



**Regional  
workshop on  
strengthening ART  
data use in Asia  
and the Pacific:  
examples from  
USG, national and  
multilateral  
partners**

**Meeting Report**

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**USAID | ASIA**  
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**World Health  
Organization**

South-East Asia Region Western Pacific Region

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## Acronyms

ART	Antiretroviral therapy
ARV	Antiretroviral drugs
CDC	US Centers for Disease Control and Prevention
DOT	Directly observed therapy (for TB)
ESTHER	Ensemble pour une Solidarité Thérapeutique Hospitalière En Réseau
FHI	Family Health International
FHI/APRO	FHI Asia Pacific Regional Office
KHANA	Khmer HIV/AIDS NGO Alliance
M&E	Monitoring and evaluation
MOH	Ministry of Health
NHSO	National Health Security Office (Thailand)
NCHADS	National Centre for HIV/AIDS Dermatology and STDs (Cambodia)
OVC	Orphans and vulnerable children
PEPFAR	United States President's Emergency Plan for AIDS Relief
PLHA	People living with HIV/AIDS
PMTCT	Preventing mother-to-child transmission (of HIV)
PMIS	Patient monitoring information systems
STI	Sexually transmitted infection
TB	Tuberculosis
TUC/CDC	Thailand Ministry of Public Health-U.S. CDC collaboration
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
VAAC	Vietnam Administration for HIV/AIDS Control
WHO	World Health Organization

## Executive summary

Antiretroviral treatment (ART) is extending the lives of people living with HIV (PLHIV). Though ART has become more widely accessible globally since the early 1990s, getting antiretroviral drugs (ARV) to those who need it most continues to be a challenge. As access increases, so does the need to assure that systems are in place to report on outputs and outcomes in a timely manner. Such data are vital to ART programs, as not only do they assist in tracking progress towards achieving global goals, but they also inform the day-to-day implementation of treatment programs. Without an adequate measurement of what is being done, countries risk losing opportunities to prevent premature deaths and potential ARV resistance; they also do not have the information critical to assure PLHIV on ART receive appropriate care at the appropriate time to improve and maintain their quality of life.

Acknowledging the need to share experiences and lessons learned in order to inform future direction, the U.S. Government (USG), World Health Organization (WHO) and other partners organized the first “Regional workshop on strengthening ART data use in Asia and the Pacific: examples from USG, national and multilateral partners” in Bangkok, Thailand from 18-19 May 2009. This two-day workshop provided a forum for national and international experts to present lessons learned and discuss specific challenges faced in most resource-poor settings throughout the region. These presentations and discussions catalyzed a joint action plan to be taken on board by donors, national governments and other stakeholders working in this field.

Specific workshop objectives included:

- sharing experiences and lessons learned in using ART data for efficient program strengthening and improved patient treatment and care;
- raising awareness about key challenges related to ART program monitoring and identify issues for potential follow up; and
- providing participants with technical resources related to improved data

use to inform programs at the community and national levels.

The first day of the meeting focused on presenting global experiences and highlighted WHO's and the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) contributions to the field. Several countries complemented these presentations by sharing lessons learned in routine monitoring of ART programs.

Day two focused on evaluation efforts and strengthening data use. Several country presentations highlighted cohort studies being conducted in the region, the integration of early warning indicators for preventing and minimizing emerging drug resistance, the use of triangulation to enhance existing program data, and the need to strengthen data linkages between services.

Specific recommendations arising from this meeting include:

- The need for a clearly defined standard minimum data set, SOPs and guidance based on the national M&E framework which are based upon national care and treatment guidelines and include clear targets. Some of this work has already been imitated by organizations such as WHO, but further dissemination and support for implementation at the sub-national level is needed. For the region, it is also important to consider how MARP specific indicators fit into routine data collection.
- Advocacy efforts are needed to strengthen MOH ownership, consensus building, coordination and commitment across all partners.
- On going support and capacity building is essential and must be advocated for and supported in order to assure staff at all levels have the required skills to collect. Report and use program data.
- Need to strengthen continuous quality improvement processes at facility and community levels to improve quality of care, this includes looking into specific issues such as:
  - Data quality improvement
  - Integration of HIV early warning indicators into routine data collection

- Strengthening linkages and communication between all related HIV health services within a continuum of facility and community care and treatment
- Strengthening linkages and communication between prevention programs for MARPs and a continuum of prevention, care and treatment
- Facilitating the involvement of PLHA in all processes of data collection, analysis, interpretation and use
- Data use for quality improvement can be adapted to existing country resources, this includes basic discussions on issues such as “lost-to-follow up” at facility level and ways to improve retention through to thinking about developing methods for extracting a “package” of process indicators with comprehensive care team level discussions and problem solving identification (lengthy capacity building exercise).
- Rationalization and coordination of evaluation studies to inform specific programmatic questions. This involves:
  - Defining operational research (OR) priorities and creating a national agenda
  - Disseminating and discussing OR results with clinicians, policy makers and partners (could be done through ART symposia, for example)
  - Establishing inventories of local planned, on –going, or completed OR
  - Include self-reported QoL and well-being and measures of risk behavior and socio-economic status which contribute to adherence, loss to follow-up and necessary counseling and other interventions into such efforts
  - Need for qualitative methods to complement existing data, such methods will facilitate answering “why?”
- Increasingly looking at cost effectiveness for advocacy purposes:
  - Prevention vs. treatment, promotion of VCT for early treatment vs. poor treatment outcomes, community support and adherence counseling vs. 2nd line drug costs
- Promoting the triangulation and synthesis of data from surveillance, routine monitoring and OR to inform program planning (consensus meetings)
- Facilitation of resource mobilization for M&E:
  - GFATM: 6-10% overall proposal for M&E

Country presentations illustrated the considerable progress made over the last few years in M&E of ART, leading to better knowledge of general population treatment coverage and ARV regimens which have been used to support scale up of ART across the region. But there remain many issues to be addressed. As the first meeting of its kind in the region, participants appreciated the opportunity to come together, learn from each other and mutually agree on core challenges and recommendations. It is hoped that this will be the first of such meetings and that the dialogue which was initiated can be followed up and evolve as needed over time.

