



**MeSH Consortium**

Measurement & Surveillance  
of HIV Epidemics

# HIV Case Based Surveillance & Patient Tracking Systems

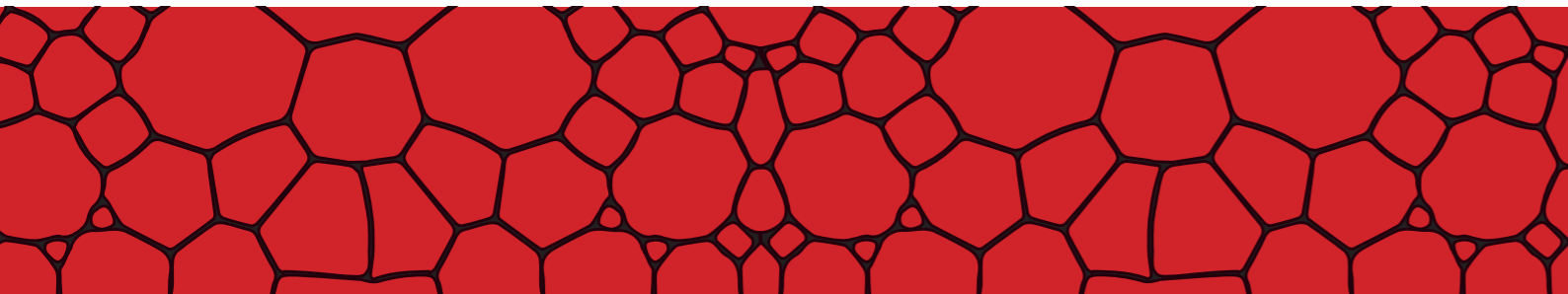
Results from Four Situational  
Assessments in High Burden,  
Low-Resourced Countries

Conducted by the Measurement and Surveillance of HIV Epidemics (MeSH) Consortium

[www.mesh-consortium.org.uk](http://www.mesh-consortium.org.uk)

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## EXECUTIVE SUMMARY

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HIV case-based surveillance (CBS) refers to an approach to surveillance that involves the reporting of individual-level information from each person diagnosed with HIV to the public health agency responsible for monitoring and controlling the HIV epidemic. 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, these events are collected and maintained longitudinally.

To facilitate the development of CBS in resource-limited countries the Measurement and Surveillance of HIV Epidemics (MeSH) Consortium conducted situational assessments in Tanzania, South Africa, Kenya and Haiti from August 2015 through April 2016. A standardized protocol and data collection tool were utilized to ensure a uniform approach to the situational assessments that took into consideration the context for each country in relation to CBS. The assessment included: 1) a desk review of relevant materials on HIV surveillance, 2) interviews with stakeholders, and 3) site visits. Prior to each assessment, the MeSH assessment team met with government and other stakeholders from the countries to confirm the specific focus of each assessment, adapt the protocol and tool, develop a list of documents to review, and identify stakeholders for interviews and sites for visits. Findings from the assessments were categorized as strengths, weaknesses, opportunities, and threats (SWOT). These findings were summarized and presented at a debriefing session with stakeholders followed by discussion of opportunities and recommendations.

Countries were selected to include variation on the stage of readiness for CBS. Tanzania had expressed a strong interest in development of CBS. South Africa has a multi-facility-based integrated patient monitoring system and a national electronic repository of all CD4 and viral load tests that may serve as a model for capturing data from electronic systems for use in CBS. Kenya is in the early stages of CBS implementation and Haiti has a moderately well-established CBS system that was built off of existing electronic patient monitoring systems.

Detailed summaries were developed as a case study for each country and findings were then generalized. The assessments revealed substantial interest in, and support for CBS as a way to more effectively monitor the epidemic with the recognition that CBS requires additional resource. All of the countries assessed conduct routine HIV programme monitoring that collects information on the number of persons tested for HIV, number of new HIV diagnoses and number of persons accessing HIV care and treatment services. At the facilities, individual level data are collected and entered into registers and individual patient records. Current reporting of these data to the Ministry of Health is done in aggregate. Review of systems and discussions with stakeholders revealed significant problems with data quality. Unstable power sources and internet access was a problem in many regions which adversely impacts all electronic and networked systems.

The findings from the situational analyses support the development of CBS systems to systematically capture routinely collected health data to describe and monitor the epidemic for program planning and evaluation and ultimately disease control. Although it may be possible to adapt some of the current program and patient monitoring systems to function effectively for CBS, there was wide variation in the systems examined and few that were open-source. The recommendations provide guidance to countries on the development of CBS. The approach to develop CBS should match the capacity and resources of the country and leverage existing systems. Often policies and procedures need to be updated for implementation of CBS to ensure standard reporting and data security and confidentiality. Data collection and use should be specified to evaluate and enhance quality of data. The MeSH protocol and tool is provided as a resource to be utilized by countries to assess the feasibility of implementing CBS or to evaluate and enhance an existing CBS system.

## INTRODUCTION

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Universal health coverage is one of the key health targets of the Sustainable Development Goals (1). The draft WHO Global Health Sector Strategy on HIV 2016-2021 maps the way forward towards universal health coverage for HIV (2). The draft strategy makes clear that to achieve universal coverage for HIV it is essential that HIV services are accurately targeted and effective. To measure the precision and impact of HIV services, WHO released consolidated guidelines in 2015 recommending the use of ten global indicators to collect information along the cascade of HIV care and treatment (3). Six of these indicators use data that originate from patient diagnosis, testing and medical records.

The Sustainable Development Goals (SDG 17.18), the draft Global Health Sector Strategy, and the draft WHO Global Health Sector Strategy recommend developing a comprehensive strategic information system to provide high-quality, timely and reliable data disaggregated by population characteristics across the different levels of a health care system (1-3). HIV case-based surveillance (CBS) is such a system and refers to an approach to surveillance that involves the reporting of individual-level information from each person diagnosed with HIV to the public health agency responsible for monitoring and controlling the HIV epidemic. CBS is also called case notification and is conducted for many infectious diseases in order to control and prevent disease.

In CBS, information from individual cases (i.e. persons) is maintained as disaggregate data in a database at the national and often also sub-national level. As information along the course of disease from diagnosis to entry into care, initiation of ART, viral suppression, and death are needed to measure progress towards epidemic control, data on each of these events is collected and maintained longitudinally. This is a distinctive characteristic of CBS systems and distinguishes it from aggregate reporting. In order to accurately add new information pertaining to an existing case record, and to also distinguish duplicate case reports (i.e. two or more reports for the same individual), a CBS system must be designed to permit matching to identify information relating to the same individual from information concerning a new, previously unreported individual.

A well-functioning HIV CBS system can provide timely longitudinal population-based data collected from medical records to the local, regional, and national levels. These data can be used to determine and describe the geographic, demographic and risk factor distributions of HIV. This in turn will improve the quality of information provided to national AIDS program coordinators and other relevant partners for program planning and evaluation. Interest for developing and implementing CBS systems that takes into consideration current routine patient information systems and emerging technologies is growing among sub-Saharan African countries and other resource limited countries.

To facilitate the development of CBS there is a need to evaluate existing data collection systems to identify what works and understand how to leverage these for CBS. It has been suggested that once the limitations of current systems are identified it becomes easier to elaborate a national plan for surveillance, and that one of the best approaches to reaching a consensus for a sound surveillance plan is to discuss the country's needs with the main partners (4).

To identify systems that are context appropriate, feasible, scalable, and sustainable to implement CBS the Measurement and Surveillance of HIV Epidemics (MeSH) consortium conducted situational assessments in Tanzania, South Africa, Kenya and Haiti from August 2015 through April 2016. With funding from the Bill & Melinda Gates Foundation, the assessments were conducted in collaboration with WHO, the Centers for Disease Control and Prevention (CDC), Joint United Nations Programme on HIV/AIDS (UNAIDS), the Global Fund to Fight AIDS, Tuberculosis, and Malaria, ministries of health (MOH) and other within country stakeholders. The main objective of the assessments was to identify the strengths, weaknesses, opportunities and threats to CBS.

## METHODS

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A protocol and data collection tool (<http://mesh.lshtm.ac.uk/files/2015/10/CBS-Protocol-SWOT-Tool-2016.pdf>) were developed to ensure a standardized approach to situational assessments that took into consideration the context and focus for each country in relation to CBS. The assessment included three parts: 1) a desk review of relevant materials on HIV surveillance for the country, 2) interviews with stakeholders, and 3) site visits.

The desk review examined standard registers and medical records that capture individual level data, surveillance and program monitoring reporting requirements and regulations, death certificates, strategic plans, reports and system evaluations. Interviews were conducted with persons knowledgeable about HIV strategic information, involved with other infectious disease surveillance activities, and working in HIV testing and care and treatment programs, vital registration, and laboratories. Site visits were conducted to understand human resource capacity, availability of data relevant to CBS, electronic systems, data flow, storage, transfer, quality, standards, and laboratory systems.

The protocol was intentionally designed to be a comprehensive tool that could be adapted for the particular focus of the assessment within each country. For example, in countries with established CBS systems the tool was used to evaluate the system whereas, in countries planning for CBS the tool was used to conduct a situational analysis to inform the development and implementation of CBS. The following standardized tools, included in the protocol, were developed for the assessment: Document Review Checklist, Document Request Checklist, Interview Guide, Site Visit Checklist, and Debrief Form.

Countries were selected to include variation based on their stage of readiness for CBS. Tanzania had expressed a strong interest in developing CBS. South Africa was included as it has a multi-facility-based integrated electronic patient monitoring system with interoperability and a national repository of all CD4 and viral load tests that may serve as a model for capturing data from electronic systems for use in CBS. Kenya is in the early stages of CBS implementation and Haiti has a moderately well-established CBS system that was built upon existing electronic patient monitoring systems.

Prior to each assessment, the MeSH assessment teams (MeSH members and in-country participants) met with government and other stakeholders from the countries to confirm the specific focus of each assessment, adapt the protocol and tool, develop a list of documents to review, and identify stakeholders for interviews and sites for visit. Findings from the assessments were categorized as strengths, weaknesses, opportunities, and threats (SWOT). These findings were summarized and presented at a debriefing session to stakeholders followed by discussion of opportunities and recommendations. More detailed summaries were developed as case studies.



