unwilling to travel for the EID.

The ICTC then asked for the address of the PLHIV in Jagdalpur; and the consultant coordinated with the SACS at Chattisgarh to identify an ICTC close to the address.the necessary supplies and logistics were provided by the SACS in Chattisgarh to enable the EID for the child. The test however, was negative.

Some of the challenges in implementation are the non-availability of hardware; poor or no internet connectivity and the perception among counsellors that they are overworked. One day training for counselors was completed in six batches which was felt to be inadequate. The need for refresher training has been articulated by almost all the stakeholders, who were met.

Though there is support from the officials at the OSACS, the significant push from the PPTCT consultant has ensured that all the PPTCT data has been entered and she is now ensuring the entry of the general clients. According to the SACS Official, she is entirely dedicated to monitoring the data upload and overseeing the M&E. According to one ICTC counsellor, "she first made us enter two years data, then two years and like that she had made us enter data from 2012". The process however, is significantly person dependent and her dynamism is pushing the process. It would help to have the process institutionalized so that the effort continues in her absence too.

Telangana

Telangana was formed in 2014 and has undergone significant restructuring of systems and human resources across Government Departments. Though PALS was introduced in 2015, thus far it has not been implemented in the state. As of January 2018, only 7 percent of the existing PLHIV data from 2012, has been entered in PALS. Only one district in the state – Nizamabad is presently using PALS.

Challenges faced in the implementation of PALS

Interactions with officials from SACS indicate that there are several challenges that impede the implementation of PALS:

Hardware challenges

- The primary challenge is the lack of computers at the facility level across the state. The state has requested NACO for computers and it is expected that 196 computers would be received by the end of March 2018

- While some states have requested ICTC counselors to enter data into PALS from internet café's; in Telangana, it was felt that patient confidentiality could be breached in the process. Further, many felt that it was very cumbersome to carry multiple registers to the internet café for data entry

- Also, since there was no monetary support provided to pay the internet café's, the counsellors didn't not seem keen to enter data, by paying out of their pocket.

"In the last year alone, we had over 11,000 cases of PLHIV; it would be very cumbersome to carry details of so many clients to internet cafés for entry" **– SACS official**

Human Resources

- Due to the state reorganization, availability of personnel at every level has been an issue. This has compromised the ability to enter the data and more importantly, monitor the data entry.

Challenges in data management

There are several data management challenges, which the state is at present resolving –

- Lack of standardized registers/ formats – the state has not printed registers in several years and in many centers, the ICTC counsellors have bought their own notebooks for record keeping. Thus, fields/ columns for data collection are not standardized

- Prior to 2011, there was no system of a PID number or a Pre-ART number, only an ART number was given. There are thus several clients with only an ART number, making entry in PALS difficult

- Further, the ART number is not unique (starts from 1 for every facility, every year); and it is thus believed that there are many duplications in the data; one official mentioned 20-30percent duplication

- It is also believed that for several PLHIV, details of address and phone, available in the ICTC records are incorrect

The PD highlighted that there are huge challenges with the CD4 and ART initiation in the state, given the numbers of PLHIV and the fact that the state has recently been formed. The PD, SACS has requested the support of C-DAC for enabling this. The process of data clean up has begun and efforts are on to identify genuine cases and track them. Details of all PLHIV in each ICTC are being verified by the counsellor, by calling the available numbers/ calling villages to enquire if the concerned person is alive or dead. Duplications based on name, age and other indicators are being identified and removed. It is expected that once this exercise is completed, entries would be done on PALS.

Budget constraints

- Being a new state, Telangana and consequently SACS is facing budget constraints. The need for additional funds, for human resources and operational costs was highlighted. The officials felt that there is need for more funds, over and above, what is being made available currently by NACO.

- The need for additional budget was also reflected in the view that while the hardware in the form of computers, may be provided by NACO, the states needs additional resources to ensure internet connectivity.

Another challenge is that the number of districts in Telangana has increased from 10 to 31. This has led to restructuring of systems and staff at the district level. PALS would also have to be restructured to reflect these changes and ensure that the new districts and facilities are incorporated.

While there have been several challenges that have limited the ability of the state to implement PALS; SIMS and IMS are operational at the district level across the state. Information from ICTCs and ART centers are sent in hard copies to the district level for electronic entry. At the district level, if a computer is not available at the facility level, the ART data manager uses an internet café.

Case 7: Nizamabad District Hospital – Facility Using PALS in Telangana

Nizamabad district, and particularly the District Hospital Nizamabad is the only district/ facility where PALS is currently used in the state. The PPTCT counsellor and ART data manager in this facility have undergone the PALS training, held in the state in April 2017.

As the facility has access to computer and internet services; they started data entry, following the training. Both the PPTCT counsellor and the ART data manager share the one computer available to enter their respective share of the data in PALS. The counsellors felt that the software was very useful and easy to use.

They mentioned the following benefits of PALS:

- Details of each case are consolidated as a single record (as opposed to multiple registers)
- Using the work-plan feature, pending cases are easily identified (earlier this was being done manually, which was time consuming and prone to errors)
- Duplication is avoided
- For HIV positive women, who are pregnant the second/third time, their earlier case details and history are available on PALS
- Spouse details for every positive client is readily available, making follow up easy
- They also felt that it reduces errors in data maintenance, across registers for the same client

The District ICTC Supervisor, Nizamabad, commended the effort of the facility in implementing and using PALS and felt that the effort is entirely self-motivated. "The staff in the facility is implementing PALS entirely of their own effort. Having used the software, they are able to understand its benefits", said the DIS.

