Best Practices in Strategic Information

Best Practices Series 4

Cohort tracking of PLHIV on ART in Sri Lanka

Technical Assistance support and submitted by

The Voluntary Health Services (VHS),

Supported by **Centers for Disease Control and Prevention (CDC),**

(VHS-CDC Project),

Rajiv Gandhi Salai, T.T.T.I. Post, Taramani, Chennai – 600 113,

Tamil Nadu, INDIA.

Submitted to

National STD/AIDS Control Programme (NSACP)

Ministry of Health, Nutrition & Indigenous Medicine, Govt. of Sri Lanka

No.29, De Saram Place, Colombo 10, Sri Lanka.

MINISTRY OF HEALTH SRI LANKA

NATIONAL STD/AIDS CONTROL PROGRAMME

VHS

Best Practices in Strategic Information

Best Practices Series 4

Cohort tracking of PLHIV on ART in Sri Lanka

Technical Assistance support and submitted by

The Voluntary Health Services (VHS),

Supported by **Centers for Disease Control and Prevention (CDC),**

(VHS-CDC Project),

Rajiv Gandhi Salai, T.T.T.I. Post, Taramani, Chennai – 600 113,

Tamil Nadu, INDIA.

Submitted to

National STD/AIDS Control Programme (NSACP)

Ministry of Health, Nutrition & Indigenous Medicine, Govt. of Sri Lanka

No.29, De Saram Place, Colombo 10, Sri Lanka.

MINISTRY OF HEALTH SRI LANKA

NATIONAL STD/AIDS CONTROL PROGRAMME

VHS

This publication was supported by the Grant or Cooperative Agreement Number 6 NU2GGH001087-05-02, funded by the Centers for Disease Control and Prevention, (CDC) US and PEPFAR. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention, US PEPFAR or the Department of Health and Human Services.

Foreword

HIV/AIDS response globally has been a fountainhead of innovations and best practices that were evolved to customise the program and match the needs of the epidemic. Last three decades of HIV programming has seen several systems and initiatives that evolved to be called global best practices. A few efforts have been made to systematically document such best practices in HIV/AIDS response so that the lessons learnt from them can benefit the other programs or other areas or countries. These best practices span the entire spectrum of the HIV/AIDS program primarily focussing on prevention and treatment strategies, service delivery, community participation, multi-stakeholder response, financial systems and supply chain. However, there are very limited instances of documenting best practices in Strategic Information Management related to HIV/AIDS.

National STD/AIDS Control Programme of Sri Lanka has evolved robust Strategic Information Management systems over the decades, upon the foundations of the much stronger STD control program in the country. STD surveillance system, HIV case reporting system, HIV cohort tracking system and data dissemination practices are some shining examples of best practices in Strategic Information for HIV/AIDS that NSACP has developed over years. An exercise has been carried out to systematically review such initiatives from the lens of documenting best practices and this publication is an outcome of such an effort. I sincerely hope that this publication will not only highlight the achievements and lessons learnt from the past experiences, but also show us the way forward in further strengthening them.

In preparation of these best practices, we thank Dr Ariyaratne Manathunge, Consultant-Venereologist and Coordinator-SIMU, NSACP for his leadership and coordinating the technical assistance to NSACP as nodal officer for SIMU-NSACP. His strategic guidance in developing and bringing out the best practices document (book on best practices, best practices series and book of abstracts on best practices) covering both existing and emerging is highly appreciable. As a part of this, VHS-CDC Project in partnership with NSACP is bringing out "Best Practices Series" covering one book on each best practice on Strategic Information. In this regard, this book on best practice titled *"Cohort tracking of PLHIV on ART in Sri Lanka"* has been developed for effective dissemination. We also appreciate the contributions made by SIMU team, all the NSACP senior officials, key stakeholders and peripheral STD clinic team members in developing these best practices.

We appreciate the technical support being extended by VHS-CDC Project with the support of Centers for Disease Control and Prevention (CDC-INDIA) in planning and conducting this study in a participatory manner for introducing evidence based comprehensive capacity building plan for the Strategic Information Management team.

We would like to thank The Voluntary Health Services (Cooperative Agreement Implementing Partner of CDC) for their contribution in bringing out this publication on 'Best Practices in Strategic Information under NSACP' with the review and suggestions from NSACP.