## UNITED REPUBLIC OF TANZANIA

### Background

In Tanzania data are collected for routine programme monitoring activities and are reported in aggregate to a district focal person who is responsible for entering the data into the Health Management Information System (HMIS) through the District Health Information System (DHIS-2). At present, DHIS-2 contains aggregate data from every health facility offering HIV services which is available to district, regional and national level planners.

Various programmes and projects within the Ministry of Health and Social Welfare (MoHSW) also have their own reporting mechanisms, including the prevention of mother-to-child transmission (PMTCT) and the care and treatment clinic (CTC) programmes within the HIV sector. Many facilities report individual level data to the national CTC system through the CTC2 database. The CTC2 database collects the facility-specific CTC2 patient number but not names or a national identity number. Because they are line-listed there is substantially greater flexibility in data analysis than in the aggregate data systems and as such, the CTC2 data are analysed and used by the National AIDS Control Programme, (NACP) and stakeholders for programme planning.

Both the DHIS-2 and CTC data have limitations. For example, there is a high probability that duplicate records are present in the CTC2 and DHIS-2 databases, thereby preventing an accurate assessment of the number of diagnosed persons or of individual care pathways.

### Scope of the assessment

The goal of this assessment was to evaluate the feasibility and acceptability of and recommendations for the next steps towards developing a secure, high-quality and timely HIV CBS system. Topics assessed included degree of interest in CBS from stakeholders, the need for changes in policies and additional resources (financial and human), data sources and quality of data, and the presence of unique identifiers that could be used to link, and where relevant de-duplicate, records pertaining to the same individual.

The assessment began with a meeting of stakeholders to review and adapt the SWOT data collection tool to meet the specific country needs, and to provide guidance on the number of facilities for site visits based on the systems currently in use. To assess needs in both urban and rural areas with substantial disease burden, the SWOT exercise was focused in two distinct regions in Tanzania, Dar-es-Salaam and Mwanza.

Interviews were conducted at several levels. Nationally, interviews were conducted with individuals delivering health services (primarily HIV), monitoring infectious diseases (including tuberculosis, sexually transmitted infections and other diseases), and supporting interventions and services. In addition, Tanzania-based personnel from international organisations (WHO, UNAIDS, CDC), and local implementing partners working with the MoHSW, were interviewed. At the sub-national level, regional and district health officers were interviewed, including the Regional Medical Officer, District Medical Officer, Regional AIDS Control Coordinator, District AIDS Control Coordinator, Regional Tuberculosis and Leprosy Control officer, and District Infectious Disease Surveillance personnel. Site visits were made to select health facilities and laboratories providing HIV services in the Dar-es-Salaam and Mwanza regions. Sites were selected based on the facility ownership (i.e. private and government) and size (i.e. regional hospital, health centre, and dispensary). Twenty-three interviews were conducted with stakeholders at the national, regional, district, and facility levels and nine facilities (tertiary, secondary and primary sites) were visited.

### Findings

The main findings from the interviews and site visits are summarized in Table 1.

Few of those interviewed were familiar with CBS. However, most were aware of other HIV reporting systems, including CTC2. Once the limitations of aggregate data and the benefits of CBS were explained, there was consistent support for CBS. Persons interviewed reported that selected infectious diseases are reported on a case-basis. Confidentiality and security of monitoring and evaluation data were addressed by excluding personally identifying variables beyond the facilities.

Review of registers and medical records indicated that the variables required for CBS to produce key indicators along the care cascade are available. Patient-level information including names and dates of birth are available in patient medical records. CTC and the Prevention of Mother-to-Child Transmission (PMTCT) data collection tools are standardized but referral and transfer forms are not. The CTC2 database includes data from selected care and treatment facilities but not from HIV testing sites. It is worth noting that most service-level systems are paper-based.

There is interest in adapting current data systems for use in CBS but these systems have limitations. The CTC2 system is line-listed and contains all of the variables needed for CBS but only collects data once a patient has entered care. Data from the CTC2 system are sent to the national level but without the patient name or other personal identifiers. The CTC2 system starts at entry into care, therefore losing anyone with an HIV diagnosis who does not obtain care. In reporting facilities the CTC2 paper forms are completed, but not all facilities report to the CTC2 database (at the time of the assessment approximately 50% of sites providing HIV care and treatment reported to the CTC2 database). The DHIS2 database includes HIV diagnosis as well as PMTCT data but only collects aggregate data and does not include all of the data required for CBS. Although it appears that there is adequate staffing to meet current reporting requirements (e.g. into DHIS2 and CTC2), CBS will likely need additional human resources as currently data quality assurance is not being enforced (including reviews of completeness and accuracy of data), and there is limited use of data beyond mandated program reporting.

Various information technology issues were observed: there are limitations in infrastructure, connectivity, and interoperability (for example CTC2 and DHIS2 are not interoperable, although plans to extract data from CTC2 into the DHIS2 reports are well advanced), and vital statistics data cannot be linked with current HIV systems. There is also a shortage in the human resource capacity for information technology.

### Unique identifiers

Unique identifiers that would work for CBS do not currently exist in HIV testing and counselling (HTC) and care programs. The CTC2 number appears to be unique within each facility but not across facilities. As such, record matching and de-duplication beyond the facility is not possible. Names and dates are collected, although not comprehensively. Currently there is no national identify number. However, there have been discussions focused on exploring the possibility of enhancing the CTC system to maintain identifiers at the national level.

### Policy

National policies that are applicable across all programs regarding case-based disease reporting, security, and confidentiality of paper and electronic records do not exist. There are no data release policies.

**Table 1.** Summary findings from SWOT analysis for key areas of interest in Tanzania.

	STRENGTHS	WEAKNESSES
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- The current system is a strong foundation for CBS.</li> <li>- Systems for collecting data from all points of the cascade exist.</li> <li>- Procedure for reporting aggregate data from clinics to sub-national / national level can be built on.</li> <li>- Understanding of the need for a unique identifier is present throughout HIV program monitoring system.</li> </ul>	<ul style="list-style-type: none"> <li>- Over reliance on paper-based registers and aggregate reporting.</li> <li>- The unique identifier for patients (facility CTC number) is inadequate for CBS.</li> <li>- Full potential of data are rarely utilized at all levels.</li> <li>- The interconnectivity between the patient records and DHIS reporting system needs to be developed.</li> <li>- Data quality needs to be addressed.</li> </ul>
<b>Political and organisational support, governance, and human resources</b>	<ul style="list-style-type: none"> <li>- Strong support from PEPFAR partners for clinics, regions and MoHSW.</li> <li>- Committed, hard-working health workers in many clinics.</li> </ul>	<ul style="list-style-type: none"> <li>- Separate policies within different departments and programmes (e.g. key populations).</li> <li>- Lack of training and resources.</li> <li>- Reporting / data staff do not have sufficient time available.</li> <li>- Partner activities not harmonised.</li> <li>- Financial sustainability of comprehensive, high-quality, timely reporting system</li> </ul>
<b>HIV care and treatment cascade; data collection and reporting</b>	<ul style="list-style-type: none"> <li>- Data collection in CTC and PMTCT is comprehensive and standardised.</li> <li>- Referral and transfer process between clinics exists (not operated universally and documentation is weak).</li> <li>- Data are collected in health facilities (paper record) and sometimes used for clinical management of patients.</li> <li>- Data are reported to district and national level (indicators).</li> <li>- Tracing and tracking missed appointments exists (not operated universally).</li> <li>- Unique identifier for CTC (useful within but not necessarily between clinics).</li> <li>- Feasible to add name to HIV testing and counselling (HTC) register.</li> </ul>	<ul style="list-style-type: none"> <li>- Subsequent testing among persons diagnosed with HIV.</li> <li>- High attrition from HTC to CTC.</li> <li>- CTC electronic data is not a surveillance tool, more a basic electronic medical record.</li> <li>- Electronic data seen as an "extra" task – not much utilisation within clinics.</li> <li>- UIs not based on master facility list, and names not consistently available for de-duplication.</li> <li>- Guidelines and standard operating procedures are not widely understood / used.</li> <li>- Data quality assessment infrequent; most do not check quality regularly.</li> <li>- Over estimation of lost to follow-up due to lack of data linkage between care facilities.</li> <li>- Variable support from partners and not available to all clinics.</li> </ul>
<b>Reporting systems for HIV and other notifiable diseases</b>	<ul style="list-style-type: none"> <li>- DHIS-2 is universal reporting mechanism in Tanzania; monthly reports of aggregate data.</li> <li>- Quarterly report of aggregate CTC data.</li> <li>- District reporting meetings provide means for identifying and sharing best practice and for networking.</li> <li>- Periodic analysis of CTC data by the National AIDS Control Program.</li> <li>- Programming at national level exists and is trusted by MoHSW.</li> </ul>	<ul style="list-style-type: none"> <li>- DHIS-2, CTC and the Presidents Emergency Plan for AIDS Relief (PEPFAR) all have separate reporting requirements and all relate to aggregate data.</li> <li>- Potential duplicate counting of HIV-diagnosed people due to repeat testing and lack of de-duplication.</li> <li>- Potential underestimation of HIV diagnoses due to incomplete reporting.</li> <li>- Data printed out at clinic and re-entered at districts into DHIS-2.</li> <li>- Private clinics do not report fully.</li> <li>- Little use of available data.</li> </ul>
<b>Linking clinical data with laboratory, pharmacy and other data</b>	<ul style="list-style-type: none"> <li>- Lab systems exist with CD4 in many clinics and viral load in regional labs.</li> <li>- Most labs have electronic systems, (not linked to other systems).</li> <li>- Many pharmacies have electronic system for drug ordering (not linked to CTC).</li> </ul>	<ul style="list-style-type: none"> <li>- No links between clinic and lab data.</li> <li>- No links between clinic and pharmacy data.</li> <li>- Rapid tests used for HTC are not reported to lab.</li> <li>- Lack of resources to identify deaths that occur in the community.</li> </ul>