## 1. Introduction

The first regional workshop on monitoring and evaluation (M&E) of antiretroviral therapy (ART) programs in Asia and the Pacific was attended by a total of 78 participants from Cambodia, China, Lao People's Democratic Republic, Malaysia, Myanmar, Papua New Guinea, Thailand and Vietnam. Representing national, academic, donor and nongovernmental organizations (NGOs), participants shared experiences and lessons learned in monitoring and evaluating outputs and outcomes of ART programs through presentations from experts with experience with ART programs at all levels. Plenary discussions, case studies and small working groups were used to assist and encourage participants to identify lessons learned and think strategically around how data use can be improved. Specific workshop objectives included:

- sharing experiences and lessons learned in using ART data for efficient program strengthening and improved patient treatment and care;
- raising awareness about key challenges related to ART program monitoring and identify issues for potential follow up; and
- providing participants with technical resources related to improved data use to inform programs at the community and national levels.

Participants were welcomed to the meeting by:

- Dr. Anupong Chitwarakorn (Senior Expert in Preventive Medicine, Thailand Ministry of Health);
- Dr. Maureen E. Birmingham (WHO Representative to Thailand);
- Dr. Michelle McConnell (Senior Technical Advisor, Global AIDS Program/Thailand, Thailand MOH-US CDC Collaboration);
- Dr. Cameron Wolf (Regional HIV/AIDS Technical Advisor, USAID/Regional Development Mission Asia); and
- Ms. Gail Steckley (Deputy Director, Asia Pacific Regional Office, Family Health International).

Data use served as a basis for all presentations, with discussions focusing on how data are obtained through routine

monitoring and special evaluation efforts. The meeting looked at how these data can be interpreted and transformed into information that can be used to make programmatic decisions. Presentations focused on sharing lessons learned in a broad range of areas related to the M&E of ART programs. Topics covered included using electronic data systems, methods and challenges around assuring data quality, improving access to data and fostering its use, integration of early warning indicators (EWI) of antiretroviral drug resistance into routine monitoring, the need for data linkages between ART programs and other services such as directly observed therapy (DOT) for tuberculosis (TB), and approaches for measuring quality of life among PLHIV.

Throughout the meeting participants were encouraged to think about the specific challenges faced in the region, particularly in relation to working with most-at-risk populations (MARPs). Working group discussions brought participants together to discuss specific topics and to reach consensus on core challenges as well as recommendations.

## 2. ART program monitoring: state of the art and regional experience

The meeting began with an overview of the “state of the art” in monitoring of ART programs. Opening plenary presentations were given by representatives from WHO and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR). Vietnam, China, Thailand, Cambodia, Papua New Guinea, and Malaysia shared country-specific experiences, challenges, and some lessons learned in using electronic patient management systems, stimulating community-based data collection, and improving data use. Quality improvement models that assist in program planning and implementation were also presented.

Completeness and accuracy of data are directly linked to information quality and its use. Routine monitoring generally flags problem areas, for example but gaps can still exist (e.g. determining the causes of the problem). Operational research and surveillance supplement routine reporting and evaluation, as Dr. Padmini Srikantiah, Medical Officer, WHO/Regional Office for South-East Asia (SEARO), discussed during her presentation on best practices compiled by WHO.

Supplementation includes periodic review and revision of recording and reporting tools, especially in the initial years of an M&E system. Training supported by ongoing supervision builds capacity and is essential to obtain high quality data. Use of data is essential for program improvement. One unified M&E ART system in the country is optimal but is easier said than done.

In trying to promote complete and accurate recording, the WHO and partners developed an HIV care and antiretroviral treatment recording and reporting system training toolkit. Developed in 2006, the toolkit contains detailed information for monitoring and evaluation; it can be accessed at:

[http://www.searo.who.int/en/Section10/Section18/Section1372\\_9911.htm](http://www.searo.who.int/en/Section10/Section18/Section1372_9911.htm)

Ms. ThuVan Dinh, Strategic Information (SI) and M&E advisor, USAID/Washington, presented on PEPFAR’s global experience to date in the M&E of HIV programs

(including ART), as well as future work in this area.

PEPFAR seeks to reduce workload at the country level through better alignment with other donors, such as harmonizing reporting of indicators at the country level. PEPFAR also aims to achieve efficiency by aligning M&E activities in accordance to the epidemiological needs of countries. In this way countries can focus on a core set of indicators that are appropriate for their individual needs, and the programs being implemented. While M&E systems have been widely used and adapted based on country experience, there are some areas that need to be explored. Future plans include seeking estimates of cost-effectiveness as a part of routine monitoring and shifting priorities as programs mature. That is, once an ART program evolves from its startup period, specific indicators monitoring its infancy should be replaced by others addressing issues of access, coverage, equity, and outcomes.

Dr. Ray Ransom, SI Chief, U.S. Centers for Disease Control and Prevention (CDC)/Vietnam, presented on PEPFAR’s experiences with information strategies in Vietnam. Vietnam has implemented electronic information systems for HIV care and has learned that treatment programs require broad support to be effective. This includes support from technical staff (Ministry of Health [MoH], donors, point-of-service personnel) and their input and leadership (planning and project management), clinic ownership and professional software development (and its maintenance). Such systems must be flexible, adapting to the needs of the treatment programs they monitor.