We acknowledge and thank the VHS-CDC Project team for their immense support in ensuring partnerships and continue to provide strategic technical support to NSACP on Strategic Information and serving as instrumental in bringing out this document. We appreciate and acknowledge the technical support extended by VHS-CDC Project and their team in identifying, collecting, documenting and bringing out these best practices. These best practices will be of very much useful for dissemination at national and international level.

We thank United States President's Emergency Plan for AIDS Relief (PEPFAR), Centers for Disease Control and Prevention (CDC/DGHT-India) and their team for their support in this model inter-country initiatives and contribution in evolving a comprehensive TA plan and coordination mechanism. We greatly appreciate and acknowledge PEPFAR and CDC/DGHT-India for their financial and technical support and providing strategic technical assistance. Also thank for the support extended in bringing out this document.

Dr Rasanjalee Hettiarachchi,
Director,
National STD/AIDS Control Programme (NSACP),
Sri Lanka.

Acknowledgements

Voluntary Health Services – Centers for Disease Control & Prevention (VHS-CDC) Project is pleased to bring out this special document on 'Best Practices in Strategic Information under National STD/AIDS Control Programme, Sri Lanka'. This is a unique endeavour made in close collaboration with and guidance of Strategic Information Management unit of NSACP to systematically document the best practices in Strategic Information of HIV/AIDS in Sri Lanka. This exercise aimed to look at the existing and emerging SI initiatives from the lens of a best practice assessment and bring out the operational details, historical perspective, lessons learnt, potential for further development and recommendations for action. The methodology adopted and implemented with rigour ensured that it followed the globally recommended approaches while customising it to the context of Sri Lanka's program.

We wish to highly appreciate and acknowledge the leadership, support and guidance being extended by the Director, NSACP, Sri Lanka in the entire process of technical collaboration and bringing out this report.

We sincerely acknowledge and appreciate the critical leadership and guidance provided by Dr Ariyaratne Manathunge, Consultant-Venereologist and Coordinator-SIMU, NSACP, Sri Lanka in planning, execution, providing strategic guidance, sharing experiences and coordination of the entire process of development and finalisation of the document on best practices.

We also acknowledge the contributions of the entire SIM unit of NSACP. Further, we appreciate and thank contributions made by the key stakeholders: senior officials-NSACP, SIMU team, EIMS development team, website development team, consultants-Venereologist from various STD clinics, SI team members working at peripheral STD clinics and all those who has contributed for this documenting the best practices.

We would like to appreciate the strategic guidance and coordination extended by Dr T Ilanchezhian, Senior Technical Advisor, VHS-CDC Project in planning and completion of the entire document and providing needful technical support in bringing out this document by adopting a participatory process.

We acknowledge the contributions of Dr Yujwal Raj, Technical Advisor-SI, VHS-CDC Project for his technical expertise in developing the best practices and contributing in development of this document in a more meaningful manner.

VHS-CDC Project has undertaken efforts to bring out publications in the form of: book on best practices, best practices series and book of abstracts for dissemination by NSACP at national and international level. As a part of this technical cooperation initiatives, VHS-CDC Project in partnership with NSACP has also developed "Best Practices Series" on seven titles as one Best Practice book on each title.

VHS-CDC Project and VHS place on record our sincere thanks and gratitude to Dr Timothy Holtz, Country Director, CDC/DGHT-India for his dynamic leadership and strategic guidance being extended in providing Technical Assistance to NSACP, Ministry of Health, Nutrition & Indigenous Medicine, Govt. of Sri Lanka and Mr Lokesh Upadhyaya, Associate Director for Management and Operations and Ms Srilatha Sivalenka, Public Health Specialist, CDC/DGHT-India and CDC team for their ongoing technical guidance and support in this technical assistance initiative.

We also thank Ms T Sudha, Senior Program Associate, VHS-CDC Project for her support in ensuring communication and coordination.

We trust that, these documents will be of more useful to the readers for understanding the best practices for adoption and replication.

Once again, we acknowledge the support extended by SIMU unit-NSACP, NSACP and CDC in providing technical assistance to NSACP on SI related initiatives.