	OPPORTUNITIES	THREATS
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Define a unique identifier which would link HIV services and facilitate de-duplication.</li> <li>- Enhance data quality systems and supervision, including the use of the data.</li> <li>- Build a career structure for those working with the data to improve understanding of the data at the various levels.</li> </ul>	<ul style="list-style-type: none"> <li>- If CBS requires additional data collection, it will put pressure on the resources and staff time, which may undermine clinical care and/or data quality.</li> <li>- Data quality and utilization needs to be addressed</li> </ul>
<b>Political and organisational support, governance, and human resources</b>	<ul style="list-style-type: none"> <li>- Integrate reporting within MoHSW, including tuberculosis and infectious disease surveillance as part of an improved reporting system.</li> <li>- Commitment from partners and donors to support CBS.</li> <li>- Build a career structure for those working with data to improve understanding at all levels.</li> </ul>	<ul style="list-style-type: none"> <li>- Needs of donors for particular reports / data may undermine single reporting mechanism.</li> <li>- Over reliance on partners may limit sustainability.</li> <li>- New technology often seen as a threat to existing jobs.</li> </ul>
<b>HIV care and treatment cascade; data collection and reporting</b>	<ul style="list-style-type: none"> <li>- Increase links between clinics and programmes and strengthen links between HTC, PMTCT and CTC bringing in communities / key populations.</li> <li>- Enhance referral systems.</li> <li>- Update CTC forms to include CD4 counts and viral load results.</li> <li>- Develop and universally introduce UI at time of HIV diagnosis.</li> <li>- Tanzanian national identifier and the master facility list being developed and would enable better de-duplication if collected as part of patient care at all health facilities.</li> </ul>	<ul style="list-style-type: none"> <li>- Multiple testing points of entry. Need to ensure comprehensive reporting including community and key populations.</li> <li>- CTC does not focus on monitoring patient care or facilitating linkage between sites.</li> <li>- Data quality assessment systems are not in place at all levels.</li> <li>- Universally applied quality management procedures, including quality control in laboratories, not in place.</li> <li>- Lost referral and transfer forms inhibit patient access to services.</li> </ul>
<b>Reporting systems for HIV and other notifiable diseases</b>	<ul style="list-style-type: none"> <li>- Tanzania government create a single reporting system.</li> <li>- DHIS-2 Tracker (a feature within DHIS2) can accommodate patient level reporting.</li> <li>- Since much data exists in CTC2, develop a system to automatically extract and report on clinic-level data.</li> </ul>	<ul style="list-style-type: none"> <li>- De-duplication procedures needed.</li> <li>- Currently unable to extract variables from clinic and laboratory databases.</li> <li>- Lack of resources and staff at paper-based clinics and private health facilities for reporting.</li> </ul>
<b>Linking clinical data with laboratory, pharmacy and other data</b>	<ul style="list-style-type: none"> <li>- Link lab data and pharmacy data from clinics through a unique identifier.</li> <li>- Enhance vital registration to link deaths to clinical records.</li> </ul>	<ul style="list-style-type: none"> <li>- Staff shortages and lack of training will compromise completeness and quality of data.</li> </ul>

### Interpretation of findings

Based on the assessment, it was determined that HIV case-based surveillance is possible for Tanzania and there is a high degree of acceptability from stakeholders and implementing partners. Basic systems are in place to build a strong CBS system in the country. Although not contained in a single national database currently, the data regarding diagnosis, entry into care, CD4 results, and ART initiation are available. Tanzania has not yet adopted routine viral load monitoring for patients on ART. Gaps in data for CBS are mainly in obtaining unique identifiers; although data quality was also found to be a significant issue.

There is staffing at the national, sub-national and facility level specific to HIV monitoring and evaluation and surveillance. In implementing CBS, it needs to be determined what role these existing staff would have and/or what new cadre of personnel would be required. It will be essential that staff with some capacity to manage and report out data be included within the organizational structure of facilities. There is a need for additional trained staff that can effectively manage and analyse surveillance data.

It was determined that there are gaps in policies/laws regarding HIV reporting and data confidentiality. These gaps will need to be addressed to facilitate successful implementation of CBS.

### Recommendations

- For successful CBS implementation, policies in the following areas are required: HIV reporting, patient confidentiality, data security, data release, and vital registration (reporting of deaths).
- Specific areas for CBS must be addressed:
  - Explore options for unique identifiers that can effectively de-duplicate records; this could include enhancing the CTC system to maintain identifiers at the national level; a pilot is recommended to test various options for unique identifiers
  - Determine sentinel events to include in CBS and identify methods to obtain these
  - Develop data quality assurance including internal checks
  - Determine role of facilities, district and regional level staff in CBS
  - Identify technology systems to develop or enhance for CBS
  - Determine frequency of reporting and reportable variables
  - Develop approach for implementation (e.g. staggered or national, with or without pilot testing)
- Relevant Technical Working Group to coordinate information technology activities so systems are not being created in parallel and to ensure that these systems facilitate CBS.
- Implement routine systems for systematic data validation and quality assurance that include internal checks.
- Streamline paper-based data collection tools and reporting processes.
- Develop methods to ensure completeness of death records.
- Enhance efforts to improve and maintain quality of laboratory techniques including improved and utilized standard operating procedures.
- Encourage a culture of data use through training ministry staff in data analysis, interpretation, and exploration of outcomes and endpoints.

## REPUBLIC OF SOUTH AFRICA

### Background

To create a comprehensive national health information system, the South African National Department of Health (NDOH) is required, under the National Health Act, to facilitate and coordinate the establishment, implementation and maintenance of health information systems at the national, provincial and local levels. HIV care and treatment is included in the national system whereas HIV surveillance is part of the HIV monitoring and evaluation system.

South Africa has implemented a national, longitudinal patient monitoring system for persons on ART – Three Interlinked Electronic Registers (TIER.Net). Prior to national implementation of TIER.Net there were over 40 HIV program based data systems in South Africa, each of which collect different variables. TIER.Net includes three options for patient management systems; a paper-based system (Tier 1), an electronic version of the paper-based system (Tier 2), and a fully networked electronic medical record (EMR) system (Tier 3). This approach allows facilities to choose the tier that meets their resources, with outputs from all three tiers being aligned so that they can be consolidated into a single reporting system. To date, the middle tier has been widely deployed, with a limited number of sites using the other tiers. TIER.Net uses standard clinical records, paper registers, software, and data exchange standards for moving data between systems. Individual-level data are collected and reported nationally including patient names and other identifiers. Although TIER.Net has modules for HIV testing and pre-ART care, neither of these is currently used.

South Africa also has a national laboratory data warehouse that collects all CD4 and viral load tests from person receiving HIV care. The National Health Laboratory System (NHLS) provides laboratory and related public health services to over 80% of the population, and nearly all public sector services, through a national network of laboratories. CD4 and viral load testing is standard for ART patients in South Africa and is performed at centralized laboratories all using the same national laboratory information system (LIS), which facilitates electronic reporting. The LIS captures individual level data, including identifiers provided by the facilities ordering the tests. A scannable barcode is provided for each unique patient.

There are a number of distinct personal identifiers in use in South Africa. Some of these are HIV-specific, while others are for general use.

In summary, in South Africa patient-level, longitudinal data are collected in a single patient monitoring system, regional laboratories conduct CD4 and viral load test results, and systems include personally identifying data. These may serve as a model for a national case surveillance system.

### Scope of the assessment

The goal of this assessment was to assess how the TIER.Net system, the NHLS, and patient identifiers could be used for CBS. The Western Cape Province was selected as a region where the TIER.Net system and identifiers could be explored. The NHLS is based in Johannesburg.

Seven interviews were conducted with stakeholders at the national and regional level, and the NHLS data warehouse. Projects were examined in order to understand the different methods used to uniquely identify patients (Jembi Health Systems, Provincial data centre, HE2RO), and two facilities and one regional laboratory were visited.



## Findings

The main findings from the interviews and site visits are summarized in Table 2.

### TIER.Net

The TIER.Net system has been successfully implemented. However, most facilities lack reliable internet and infrastructure required for the Tier 3 system. Site visits are performed as part of monitoring and evaluation standard operating procedures to ensure data quality. Available TIER.Net modules for HIV diagnosis and pre-ART are currently not used, although it seems feasible to implement these given adequate resources. TIER.Net can be used to estimate the number of patients on ART and, with the addition of the HTC and pre-ART modules, could be used for CBS.

### NHLS

The NHLS includes scannable barcodes for each test that uniquely identify the patients and assists with data quality. The NHLS data warehouse has developed an algorithm utilizing the various identifiers to match and de-duplicate tests. The NHLS data warehouse currently uses the data to estimate care cascade measures by taking the number of people with a CD4 test as a proxy for the number entering into care, the number of people with a viral load test as a proxy for the number on ART, and the result of the viral load test to indicate the number virally suppressed.

### Unique identifiers

A number of systems produce personal identity numbers that may be useful in de-duplicating patient records (within all levels of TIER.Net and at the NHLS) if collection of these identifiers is routinely conducted in care and laboratory settings.

- *National civil identifier* – the national civil identifier is available to all citizens and is currently utilized as an identifier in health systems. Approximately 10% of population are non-citizens and do not have this identifier, therefore health systems rely on name and date of birth to uniquely identify individuals.
- *NDOH health patient registration system (HPRS)* – health care is available to everyone; therefore a health patient registration system is being developed to provide everyone with a health identity number in support of the eHealth Normative Standards Framework (eHNSF) which is promoting system interoperability. The civil identity number will remain a valuable secondary unique identifier for linking patient data and preventing duplicate registrations.
- *Western Cape Province patient master index (PMI)* – a centralised hospital information system, implemented in 2000, which brought all 52 hospitals and 400 clinics in the Province into a single system. Patients in the public sector in the Western Cape have the same folder number (i.e. the PMI number) in all facilities.
- *Jembi Health System patient master index* – Jembi conducts software development, specialising in system interoperability. Data from systems are merged and matched through a PMI. Their PMI is currently being piloted in select facilities in the Western Cape Province. The majority of the software is open source.
- *Western Cape Provincial Health Data Centre* – merges data from multiple patient-level sources in the Province; the data merge is in the implementation phase, developing a de-duplication algorithm based on a complex probability match in order to track patients across services.
- *NHLS Central Data Warehouse (CDW)* – developed an algorithm for de-duplication of all laboratory data covering an estimated 300 million tests nationally.
- *Research linked to the NHLS CDW* – In partnership with the NHLS, a research organisation (HE2RO) further adapted the above de-duplication approach (based on the Jaro-Winkler string distance method) in order to facilitate cascade analyses by geographic reporting units. The National Institute for Communicable Diseases and the Centre for HIV & Sexually Transmitted Infections have estimated cascade parameters based on the consolidated, de-duplicated CDW viral load and CD4 data.

## Policy

National policies exist that are applicable across all programs regarding case-based disease reporting. The South African government's selection of a single patient monitoring system and ensuring that this system was functional for all types of facilities is significant. Policies regarding case reporting were not fully explored but it was suggested that the government would not approve mandating HIV case reporting.