It is anticipated that with the provision of computers by NACO and the resolution of issues such as internet connectivity, human resources; the entry of PALS data would be done across the state.

Based on the case studies of three states, the key aspects that have enabled the implementation of PALS are

- Regular support and monitoring from the State Officials, who have not only provided support but also monitor progress

- Ways of incentivizing and motivating the staff across facilities, either by provision of funds for data entry in internet café's (as was also done in Punjab according to a NACO official) and by giving commendation certificates (as was done in Odisha.)

2.4 Stakeholder perspectives on PALS

Stakeholders and users of PALS from across states appreciated the system and its features, while also highlighting challenges in its effective use. This section maps stakeholder perspectives on both the advantages and challenges of PALS and the way forward.

Advantages/ Benefits of PALS

Stakeholders	Advantages/ Benefits of PALS
NACO	• Enables epidemic surveillance – identification of geographic trends (locations with higher prevalence) and migration patterns • Effective case-based tracking and follow up of PLHIV • Data management - Up-to-now, NACO did not have a PLHIV profiling; this could be gathered through PALS • 70 percent of the workload at the state and national levels would reduce once PALS is completely implemented. To enable the 90:90:90 tracking, one staff in each state is completely dedicated to compile data
SACS/DAPCU	• Can be used to identify epidemic trends; the system provides case details segregated by age, sex, gender and geographies • Program Management • Data available by client cohorts and service access; enables data analysis across time periods • Data available at a single click; some DAPCU staff mentioned that the dashboard analytics are extremely useful and help to instantly provide statistics during meetings • Reports/dash board analytics are used to follow up with facility level staff during review meetings • Ensures follow up and case tracking – through cross-verification with SIMS, so that no case is lost; and through real-time linkage between ICTC and ART • Excel line-listing can be generated from the system • Complete records for each client and linkage across facilities, districts and states • Linkage across client cohorts - linkage of EID, spouse details etc. • Standardized formats - state officials felt that earlier the line-listing formats kept changing, however with PALS, it has been standardized • Data accuracy - data from PALS is authentic as it is name-based, and can be verified • Duplication of client details is avoided • Reduction in workload for data management
Facility level users	• Consolidated information for each individual, enabling individual based tracking • Enables continuity (for instance, even if a register is lost, the data is still available on PALS; or if there is a change in counsellor, PALS enables continuity, as all case details are available in one place - do not have to look at multiple registers) • Data duplication is avoided • Enables identification and tracking of clients across facilities, districts and states; even if clients have accessed services at a facility other than the one referred to, the ICTC counsellor would be able to view the treatment details • Enables tracking and follow up of spouse and infants • Dashboard enables data comparison by age and sex • Use dashboard statistics to coordinate with DAPCU and ICTCs • Use of work plans to generate due lists for follow up • Line-list can be directly generated from PALS and sent to district for review • User friendly
Developer	• Individual case reporting and monitoring • Data aggregation based on individual information • Duplication of cases is avoided • Improved data quality • Supports program management – planning of activities, assessment of service needs, performance analysis of facilities

The matrix given above, highlights stakeholder perspectives on the benefits of PALS across user groups, at different levels. While the benefits of PALS as a system that ensures comprehensive individual-based record keeping, and aggregation/analysis of data based on the individual information is recognized across user groups; the perspectives of stakeholders on the 'utility' of PALS slightly varies across levels.

At the national level, PALS is seen primarily as a tool that enables epidemic surveillance through accurate record keeping and linkage across geographies, PLHIV cohorts and service delivery points. While the same was being done earlier through excel sheets, it is expected that PALS would enable a more efficient and accurate process. At the state and district levels, it appears that PALS is seen more as a program management tool. While its capacity to enable epidemic surveillance is recognized; at present, PALS is being used primarily to bridge data gaps, for reporting, and to enable decision making on tracking and follow up at the district levels.

> "SIMS was showing us 8000 ANC positive cases, however, when the surveillance data was released, 1200 ANC positive cases were identified for Tamil Nadu. That is when we realized that we need a more robust and case-based tracking system for HIV" **- State M&E officer, Tamil Nadu.**

Officials from border districts such as Thiruvallur mentioned that before PALS, it was very difficult to track clients from other districts and states; however, now it is easily feasible. In Telangana, the PD, SACS expects that once PALS is implemented, it would significantly help the state to follow up on clients. "At present, In Telangana, the link between ICTC and ART is lacking; there is no significant client follow up. The onus to access treatment is entirely on the client – PALS will enable us to follow up and manage the program better" she said.

At the facility level, PALS is seen as a system which helps in execution of roles through generation of due-lists for follow ups and provides data for review meetings.

Challenges in the use of PALS

Challenges in the effective use of PALS, as articulated by stakeholders are as follows:

- **Lack of Computers:** Across states, one of the challenge is the availability of hardware and this is being addressed by NACO through the provision of computers.

- **Internet connectivity:** Some facilities do not have access to internet and even if they have in some places, its speed and availability is often limited, especially with poor electricity connection in many places. The slow speed and intermittent connections also impact on the use of the software leading to errors, inability to login at times, slowing down of the computer among others.

To overcome issues of access, some states have provided monetary support to enable data entry at internet café's. It is also anticipated that the offline version would help overcome this too.

