World Health Organization

CONSOLIDATED GUIDELINES ON

PERSON-CENTRED HIV PATIENT MONITORING AND CASE SURVEILLANCE

ANNEX 3.5.2

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Annex 3.5.2 An assessment tool for person-centred HIV patient monitoring and case surveillance

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ABBREVIATIONS AND ACRONYMS

ANC	antenatal care
ART	antiretroviral therapy
C&T	care and treatment
CDC	Centers for Disease Control and Prevention
CSW	commercial sex worker
DHIS	district health information software
DQ	data quality
DRqC	document request checklist
DRvC	document review checklist
EIA	enzyme immunoassay
EID	early infant diagnosis
EMR	electronic medical record
EMTCT	elimination of mother-to-child transmission
FBN	(assessment of) feasibility, barriers and needs
Global Fund	Global Fund to Fight AIDS, Tuberculosis and Malaria
HIS	health information systems
HMIS	health management information system
HR	human resources
HTC	HIV testing and counselling
IDS	integrated disease surveillance
IG	interview guide
IT	information technology
L&D	labour and delivery
LAg	limiting antigen
M&E	monitoring and evaluation
MIP	mother–infant pair
MNCH	maternal, newborn and child health
MoH	Ministry of Health
MSM	men who have sex with men
NCD	noncommunicable disease
NGO	nongovernmental organization
PEPFAR	US President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
PWID	people who inject drugs
SA	situational assessment

SI	strategic information
SOP	standard operating procedure
SWOT	strengths, weaknesses, opportunities and threats
TB	tuberculosis
USAID	United States Agency for International Development
VCT	voluntary counselling and testing
VL	viral load
WHO	World Health Organization

Background

The World Health Organization (WHO) released new guidelines in 2015 recommending consolidated indicators to measure the coverage, gaps and impact achieved of HIV services at facility, subnational and national levels. These consolidated guidelines recommend the use of ten global indicators to collect information along the cascade of HIV care and treatment as the principal way to track the epidemic and response. Six of the ten WHO global indicators use data that originate from patient diagnosis, testing and medical records. These six indicators are as follows:

1. knowing the HIV status (proportion diagnosed with HIV)
2. linkage to care
3. initiated antiretroviral therapy (ART)
4. ART retention
5. achieved viral load suppression
6. death.

Harnessing clinical data in a format that makes them readily available for use as strategic information allows for routine measurement of these indicators at the facility, subnational and national levels.

In 2017, WHO launched the *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance.* The aim of these guidelines is to consolidate routine patient monitoring, programme monitoring and surveillance into a unified monitoring and evaluation (M&E) system. The guidelines reflect the transition from counting services delivered to a new emphasis on people and their access to linked HIV and health services as a means of monitoring the response to HIV. The main elements of this new approach are described in detail in the *Guidelines* and comprise HIV patient monitoring, HIV case surveillance and using unique identifiers for person-centred monitoring of HIV services. **A key recommendation from the *Guidelines* is to carry out a comprehensive situation analysis as the first step in transitioning to the collection of person-centred HIV strategic information for patient monitoring and case surveillance.**

Purpose

This *Assessment tool for person-centred HIV patient monitoring and case surveillance* provides a process for developing a comprehensive situation analysis of existing HIV strategic information systems, formats and tools. The *Assessment tool* consists of three components:

1. the document review and information collection tool;
2. the strengths, weaknesses, opportunities and threats (SWOT) analysis table that identifies three to five top-line priority actions;
3. the scorecard and priority action plan that summarizes three to five priority actions and estimates the resources required to initiate them.

Results from preliminary assessments carried out in several countries were used to inform the adaptation of the 2017 WHO *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance.*

The following components will be addressed in the assessment tool:

1. assessment of the status of person-centred HIV patient monitoring, case surveillance and use of unique identifiers in relation to the WHO guidelines;

2. overall summary of the status of patient monitoring and case surveillance opportunities and options;
3. recommendations for next steps, including priority actions and initial costing.

Methods

The assessment begins with a meeting of stakeholders to review the data collection tool template and to adapt it to meet the specific country needs. The data collection tool is comprehensive so it needs to be modified to focus on the specific country context. For example, in countries with established case surveillance or patient monitoring systems, the tool can be used to evaluate that system, not to build it. In other countries, it will be used as a planning tool to define the needs, and inform the development and implementation of case surveillance vis-à-vis the existing patient monitoring and other information systems. The assessment begins with a desk review of key documents and forms, followed by key informant and stakeholder interviews at the national, subnational and facility levels. Additionally, site visits are made to selected facilities and other relevant units, e.g. national or regional laboratories that conduct HIV-related tests.