### Interpretation of findings

Based on the assessment, it was determined that multiple data systems exist in South Africa which could be utilised for HIV CBS.

Both TIER.Net and the NHLS collect patient-level data at a scale which is reflective of the national treatment program. In relation to post-ART registration, these systems could be seen as best practice for CBS. A limitation of these systems is that neither currently includes diagnosis / pre-ART data. The three tier system provides an approach to meet the needs and capacity of a facility. Crucially, this approach avoids pushing the adoption of an EMR/new technology in all sites irrespective of capacity.

Laboratory reporting of HIV surveillance data is feasible given that regional laboratories conduct all of the CD4 and viral load tests which are then entered into an electronic system and are reported to NHLS. However, implementing laboratory reporting of HIV diagnosis data at the facility level could be compromised given their limited resources.

There are national identifiers in place which assist in HIV monitoring and evaluation/surveillance, allowing for de-duplication of cases at the national level. However, there are a number of de-duplication efforts that may be replicating effort. Data quality assurance systems are also in place and implemented.

### Recommendations

- The approach to patient monitoring and reporting into monitoring and evaluation/ surveillance systems should match the capacity of the region/facilities. The three tier system provides an approach to meet the needs and capacity of a facility and continued use is recommended.
- Linking data from HIV testing into analyses would be beneficial. This would be possible by adding testing to the data collected by the NHLS and/or allocating resources to implement the HTC and pre-ART modules within TIER.Net
- Countries should involve the national and regional level MOH in developing data systems and standards.
- The social and political context of the country needs to be considered before implementing CBS. In South Africa it should be possible to develop the current patient monitoring and laboratory reporting systems to create an enhanced monitoring system that accommodates most of the features of a CBS system without mandating HIV reporting.
- Communication of stakeholders is imperative at the national and regional level. Multiple groups are working on de-duplication of national datasets, often fully independent of each other.



**Table 2.** Summary findings from SWOT analysis for key areas of interest in South Africa.

	STRENGTHS	WEAKNESSES
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Person-level data are already being tracked by existing systems which could be utilized for CBS.</li> <li>- Systems for collecting data from all points of the cascade exist.</li> <li>- Multiple methods of de-duplication are present.</li> <li>- System interoperability is being actively pursued.</li> <li>- The public health system acts as one provider; where the electronic platforms for doing so exist, clinicians within a province can see all the health information on a patient regardless of the facility in which they were seen.</li> </ul>	<ul style="list-style-type: none"> <li>- Diagnosis and pre-ART data are not being routinely digitised at patient-level in current systems.</li> <li>- The national civil identify number is inadequate as it includes personal identifying information and is available only to South Africa citizens.</li> </ul>
<b>Monitoring systems for HIV</b>	<ul style="list-style-type: none"> <li>- Strong support from PEPFAR partners for clinics, regions and MoHSW.</li> <li>- Committed, hard-working health workers in many clinics.</li> </ul>	<ul style="list-style-type: none"> <li>- Separate policies within different departments and programmes (e.g. key populations).</li> <li>- Lack of training and resources.</li> <li>- Reporting / data staff does not have sufficient time available.</li> <li>- Partner activities not harmonised.</li> <li>- Financial sustainability of comprehensive, high-quality, timely reporting system.</li> </ul>
<b>Unique identifiers and de-duplication</b>	<ul style="list-style-type: none"> <li>- Existing national civil identity number – the majority of people have one.</li> <li>- Developing a health identifier which would cover those without national civil identity number.</li> <li>- Facilities provide a patient identity number.</li> <li>- CDW has capacity to de-duplicate 300 million records in 10 days.</li> <li>- Successful PMI over many years in the Western Cape, for over 6 million people.</li> </ul>	<ul style="list-style-type: none"> <li>- Large percentages of immigrants are not eligible for national civil identity number.</li> <li>- Laboratory staff unaware of how data are used at the national level.</li> <li>- Connectivity and infrastructure lacking at many primary care facilities with respect to implementing health identity number.</li> </ul>

	OPPORTUNITIES	THREATS
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- The Health Patient Record System is in active development as a national PMI and needs to be tested.</li> <li>- Development of a system to track rapid tests for individual level diagnosis data that can be linked to treatment data.</li> </ul>	<ul style="list-style-type: none"> <li>- There is a risk that parallel initiatives on de-duplication could result in different outputs which could fragment utilization at the province level.</li> </ul>
<b>Monitoring systems for HIV</b>	<ul style="list-style-type: none"> <li>- Develop a system to track rapid tests for diagnosis data either through TIER.Net or the LIS (by sending the results with specimens routed to regional laboratories).</li> <li>- CDW sends text and email alerts to the National Institute of Communicable Diseases surveillance unit when positive cases are identified which may be useful for CBS.</li> <li>- Multiple mobile applications exist for tuberculosis reporting; potential to create for HIV.</li> </ul>	<ul style="list-style-type: none"> <li>- Staff shortages exist and could further compromise completeness and quality of data.</li> <li>- Parallel systems send laboratory results to facilities which are not always filed properly.</li> <li>- Tuberculosis is a notifiable disease although data in the disease information system are considered more reliable than the notification system. The same would likely occur for HIV if notification were to be considered.</li> <li>- Some facilities already have an EMR system which reports to DHIS, and feel TIER.Net is duplicative.</li> </ul>
<b>Unique identifiers and de-duplication</b>	<ul style="list-style-type: none"> <li>- Multiple successful de-duplication algorithms exist; comparison yet to be done.</li> <li>- Laboratory data utilization for cascade to care measures.</li> <li>- HPRS a promising opportunity for a national PMI.</li> <li>- Triangulation of system data (eg. TIER.Net and laboratory) is a unique opportunity to differentiate the completeness of data.</li> </ul>	<ul style="list-style-type: none"> <li>- Differences in metrics from different systems can result in a lack of confidence in some of the source data.</li> </ul>

## REPUBLIC OF KENYA

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### Background

The Kenya Ministry of Health (MOH) determined that HIV surveillance would be strengthened by moving from aggregate reporting of persons diagnosed with HIV to a case-based surveillance (CBS) system. In 2015, a CBS pilot was performed in Kenya to collect information on the feasibility and acceptability of CBS. The CBS pilot was developed through a technical working group comprised of representatives from the MOH National AIDS and STD Control Programme (NASCO), Kenya Medical Research Institute (KEMRI), CDC/Kenya, University of California, San Francisco, Walter Reed Project United Army Medical Research Unit Kenya, and participating counties and other stakeholders involved in either technical or financial support for CBS. The pilot was conducted at 124 facilities in two high prevalence counties. Cases were collected retrospectively by sub-county surveillance officers and by health care providers who were paid to add this onto their clinical work.

A large number of facilities included in the pilot were located in rural and remote settings thereby requiring substantial travel time by the surveillance officers. The sub-county MOH surveillance officers were not able to complete their normal work duties during the pilot. This called into question the sustainability of this method as a routine surveillance activity.

### Scope of the assessment

The goal of our assessment was to explore reporting options that might be less demanding of human resources than reporting by surveillance officers or paying providers to report cases. We examined the potential for reporting from electronic medical records (EMRs), laboratories (as a stand-alone system or in conjunction with provider/surveillance officer), and providers (clinical and HIV testing counsellors) without additional compensation. Available personal identifiers that exist and that are collected as part of HIV diagnosis and care were also explored.

Interviews with key stakeholders were carried out and site visits were made at select representative health facilities and laboratories providing HIV services. During site visits, data flow / systems were observed and interviews were conducted with various facility staff to learn about the use of EMRs, how laboratory HIV tests were conducted, and the potential for providers to report cases. Six interviews were conducted with stakeholders from EMR implementing partners (International Center for AIDS Care and Treatment Programs (ICAP), International Training and Education Center for Health (I-TECH), and Palladium), laboratory information management systems (LIMS) implementing partners (National HIV Reference Laboratory (NHRL)), and the Clinton Health Access Initiative (CHAI). A presentation and question and answer session was also provided by the CDC Health Systems and Evaluation Branch. Additionally, three regional laboratories and eight facilities were visited.

### Findings

The main findings from the interviews and site visits are summarized in Table 3.

#### EMR reporting

EMRs have been implemented in Kenya to maintain the standard MOH clinical information on HIV patients. There are four nationally accepted EMRs: IQCare, OpenMRS (KenyaEMR), CPAD and FundSoft. Most of the EMR installations have been KenyaEMR (n=341) and IQCare (n=324). Facilities using OpenMRS can modify the variables collected which can impact the data available for CBS. EMR installation is done by one partner but the facility partner must maintain the system, with little support for staffing. The lack of support for staff and electricity costs were reported as the reasons that 30 facilities discontinued using their EMR. CPAD is only used at facilities managed by ICAP, and FundSoft is utilized by larger facilities which offer a wide range of health services in addition to HIV and therefore require a billing component in their EMR. KenyaEMR is a web-based system which is, therefore, problematic when connectivity is down or slow.

At 335 health facilities information regarding the patient is entered into the EMR by the providers at the time of the patient visit (also referred to as 'point-of-care' data entry). Eleven of the sites are paperless and rely exclusively on the EMRs, and at the remaining facilities data entry is performed by a data clerk after the end of the patient visit when the medical record is no longer in use. In accordance with national policy, the majority of the facilities with point-of-care data entry also maintain a paper record. This means that in addition to completing registers and paper-based medical records, providers and staff must also enter data into the EMR. Additional funding in 2015 was used to support data entry clerks to enter historical records into the EMRs.

Interoperability between EMRs is currently not available, although several groups are in the process of developing systems. For the most part, LIMS and the electronic antiretroviral therapy (ART) dispensing systems are not integrated with the EMRs.

All facilities reported experiencing periodic power outages and only larger facilities had back-up generators. It is worth noting that during our SWOT two facilities were experiencing power outages and were unable to use their generators (one was broken and the other lacked fuel). Both power outages and non-functioning generators were reported as ongoing problems. During outages only paper records are completed and data entry clerks enter the data retrospectively once power has returned.

Data quality assessments are rarely performed and when they are, only a small sample of records (e.g. 15 records per facility) is reviewed. The data in the EMR have not been systematically compared against information in the paper medical record, as such, the validity of EMR data is not known.