- **Human Resource challenges**: Officials from NACO highlighted that in district and medical college hospitals, where the client load is high, it often becomes difficult for ICTC counsellors to spare time for entry into PALS. Further, that there are several un-filled positions across states, leading to greater workload on existing staff. In Telangana, given the restructuring of districts, the state is yet grappling with human resource allocation.

- **Multiple systems of data recording and reporting:** As mentioned earlier, there are multiple online and offline systems of record keeping for HIV. Staff at ICTC and ART centers often maintain both paper-based records, as well as ensure online up-dation in software. They also maintain client details on excel files as line-lists. Thus, the same information is entered in registers, excel files and multiple software, making it difficult for staff to manage at times.

> "There are so many software's – IMS, SIMS, PALS and in addition excel line- listing and registers. All of these collect nearly similar information and most of them do not speak to each other"
> **- SACS official, Telangana.**

However, an official at NACO also pointed out, that during client interface, it may be difficult for the counsellor to directly enter details into the system, and hence registers may have to be maintained.

Staff at ART centers are skilled and experienced at using the IMS and feel that it is more useful to their work, as compared to PALS.

> "For ART, IMS is more useful, while we are doing data entry in PALS, it would be good if we are trained to understand the merits of the system"
> **- ART Data Manager, Thiruvallur District, Tamil Nadu**

NACO officials also highlighted that in states such as Maharashtra, where they have mastered the excel line-listing and it serves as an effective tool for monitoring, there is a reluctance to shift to PALS.

- Capacity building: In most states, training on PALS has been undertaken only once, when it was the PPTCT -ART Linkage software. No significant training has been done after the launch of integrated PALS. Further, in several states, such as Tamil Nadu, the initial training was attended only by select staff.

> "Only one round of training on PALS was done, when it was a PPTCT system, we do not have funds for further training"
> **– TNSACS.**

> "We received training long ago from the DPM and MEO, who attended the training; we are unaware of the many beneficial features of the system"
> **– IOG Hospital, Chennai**

Thus, most users have learnt PALS on the job and through reading of the training manuals. Consequently, they are unaware of the various functionalities and features of the system, such as – searching for an existing client, use of dashboard and analytics, work-plans, report generation, color code indications etc. For instance, a SACS official in Tamil Nadu said that the 'Search patient' feature not used well – if a client goes to a new ICTC and does not take the PID number/ card, it is entered as a duplicate. Similarly, many were unaware that the workplan feature generates due lists of follow up; or that the excel line-list can be generated directly from PALS.

The need for capacity building on the use and features of the system was articulated by all stakeholders from the state to the facility level. It is considered essential for effective use of PALS. One of the state officials also felt that many of the ICTC counsellors are not very computer savvy and hence basic training on computers is also essential.

- **Lag in data entry:** Another challenge reported by officials from TNSACS was the lag in data entry at the ICTC. At present, the system is such that the ICTC enters all data into PALS at the end of each week; by then, in several clients have already gone to the ART, hampering the effectiveness of PALS. The need to enable a process, where entries could be done as soon as possible was articulated.

- **Request for additional features:** Despite having made several changes and iterations to the system, users continue to ask for newer features and fields, making it difficult to freeze the process of software development. During interactions in various states, several requests were made to the research team as well – SMS/ pop-up alters for follow ups, strengthening of EID reports, permission to allow editing at the facility level and change in name format for Tamil Nadu (the last name field is mandatory in the system; in Tamil Nadu, most persons do not have last names), among others

Way forward

Nearly all officials felt that PALS is a system for the future. The state M&E officer in Tamil Nadu felt that it could lead to a completely paper less system of record keeping. However, 3 aspects were articulated as key for its sustained and effective implementation:

- Ensuring hardware and access to high speed internet
- Rigorous and sustained capacity building
- Linkage with other information systems such as IMS and SIMS

Officials at NACO also felt that while in the initial phase of implementation, motivation and monitoring of staff may be needed; however, once they see the merits of the system and how it enables comprehensive record keeping for each client, they would be self-motivated to ensure on-time entry.

Future scope - the expected future scope of PALS is seen as follows:

- Automated SMS alerts to service providers and individual
- Linkage to MCTS of MoHFW for ANC service delivery and IMS of NACO for drug adherence monitoring
- App enabled system for better service delivery
- Extension of PALS to offline version to ensure documentation of the services from hard to reach areas

Linkage with private health service providers and field level platforms such as the VHND is also suggested.

Offline mode of PALS

An offline mode for PALS is ready for launch. Details of the same are given as follows:

Offline Data Entry refers to storage or entry of information related to a database without the requirement of any internet connection. Offline data entry is very simple and only requires basic knowledge on Excel and requires little knowledge of using the internet and basic computer.

Need of the offline data entry module: During the capacity building process, states with heavy backlog in data entry such as Andhra Pradesh, Maharashtra and some North eastern states had requested for offline data entry module. They felt that it would help the ICTCs who are facing problems like lack of computers, internet connection and regular access to electricity. They felt that it would benefit ICTCs located in hard to reach areas. It was also felt that the Offline data module can be used for uploading bulk data.

Process of offline data entry: End user must download the pre-defined excel template from PALS website and this template will function similar to the online PALS data entry screen. End user need to enter the data in excel template and after data entry, generate XML sheet and send it to DAPCU officials. DAPCU official will upload the XML file to online PALS. Offline upload facility is only provided to DAPCUs.