Some key points to consider when contemplating the use of an electronic system include:

- Electronic systems do not necessarily mean paperless systems; the electronic system may still rely on paper based data collection, for example.
- Information comes at a cost: every piece of information takes time to collect, manage and use.
- There is an inverse relationship between the amount of information and quality; the more that is collected, the more likely there are to be issues around the quality of information.

- Indicators such as weight, CD4 cell count and ARV regimen changes over time are useful indicators that contribute not only to national reporting, but can be used at the clinical level to determine appropriate patient care.
- Standard reporting can be complemented by detailed clinical and behavioral data in order to answer specific questions and obtain a comprehensive understanding of the situation. Additional information such as this can be collected from a sample or through a special study.
- Finally, system requirements will evolve; this requires significant thought into the initial development of an electronic system so that flexibility is built in to address evolving needs over time.

Complementing Dr. Ransom's presentation, Dr. Do Thi Nhan, Deputy Chief of Treatment and Care Unit, MoH/Vietnam, presented an overview of the Vietnamese national ART data collection system. The system arose in response to the routine data reporting system become fragmented and inefficient. In response to this a system was developed using standardized recording tools for monitoring recipients of ART; these tools include early warning indicators of drug resistance. The system collects data on a variety of demographic variables which also assists in looking at outcomes of the national ART program.

While the system has assisted in many ways, challenges remain. Software supporting data management to inform individual patient care is not yet available, for example, and lack of staff with the required capacity to use the system persists. In addition, high staff turnover often leads to loss of institutional memory, compounding the challenges being faced in implementing such a system.

Similar to Vietnam, China has also developed an electronic system to track progress over time. Ms. Ma Ye, Deputy Director, Div. of Treatment and Care of National Center for AIDS Control and Prevention, China Centers for Disease Control and Prevention (China CDC), presented China's web-based information system that is maintained by the China CDC. The system covers both adults and children and uses Datafax software with double entry at the national level. Data are

collected at the clinical level using paper-based forms. Once completed, these forms are then faxed to the national levels where the forms are automatically "read" and converted into electronic data maintained in a national database. In order to assure data quality, the national center responsible for quality management uses an annual data-quality monitoring program.

This system manages over 1,600 counties, a level of coverage that taxes current capacity. The current system processes data by county, and – compounded by a lack of capacity – the system does not record information on the exact treatment site within the county.

In response to these challenges, a more detailed system will be launched soon. It will include:

- a web-based data collection system for use at the national and sub-national levels and local data quality control;
- coded treatment sites so the system can monitor the situation of each site; and
- additional functions which will assist clinical staff in patient management.

In Thailand, Dr. Peeramond Ningsanond, AIDS Management Fund Expert, National Health Security Office (NHSO), reported that there has been universal access to ART since 2006. In 2007 the NHSO introduced a paperless system to monitor patients throughout the country. The management framework of the program consists of two parts: benefit package and support system. The benefit package includes drugs, laboratory services, counseling and condoms. The support system focuses on personnel training, quality improvement and M&E.

The Thai National AIDS Program consists of four core modules and four auxiliary ones. Data in each module can be linked together by an ID number. This number protects the identity of patients as users can only access data of patients in their site's cohort. The system connects all facilities in a centralized database through a web application running in real-time on the Internet. All data are sent to the NHSO electronically.

Mr. Touch Sokha, Program Management Officer, Khmer HIV/AIDS NGO Alliance (KHANA), discussed KHANA's experience



in Cambodia. KHANA has developed a coordinated response to the HIV pandemic by scaling-up home-based care projects, including education about sexually transmitted infections (STIs), and support and treatment programs for PLHIV, and orphans and vulnerable children (OVC). Among KHANA's priorities is adherence counseling – support to assist patients to continue their treatment regimens. However, this can be challenging because of the stigma and discrimination patients face from being HIV-positive.

The NGO's approach to M&E of ART programs focuses primarily on collecting data from patients and local facilities providing care, with fewer indicators from district and national levels. M&E tools, however, are linked between and across levels of care in an attempt to provide comprehensive patient information.

Representing the Papua New Guinea Ministry of Health (MoH), Ms. Apa Parunga, National ART Data Manager, Department of Health, Disease Control Branch, STI, HIV and AIDS Unit, presented on Papua New Guinea's ART program, which began in 2004 under the WHO "3x5 Initiative". Since the inception of the program, it is estimated that 67% of PLHIV are now on ART. An HIV/ART data collection paper-based tool captures new patients enrolling in the ART program for each reporting month. A cumulative ART data sheet captures all patients on ART.

ART data, however, remain at the national level, rather than at provincial and district levels, which is where a gap in M&E exists. For this reason, the current ART EpiData database will be replaced later this year by a new MS-Access database that houses standardized national M&E forms.

Requisite with the new database is training provincial staff and health workers on its use at national and sub-national levels. Because travel around the country is challenging due to the topography, infrastructure development will also aid M&E. The provision of computers and other essential accessories like Internet access to regional ART sites are also needed to assure the successful implementation of this data collection and use system.

In Malaysia monitoring and evaluation of ART is evolving based on experiences to

date. Dr. Norhizan bin Ismail, Head of Surveillance and M&E Unit, MoH, AIDS/STD Section reported that as yet there are no specific data on the number of injection drug users on ART. Still, use of highly active ART (HAART) has increased four-fold in Malaysia between 2003 to 2008.

In 2003 the Government of Malaysia established the National HIV/AIDS treatment registry to monitor the frequency, distribution and outcomes of HIV/AIDS treatment including ART. A census datasheet replaced the registry in 2007. However, poor response from treatment sites, incomplete data entry forms, time lags in reporting and spiraling costs proved the system's effectiveness had been compromised.