Reporting to MOH is done aggregately from facilities directly to NASCO using standard MOH forms. Staff indicated that the EMRs are programmed to do this and therefore reporting was not burdensome.

With the purpose of performing cohort analyses (i.e. to measure 12 month retention), a data warehouse was developed and is maintained by Palladium. The warehouse collects historical data and also requires ongoing quarterly reporting from facilities with EMRs. With the exception of facilities operated by one implementing partner (ICAP), facilities were not able to electronically submit data to the warehouse. As such Palladium staff travelled to each facility to download the data onto usb drives and then upload data into the warehouse. The variables obtained from the EMRs for the data warehouse are grouped into seven extracts: Patient Master List, ART Patient List, Patient Baselines File, Pharmacy Encounters, Laboratory Request & Results Details, Clinical Encounters List, and Patient Status. As names are not included the de-duplication of records relies on the Comprehensive Care Clinic (CCC) number, a unique patient number within a facility. At the time of the SWOT, 347 (52%) of the EMR facilities were reporting data to the warehouse. Staff at Palladium indicated that it is possible to create a separate module within the data warehouse that could include names and other personal identifiers for CBS.

A notable system in Kenya is the Eastern Deanery AIDS Relief Program which operates 14 health facilities in the Nairobi area. They have developed their own fully integrated, networked and paperless EMR system. It includes an interoperable LIMS and pharmacy system. Each facility has a data manager, and data are stored on a central server. All patients are registered in the EMR, prior to HIV testing or receiving services. The system has many identifiers including the national identity number. They have mobile technology for field workers to gather data. They also perform viral load testing at their central laboratory and CD4s at three of their laboratories. It is a closed system that requires substantial resources, and highlights what can be achieved should resources be available.

### Laboratory-reporting

CD4 testing is done at the time patients enter care and every six months until ART is initiated. A CD4 test is obtained when ART is started, and then subsequently the patient is monitored using viral load measurements. Viral load tests are obtained six months following ART initiation and annually thereafter.

There are seven regional laboratories which conduct viral load and early infant diagnostic (EID) tests. All of these use a LIMS which captures patient-level data. Six of the LIMS systems were developed by Strathmore University in partnership with Clinton Health Access Initiative. In these six systems, the patient CCC number, age, and facility are collected but not the patient's name. Facilities that use these regional laboratories maintain a cross-reference log of submitted specimens, CCC number and, at times, patient name, to link returned test results to the patient's files.

The NHRL functions as the seventh regional laboratory. The NHRL developed its own LIMS which captures name, CCC number, age and facility. Although there is a national laboratory requisition form for viral load testing that includes patient name, as well as a number of other variables relevant for CBS, most of the facilities and laboratories visited did not use it. Test results from all of the regional laboratories are sent back to facilities by e-mail to a personal e-mail account, or in some cases, to the facility email account. Results are not encrypted and there did not appear to be any specific security measures in place. Some of the small facilities use transporters to carry specimens to the facility-based laboratories and to carry paper-based test results back to the facilities. This appeared to be a more secure mechanism. It is worth noting that the laboratories did not have policies regarding confidentiality and security of data.

CD4 testing is performed at many of the larger facilities. Smaller facilities that lack on-site laboratories send their specimens to the larger hospitals for CD4 testing. Laboratories record all specimens received for CD4 testing in the MOH registers or logbooks, including date of receipt, patient name, CCC number, and test results. Paper copies of test results are placed in the medical records. Results are entered into EMRs from the paper result. There are a few facilities where the LIMS is fully integrated with the EMR so that test results are automatically recorded in the EMR.

Rapid, point-of-care HIV testing is the standard procedure for HIV diagnosis. Therefore, tests and test results are not included within the regional LIMS. Information on the first HIV-positive test is most reliably available from HIV testing registers (e.g. HTC, antenatal clinics, and voluntary medical male circumcision programs).

NASCOP has developed a national web-based portal in which all viral load and EID tests are pulled from the seven regional laboratories performing these tests. The relevant CBS variables collected include the CCC number, the reason for the test, and test result. In consideration as a potential source of data for CBS it should be noted that as the NASCOP system is used to monitor laboratory commodities and workload no attempt has been made to identify and remove duplicate records.

### Provider/facility staff reporting

At the voluntary HIV testing sites information for all persons testing is recorded in a register which contains patient names, the test date, and result. Health care providers and HIV test counsellors complete standard MOH forms which contain the individual-level information necessary for CBS including risk behaviour. The referral form for transfers does not indicate date of diagnosis.

The number of positive tests varied by facility but in general less than one client per day tests positive at medium and smaller facilities. When asked about the possibility of completing HIV case report forms for each patient who tests positive, the majority of counsellors indicated that this would not be burdensome, particularly if the number of variables required was small. In contrast, discussions with

the nurse-managers/in-charge and providers indicated that the current demands on their time for patient management preclude the possibility of reporting patients for CBS. However, it was noted that a records clerk based at the facility might be able to report cases.

### Unique identifiers

Patient names and age are collected in the HIV testing register and at laboratories that conduct CD4 tests, while names and dates of birth are recorded in medical records. Names are not recorded at six of the seven regional viral load/EID laboratories. At the time of initiating care, all patients are assigned a facility-specific unique number (the CCC number) that includes the facility number listed on a national facility master list and a serial number. This number is unique to the patient, although if a patient self-transfers they will be given a new CCC number and the information from the two clinics will not be linked. Kenyan adults (aged 18 and above) are able to obtain unique national identification numbers but these have not been collected as part of routine care. There were discussions indicating that Kenya may provide these numbers to children but it was not evident if this is currently underway. NASCOP has modified the registers to allow for collecting national identifier as well as any additional identifiers that may be available in the future. The HTC register is also being modified to include date of birth and the counsellors are supposed to document the CCC number to indicate that the patient entered care.

Information on date and place of HIV diagnosis is not always obtained for patients who transfer for care. However, all other variables needed for case reporting are collected on the CCC/blue card. Efforts are underway to include the Integrated Population Registration System (IPRS) as a national unique personal identifier, by having an electronic module in the EMR link to the IPRS system to search for the patient in the system and provide identifiers.

### Policies

Kenya has reporting regulations on infectious diseases, which includes case-based reporting for some diseases and aggregate reporting for others, including HIV. Therefore, it was determined that additional regulations for reporting HIV/AIDS in a case-based system were not needed. There are gaps in policies and standard operating procedures regarding data security and confidentiality, and the functions, purpose, data quality and utilization of EMRs, LIMS and the data warehouse. The existing birth and death registration systems are paper-based.

**Table 3.** Summary findings from SWOT analysis for key areas of interest in Kenya.

	STRENGTHS	WEAKNESSES
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Person-level data are already being collected by existing systems.</li> <li>- System interoperability is being actively pursued</li> </ul>	<ul style="list-style-type: none"> <li>- Diagnosis data are not currently entered into medical records.</li> </ul>
<b>EMR reporting</b>	<ul style="list-style-type: none"> <li>- The majority of facilities with over 500 patients have an active EMR.</li> <li>- EMRs contain the necessary variables for CBS.</li> <li>- Most EMR facilities have all historical data entered.</li> <li>- Data warehouse is in development.</li> </ul>	<ul style="list-style-type: none"> <li>- Separate policies within different departments and programmes (e.g. key populations).</li> <li>- Lack of training and resources.</li> <li>- Reporting / data staff do not have sufficient time available.</li> <li>- Partner activities not harmonised.</li> <li>- Financial sustainability of comprehensive, high-quality, timely reporting system</li> </ul>
<b>Laboratory reporting</b>	<ul style="list-style-type: none"> <li>- CD4 and viral load tests are routinely conducted.</li> <li>- Viral load and EID are conducted in regional labs and all utilise a LIMS.</li> <li>- Standard viral load test form exists.</li> <li>- Specimen transport from smaller to larger facilities works well.</li> <li>- Standard HTC register being utilized.</li> </ul>	<ul style="list-style-type: none"> <li>- Reliable connectivity and infrastructure remain an issue.</li> <li>- OpenMRS is web-based and data cannot be entered when internet connectivity is slow or down or power is down.</li> <li>- There are insufficient resources committed to supporting systems.</li> </ul>
<b>Provider reporting</b>	<ul style="list-style-type: none"> <li>- Standard forms and registers are being utilized.</li> </ul>	<ul style="list-style-type: none"> <li>- Need additional identifiers on registers (e.g. date of birth on HTC and date of diagnosis on antenatal).</li> <li>- Transfer forms do not include sufficient data for CBS.</li> </ul>

### Interpretation of findings

Based on the assessment, all of the reporting options explored, including continued use of surveillance officers, could be used in Kenya for HIV CBS. The choice of the reporting system will depend on the particular circumstances.

EMR reporting is promising as it is possible to program most EMRs to produce reports. However, the amount of work required to do this was not assessed as part of the SWOT. Although several groups are in the process of developing interoperability between EMR systems, none currently exist. As most EMRs were not networked, reporting would come directly from each facility or, in some situations, from a specific implementing partner that oversees several facilities (e.g. ICAP). HTC data are not entered into the EMRs. There appear to be discussions regarding creating a HTC module for EMRs which should overcome this limitation. Data quality assessments are insufficient and in particular validating EMR data against the paper records should be done prior to investing in CBS reporting from EMRs.

Given that obtaining EMR data for the data warehouse is already occurring, building in a specific CBS module which includes identifiers may be cost-efficient. Also, reporting to the data warehouse occurs quarterly. Facilities indicated that they are up to date with data entry which appears to have been the result of one-time added resources. The ability to maintain complete EMRs should be reassessed particularly in light of inconsistent electricity and internet connectivity.

For laboratory reporting, changes would be necessary to facilitate CBS as the systems have patient level data but only limited identifiers. To be used as an additional source of data for CBS, the regional LIMS and NASCOP viral load/EID system would need to be enhanced to include additional security measures, names and other personal identifiers, and potentially additional information such as date of diagnosis. Standard, national policies and procedures for managing and securing laboratory data need to be developed. Although CD4 results are paper-based, they are entered in the EMR.