PALS does the following validations upon uploading the XML file

- **Check for duplicate PID:** Validates each record uploaded with existing data base for identifying duplicate PID, if any duplicate PID is found, PALS would generate an error message "PID is already exists" and will not upload the record.

- **Data inconsistency:** After upload, PALS would check for consistency of each field and check if information for the mandatory fields have been entered too. If any inconsistency is found or if the data is missing, the system will not upload the record and an error message "Following fields are missing/not matching" would appear.

- **Keep track of offline upload status:** System will track all the offline upload records with date and time, file name and even the names of persons who had uploaded.

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[1]In states such as Tamil Nadu, in facilities that do not have computers, ICTC counsellors are provided with Rs. 100 per month to enter data using internet café's; or are encouraged to use other general computers that may be available in the case of an integrated health facility. In one facility in Tamil Nadu, the counsellor reported that the computers are old, with poor processor configuration and newer computers would enable faster data entry

3.1 Global efforts on Health Records for HIV – a review of literature

National Electronic Health Record (EHR) systems have made big headway across developing countries as it has become increasingly clear that last mile connectivity and overall efficiency is not possible without e-health initiatives. Multiple uses of EHR systems are now reported across 47 percent of WHO member countries[12]. E-health covers multiple types of interventions that include use of:

- mHealth to use smartphones as platforms to reach last mile patients with care and services
- tele-health for remote patient care and services
- Electronic health records for patient information tracking
- Applying analytical tools to large data sets for predictive modeling

For HIV and STI interventions as well, the use of mHealth and internet-based innovations has shown a positive impact on clinic attendance rates (70 percent), ART adherence (69 percent), risk reduction behaviors (67 percent) and self-care (100 percent)[13].

Well-functioning EHR systems have typically been seen to be operating at scale in upper middle or high-income countries[14]. India is possibly the only developing country where a well-functioning EHR exists at scale, and specifically dedicated to HIV. However, smaller scale efforts have been undertaken to develop EHR systems for HIV patients as well as innovations for integrating patient information tracking with HIV service delivery and adherence tools. Lessons from these systems and innovations are as follows:[15]

Geography	Lessons from application of HER
1. Zambia - an HIV treatment program evaluated 29998 HIV-positive patients for ARV treatment from 2004 to 2005	Using custom reports from the medical information system, community healthcare workers could track down 32 percent of patients who had started ART but not returned. Only 28 percent returned after one attempt to remind. Hence, detection of missing patients and reminders through multiple channels are all essential for continuity of care
2. Haiti - PIH/ZL deployed a web based EHR across 9 hospital sites	This patient information tracking system reports a strong correlation between early entry of CD4 count in the system and early treatment of high risk patients. High-risk patients with CD4 counts below 100 were almost all treated within 1 week. Integrating community health workers in the follow up process ensures that data is updated on patient deaths, transfers and other issues quickly and the team can work on identifying missing patients
3. Rwanda - Data on HIV managed with newer version of EHR used in Haiti across 6 clinics run by PIH	Patients who fail to come for follow-up visits are highlighted in monthly reports. Local evaluation of the data allowed clinic staff to identify that follow up decline was correlated with stopping food supplementation which was then immediately addressed. Such localized report generation and regular analysis by local staff can help develop essential strategies for maximizing follow up
4. Malawi - Baobab Health Partnership	The EHR, launched in 2001, provides unique IDs to patients and has covered more than half a million patients across 3 urban sites. Upon registration, each patient is given a bar-coded label with their ID, affixed to their 'health passport'. Bar-coding as an innovation offers unique opportunities for avoiding duplication and for outreach to registered patients, tracking missing patients and offering incentives based on regular follow up.

Chapter - 3
PALS in Global and National Contexts

[12]Global diffusion of eHealth: making universal health coverage achievable. Report of the third global survey on eHealth. Geneva: World Health Organization; 2016

[13]Daher J, Vijh R, Linthwaite B, et al

Do digital innovations for HIV and sexually transmitted infections work? Results from a systematic review (1996-2017)

BMJ Open 2017;7: e017604. doi: 10.1136/bmjopen-2017-017604

[14]Global diffusion of eHealth: making universal health coverage achievable. Report of the third global survey on eHealth. Geneva: World Health Organization; 2016

[15]Fraser HS, Allen C, Bailey C, Douglas G, Shin S, Blaya J. Information Systems for Patient Follow-Up and Chronic Management of HIV and Tuberculosis: A Life-Saving Technology in Resource-Poor Areas. Journal of Medical Internet Research. 2007;9(4):e29. doi:10.2196/jmir.9.4.e29.