In order to address this, immediate next steps include standardizing ART patient monitoring tools at all ART sites and obtaining consensus on core indicators to measure across the country.

Thailand and Cambodia shared their experiences with using monitoring data to strengthen and improve program planning and implementation. These efforts revolve around using quality measures to assure that PLHIV (and in some cases their families) are receiving appropriate care in a timely manner.

HIVQUAL is a model to strengthen capacity to improve the quality of care for all people living with HIV, regardless of whether or not they are on ART. Dr. Chitlada Uthaiapaiboon, Chief, Care and Treatment Section, CDC/TUC, shared Thailand's experience with HIVQUAL-T, which was modeled on the HIVQUAL Project in the US. HIVQUAL-T offers a simple, specific methodology for measurement of clinical performance based on a sampling strategy using a systematic, standardized process. Implemented in 2002, HIVQUAL-T comprised:

- annual performance measurement using a random sample of eligible HIV cases and computer-generated reports;
- a hospital-based quality improvement process ; and
- a quality improvement infrastructure.

A software program in HIVQUAL-T facilitates performance measurement and reduces the burden of medical record review through simple data-entry screens. Individualized facility-specific data reports on core indicators can be generated immediately following data entry. Data submitted by participating clinics can be aggregated for M&E at provincial and national levels to inform policy and planning. Comprehensive information about the HIVQUAL tool and where it has been implemented is available at: <http://www.cqihiv.com/>.

Dr. Mean Chhi Vun, Director of the National Centre for HIV/AIDS, Dermatology, and STDs (NCHADS), discussed Cambodia's quality improvement initiative, the goal of which is to improve quality of care and treatment services provided to PLHIV in Cambodia. It is doing this in several ways. An electronic database helps manage data which come from continuous visits to ART sites. Support in this area comes from NCHADS.

Successful ART programs must be able to identify ART-eligible PLHIV and to ensure those who begin ART adhere to their regimens. Cambodia's program does this through education and improved communication between all actors – patients, clinical teams, home-based care staff, community-support teams and data management teams. As in many other country settings, follow-up visits to patients are key to adherence.

Participants divided into small groups at the end of the day to review and discuss presentations. On day one the small groups focused on addressing how to strengthen routine reporting of ART programs; participants were asked to brainstorm challenges and come to a consensus around key issues that could be immediately addressed. As a second step, participants were asked to make recommendations on how the core challenges they agreed upon could be overcome. The challenges most often cited on day one fell into the following broad categories:

- Coordination and guidance
  - lack of standardized guidance, particularly for community reporting systems which need to link into (often electronic) systems at district and national levels;

- lack of a comprehensive set of standard, proven effective indicators;
- lack of standard operating procedures and guidance based on national M&E frameworks
- Infrastructure development
  - lack of hardware and software;
  - lack of Internet access and on-going technology support
- Human resources
  - lack of trained staff at all levels;
  - loss of institutional memory and capacity due to high staff turnover

Participants recommended the creation of standardized indicators for all levels of care. Available technologies for data collection, input and collaboration need to be implemented and health personnel taught how and why to use them. This will foster a sense of ownership of data and programs. Alongside this, increasing capacity of health staff at all levels will lessen the effects of job turnover (loss of institutional memory). This will require significant investments in capacity building and on-going mentoring, especially if new electronic systems are to be deployed. While infrastructure is a key challenge it was noted that introduction of computers and software can be done in stages, initially at the national and gradually extending to the sub-national level. It was acknowledged that such efforts require additional resources and countries are encouraged to leverage funding opportunities that arise, particularly those provided through the Global Fund to Fight AIDS, TB and Malaria (GFATM).

### 3. Effective process and outcome evaluations of ART programs

The second day of the workshop looked specifically at the evaluation of ART programs and Thailand and Vietnam shared their experiences in carrying out cohort studies. Also addressed in day two were issues around improving data use; bearing in mind that some outcome/impact evaluation studies may be unfeasible (in the short-term) in some countries, presentations around use highlighted routine indicators that can supplement existing data (such as WHO's early warning indicators), the regional HIV data hub, data triangulation, and the use of data from multiple service points through the strengthening of linkages across

services provided at the clinical and community levels.

Dr. Suwat Chariyalertsak, Deputy Director, Research Institute for Health Sciences, Chiang Mai University, discussed a long-term ART cohort study conducted by Chiang Mai University, which looked at reducing dropout and increasing adherence to HAART in northern Thailand.

Clinical outcomes of ART studies usually involve outcomes such as CD4 count, viral load, drug resistance, ART regimens and mortality. Long-term cohort studies, however, can determine other impacts of ART and HAART to individuals and society, such as changes in the use of health services, socio-economic status, risk behaviors and the effects of stigma and discrimination. Together, the data resulting from such efforts can provide a comprehensive overview of how a program is performing and of its outcomes. Issues such as quality of life can be measured and used to help determine the best interventions and necessary improvements of services.

Dr. Rachel Burdon, Senior Technical Officer, Treatment and Clinical Care, Family Health International (FHI) Vietnam, reported on a longitudinal assessment in Vietnam. Using two PEPFAR-supported clinics in Ho Chi Minh City, this longitudinal assessment allows for the monitoring of outcomes and impact of care, treatment and support interventions, including ART, for PLHIV.