	OPPORTUNITIES	THREATS
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Addition of names to systems.</li> <li>- Potential interoperability between EMR, regional lab, facility lab (if LIMS), pharmacy, and billing systems.</li> </ul>	<ul style="list-style-type: none"> <li>- Lack of policies for systems, including data use and security. When policies do exist they are often not being followed.</li> </ul>
<b>EMR reporting</b>	<ul style="list-style-type: none"> <li>- EMR developers mentioned creating a module for HTC data.</li> <li>- Could create a separate DataMart module for CBS with identifiers in the data warehouse.</li> </ul>	<ul style="list-style-type: none"> <li>- Staff shortages exist and could further compromise completeness and quality of data.</li> <li>- Data back-ups vary between EMRs and facilities; one site was observed to have lost all of their data due to the lack of a back-up system.</li> </ul>
<b>Laboratory reporting</b>	<ul style="list-style-type: none"> <li>- Viral load turn-around time varies by regional lab and could be addressed.</li> <li>- Develop policies and standard operating procedures for lab management, LIMS and NASCOP national viral load/EID system.</li> <li>- Update LIMS system to include additional data.</li> </ul>	<ul style="list-style-type: none"> <li>- Name is excluded from six of the seven regional lab LIMS.</li> <li>- Test results for viral load and EID are being emailed insecurely to facilities.</li> <li>- Reagents stock outs lead to a back-log.</li> </ul>
<b>Provider reporting</b>	<ul style="list-style-type: none"> <li>- New diagnoses at most facilities are small enough to have counsellor complete CBS form.</li> </ul>	<ul style="list-style-type: none"> <li>- Patients often retest; if not enough identifiers are collected, difficult to match cases and account for duplicate records.</li> </ul>

Investment in developing electronic systems for CD4 tests may be worthwhile.

For provider reporting, it was determined that health care providers would not be compliant with reporting due to time constraints. HTC counsellors could likely report new diagnoses, as there are fewer variables and the amount of new positives per HTC counsellor is relatively low. We did not assess the feasibility of reporting by nurses at antenatal clinics where the work load may be greater than that of HTC counsellors.

In addition to ensuring that patient names are included in all registers and LIMS, a national unique identifier needs to be collected as part of HIV testing and care. The success of modifying the monitoring and evaluation tools to include the national identifier should be evaluated after the tools have been in use for 12 months.

### Recommendations

- The approach to CBS should match the capacity of the county/facilities. Having multiple approaches (EMR reporting, lab reporting, surveillance officer reporting, HTC reporting) to obtain the same data, which meets the needs and capacity of the facility is important.
- The MOH should engage with county health and surveillance officers to determine optimal reporting mechanism within each facility, build local surveillance capacity, and empower counties to oversee and manage CBS activities including data use.
- The MOH should learn more about Eastern Deanery AIDS Relief Program as an example of best practices and explore how to replicate this system elsewhere.
- Facilitate communication between stakeholders at the national and regional levels to avoid duplicative efforts.
- When developing systems, policies should be developed or updated to match the new systems. Specifically policies for the LIMS and the data warehouse should be developed and promoted. Policies to ensure the security of patient data are essential.



- Develop minimal standards for the completeness, accuracy, and timeliness of EMR data and evaluate all EMRs to ensure they meet these standards prior to CBS.
- Determine personnel and time required for programming EMRs to report out cases, including systems to identify and report sentinel events.
- Develop a plan and timeline to assist EMR facilities in moving to paperless systems to avoid duplicate recording of medical information while ensuring all data currently available in registers are captured and stored securely.
- Ensure that all clinical specimens are submitted to laboratories with patient names and modify LIMS to collect names, the national identifier, and other potential identifiers that may be developed in the future. Ensure that standard MOH laboratory requisition forms are used.
- Consider digitalizing CD4 registers.
- Assess need for increasing the number of surveillance officers and records clerks for reporting cases at lower volume facilities without EMRs or whose EMRs do not meet standards for reporting.

## REPUBLIC OF HAITI

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### Background

In order to obtain information about the scope of the HIV epidemic and better understand its impact, the Haitian MOH mounted a decade-long effort, in collaboration with international donors and implementing partners, to establish national HIV case-based surveillance. The resulting system has been in operation since 2008, and features name-based case reports collected via an electronic case reporting platform and through automated data feeds from the country's major EMRs. The system is maintained and implemented on behalf of the MOH by the National Alliance of State and Territorial AIDS Directors (NASTAD).

A governmental mandate requires that health facilities report data about all persons infected with HIV. This includes reports of new diagnoses and reports of clinical data for persons receiving care and treatment. These data are collected via two mechanisms: 1) reports of initial HIV diagnoses submitted by testing sites; and 2) ongoing clinical outcomes reported via EMRs. Test sites report new HIV diagnoses using a standard HIV case notification form which is completed and submitted after patient post-test counselling. The form collects the patient's name, address, demographic characteristics, and HIV risk factors in HIV testing. A paper version of the case report form is filled out by the HIV test counsellor and subsequently entered into an electronic reporting platform for submission to the case surveillance system. The second reporting mechanism, submission of case data via EMRs, is performed through automated feeds of longitudinal patient care data from the country's three EMR systems. These longitudinal data include: sentinel events, such as pregnancy, diagnosis of tuberculosis or sexually transmitted infections, and patient death; CD4 and HIV viral load test results; prescription and pick up of HIV-related medications; and date of last patient clinical encounter.

Data cleaning is routinely performed to eliminate duplicate reports and ensure data quality and completeness. A matching algorithm was developed to identify duplicates and allow previously-reported cases to be updated with new longitudinal data. The algorithm uses patient name, date of birth, sex, and mother's first name. Case matching and deduplication is done through an automated process followed by manual adjudication if needed.

All notification data are stored on a secure server in a national HIV surveillance database, with access limited to key MOH staff and authorized implementing partners. A de-identified, confidential analysis data set is created periodically and distributed to an analytic team for creation of epidemiologic reports and publications. Surveillance data about cases who drop out of HIV care are provided to community health workers working at clinical sites to assist them in re-locating and re-enrolling patients.

### Scope of the assessment

Because Haiti has conducted HIV CBS since 2008, the goals of this assessment were focused on the strengths, weaknesses and gaps in the current system. Through this exercise, the assessors strove to: 1) better understand how HIV CBS was designed, implemented and supported to serve as a potential model for other countries; and 2) develop recommendations to further improve the system. Topics assessed included the degree of knowledge and support for HIV CBS among stakeholders, the level to which CBS was integrated with surveillance for other diseases, funding and human resource needs to support and sustain the system, and gaps and weaknesses that impact data quality, timeliness and use for programming and disease response.

Before initiating the assessment, meetings were held between the MOH and its partners, including the CDC, the Pan American Health Organization (PAHO)/ the WHO and NASTAD, to review the SWOT protocol and adapt it to meet Haiti-specific needs. The assessment was implemented in April 2016, and included both a review of relevant background and policy documents and interviews with key

stakeholders at the national, departmental (regional) and institutional levels.

Interviews were conducted in the capital of Port-au-Prince and in two other regions. A total of 12 health facilities were visited, including hospitals, HIV treatment centres and local health centres. Multiple visits occurred with MOH programmes and directorates, including three regional health departments; the National AIDS Program; the Department of Epidemiology, Laboratory and Research; and the Planning Unit. In addition, key national partners were interviewed, including CDC, WHO and NASTAD. Finally, interviews were conducted among the three health systems that administer EMRs: The University of Washington/I-TECH, the Haitian Group for the Study of Kaposi's Sarcoma and Opportunistic Infections (GHESKIO) and Partners in Health/Zanmi Lasanté (PIH/ZL).

### **Findings**

A total of 25 interviews and site visits were conducted. Results from these interviews and site visits are detailed in Table 4. Summary findings include the following:

#### **Data Quality**

HIV CBS has been in place in Haiti for eight years and has continued to mature and improve over time. The system allows for presentation of data with very high granularity, including clinical cascades. Because of the recent addition of new clinical variables to the longitudinal data reported by EMRs, the system has the ability to track patient linkage to, and retention in care down to site level, and by neighbourhood of residence. A pending national report, which was viewed by the assessors in draft form, demonstrates a wealth of information the system can provide, namely census-level HIV monitoring data. Interviewees indicated that the detailed level of available data allows for program planning and epidemic control at all levels, and can be used to evaluate and improve the quality of care and treatment. Despite these strengths, some system data are less than optimal or are missing. Data on key populations such as men who have sex with men and sex workers are under-reported. There is no functioning vital statistics registry in Haiti, and deaths among persons with HIV are infrequently reported. Finally, although CBS participation is estimated at >90% for public institutions, there is a lack of information about participation from private, for-profit health institutions. The Tuberculosis Control Program has developed a method to ensure that private health facilities report patients with tuberculosis; a similar approach could be used to compel HIV reporting from the for-profit health sector.

#### **Reporting System**

Negative perceptions exist about a lack of sustainability for this system, particularly as it costs more than other surveillance efforts. Similarly, some perceive that HIV CBS has been "outsourced" because it is maintained by a non-governmental organization (NGO). Respondents frequently noted that the current HIV CBS platform in Haiti could easily be expanded to allow surveillance of other infectious and chronic diseases. Such an expansion could help to assure system sustainability. Over the next several years the system will transition toward greater oversight and administration from the MOH. EMR data feeds have frequently been delayed over the past year because of updates to reporting methods and variable requirements. It was observed that the system may be collecting too many variables; focusing more on the key indicators/variables recommended by WHO could improve efficiency. At present, test results and laboratory data are extracted from EMRs; the national public health laboratory is implementing a new LIS, which offers the possibility of obtaining CBS reports directly from the laboratory in the future.

### **Interpretation of findings**

Through a sustained collaborative effort, the Haitian MOH and its partners developed and implemented an advanced health information system which complies with WHO and UNAIDS recommendations for second generation HIV surveillance. The system has the potential to provide sufficient data for planning, evaluation and decision-making at all levels, and includes variables that characterize patient linkage to and retention in care. In addition, the system uses existing EMR data, thereby reducing the cost of data collection. Assessment findings suggest that HIV CBS in Haiti has helped to reinforce and strengthen MOH technological and epidemiologic capacities.

To assure that HIV CBS data are sufficiently leveraged, capacity for data visualization and analysis needs to be expanded, particularly at the regional and site levels. In order to maximize system sustainability, HIV CBS should be better integrated with other public health surveillance efforts. In addition, in order for the system to fully transition to Haitian MOH oversight, human resource needs and gaps should be assessed and addressed.