5. Thailand – EHR combined with HIV service delivery for MSM, TG high risk groups[16]	Study was done from December 2015 – May 2016 with 186 MSM and TG participants. EHR combined with individual visibility to patients with follow up service delivery of testing and counseling (through online or clinic-based mechanisms)
	This mechanism, in addition to patient tracking, allowed patients the ability to exercise choices in the process of accessing HIV related services, with the option of retaining anonymity through online service access. This also shows that an EHR tailored by the requirements of the target group can effectively incorporate service delivery also. The ability to have easy and quick access to their medical record also allowed patients to review and interact with their record on an ongoing basis, becoming active participants in the process of their treatment. This model focused on using the EHR to empower the patient
6. China - Web-based intervention in increasing HIV testing and treatment uptake among MSM[17]	202 MSM participated in the study. Participants were given access to online program including an information exchange website and a bulletin board system. These were combined with adherence tools like an individualized online counseling with trained peer educators, and an animation game. The intervention group had significant increases in motivating partners to accept HIV testing compared to control group

Thus, given specific needs, each of the innovations enables tracking/ follow up of various cohorts of HIV positive clients. Extensive literature review indicates one other system, implemented in USA, which enables similar data capture and linkage. The CAREW are is a longitudinal electronic patient health information system designed to assist providers of HIV/AIDS care across clinics, monitor, quality and reporting activities. The system can be run as a stand-alone installation or a fully networked application connecting multiple care providers. First released in the year 2000, the system captured basic client demographics, services and limited clinical information. It was modified in 2003-04 to include a detailed clinical module including information on vital signs, medication, screening tests, immunization, diagnosis of medical conditions and space for the medical service provider to store notes. In 2008, it was further revised to include performance monitoring through reports and 'drill down' functionality[18].

The review of literature based on internet search does not seem to provide significant evidence of case based tracking and real-time linkages in HIV; however, there have been efforts to ensure adherence to ART.

Several mHealth and tele health innovations have been undertaken, globally to enable last mile connectivity for case detection and adherence to ART. For HIV/STIs, a randomized controlled trial in Kenya demonstrated the effectiveness of mHealth based SMS innovations on adherence to ART[19]. A systematic review focusing on long term management of HIV/AIDS and tuberculosis also reported mobile phone technology as an effective tool for long term management[20]. In Zambia and South Africa, telehealth coupled with home-testing kits has allowed individuals to have the guidance of a health professional in the privacy of their homes. In another example, the Cape Town-based Cell-Life company's EMIT program[21] is an application for off-line data collection on cell phones, with the data then uploaded onto the district health information system.

PALS, an EHR innovation, is a client-based tracking system for people living with HIV, in India. It lists HIV positive clients and captures demographic and service access; while enabling real-time linkage across geographies, service delivery points and client cohorts. While there isn't significant literature on EHR innovations in other contexts, PALS has the following features:

• Individual based data capture for various PLHIV cohorts – General, Pregnant women and infants
• Realtime linkages across geographies
• Report and work-plan features for program monitoring and follow ups
• Data aggregation and dashboard for epidemic monitoring

A challenge in the use of EHR systems highlighted in literature, is that in the context of HIV, ICT and EHR often to tend to operate in silos and not across the cascade of services. To achieve the UNAIDS 90-90-90 goals, enabling last mile connectivity and linkages to other systems of data management are essential.

[16]Anand T, Nitpolprasert C, Kerr SJ, et al. Implementation of an online HIV prevention and treatment cascade in Thai men who have sex with men and transgender women using Adam's Love Electronic Health Record system. Journal of Virus Eradication. 2017;3(1):15-23.

[17]Purnomo J, Coote K, Mao L, et al. Using eHealth to engage and retain priority populations in the HIV treatment and care cascade in the Asia-Pacific region: a systematic review of literature. BMC Infectious Diseases. 2018;18:82. doi:10.1186/s12879-018-2972-5.

[18]Development, use, and integration of a nationally-distributed HIV/AIDS electronic health information system; Milberg JA, J Am Med Inform Assoc 2016;23:1190–1194. doi:10.1093/jamia/ocv212, Brief Communication

[19]Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): a randomised trial: Lester RT, Ritvo P, Mills EJ, Kariri A, Karanja S, Chung MH, Jack W, Habyarimana J, Sadatsafavi M, Najafzadeh M, Marra CA, Estambale B, Ngugi E, Ball TB, Thabane L, Gelmon LJ, Kimani J, Ackers M, Plummer FA: Lancet. 2010 Nov 27; 376(9755):1838-45.

[20]Purnomo J, Coote K, Mao L, et al. Using eHealth to engage and retain priority populations in the HIV treatment and care cascade in the Asia-Pacific region: a systematic review of literature. BMC Infectious Diseases. 2018;18:82. doi:10.1186/s12879-018-2972-5

[21]Innovative use of cellphone technology for HIV/AIDS behaviour change communications: 3 pilot projects; Katherine de Tolly and Helen Alexander, Cell-Life, Cape Town

3.2 National efforts on HIV record keeping

Strategic Information (SI), according to the National Strategic Plan for the HIV/AIDS and STI 2017-2024 is the "most important piece that shapes the direction and quantum of the response to the HIV/AIDS epidemic". And, according to the document "a strong monitoring, evaluation and surveillance (MES) framework has been fundamental to the India's successful response to the HIV/AIDS epidemic.