This study is an observational Cohort study of adults ( $\geq 18$  years) on ART followed up at set time points (baseline, 6, 12, 18 and 24 months... onward). At the time of recruitment the number of patients at the clinics was approximately 600 and ART was restricted to those most immunologically suppressed/clinically unwell. The cohort was predominantly male (83%) and poor (more than 50% had an income of 100 USD/month) and 66% admitted to a previous history of injecting drug use. At baseline 81% were at clinical stage 3 or 4 and the median CD4 count was 46 cells/mm<sup>3</sup>. Rates of Hepatitis B and C were 11% and 25% respectively. At baseline IDU differed from non-IDU in that they were more likely to present at clinical stage 4, more likely to have TB and their median CD4 count at baseline was much lower (37 cells/mm<sup>3</sup> in IDU compared to 73 cells/mm<sup>3</sup> in non-IDU). Overall survival

rates were 90% at 12 months and 89% at 24 months for all PLHIV. After 24 months on ART the median CD4 count of IDU was 245 cells/mm<sup>3</sup> and in the non-IDU population this was 268 cells/mm<sup>3</sup>.

In this cohort reported rates of current drug use were very low with only 2 participants reporting current IDU at baseline. This increased to 9 at 6 month follow-up and stabilized to 6 at each of the subsequent follow-up interviews. Only two participants reported having shared syringes or needles. In contrast, rates of 'any drinking' and 'binge' drinking were high with 60% of the cohort reporting any alcohol use and 17% reporting binge drinking at 24 months.

Results showed that self-reported adherence to ART was < 95% in only 0.0% to 1.5% of participants (as assessed by percentage of pills/doses taken). Adherence as assessed by attendance at pharmacy to receive ART was < 95% in only 0.0% to 3.1%. However a qualitative study of this population found that adherence is much poorer than reported by the quantitative data; adherence is generally good in the first six months then decreases over time. This is most likely due to the fact that patients begin to feel better after the first six months and hence may increasingly miss or even stop treatment. This is a challenge in all ART programs and adherence needs to be closely monitored over time in order to reduce the likelihood of developing resistance.

To complement Dr. Burdon's presentation, Dr. Diane Bennett, Senior Epidemiologist, WHO/Geneva, recommended monitoring a feasible set of early warning indicators from all ART sites. An alternative where this may not be feasible is to use a nationally representative subset of sites from where these data can be routinely collected. Such indicators include adherence to ART refill appointments at pharmacies. This indicator is better than CD4 cell response as a surrogate for viral load.

Unlike most other national indicators, early warning indicators are reported on a site-by-site basis. Suggested indicators to include in routine reporting include:

- appropriateness of prescribing practices;

- % lost to follow up during the first 12 months of ART;
- patient retention on first-line ART;
- timely pick up of ARV;
- keeping ART appointments; and
- drug supply continuity.

WHO has developed a comprehensive Excel-based tool that can facilitate tracking of these indicators at the clinical level. It is anticipated that WHO will increasingly advocate for the inclusion of EWIs into routine reporting as a way of supplementing routine data already collected. Such indicators can assist at various levels: at the clinical site for individual patient care, and at other levels to inform policy and drug supply chain management. For more information on EWIs, please see: <http://www.who.int/hiv/topics/drugresistance/indicators/en/index.html>.

Only data that are available will be used. Dr. Michel Carael, Data Hub Manager, UNICEF, presented the HIV data repository which was launched in 2008. The data hub is an online resource hub providing comprehensive and easy-to-access HIV and AIDS data for Asia and the Pacific. It provides standardized, user-friendly data on most-at-risk population groups, women, children and young people, disaggregated by age and sex. Where available, the hub also includes information from the provincial and district levels, and provides updates on national HIV prevalence rates, risk behaviors and national responses.

Data in the hub come only from reliable sources such as government reports and well-known journals. It is for use by NGOs and others working in countries where data are scarce or unavailable. The data hub is accessible at: [www.aidsdatahub.org/](http://www.aidsdatahub.org/).

In some cases, comprehensive data are not available from any single source. This requires data from multiple sources to come together in order to inform program decisions. Dr. Wiwat Peerapatanapokin, Analysis and Advocacy Project (A<sup>2</sup>) Regional Technical Support Team, East West Center, explained that A<sup>2</sup> is a process for getting the 'big picture', making whole the often-fragmented links between behavioral, epidemiological and response data.

There has been a lack of synergy between the data analysis and the advocacy processes: most analysis results are not advocated to the right decision makers; and many advocacy efforts are not linked to evidence.

A<sup>2</sup> uses existing local data to build a common understanding of the HIV pandemic, analyzes the effectiveness of current responses and engages policymakers to translate this information into effective programs. It has been implemented in Bangladesh, China, Thailand and Vietnam. Additional information on the A<sup>2</sup> is available at: <http://www.sharegmr.org/programinfo/a2>.

Because PLHIV often access multiple services at multiple locations, there is a need to strengthen linkages across the various clinical and community-based services accessed by PLHIV. Without this information, it will be a challenge to gain an understanding of how comprehensive and effective a care package is. Dr. Dongbao Yu, Epidemiologist, WHO/Western Pacific Regional Office (WPRO), reported on three interlinked patient monitoring systems developed by WHO. Those systems cover HIV care/ART, maternal and child health/preventing mother-to-child transmission of HIV (MCH/PMTCT) (including malaria prevention during pregnancy) and TB/HIV.

Dr. Yu also discussed how the universal access M&E Framework measures three dimensions of progress – availability, coverage and outcomes/impacts – within the context of four interventions – prevention, testing and counseling, treatment and care, and strengthening health systems.

ART data is essential for monitoring health sector response. Patient monitoring systems are useful for defining data elements for individual clinical care, program management and reporting. Such systems are vital to harmonizing data collection for ART with TB/HIV and PMTCT. This is an evolving process as the indicators and reporting protocols are being constantly improved and harmonized.