Dr Joseph D Williams,
Director Projects,
The Voluntary Health Services (VHS),
Chennai/INDIA.

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
CDC	Centers for Disease Control and Prevention
DIC	Drop in Centre
EIMS	Electronic Information Management System
EPI	Epidemiology
FSW	Female Sex Worker
GFATM	Global Fund to Fight AIDS, TB and Malaria
HIV	Human Immunodeficiency Virus
IEC	Information, Education and Communication
KP	Key Population
LFU	Loss to Follow Up
MSM	Males who have sex with males
NGO	Non-Government Organisation
NRL	National Reference Laboratory
NSACP	National STD/AIDS Control Programme
NSP	National Strategic Plan
PHI	Public Health Inspector
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
SI	Strategic Information
SIMU	Strategic Information Management Unit
SMO	Social Media Outreach
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
UNAIDS	Joint United Nations Program on HIV/AIDS
VHS	Voluntary Health Services
WHO	World Health Organisation

Cohort tracking of PLHIV on ART in Sri Lanka

EXECUTIVE SUMMARY

Background: Taking advantage of the low-level epidemic and a relatively smaller number of PLHIV in the country, NSACP has taken measures to ensure that every PLHIV is linked to treatment and care, and followed up closely on ART. Documentation and reporting systems have been set up to ensure longitudinal cohort tracking of PLHIV on ART.

Objectives: To monitor the treatment adherence and progress of PLHIV receiving ART and estimate the survival among PLHIV on ART

Implementation Highlights: Extensive, well-documented case files for all PLHIV is the primary source of information for cohort tracking and cascade analysis of PLHIV data. Individual level reporting in electronic form ensures computerisation of key variables required for cohort tracking. Active tracking & follow-up of LFU by PHI/Nurse ensures that treatment adherence of PLHIV is high. High level, uniform reporting from all HIV clinics ensures that the data is complete and updated. Systematic analysis & periodic dissemination of the longitudinal data ensures the utility of the data in the program.

Conclusion & Lessons Learnt: Ensuring individual level reporting of progress of PLHIV on ART from all HIV clinics right from the early stages of ART program is a best practice under NSACP. This system can further be strengthened through shifting to an electronic data management system.

BACKGROUND AND RATIONALE

STD clinics form the central pillar for the HIV/AIDS response. With the advent of HIV, the functions of screening for HIV and management of confirmed HIV positive cases have been added to the STD clinics. Some of them have been upgraded into HIV clinics where Anti-Retroviral Treatment is provided. The way in which HIV/AIDS control and management is integrated into the ongoing STD control program and infrastructure is unique to Sri Lanka. HIV Screening and treatment for HIV positives are provided through same facility making it more patient friendly. Consultant Venereologists provide all the required clinical care for out-patient and in-patient HIV cases. Separate cadre of public health inspectors are available for tracking and follow up of lost-to-follow-up cases, contact tracing, etc.

With this background system for HIV care in place, SIM unit of NSACP has introduced computer-based cohort tracking of HIV positive cases receiving Anti-retroviral treatment (ART). This ensures quarterly reporting of individual level patient information from all HIV clinics to SIM unit of NSACP. This is a simple and effective means of ensuring that all HIV cases are adherent to their treatment as well as generating programmatic evidence on survival, mortality, etc. Thus, it is important to document this as a best practice under Strategic Information.

OBJECTIVES

The excel-based cohort tracking system has been developed by SIM unit for tracking of PLHIV on ART with the following objectives.

1. To monitor the treatment adherence and progress of PLHIV receiving ART
2. To estimate the survival on ART among PLHIV at 12, 24 and 60 months for ART program monitoring
3. To take measures to minimise lost-to-follow-up and enhance treatment retention

DETAILS OF IMPLEMENTATION

Every case of confirmed HIV positive is registered into the pre-ART register till the time clinical evaluation and laboratory assessments are completed and ART is started. Once ART is started, the details are entered into the main ART register. The register documents the basic demographic information, WHO staging, weight, CD4 count, ART regimen started, any regimen changes, death, transfer-out details, and monthly visit status of the patient. This register is regularly maintained and updated by the staff nurse at the HIV clinic for every visit of the patient.