The key stakeholders to participate in this situation analysis include representatives from the Ministry of Health (MoH), WHO, HIV programme officers, M&E officers, strategic information (SI) officers, technical working groups on HIV, and partner agencies supporting case surveillance and patient monitoring systems, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund) and the US President's Emergency Plan for AIDS Relief (PEPFAR).

This assessment aims to guide the implementation of the 15 key recommendations in the Guidelines:

1. Minimum dataset for patient care
2. Transitioning to "treat all"
3. Simplification of tools
4. Integration and linkages
5. Data quality review and use for quality of care
6. Standardization of core sentinel events and indicators
7. De-duplication of records to support facilities and improve data quality
8. Country situation analysis
9. HIV diagnosis and building on patient monitoring
10. Key population data
11. Promote and use unique identifiers
12. Transition progressively from paper-based to electronic patient information systems
13. Strengthen and establish different data security levels
14. Invest in data systems and ensure interoperability
15. Use individual data to improve programmes and long-term chronic health care.

The assessment will describe and evaluate the current patient monitoring and HIV surveillance systems. Country representatives provide input to adapt the tools to meet the country context and provide guidance on the key informants to interview, the organizations and facilities to visit, etc. The following standardized tools have been developed for the situation assessment:

- Document review checklist
- Document request checklist
- Interview guide
- SWOT analysis tool, including results
- Results scorecard, including priority actions and approximate investment requirements
- Site visit checklist
- Debrief form.

Document review checklist (DRvC) for HIV case surveillance

Reviewer(s): _____ **Date:** _____

Person(s) providing documents: _____

Obtain the following documents for review at least two weeks prior to conducting the assessment. The assessment team should divide the workload to draft a summary paragraph for each item below to be compiled into a global summary document that should be completed at least one week prior to the assessment.

DRvC-1. Existing patient-level/clinical data collection systems from care and treatment (C&T), HIV testing and counselling (HTC) (case surveillance only), tuberculosis (TB) (patient monitoring only), maternal, newborn and child health (MNCH), including prevention of mother-to-child transmission (PMTCT) and early infant diagnosis (EID)

- These sources should include systems and tools used by the MoH and other implementing partners. These are likely to include:

☐ Registers (C&T, HTC, PMTCT, home-based testing and counselling, EID, pharmacies, laboratories), which can be both paper-based and electronic

☐ Facility-held patient cards/standardized medical records

☐ Patient-held medical records/booklets

☐ Electronic medical record (EMR) systems and patient-held electronic medical cards (e.g. SmartCare in Zambia).

- For each data source, determine the following:

☐ Developmental stage (early, middle or advanced) of each key data component

☐ Variables collected and how they differ across facility level and/or by partner

☐ Inclusion of patient identifiers (name, date of birth) and individual-level identification methods (national-level identification numbers, clinic-assigned patient numbers, regionally assigned patient numbers, biometrics)

☐ Flow of data

☐ If sources are being linked/integrated

☐ How each data source is being analysed and how the information is being used to manage patient care, guide programme planning, implementation, review, etc.

DRvC-2. Reports: disease notification (for case surveillance only), patient information systems, data quality assessments/evaluations of paper and electronic patient management systems

• Determine the following:

☐ Developmental stage (early, middle or advanced) of each key data component

☐ Quality and functionality of current reporting systems

☐ Quality, completeness and functionality of cohort and cross-sectional reports (for patient monitoring)

☐ Quality and completeness of surveillance data (for case surveillance only)

☐ Types of electronic systems being utilized and coverage of those.

DRvC-3. Existing policies: for patient monitoring and case surveillance – HIV reporting regulations, and for case surveillance only – other disease notification regulations, data release from patient information systems (paper-based and electronic, including EMRs) and vital registries

• Determine the following:

☐ Developmental stage (early, middle or advanced) of each key data component

☐ Variables required to be reported and the format

☐ If individual-level identifiers are required to be reported

☐ Gaps in reporting policies

☐ Gaps in data release and confidentiality.