Dr. Chawalit Natpratan, Deputy Director, Technical Support, FHI Indonesia, discussed the data needs for linking directly observed therapy (DOT) for TB

and ART programs. Goals of linked systems include establishing a mechanism for collaboration between partners to decrease the burden of TB in PLHIV and the burden of HIV in TB patients. Governments and partners need to establish indicators for action such as screening for TB in HIV care and treatment settings.

Cambodia provides a good example where ART and DOT programs are linked. Both therapies are offered in large hospitals. DOT is included in health centers and there is work at the national level to strengthen provider-initiated HIV testing and counseling linkages from the health centers to the hospitals.

Accurate recording and reporting between health centers and hospitals are vital steps in the process of patient care. In most countries patient intake forms created by WHO are used which have HIV data incorporated. These need to transition to electronic copies with required fields for health staff to enter TB-specific data. Databases need to be created as well, to store information, which will make it more readily available to health professionals.

While linkages across clinical services are important, they are also needed at the community level. Ms. Kimberly Green, Regional Senior Technical Officer, FHI Vietnam, discussed the role of ART in the continuum of care. The continuum of care is a structured network that links essential care, support, treatment and prevention services for PLHIV and families from the home, community and health-service levels. It is often based around a hub of care such as outpatient clinics where PLHIV receive the mainstay of their care, support, treatment and prevention services.

Where continuum of care networks exist, they generally include links to and from clinics offering ART and other facility-based services (e.g. counseling and testing, PMTCT, DOT); and links to and from community services (e.g. community and home-based care teams, PLHA support groups, care for OVC).

Continuum of care networks bear positive, proven benefits:

- better ART adherence and survival rates;
- reduced loss to follow-up;

- improved social support and emotional well-being; and
- reduced costs to PLHIV and the health system.

National guidance on services should be part of a continuum of care model, and indeed this guidance is urgently needed in many countries in Asia. National guidance on monitoring the continuum of care is also needed.

Working groups on day two looked at evaluation and were broken into thematic areas of work: data triangulation, continuum of care, cohort studies, and quality assessments. Each group was tasked with identifying the key questions that could be answered by the various approaches as a way of identifying potential core indicators. Groups looked at data needs from the client, facility, sub-national (i.e., district or provincial) and national levels. While specific questions to be answered by the various approaches that may assist in evaluating an ART program were not fully developed, participants made significant first steps in listing challenges that, if resolved, would strengthen evaluation efforts. Participants cited many of the same issues discussed on the first day among the barriers to effective evaluation of ART programs. Other challenges included ensuring the quality and comprehensiveness of programs within a continuum of care for PLHIV (increasing numbers of patients adhering to their ARV regimens; creating electronic IDs to protect confidentiality of patients; collaboration/ coordination between programs like ART and TB; standardized tools for evaluation; required reporting fields; strengthen routine patient monitoring information systems [PMIS]; community attitude surveys). Finally, continuum of care networks and their linkages to programs focusing on other health issues have shown proven results; these should be strengthened to provide PLHIV a more comprehensive level of care and commensurate increase in quality of life.

#### **4. Conclusion and recommendations**

Meetings such as this one can contribute to sharing of best practices, which can lead to standardization of practices, improved understanding of data quality, formation of guidelines and reaching consensus on core indicators – all with the

goal of helping people lead healthy lives as part of a cohesive continuum of care.

Efforts by donors, national aid agencies and the UN family are underway to harmonise ART indicators, particularly those used for UNGASS and Universal Access (UA) reporting. At the country level progress has been made in national routine monitoring systems and an increasing number of countries have national M&E guidelines and have developed clear data management systems. In some places a standardization process is underway for data collection and reporting. In addition, patient databases have been introduced and some countries such as Vietnam are using a web-based data storage and transfer systems.

Increasingly paper-based systems are being replaced by electronic data collection and storage systems and data sharing processes are being introduced at different levels through national, regional and global databases.

Progress is also being made to finalize guidance for monitoring HIV drug resistance prevention and monitoring. Some countries have piloted EWI data collection and there are some examples of in-depth analysis initiated within ART cohorts for evaluation. For example, some cohorts are reporting on opportunistic infection (OI) incidence, ART adverse effects, adherence and ART failure rates, loss to follow-up, outcomes among most-at-risk populations (MARPs) and quality of life.

Actors in the health arena are increasingly looking at the broader continuum of care – the context in which one lives a healthy life. Provision of ARVs alone can keep people alive, but that does not necessarily mean one's quality of life is improved. Data are showing that continuum of care models are reducing the loss to follow up rates – that is, HIV-positive patients dropping out of care programs – which is a powerful indicator of the importance of holistic care.

Specific recommendations arising from this meeting include:

- The need for a clearly defined standard minimum data set, SOPs and guidance based on the national M&E framework which are based upon national care and treatment

guidelines and include clear targets. Some of this work has already been imitated by organizations such as WHO, but further dissemination and support for implementation at the sub-national level is needed. For the region, it is also important to consider how MARP specific indicators fit into routine data collection.

- Advocacy efforts are needed to strengthen MOH ownership, consensus building, coordination and commitment across all partners.
- On going support and capacity building is essential and must be advocated for and supported in order to assure staff at all levels have the required skills to collect. Report and use program data.
- Need to strengthen continuous quality improvement processes at facility and community levels to improve quality of care, this includes looking into specific issues such as:
  - Data quality improvement
  - Integration of HIV early warning indicators into routine data collection
  - Strengthening linkages and communication between all related HIV health services within a continuum of facility and community care and treatment
  - Strengthening linkages and communication between prevention programs for MARPs and a continuum of prevention, care and treatment
  - Facilitating the involvement of PLHA in all processes of data collection, analysis, interpretation and use
  - Data use for quality improvement can be adapted to existing country resources, this includes basic discussions on issues such as “lost-to-follow up” at facility level and ways to improve retention through to thinking about developing methods for extracting a “package” of process indicators with comprehensive care team level discussions and problem solving identification (lengthy capacity building exercise).