The MES framework of the HIV/AIDS program in India consists of two broad groups. One, the epidemic surveillance and two, program monitoring. The overview of the MES framework of the HIV/AIDS program is given below

Epidemic Surveillance

Population/facility-based surveillance
• HIV Sentinel Surveillance (HSS)
• Integrated Biological & Behavioral Surveillance (IBBS)
• NFHS 4

Individual / Case based surveillance
• PLHIV-ART Linkage System (PALS)
• Inventory Management System (IMS)

Program Monitoring
• Strategic Information Monitoring System (SIMS)

• Service Uptake – Quantity, quality, efficiency

• Service coverage – HIV related risk behaviors

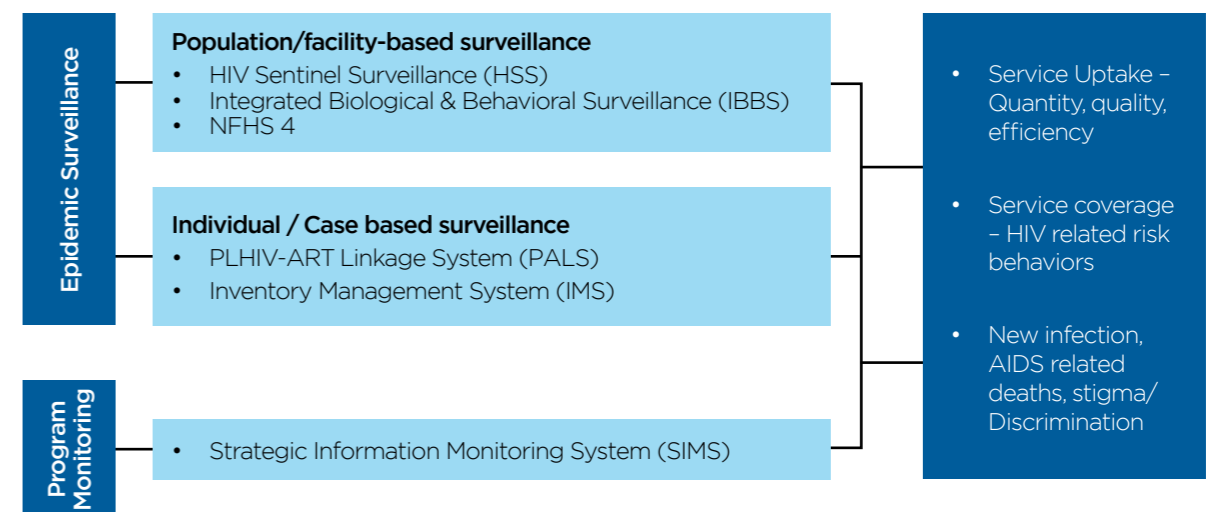• New infection, AIDS related deaths, stigma/ Discrimination

Figure 13: MES Framework for the HIV/AIDS Program in India

Epidemic Surveillance[22]

The HSS provides evidences on the level of HIV epidemic and its trends across population groups and locations. Data from HSS, 2016-17, available from 829 ANC sites and 494 key and bridge population sites, enable the generation of the HIV burden at national and state levels in the country.

The IBBS helps to generate evidence on characteristics of Key Populations and Bridge Populations, their vulnerabilities and risk behaviors to support planning and prioritization of program efforts at the district, state and national levels. Both HSS and IBBS provide critical evidence that has guided the program to be finetuned to emerging needs. HIV is also covered in large scale Demographic and Health Surveys - household surveys such as the NFHS-4.

Inventory Management System (IMS): IMS is an online "Inventory Management System" developed to digitally record the supply chain of the ARV drugs and importantly record the ARV drug distribution to clients and enable real time customized reports at the facility/SACS and NACO levels. IMS was officially launched by NACO in December 2014, across the country in all ART Centers. It has two components; one, provides details of the receipt and dispatch of inventories across the chain and stock management and the other which is on client / patient management. The client/ patient management lists the individual client, and a unique bar code is assigned to each client.

The client details captured by the system include the following

- Patient details - Name, age/DOB; address; contact details; Aadhar number
- ART details - date of registration, Pre-ART Number; ART Number, Regimen, Patient status
- CD4 details - Baseline CD4 date and count; last CD4 date and count and next CD4 date
- Linked out & transfer details - linked out status and facility, transferred out status and facility.

The client / patient management enables the

- Automatic updating of the status of Lost to Follow ups
- Provides status details of on ART, pre-ART, dead and opted out
- Patient migration tracked through transfer in & out process
- CD4 details of both baseline and last count
- Details of age, category (adult / pediatric); date of registration etc.

The primary reporting unit for the IMS is the ART center, information entered at the ART center is reviewed by the DAPCU (where they exist) or directly by the CST division of the SACS and then NACO.

Program Monitoring

Strategic Information Management System (SIMS)[23]: SIMS was developed as a solution to improve data management, analysis and use. It was meant to overcome aspects of fragmented data collection; inadequate quality control and limited options for advanced data analysis and data visualizations. SIMS, a web-based application was launched in August 2010 and the roll out at the country level was done between August-December 2011. It is a reporting unit-based data capturing application and enables monthly reporting from over 30,000 units across the country. The application enables automatic aggregation of key indicators and enables different types of data analysis. The application also has customized dashboard reports on key indicators for each program component at all levels.

The data flows from the reporting unit at the sub-district level (for instance an ICTC) to the DAPCU (where they exist) or directly to the SACS and then to NACO at Delhi. There is feedback that flows back to the reporting unit at the sub-district level. The reporting unit uses the information to evaluate the performance against targets; DAPCU where they exist use the data to assess district level trends; SACS use the data to assess the state level trends and NACO uses the information to inform resource allocation.

SIMS has three modules - (a) an Admin module for the creation of the reporting unit and its activation, user rights and management of passwords; (b) the MIS module where the data entry is done, entered data is validated, modifications, if any are made and the data is exported; and (c) the reports and analytics module which enables the analysis and the dashboards for viewing key indicators.

The above-mentioned systems are built on a software platform to enable real-time data capture. In addition, there may also be state specific information systems – such as the Supply Chain Management System (SCMS) in Tamil Nadu.