Patient case files are maintained by the consultant Venereologists with utmost care. All the clinical and risk behaviour related information besides counselling details, laboratory tests, opportunistic infections, etc. are documented in great detail for every visit of the patient. Patient case files present a complete longitudinal view of the patient's journey from detection till the current date and is an important source of information for preparation of ART quarterly returns as well as updation of cohort database.

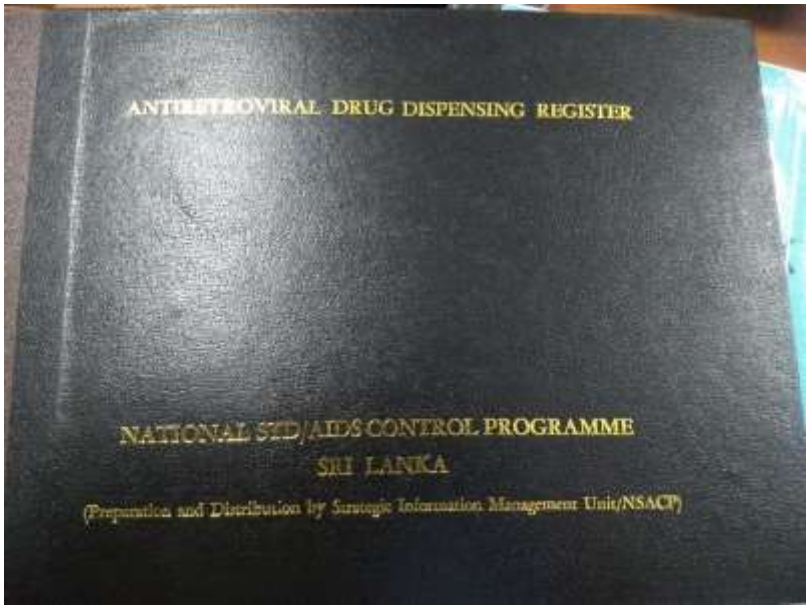
Besides the main register and patient case files, HIV clinic maintains several other registers related to the patient care as well as clinic management. One of the important registers is the LFU tracking register maintained by the PHI. PLHIV who don't visit the HIV clinic on the scheduled date are followed up by the PHI through phone, mail or physical visit to the household. All the tracing efforts are documented in the LFU tracking register.

On a quarterly basis, the individual level information on the key variables in ART register along with details of viral load testing are entered into a standard Excel-based database by the staff nurse or PHI. This database is forwarded to SIM unit where it is verified and taken for further compilation and analysis. SIM unit compiles quarterly database received from all HIV clinics, undertakes quality checks, conducts analysis for treatment adherence rates, survival rates and other global indicators such as 90-90-90. The analysed data is used to fulfil the international reporting requirements as well as published in the annual report.

Registers maintained at HIV clinics

The following registers are maintained at all the HIV clinics in the country:

1. Pre-ART Register
2. ART Register
3. Patient White Card
4. Appointment register
5. Patient case files
6. Defaulter tracing register
7. Interview & contact tracing register
8. Investigation register
9. Death register
10. Quarterly returns file
11. PMTCT register
12. Children living with HIV register
13. Register of drug resistance tests
14. Cotrimoxazole prophylaxis register
15. Register of Contraceptive methods for HIV infected women
16. HIV co-infections register
17. HIV-TB register
18. Register on non-communicable diseases & STDs among PLHIV
19. Hepatitis B vaccination register



Key personnel involved in data management: Staff Nurse & Public Health Inspector under the overall supervision of the Consultant Venereologist. Staff at each HIV clinic work as a cohesive team with complete ownership, mutual cooperation and teamwork.

Personal & Data confidentiality: Except on the case files and in the main register where the STD cases are registered, names of the patients are not documented elsewhere. All references are done through unique case ID/ file number issued to each case. Even in cases where the doctors and the facility staff identify the STD cases personally, they ensure complete confidentiality of the information and this has led to strong rapport building with the patients. This in turn contributes to better defaulter tracing and contact tracing and treatment adherence.

Community Participation: Being an SI initiative, there is no direct participation of the beneficiaries and communities in the data management system. However, as noted above, community participation is ensured in the delivery of HIV services through strong rapport building approaches adopted by the HIV clinics and the follow-up and tracing efforts by the facility staff. Engagement with the key population communities is also improving over time with increasing access and utilisation of ART services by them.