- Rationalization and coordination of evaluation studies to inform specific programmatic questions. This involves:
  - Defining operational research (OR) priorities and creating a national agenda
  - Disseminating and discussing OR results with clinicians, policy makers and partners (could be done through ART symposia, for example)
  - Establishing inventories of local planned, on-going, or completed OR
  - Include self-reported QoL and well-being and measures of risk behavior and socio-economic status which contribute to adherence, loss to follow-up and necessary counseling and other interventions into such efforts
  - Need for qualitative methods to complement existing data, such methods will facilitate answering "why?"
- Increasingly looking at cost effectiveness for advocacy purposes:
  - Prevention vs. treatment, promotion of VCT for early treatment vs. poor treatment outcomes, community support and adherence counseling vs. 2nd line drug costs
- Promoting the triangulation and synthesis of data from surveillance, routine monitoring and OR to inform program planning (consensus meetings)
- Facilitation of resource mobilization for M&E:
  - GFATM: 6-10% overall proposal for M&E

WHO/WPRO indicated that they could assist countries in a variety of ways. These include providing regional M&E guidelines for MARPS and operation guidelines; the documentation of critical elements of Continuous quality improvement (case study from Cambodia), and provision of technical assistance on data triangulation to inform program planning and in setting up OR agenda

In summary, important progress has been made in harmonizing indicators and standardizing data collection but more needs to be done in these areas. This workshop highlighted the different stages of M&E of ART implementation that countries in the region have achieved and

shown how fora such as this workshop can provide great benefits in sharing experiences and information. The outcomes of this workshop can serve as a spring board for more focused workshops addressing specific issues in the future.

For those who would like access to the presentations of the meeting, a CD-ROM is available from Family Health International (FHI). Please send an email to Shanthi Noriega at [snoriega@fhi.org](mailto:snoriega@fhi.org).

## **ANNEX 1. PLANNING PROCESS**

A steering committee was formed with participants from WHO (Drs. Dr. Nicole Seguy and Yu Dongbao), US CDC (Dr. Michelle McConnell), USAID (Dr. Patchara Rumakom, Ms. Nithya Mani, Ms. Thuvan Dinh, and Dr. Cameron Wolf), and FHI (Ms. Cristina Garces, Ms. Shanthi Noriega, Ms. Aranya Gnamwong, Mr. Kritsiam Arayawongchai, and Ms. Krittaporn Termvanich) in order to guide the development process. Several meetings were held with members and relevant colleagues to assure that sessions met country needs and expectations. The steering committee developed and refined the meeting

objectives, agenda, identified speakers and developed all guidance materials for working group sessions.



## Annex 2. Meeting agenda

<b>Day 1: Program monitoring: state of ART and regional experiences</b>		
		<b>Chair:</b> Mr. Geoff Clark <b>Co-chair:</b> Ms. Shanthi Noriega
7:30 – 8:00	<b>Registration</b>	
8:00 – 8:30	<b>Welcome and introductions</b>	MOPH, WHO, USCDC, USAID and FHI
8:30 – 8:45	<b>Overview of the agenda and agreement on objectives</b>	FHI
8:45 – 9:15	<b>WHO’s best practices in ART monitoring and evaluation</b> <ul style="list-style-type: none"> <li>• Presentation on WHO Monitoring and Evaluation strategy and toolkit.</li> </ul>	Dr. Padmini Srikantiah, Medical Officer, WHO/South East Asia Regional Office
9:15 – 9:45	<b>ART M&amp;E data use and linkages at all levels: the U.S. President’s Emergency Plan for AIDS Relief experience</b> <ul style="list-style-type: none"> <li>• Presentation on M&amp;E framework for ART programs and data collection and use at various levels by various decision makers. Discussion on how these data link at the different levels to inform sub national and national progress towards meeting program goals based on USG’s experience during the first phase of PEPFAR.</li> </ul>	Ms. Thuvananh Dinh, M&E Advisor, USAID/Washington
9:45 – 10:00	<b>Coffee break</b>	
10:00 – 11:45	<b>Sharing experiences and lessons learned in ART program monitoring in the region</b> <p>National and community level monitoring needs and approaches. This session will provide an overview of what is being routinely collected and how it is used at the national and sub-national levels. Presentation will discuss challenges and propose ways of overcoming these.</p> <ul style="list-style-type: none"> <li>• Strategy for Patient Management Systems.</li> <li>• Country experiences and lesson learned in ART program monitoring.</li> <li>• Country experiences and lessons learned in ART program monitoring at the national level.</li> <li>• The Vietnam experience in monitoring ART program.</li> </ul>	Dr. Ray Ransom, Strategic Information Chief, PEPFAR Vietnam  Ms. Ma Ye, Deputy Director, Care & Treatment Division, National Center for HIV/AIDS Control and Prevention, CDC (China)  Dr. Do Thi Nhan, Deputy Chief of Care and Treatment, Vietnam Administration of HIV/AIDS Control
11:45 – 12:45	<b>Lunch</b>	