DRvC-4. Strategic plans: patient monitoring and disease notification strategic plans, including but not limited to HIV, HIV surveillance strategic plans, national HIV strategic plans

• Determine the following for patient monitoring only:

☐ Strength of the strategic plan for patient monitoring

☐ Future plans for patient monitoring

☐ Uses and dissemination of data.

• Determine the following for case surveillance only:

☐ Nature of the epidemic

☐ Future plans for HIV surveillance

☐ Strengths of the strategic plans for HIV surveillance

☐ Uses and dissemination of data.

For case surveillance only:

- Assess the availability of the following case surveillance measures:

☐ HIV diagnosis date

☐ Entry to care date

☐ CD4 results and date (first and follow up)

☐ Viral load (VL) results and date (first and follow up)

☐ Any additional (to CD4 and VL) follow-up information highlighting retention in care

☐ Initiation of ART date and regimen

☐ Advanced HIV diagnosis date (WHO stage III or IV)

☐ Death date and cause of death.

DRvC-5. Vital registration and statistics forms (for case surveillance only)

- Determine the following:

☐ Developmental stage (early, middle or advanced) of each key data component

☐ Format of vital records

☐ Variables collected

☐ Death registration requirements and methods.

DRvC-6. Information system plan for HIV, TB and health management information system (HMIS)

- Determine the following:

☐ Developmental stage (early, middle or advanced) of each key data component

☐ Data system structure – key databases and interoperability

☐ Confidentiality and security of data

☐ Use of unique identifiers.

Notes (e.g. reasons documents not provided, additional contacts):

Document request checklist for patient monitoring system

Complete the checklist and provide the following documents to assist in preparing for the assessment.

Documents provided

DRqC-1. Clinical/medical records

Yes	No	Not available	
☐	☐	☐	Facility-held patient cards/standardized medical records used by MoH and implementing partners
☐	☐	☐	Patient-held medical records/booklets used by MoH and implementing partners

Yes	No	Not available	
☐	☐	☐	EMR systems and patient-held electronic medical cards

DRqC-2. Registers and other data collection forms and list of variables in electronic database or system

Yes	No	Not available	
☐	☐	☐	C&T (pre-ART and ART registers, appointment book, transfer/referral forms)
☐	☐	☐	Community-based HIV monitoring tools
☐	☐	☐	TB (patient record, registers)
☐	☐	☐	MNCH (patient records – maternal health card, child health card, labour/postpartum record), registers (antenatal care [ANC], labour and delivery [L&D], EID/mother–infant pair [MIP], PMTCT, other)
☐	☐	☐	Home-based testing and counselling (case surveillance only)
☐	☐	☐	Pharmacy
☐	☐	☐	Laboratory

DRqC-3. Plans and reports

Yes	No	Not available	
☐	☐	☐	Strategic plans: national HIV strategic plans, patient monitoring (as part of M&E, HMIS, SI or by itself) strategic plan (patient monitoring only), disease notification strategic plans (case surveillance only), including but not limited to HIV, HIV surveillance strategic plans (case surveillance only)
☐	☐	☐	Reports: disease notification (case surveillance only), patient information systems for HIV (cross-sectional and cohort), TB and MNCH, data quality assessments/evaluations of paper and electronic patient management systems

DRqC-4. Vital statistics (case surveillance only)

Yes	No	Not available	
☐	☐	☐	Methods for recording and maintaining vital statistics
☐	☐	☐	Vital registration and statistics forms and documents outlining requirements for completing forms
☐	☐	☐	Vital registration and statistics forms and documents outlining requirements for completing forms

DRqC-5. Disease notification and data release policies and forms (case surveillance only)
(note if reported in aggregate or individual level and if names are included)

Yes	No	Not available	
☐	☐	☐	HIV reporting regulations
☐	☐	☐	HIV notification forms
☐	☐	☐	Other disease notification regulations
☐	☐	☐	Data release from patient information systems (paper and EMR)
☐	☐	☐	Vital registries

Notes (e.g. additional documents reviewed; reasons documents not provided):

Interview guide (IG)

Schedule interviews with the following stakeholders at least one week in advance of the assessment. Some of the interviews may occur during the site visits.

To schedule the interviews, provide a brief overview of the assessment and why it is being conducted. For example:

"We are interested in learning more about HIV surveillance in [country] so that we can understand the current status, identify gaps, and produce a prioritized and costed action plan for strengthening individual-level HIV data and HIV case surveillance and patient monitoring. Case surveillance provides longitudinal data to track individuals through the cascade of HIV diagnosis and care. This evaluation is to assess the current surveillance system (patient monitoring, case surveillance, unique identifiers, use of data, etc.) and their utility for case surveillance."