There are also several offline/ manual systems of data capture, which feed into one or more MIS's.

An overview of the manual systems of data management are as follows:

ICTC	ART
• ICTC client register - for general and ANC clients (basic demographic details) • PID register – for general and ANC clients • ANC Counselling register • ANC line-list register • General line-list register • Infant register • HIV-TB register/ RNTCP Register • Stock register	• Pre-ART register • ART Register • EID register • Exposure register – for all children of HIV positive mothers • Green book • White card – with case details, a copy of which is given to the client

At the point of client interface, information is first noted in all the above-mentioned registers, as applicable. The number and type of registers maintained may vary across states. Information from these registers is then entered in IMS, SIMS and PALS at regular intervals. While in PALS and IMS, case-based data is entered; aggregate for each facility is entered in SIMS.

[22]See Ministry of Health and Family Welfare, GOI; National Strategic Plan for HIV/ AIDS and STI 2017-2014; May 2017; National AIDS Control Organization. Downloaded on March 28, 2018.
[23]See Venkatesh S. "Strengthening Data Management Under National AIDS Control Program in India through Web-based Strategic Information Management System"; presented at AIDS 2014 conference; downloaded from internet on March 28, 2018.

Conclusion and Recommendations

HIV case-based surveillance or tracking is an approach that involves the reporting of individual-level information from each person diagnosed with HIV at the ICTC. Information along the course of disease from diagnosis to entry into care, initiation of antiretroviral therapy (ART), viral suppression, and death are necessary to measure progress towards epidemic control. Hence it is important that these events are collected and maintained longitudinally.

This document is intended as an overview of PALS as an electronic health record system for tracking individual PLHIVs, if tested positive to ensuring their linkage for ART services.

Developed with the intention of streamlining data collection and tackling the PPTCT and infant cohorts, PALS, now extended to general clients, is a key EHR innovation; globally and specifically in developing countries for case-based tracking of PLHIV.

Before the introduction of PALS, the HIV program monitoring and reporting systems had two significant limitations. First, data from persons diagnosed in HIV testing programs was not linked to data in the HIV care and treatment program monitoring systems. Hence, it was not possible to measure actual linkage to care, understand populations least likely to be linked to care, or intervene to locate and engage these persons in care. In other words, it was not possible to accurately measure or identify persons who were diagnosed but had not entered care or to measure the timeliness of entry into care. Second, beyond the facility level, monitoring and reporting systems used aggregate data which can overestimate the number of persons in care and the number of patients lost to follow-up.

The distinctive characteristic of PALS as Case Based tracking / reporting system and which distinguishes it from aggregate reporting are

- To accurately add new information pertaining to an existing case record, and to also determine duplication of records, if any; (i.e. two or more records for the same individual), PALS is designed to enable matching to identify if the information of the PLHIV is already available.

- It enables timely longitudinal population-based data collected at a facility aggregated to the facility, district, state and national levels. This can help to determine and describe the geographic, demographic and risk factor distributions of HIV. This in turn ensures that quality information is provided to NACO or SACS for program planning and evaluation.

The features of the PALS as case based electronic health record system has been outlined in the report. The report also documents the status of its adoption across states, based on field visits in three states.

PALS provides significant lessons and pointers for developing individual case-based tracking / surveillance for other health programs in the country.

Though it has been rolled-out across states in India, its implementation needs significant strengthening. Even in its limited implementation and use of functionalities, PALS appears to have generated several success stories in enabling linkage of clients across cohorts and geographies; and enabling follow up and tracking. It is thus imperative to build on this progress to ensure a complete and sustained implementation of the system.

Literature indicates that EHR systems should enable the following:

- Enhance the extraction, interpretation, and prioritization of critical health information of an individual client and for the key population groups served by the facility
- Enabling information exchange to coordinate care across providers and settings;
- Better patient engagement;
- Reduction in documentation burden;
- Better integration of care across settings

While PALS has begun enabling some of the above-mentioned aspects, it would be good to review in the future, the effectiveness of PALS as an EHR system in HIV.

Recommendations

- Rigorous and sustained capacity building of stakeholders at different levels
  - For facility level staff on the various features and use of the system to effectively enable their daily roles
  - For district and state officials on its use as a tool for program management and epidemic surveillance
- Technical support to users through phone to enable error free usage
- Monitoring at the National, State and District levels to ensure real-time data entry into the system, so linkages could be made effectively, and gaps monitored
- Formation of a core-committee at the National Level, designate a nodal officer at the state level to monitor and review the software periodically, to streamline software development and updating
- Linkage with other information management systems, such as the MCTS, SIMS and IMS to ensure efficient data capture and tracking across the care continuum

Conclusion and Recommendations

Annexure

Annexure - List of persons met

- Dr. Asha Hegde, National Consultant, PPTCT, NACO
- Mr. Tejas Mulik, Consultant PPTCT, NACO
- Ms. Srilatha Sivalenka, Public Health Specialist, US CDC DGHT India
- Dr. Joseph Williams, Director, Projects, Voluntary Health Services
- Mr. Laxman Das, Program Specialist (Information Systems), Voluntary Health Services