### **Recommendations**

The assessment identified a number of opportunities that, if acted upon, could address weaknesses and threats to HIV CBS in Haiti. These were used to formulate specific recommendations, grouped into nine domains, including: 1) roles and responsibilities; 2) system implementation; 3) technical strengthening; 4) system coverage; 5) integration with other national surveillance efforts; 6) system efficiency; 7) system effectiveness; 8) sustainability; and 9) inclusion of the private sector and system optimization for use by other chronic disease programmes. A detailed roadmap was proposed, containing key recommendations and next steps.

Among the recommendations in the roadmap, WHO suggests that the National AIDS Program and its partners focus on "6 + 1" overarching priorities:

1. Define the roles and responsibilities of each partner involved in the HIV CBS.
2. Assess resource needs for HIV CBS, particularly human resources, to determine potential needs and gaps.
3. Highlight and educate partners about the principal benefits of the system, with an emphasis on cross-cutting benefits that might increase capacity for non-HIV related public health programs.
4. Facilitate access to aggregate HIV report data for the Directorate of Epidemiology, and Laboratory Research (DELR), which they need for routine infectious disease surveillance.
5. Use WHO standards to consolidate and prioritize HIV CBS variables and indicators for analysis and quality assurance.
6. Continue efforts to improve reporting feedback and epidemiologic analysis at all levels, with an emphasis on preparation of data for sites and departments (regions). This should include access to "dashboard" data through the developing web-based visualization interface.

The final recommendation (#7) stipulates creation of a report that describes key inputs, supports and drivers that contributed to the development of the successful, high-functioning HIV case surveillance system. This report will help other low- and middle-income countries to benefit from Haiti's experience. The National AIDS Program and its partners (including CDC and NASTAD) agreed to develop this report, with assistance from the MeSH consortium and PAHO/WHO.

**Table 4.** Summary findings from SWOT analysis for key areas of interest in Haiti.

	STRENGTHS	WEAKNESSES
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Detailed, case-specific data are collected that provide an epidemiologic “census” of persons diagnosed with HIV in Haiti.</li> <li>- Data allow for planning, evaluation and decision-making at all levels, and includes variables that characterize patient linkage to and retention in care.</li> <li>- The system uses existing EMR data, thereby reducing the cost of data collection.</li> </ul>	<ul style="list-style-type: none"> <li>- Full potential for data use has not yet been realized, particularly at the local level.</li> <li>- CBS reports are frequently interrupted or delayed by infrastructure problems and by high staff turnover.</li> <li>- Haiti lacks vital statistics data, which hampers reporting of HIV mortality to the system.</li> <li>- HIV CBS does not encompass all private, for-profit health facilities.</li> <li>- Data about key population are insufficiently reported.</li> </ul>
<b>Political and organisational support, governance, and human resources</b>	<ul style="list-style-type: none"> <li>- There is strong leadership and support for the system from the MOH National AIDS Program.</li> <li>- Human resources exist at the site level, where staff have been trained and are motivated to participate in HIV CBS.</li> <li>- Consistent support from donors such as PEPFAR has assisted in development of strong strategic information systems, including HIV CBS.</li> <li>- There is a commitment from funders to continue support for HIV CBS in future years.</li> </ul>	<ul style="list-style-type: none"> <li>- Although there are plans to transition the system toward full MOH administration and oversight, this has not yet occurred.</li> </ul>
<b>HIV care and treatment cascade; data collection and reporting</b>	<ul style="list-style-type: none"> <li>- EMRs collect many clinical variables and track patient visits in a variety of ways.</li> <li>- Current HIV CBS supports creation of clinical cascades at the national, regional and local levels.</li> <li>- Data are used to assist community outreach workers to re-link patients to care.</li> </ul>	<ul style="list-style-type: none"> <li>- Not all EMRs currently report data on a regular, set schedule because of recent changes to reporting requirements and methods.</li> </ul>
<b>Reporting systems for HIV and other notifiable diseases</b>	<ul style="list-style-type: none"> <li>- There is potential for the HIV CBS platform to be expanded to encompass case-level surveillance of other notifiable conditions</li> </ul>	<ul style="list-style-type: none"> <li>- The system is not integrated with other epidemiologic surveillance.</li> </ul>
<b>Linking clinical data with laboratory, pharmacy and other data</b>	<ul style="list-style-type: none"> <li>- Pharmacy data, including prescription information and medication pickup, are accessed via EMR feeds to HIV CBS.</li> <li>- The system employs methods to ensure that unique cases are identified and de-duplicated. This process could be used for other diseases.</li> <li>- EMR reporting could be expanded to encompass additional disease and health conditions.</li> </ul>	<ul style="list-style-type: none"> <li>- Currently, there is no direct reporting of LIS data to HIV CBS.</li> </ul>

	OPPORTUNITIES	THREATS
<b>Overall findings</b>	<ul style="list-style-type: none"> <li>- Use of the data is improving, and a new web-based visualization interface will allow for easier access to aggregate findings at all levels.</li> <li>- The Tuberculosis Programme ensures participation of private clinics in case surveillance of tuberculosis by controlling distribution of medications. A similar strategy could be used for HIV ART to compel HIV reporting by the private health sector.</li> </ul>	<ul style="list-style-type: none"> <li>- The system is perceived by some as too expensive, siloed, and potentially non-sustainable over the long term.</li> </ul>
<b>Political and organisational support, governance, and human resources</b>	<ul style="list-style-type: none"> <li>- Haitian NGO staff implements and administers HIV CBS on behalf of MoH. There is strong collaboration between the NGO and MOH, which will facilitate eventual transition of the system to full MOH oversight.</li> </ul>	<ul style="list-style-type: none"> <li>- With PEPFAR funds decreasing, there is a fear that HIV CBS may have less funding in the future.</li> <li>- HIV CBS is not currently supported through local funding streams.</li> </ul>
<b>HIV care and treatment cascade; data collection and reporting</b>	<ul style="list-style-type: none"> <li>- Future HIV CBS data will include measuring care cascades at all levels, including the site level.</li> <li>- A national report will be released in June that showcases the ability of HIV CBS to track national and local clinical outcomes.</li> <li>- New WHO guidance exists that can be used to prioritize analysis of clinical variables collected during HIV CBS.</li> </ul>	<ul style="list-style-type: none"> <li>- The system may be too ambitious in its collection of clinical variables. Analysis efforts need to remain focused on key indicators.</li> </ul>
<b>Reporting systems for HIV and other notifiable diseases</b>	<ul style="list-style-type: none"> <li>- There is significant interest in assuring that HIV CBS is integrated with other epidemiologic surveillance.</li> <li>- HIV CBS platform may be useable for surveillance of other diseases and health conditions.</li> </ul>	<ul style="list-style-type: none"> <li>- A perception exists for some that HIV CBS has been “outsourced” and relies too heavily on foreign investment and personnel.</li> </ul>
<b>Linking clinical data with laboratory, pharmacy and other data</b>	<ul style="list-style-type: none"> <li>- The national public health laboratory is implementing a new LIS system that will facilitate future reporting of lab data to HIV CBS.</li> <li>- An agreement was developed to begin a direct feed of HIV RNA/DNA results to HIV CBS from the national lab. Collection of laboratory RNA/DNA data will begin in June, 2016.</li> </ul>	<ul style="list-style-type: none"> <li>- Staff shortages and lack of training will compromise completeness and quality of data.</li> </ul>



## **GENERAL FINDINGS FROM THE FOUR SITUATIONAL ASSESSMENTS**

In the countries assessed there was limited familiarity with disease surveillance in general and with HIV CBS specifically. However, once the limitations of aggregate data and the benefits of CBS were presented, sub-national and national level stakeholders indicated substantial interest in, and support for, CBS as a way to more effectively monitor the epidemic. Although support for CBS was high, there was concern over the resources needed. In particular, stakeholders indicated that CBS is feasible and sustainable if it could be conducted without adding additional work for the limited number of health care providers and surveillance officers. For the most part, stakeholders felt that having sites report data through their existing electronic systems (EMRs and LIMS) would not require substantial additions to facility level staff and based this on the current reporting requirements.

All of the countries assessed conduct routine HIV programme monitoring that collects information on the number of persons tested for HIV, number of new HIV diagnoses and number of persons accessing HIV care and treatment services. At the facilities, individual level data are collected and entered into MOH registers and, for persons in care, into individual patient records. Current reporting of these data from facilities to MOHs is done in aggregate. For the most part, the frequency and content of reports is similar between countries. All of the participating countries report aggregate data for HIV and other diseases into DHIS, although different versions are currently in use.

A CBS system must collect relevant demographic, diagnosis, care, and vital statistics information. Therefore the program data collection tools from which CBS data originate must include information required for a functional system. The required personal identifiers are patient first and last name (or a reliable coding of name), date of birth and age (age can be derived from date of birth if required), sex, and information on residence (complete or partial address such as village). Inclusion of the same national identifier across information systems will facilitate this because these identifiers are assigned at a national level, truly unique to an individual, and durable in contrast to names which may change over time. It was found that most countries have a national identifier although with limitations, such as eligibility criteria which exclude a significant proportion of the population (i.e. only for adults or only for citizens). These national identifiers were not collected as part of HIV testing and with the exception of South Africa, and not collected as part of care. The required information on HIV includes the date of diagnosis, date of first entry into care, date of ART initiation, and supporting CD4 and viral load information and vital status. Review of systems and discussions with stakeholders revealed significant problems with data quality.

### **HIV diagnosis.**

All of the countries have an HTC register from which the aggregate number of new diagnoses is reported. The antenatal, PMTCT, male circumcision, and tuberculosis program registers also conduct HIV testing and record results of tests in the registers. The personal identifying variables that are collected in the HIV testing registers vary between countries and many do not include all of the variables required for CBS. For example, some countries do not record name or date of birth. Some but not all registers will add the care and treatment clinic number for those who have entered care at the facility where tested, which facilitates locating patient medical records. Some collect risk behaviours, although under-disclosure of risk remains an issue. All HTC registers collect the date of diagnosis but antenatal or PMTCT registers may not include the date of diagnosis for women who were diagnosed prior to the current pregnancy. This is because the registers record the date of the HIV test and the result of the test but not the date of diagnosis. Because women who are known to be infected are not retested, information on date of diagnosis for these women is not recorded. Although the HIV medical records are designed to record the date of diagnosis, the forms that patients who transfer care bring to the new facility do not always include the date of diagnosis.