<b>Chair:</b> Dr. Michelle McConnell <b>Co-chair:</b> Dr. Yu Dongbao		
12:45 – 14:30	<p><b>Sharing experiences and lessons learned in ART program monitoring in the region</b></p> <p>National and community ART experience with universal access: the 30-baht scheme.</p> <ul style="list-style-type: none"> <li>• Community level monitoring needs and approaches: an overview on use at the community level and linkages with national data needs.</li> <li>• ART data use in Papua New Guinea.</li> </ul>	<p>Dr. Peeramond Ningsanond, AIDS Management Fund Expert, National Health Security Office (Thailand)</p> <p>Mr. Touch Sokha, Program Management Officer, Khmer HIV/AIDS NGO Alliance (Cambodia)</p> <p>Ms. Apa Parunga, National ART Data Manager, Department of Health, Disease Control Branch, STI, HIV and AIDS Unit (Papua New Guinea)</p>
14:30 – 15:20	<p><b>Quality improvement models</b></p> <p>Presentations on using monitoring data to strengthen and improve program planning and implementation.</p> <ul style="list-style-type: none"> <li>• HIVQUAL-T.</li> <li>• Using ART data for quality improvement in ART programs.</li> </ul>	<p>Dr. Chitlada Uthaiapaiboon, Chief of Care and Treatment Section, Thailand MOH-USCDC Collaboration (Thailand)</p> <p>Dr. Mean Chhi Vun, Director, National Center for HIV/AIDS, Dermatology and STI (Cambodia)</p>
15:20 – 15:35	<b>Coffee break</b>	
15:35 – 17:00	<p><b>Small group work</b></p> <ul style="list-style-type: none"> <li>• Discussion, reporting back and consensus building on challenges in routine monitoring and data use of ART programs and ideas for overcoming these. Begin discussion on how monitoring links to evaluation activities and other data sources.</li> </ul>	All
17:00 – 17:30	<p><b>Day summary:</b></p> <ul style="list-style-type: none"> <li>• Cross cutting lessons learned from ART monitoring.</li> <li>• Summary of consensus on recommendations for addressing ART program monitoring and data use challenges.</li> </ul>	Chair
18:00 – 21:00	<b>Welcome reception</b>	
		Poolside on 7 <sup>th</sup> floor, Conrad Hotel

<b>Day 2: Effective process and outcome evaluations of ART programs</b>		
<b>Chair:</b> TBD <b>Co-chair:</b> Dr. Cameron Wolf		
8:30 – 9:20	<p><b>Cohort studies in the region</b> Country presentations on cohort studies among ART patients. Looking at how these can be used to assess the outcome and impact on morbidity, mortality and quality of life.</p> <ul style="list-style-type: none"> <li>Enhanced Evaluation of Patients on ART at 2 HCMC clinics.</li> </ul>	Dr. Rachel Burdon, Care & Treatment Senior Technical Officer, FHI/Vietnam
9:20 – 9:45	<p><b>ART monitoring among most at-risk populations</b></p> <ul style="list-style-type: none"> <li>Experiences in ART monitoring for injection drug users.</li> </ul>	Dr. Ismail Norhizan, Senior Principal Assistant Director, AIDS/STD Section, Ministry of Health (Malaysia)
9:45 – 10:00	<b>Coffee break</b>	
10:00 – 10:40	<p><b>Early warning indicators</b></p> <ul style="list-style-type: none"> <li>Introducing indicators to inform decisions in a timely manner: WHO's work.</li> </ul>	Dr. Diane Bennett, HIV Drug Resistance WHO/HQ
10:40 – 11:00	<p><b>Improving access to data within the region</b></p> <ul style="list-style-type: none"> <li>Overview of HIV Data Hub: contents and data gaps.</li> </ul>	Dr. Michel Carael, Data Hub Manager, HIV and AIDS Data Hub Office, UNICEF (Thailand)
11:00 – 11:30	<p><b>Bringing it all together: the Analysis &amp; Advocacy Project (A<sup>2</sup>) experience in using data from multiple sources to understand and improve ART programs</b></p> <ul style="list-style-type: none"> <li>Presentation on using data from multiple sources to inform ART programming. Focus will also address these issues within the context of MARP programming in the region.</li> </ul>	Dr. Wiwat Peerapatanapokin, A <sup>2</sup> Regional Support Team, East West Center
11:45 – 12:45	<b>Lunch</b>	
<b>Chair:</b> Dr. Nicole Seguy <b>Co-chair:</b> Dr. Ray Ransom		
12:45 – 14:00	<b>ART program and data linkages into other services</b>	Dr. Dongbao Yu, Epidemiologist, WHO/WPRO

	<ul style="list-style-type: none"> <li>Guidelines for inter-linkages between ART, PMTCT and TB patient monitoring system: what does it mean for M&amp;E?</li> <li>Linking TB and ART programs: assuring data needs for effective patient management.</li> <li>Linkages in ART and continuum of care networks: perspectives and challenges for M&amp;E.</li> </ul>	<p>Dr. Chawalit Natpratan, Deputy Director, Technical Support, FHI/Indonesia</p> <p>Kimberly Green, Regional Senior Technical Officer, FHI/APRO</p>
14:00 – 16:30	<p><b>Small group work:</b> Producing, presenting and reaching consensus on recommendations for core data needs and strategies for improving data use to address the following questions:</p> <ul style="list-style-type: none"> <li>How do we know a program is succeeding?</li> <li>What are different strategies being used to encourage program use at various levels?</li> <li>What are the benefits and challenges of each strategy?</li> </ul> <p>Groups will be broken down into thematic areas.</p> <p><b>Coffee will be served during the group work</b></p>	All
16:30 – 17:30	<p><b>Meeting summary:</b></p> <ul style="list-style-type: none"> <li>Cross cutting lessons learned from ART monitoring (from day 1).</li> <li>Cross cutting lessons learned from ART evaluation activities and special studies.</li> <li>Summary of consensus on recommendations for strengthening ART program evaluations and improving data use.</li> <li>Discussion and consensus on next steps.</li> </ul>	Chair
17:30 – 18:00	<b>Closing</b>	MOPH, WHO, USCDC, USAID and FHI

### Annex 3. List of presenters and participants

\* Denotes members of organizing Secretariat

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