Capacity building initiatives: HIV clinic staff are given orientation whenever there are changes in the formats or any reporting guidelines. Quarterly and annual review meetings of the HIV clinic staff are held at NSACP where they are asked to present their facility findings. Such opportunities are also used to provide capacity building on specific areas. Besides, consultant Venereologists receive in-depth training before they are posted at the STD clinics, that builds a sense of ownership as well as management skills in managing the STD/HIV clinics.

Institutional support mechanisms: The entire system of HIV data management is managed by the program staff. The system is thoroughly institutionalised within the program, with fixed term postings for doctors and other staff. There are no external institutional support structures or mechanisms involved either at facility level or at the national level.

Costing & funding arrangements: The Strategic Information Management component of NSACP is fully funded by the Government of Sri Lanka. All the registers and formats are printed by the SIM unit and supplied to the HIV clinics. It is a very cost-effective intervention as the primary investment is in the form of time of personnel involved.

Data analysis & Dissemination: Besides the analysis of cohort data for survival analysis and mortality estimation that are presented in the annual report, SIM unit also brings out separate cohort ART data analysis reports from time to time.

KEY HIGHLIGHTS AND CONTRIBUTION TO THE PROGRAM

The key highlights of the Excel-based cohort tracking of PLHIV include:

1. Extensive, well-documented case files for all PLHIV is the primary source of information for cohort tracking and cascade analysis of PLHIV data.
2. Individual level reporting in electronic form ensures computerisation of key variables required for cohort tracking.
3. Active tracking & follow-up of LFU by PHI/Nurse ensures that treatment adherence of PLHIV is high.
4. High level, uniform reporting from all HIV clinics ensures that the data is complete and updated.
5. Systematic analysis & periodic dissemination of the longitudinal data ensures the utility of the data in the program.

OUTCOMES & ANALYTIC OUTPUTS

The most valuable outcome of the cohort tracking of PLHIV on ART is the identification of lost-to-follow ups at the facility level for immediate action, follow up and tracing efforts. Secondly, the data compiled at national level generates a strong database of all PLHIV in the country with rich information that can be used for strategic planning. The estimates of survival of PLHIV on ART at 12-60 months as stipulated by the international reporting requirements are also generated from this data. The data also enables the program to monitor the progress and against the fast track (90-90-90 targets) and End of AIDS targets.

Figure 9: Status of 90-90-90 treatment targets as of end 2017

Figure 10: Cross sectional HIV treatment cascade as of end 2017

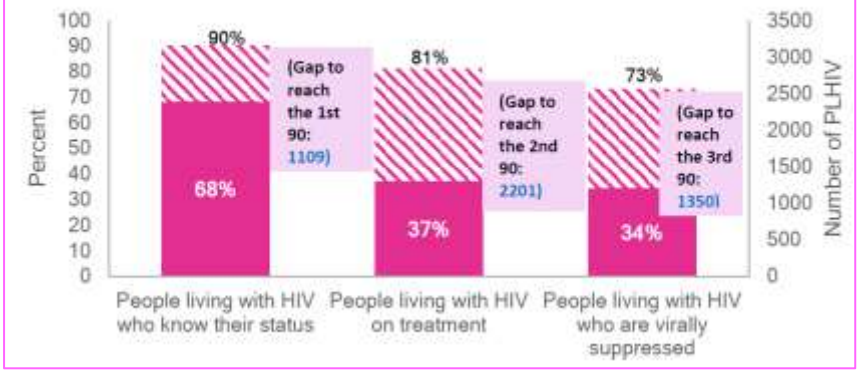
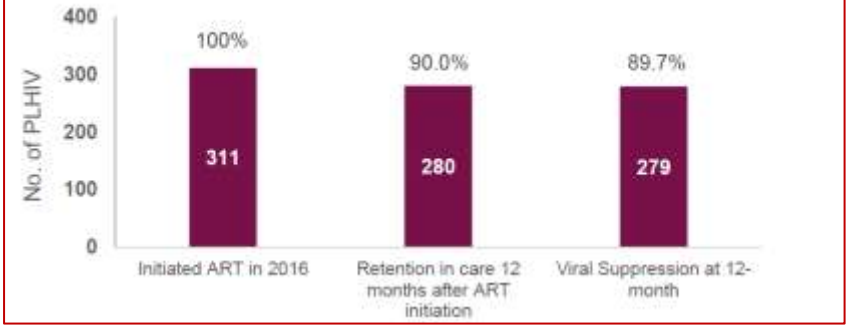