### **Care and treatment**

Registers and paper medical records are standardized in all countries assessed by the MOH and the variables collected are similar across countries. Aggregate data are collected from the standard registers to determine the number in care and the number on ART. EMRs exist in all of the participating countries although vary considerably, as often there are different implementing partners. With the exception of Haiti, none of the countries use EMRs in all of their facilities. In facilities that have EMRs, nearly all maintain both a paper and an electronic record. Most EMR data entry occurs after the paper record is completed and as such, the paper record is the source document for data in the EMR.

There are efforts in some countries to establish national data warehouses with case level data. The systems vary by country and few include names. A few systems compile data from a single program source, such as South Africa's NHLS data warehouse. Kenya is developing a data warehouse for EMRs and Tanzania compiles CTC data. The Western Cape Province is developing a data centre which will compile data from multiple sources, health facilities, laboratories, vital registries.

### **Laboratories**

In most countries, CD4 tests are conducted at facility-based laboratories that may test specimens exclusively from their facility or serve as regional laboratories and test specimens submitted from facilities. Most laboratory registers are standardized and some regional laboratories have a LIMS. Laboratory registers are designed to collect patient names and sometimes dates of birth. However, the personal identifier variables listed in the registers are inconsistent across countries with some but not others collecting the patient name. For specimens originating outside of the facility where the laboratory is based, the facility name from which the specimen is submitted is recorded in the registers. Viral load and EID testing is expanding. At this point in time, testing for HIV RNA is done at regional or national laboratories. In general, laboratories do not perform HIV antibody testing and as such information on newly diagnosed persons is not available at the laboratories with the exception of EID which is done at regional laboratories with this capacity.

### **Vital registries**

Many resource limited countries have weak vital registries with incomplete recording of deaths and causes of death. Currently systems are primarily paper-based. Recording of deaths does include the decedent's names. Vital registry data are not routinely linked to health systems to update medical records.

Electronic reporting and linkage between systems can greatly improve CBS systems. Most of the electronic systems are not networked which limits interoperability. For example, LIMS are not linked to EMRs. Typically, the regional laboratory systems send results electronically to an email or printer and from there, the results are entered manually into an EMR and the paper copy filed in the medical chart. Kenya and Haiti have multiple EMRs, which are not interoperable. As such, submission of EMR data to a CBS database would result in the CBS database receiving data with different variable names and configuration. In order for the CBS database to receive and use these disparate data requires a well-functioning interoperability system. In Haiti, for example, this issue is addressed by variable mapping within each EMR and naming conventions to assure that EMRs submit data in a uniform format.

Unstable power sources and internet access was a problem in many regions, this adversely impacts all electronic and networked systems.

In the countries that have implemented or pilot tested CBS, mandates to report HIV exist although in Kenya there were no policies regarding the data security or data release. In Haiti, an MOH mandate requires that health systems and care sites participate in CBS. Although the MeSH assessment teams



requested documents that address issues of disease reporting policies, medical record privacy, and data security, these were not provided, suggesting perhaps that they do not exist or that persons involved with HIV programs were unaware of these documents. To a large extent, programs rely on limiting the use of patient names beyond the medical records as a way to protect confidentiality.

Organizationally, HIV programs are generally independent of other health care and disease surveillance programs. This may be due to the role of donors, implementing partners, and guidelines from normative bodies which focus on HIV testing, medical care and program monitoring and evaluation and not on broader health or surveillance systems. This may be one factor that has contributed to countries need to report information into both HIV program monitoring systems as well as into DHIS.

## RECOMMENDATIONS

The findings from the situational analyses support the development of CBS systems to systematically capture routinely collected health data to describe and monitor the epidemic for program planning and evaluation and ultimately disease control. During the situational analyses in Tanzania and South Africa, it was determined that none of the existing regional or national programs or patient monitoring and reporting systems examined are sufficient to provide quality data with which to accurately monitor the indicators along the care cascade to track progress towards the UNAIDS 90-90-90 targets. In contrast, the CBS system in Haiti and pilot in Kenya demonstrated the ability to do this. These assessments provide valuable documentation of the possibility of establishing and maintaining CBS while at the same time highlighting the significant challenges that must be addressed. Identifying technical and financial resources to assist countries will go far in furthering progress towards the conduct of CBS in sub-Saharan African and possibly other resource-constrained areas.

Current HIV program monitoring and reporting systems have two significant limitations. First is that data from persons diagnosed in HIV testing programs are not linked to data in the HIV care and treatment program monitoring systems. Therefore, current systems cannot measure actual linkage to care, understand populations least likely to be linked to care, or intervene to locate and engage these persons in care. As such, it is not possible to accurately measure or identify persons who are diagnosed but have not entered care or to measure the timeliness of entry into care. Second, beyond the facility level, monitoring and reporting systems use aggregate data which can overestimate the number of persons in care and the number of patients lost to follow-up. In some non-CBS data systems with individual-level data, personally unique variables are not collected and as such, records are not de-duplicated. Although it may be possible to adapt some of the current program and patient monitoring systems to function effectively for CBS, there was wide variation in the systems examined and few that were open-source. As such, we cannot recommend an existing system for widespread use. We can however recommend approaches that may enhance developing, implementing, and conducting CBS across systems.

### Approaches for developing CBS

- The national Ministry of Health in collaboration with sub-national departments of health responsible for HIV care and treatment and disease surveillance and other stakeholders should be fully engaged in the process to ensure that the social and cultural context is considered, and to maintain appropriate buy-in and participation from key partners.
- The CBS system should match the national and sub-national ministries of health and facility capacity to implement, conduct, and sustain CBS. Specifically, consider infrastructure, connectivity, interoperability of electronic systems, human resource capacity, and vital statistics in CBS system development.

- When possible, leverage existing data systems and human resources for CBS. Assess all data sources from which CBS data will be obtained and develop a system with sufficient flexibility to include all of these with the goal of complete ascertainment of cases and reporting variables with the ability to update a case overtime.

### Policies and procedures

- Develop national policies for CBS that should include:
  - A mandate to report all persons diagnosed with HIV
  - The surveillance case definitions
  - Roles and responsibilities of all persons involved in CBS including outlining persons responsible for reporting (e.g. health care providers, facility-based records clerks, surveillance officers, HTC counsellors, laboratory personnel, staff from vital registration systems) and managing the system
  - The reporting pathway (i.e. where reports originate and where they are sent) that assures the availability of data at sub-national and national levels
  - Reporting variables and sentinel events and mechanisms for deduplication of cases. These must include patient names, dates of birth, sex, and if available, a national identity number, and data needed for monitoring strategic indicators
  - Development of a standardized case report form
  - Requirements to protect patient confidentiality and ensure data security including data release policies
- Develop standard operating procedures, technical guidelines, and performance standards for completeness, timeliness and data quality for CBS.
- Annually review and update policies and procedures to match changes in patient monitoring data collection systems, new diagnostic methods, or roles and responsibilities.
- Develop methods for ongoing communications within and outside of the MoH to understand projects and activities that may impact or duplicate CBS efforts.
- Develop regulations requiring proper identification of patients in settings that provide clinical care. The use of ID numbers in lieu of patient names for laboratory tests carry a substantial risk of misidentification and incorrect information used for patient care.

### Data collection and use

- Develop a system for the receipt, storage, and management of CBS for use at the national and sub-national levels that can accommodate receipt of data in paper or electronic formats (e.g. with an interoperability layer) in an effort to minimize duplication of systems.
- Improve data quality through regular, comprehensive assessments of completeness and accuracy, quality improvement programs, and developing a stronger culture of data use.
- Evaluate the completeness and accuracy of data in the electronic medical records relative to data in the paper records prior to relying on EMR data for CBS.
- Assess the degree of under-ascertainment of accurate risk behaviour data followed by plans for improvement particularly as it pertains to CBS. For example, obtaining case reports from programs and facilities that provide services for key populations.
- Work collaboratively with disease surveillance programs to identify ways to leverage existing systems, develop compatible systems, and integrate systems when possible.
- Update patient monitoring and management, HIV testing (includes all programs where testing is conducted), laboratory, vital statistics and other relevant program data collection tools to collect the required personal identifiers (name, DOB, sex, and any national identify number).
- Consider embedding data visualization systems to facilitate data use.

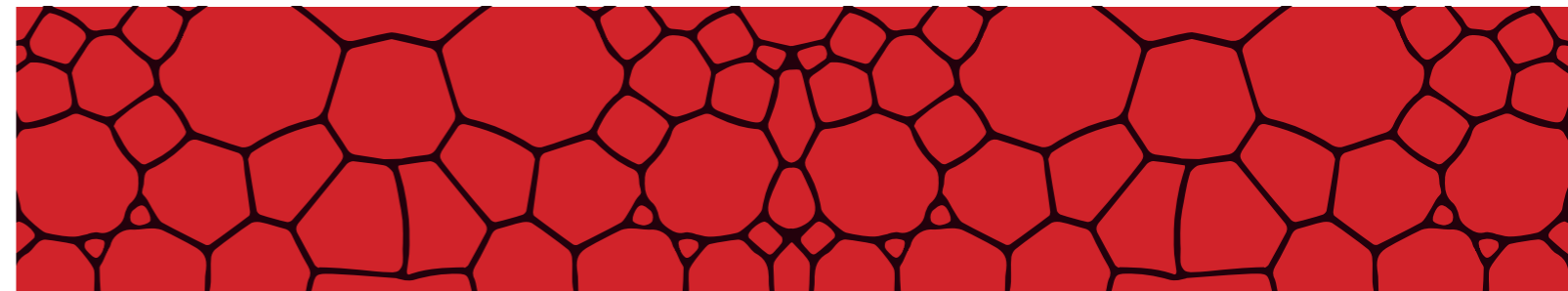
## Resources

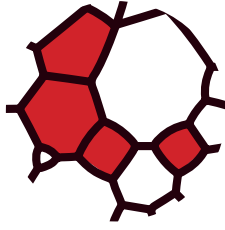
- Determine the human and financial resources required to develop, implement, and sustain CBS. This may include:
  - Costs of updating current systems for surveillance and reporting of disease other than HIV and for HIV monitoring and reporting
  - CBS database costs including an interoperability component
  - Methods used to collect case reports and the costs associated with these such as additional surveillance officers, facility data records clerks, or adaptation of electronic systems to permit these to report out to the CBS system
  - Costs related to EMR data reporting, including programming for variable mapping and data reporting, and development of secure pathways for electronic submission to the CBS database
  - Costs of improving power sources and internet service
  - Training, supervision and performance management at the site, regional and national levels
  - Data management, analysis, and dissemination

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