Tamil Nadu

Data collection done between – 27th February - 7th, March 2018

State Level officials	• Mr. Kumarasamy - Additional Director, In-charge, ICTC • Mr. Manimaran - Deputy Director, Blood Safety • Dr. Babbi - Deputy Director – CST • Ms. Kalpana – Additional Director, CST • Mr. Tangavel – Quality Manager LS • Mr. Vishnu Raj – State M&E Officer
IOG Hospital – Chennai	• Mr S. Mohammad Farooq - DPM – DAPCU Chennai • Dr. Shanmugapriya - ART Medical Officer • Mr. Manoharan, ICTC Counsellor - IOG Hospital • Mr. Vetrivel - ART Counsellor - IOG Hospital • Ms. Revathy - ART Counsellor, IOG Hospital • Mr. Babu - ART Data Manager, IOG Hospital • Mr. Vijay Prabhu - Pharmacist, ART centre, IOG Hospital
Ramachandra Medical College, Thiruvallur district	• Mr. Prasanna Kumar - MEO, DAPCU, Thiruvallur • Mr. Manikantan - ICTC Counsellor, Ram Chandra Medical College, • Lab Technician - ICTC Ram Chandra Medical College • Mr. Bala Ravikumar - ART Data Manager (Phone interaction)
District Hospital – Namakkal district	• Mr. Karthikeyan - DPM, DAPCU Namakkal • Mr. Thirnavukarasu - DIS, DAPCU, Namakkal • Dr. Suryaprakash - ART Medical Officer • Mr. Prabhu - Data Manager, ART center • Mr. Shankar - Data Manager, ART center • Mr. Ruba - ICTC Counselor
Tiruchengode block, Namakkal district	• Dr. V. Divvy - ART Medical Officer • Ms. R. Kavitha - ICTC Counsellor • Ms. R. Sangita - ICTC, Lab Technician • Ms. Gandhivani - ART counsellor • Ms. Vijaylaxmi - ART Cousnleor • Mr. Vijaypriya - ART Data Manager
Rasipuram block, Namakkal district	• Dr. Sumathi - ART Medical officer • Mr. S. Ramesh - Data Manager, ART Center • Mrs. Poonkothai - ART Counsellor • Mrs. Suganthi - ICTC Counsellor • Mrs. Revathy - ICTC LT

Odisha

Data collection done between - 5th - 10th, March 2018

State Level officials	• Mr. Sushant Kumar Swain, Joint Director-Basic Services, Targeted Interventions - TB • Ms. Trupti Mishra, State Consultant PPTCT and Convergence • Ms. Maya Rani Mohanty, Assistant Director, ICTC • Dr. Sanjay Pattnaik, Project Director (Incharge), Joint Director Care, support, treatment • Dr. Ramachandra Rout, Additional Project Director • Ms. Trupti Mishra, State Consultant PPTCT and Convergence • Ms. Maya Rani Mohanty, Assistant Director, ICTC
Interaction with officials and counsellors at State Level	• Ms. Jayanti Bala Samantray DA (M&E), DAPCU, Khordha • Ms. Snigdharani Pattnaik, Counsellor, ICTC-II, Puri • Ms. Mamata Mohanty, ICTC Counsellor, Municipality Hospital, Bhubaneswar • Ms. Bijaylaxmi Samal, Counsellor, ICTC-II, Jagatsinghpur • Ms. Anjali Das, Counsellor, ICTC, SCB Medical College, Cuttack • Mr. Himanshu Sekhar Sethi, Counsellor, ICTC, City Hospital, Cuttack
Capital Hospital - Bhubaneswar	• Ms. Sadhina Mohapatra, Counsellor, ICTC, Capital Hospital • Mr. Sanjay Mohapatra, Counsellor, ICTC, Capital Hospital • Ms. Renu Rath, Counsellor, ICTC-II, Capital Hospital • Ms. Sarita Patra, Counsellor, ART Centre, Capital Hospital • Mr. Purna Chandra Mohanty, Data Manager, ART Centre, Capital Hospital
CHC Jatani Khordha district	• Ms. Priyambada Champatiray, Counsellor, ICTC, Jatani • Ranjan Kumar Pattnaik, Laboratory Technician, ICTC, Jatani
CHC Balipatna Khordha district	• Ms. Prangya Nayak, Counsellor, ICTC, Balipatna • Ms. Banita Rout, Laboratory Technician, Balipatna

Telangana

Data collection done between– 5th – 10th March 2018

State Level officials	• Dr. Preeti Meena, IAS, Project Director, TSACS • Dr. Alimelu, Joint Director, Basic Services Division, TSACS • Dr. Gopinath, Deputy Director, STI; Deputy Director In-charge for CST and M&E • Ms. Aparna, PPCTC Consultant, TSACS • Ms. Mekhla, Deputy Director, CST • Mr. Durga Srinivas, M&E Officer, TSACS
Niloufer Hospital – Hyderabad	• Mr. Anil, PPTCT Counsellor • Dr. Babjee, ART Medical Officer • Ms. Aarthi, ART Counsellor • Data Manager, ART Centre
Officials – Nizamabad District	• Mr. Sudhakar, DAPCU – Project Officer • Mr. Srinivas, DAPCU – MIS Officer
District Hospital, Nizamabad District	• Ms. Radha, PPTCT Counsellor • Dr. Srinivas, ART Medical Officer • Mr. Mohan Rao, ART Counsellor • Mr. Krishna, ART Counsellor • Mr. Mahesh, ART Data Manager
Kamareddy block, Nizamabad District	• Mr. M. Nagaraju, ICTC Counsellor • Mr. Praveen Kumar, ART Counsellor

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GOVERNMENT OF INDIA
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