Figure 11: Longitudinal HIV cascade among PLHIV who initiated ART in 2016



STAKEHOLDER PERSPECTIVES & EXPERIENCES ON THE BEST PRACTICE

HIV clinic staff are all trained and oriented in the registers and reporting formats. Since the number of PLHIV receiving treatment at each HIV clinic is relatively not very high, except a few centres, the staff make efforts to ensure quality of data. *"We know all the PLHIV registered at our clinic personally and remember the case details of each one of them, as we have dealt with them from the time of detection. This also gives us personal rapport with the PLHIV to keep up their trust and keep them linked to care and treatment,"* said one of the consultant-Venereologists.

"ART registers are well-structured and easy to maintain. Documentation is simple and straight-forward. We are also oriented on entering the data from the registers into the excel database every quarter," said a staff nurse at one of the HIV clinics.

LESSONS LEARNT – CONTRIBUTING FACTORS, SCALE UP/ REPLICABILITY, LIMITATIONS & RECOMMENDATIONS

Some of the key contributory factors that led to the development of PLHIV cohort tracking system into a best practice in SI are as follows.

1. Robust PLHIV patient case files maintained meticulously by the doctors at HIV clinics
2. Simple excel-based tools that are easy to use, update and submit
3. Strong focus from SIM unit of NSACP on the reporting and quality of the cohort data

Some recommendations to further improve the system are as follows.

1. While the ART cohort tracking is being successfully implemented across all the HIV clinics, staff at some clinics may be provided periodic refresher trainings on the documentation and data entry steps.
2. Follow up tracking registers may be streamlined more to ensure that all the efforts to trace a case of LFU are documented.
3. Cohort database may also include LFU tracking as one of the variables.
4. Entire clinical history and progression of the PLHIV on ART may be captured once the system evolves into a completely electronic data management system.

CONCLUSION

Well-established documentation and record-keeping systems at all HIV clinics, extensively maintained and updated patient case files coupled with simple, easy to use, excel-based cohort database tool that is reported quarterly to SIM unit make the entire cohort tracking of PLHIV on ART, a best practice in strategic information. Integration of individual level reporting into the upcoming EIMS along with automated alerts for lost-to-follow-ups and monitoring of drug regimens will further strengthen the cohort tracking system under NSACP. Such an electronic system can generate automatically the desired analysis of indicators from time to time.

The Qualitative Best Practice Scorecard applied to the cohort tracking of PLHIV on ART under NSACP is presented below. This area is of high relevance and criticality to the program since it contributes to the core objectives and indicators of the program. Community participation in the data reporting system is not direct and hence not applicable. Internal stakeholders, i.e., the facility staff need greater empowerment in terms of capacity building in data analysis, reducing the burden of documentation, etc. Data confidentiality and ethical soundness in the system is high. Replicability in other programs and countries is high as NSACP sets an example in this area. It is an efficient and less time-consuming system without

the need for much resources, and hence rated high on efficiency. Effectiveness is high since the system appropriately serves its intended purpose of PLHIV tracking and retention on ART and providing evidence for key indicator generation. Sustainability is not an issue in view of the simple excel-based tools as well as the upcoming EIMS.

Qualitative Best Practice Scorecard

Category	Criteria	Rating
Context	Relevance	High
Process	Community Participation	Not Applicable
	Stakeholder Collaboration	Moderate
	Ethical Soundness	High
	Replicability	High
Outcomes	Efficiency	High
	Effectiveness	High
	Sustainability	High

KEY HIGHLIGHTS OF THE BEST PRACTICE

- **Extensive, well-documented case files for all PLHIV**
- **Individual level reporting in electronic form**
- **Active tracking & follow-up of LFU by PHI/Nurse**
- **High level, uniform reporting from all HIV clinics**
- **Systematic analysis & periodic dissemination**