Or:

"We are interested in understanding how the existing HIV patient monitoring system works in [country], so that we can develop recommendations and provide technical assistance for how to adapt and implement the updated 2017 WHO *Consolidated guidelines on person-centred HIV patient monitoring and case surveillance.* These updates and revisions will facilitate adherence to new treatment recommendations and reporting of key indicators along the HIV cascade of care."

IG-1. National-level stakeholders will be representatives from the following programmes:

- ☐ HIV strategic information (SI)
- ☐ HIV monitoring and evaluation (M&E)
- ☐ Community health (if applicable)
- ☐ Health information systems (HIS)
- ☐ Maternal, newborn and child health (MNCH), including PMTCT
- ☐ HIV care and treatment (C&T)
- ☐ Early infant diagnosis (EID)
- ☐ TB monitoring and evaluation, surveillance

- ☐ Laboratories that conduct CD4 cell and/or viral load testing
- ☐ Treatment procurement and distribution
- ☐ Quality improvement

Case surveillance only:

- ☐ Infectious disease surveillance, HMIS
- ☐ HIV testing and counselling (HTC)
- ☐ HIV surveillance
- ☐ Vital registration.

IG-2. Subnational personnel involved with:

- ☐ Disease notification (HIV and other diseases) (case surveillance only)
- ☐ HIV
- ☐ TB
- ☐ MNCH
- ☐ M&E reporting
- ☐ Other relevant programmes.

IG-3. Facility-level staff (include all levels of care and range of implementing partners):

- ☐ Clinic managers
- ☐ Health-care providers
- ☐ Data officers/clerks, records assistants
- ☐ Pharmacy manager (or pharmacy technicians if no manager)
- ☐ Laboratory manager (or laboratory technicians if no manager).

General information

Interviewer: _____ **Date of interview:** _____

Respondent organization: _____

General information about the interviews with key informants

- Greet the key informant. Introduce yourself if you have not had previous personal contact with him/her.
- Thank the key informant for taking the time to talk with you about HIV surveillance. Provide a brief overview of the situation assessment.

- Tell the informant that all responses will be kept confidential and used only to inform planning activities. If they are uncomfortable with any of the questions, they do not have to answer them and they can end the interview at any time.

Situational assessment (SA)
For case surveillance

SA-1. HIV notification process: national and subnational levels (from testing, diagnostic and care/treatment-providing facilities)

a. What are the policies, laws or regulations for HIV disease notification in the country? (Prompts: Who is required to report? What entities are involved?)

b. What is the reporting process/pathway? (Prompts: How frequently are HIV data reported?)

c. Are disaggregate or aggregate data reported? If aggregate data are reported, at what level are data aggregated?

d. What are the reportable events? HIV diagnosis? Sentinel events?

e. What variables are reported? (Prompt: are personal identifiers reported? If so, which ones? [e.g. sex, date of birth, full or part name])

f. Are key population (commercial sex workers [CSWs], men who have sex with men [MSM], people who inject drugs [PWID], etc.) data included in your system? How are they included?

g. How are issues of confidentiality and data security addressed? At diagnosis? At treatment? In ongoing care?

h. Is there a dedicated data analysis person or team? At national level? At subnational level? At facility level?

i. How are the results of the analysis presented? Is there a standard report format? To whom are the results presented or distributed?

j. How much time is spent entering, editing and storing data?

k. Has the country invested in **macro databases** for patient monitoring and case surveillance? At what level(s)? Is there a 3–5-year plan to invest in information and data systems covering information technology (IT), human resources (HR), governance, etc.?

l. Is there de-duplication of records? How are issues of duplication fed back to health facilities?

m. How has case surveillance built on and is linked to patient monitoring?

n. Has there been any evaluation of the surveillance system? If so, what were the findings?

o. Is there a link between age and retention? Elimination of mother-to-child transmission (EMTCT)? Service quality? Other outcomes? Specify _____

p. How are patient monitoring and case surveillance data used? At national level? At subnational level? At facility level?

q. What are the plans to transition towards electronic-based reporting? At what levels?

r. Are there standard dashboards and feedback routines? Electronic? Paper?

s. How are these data used routinely for programme decisions? At national level? At subnational level? At facility level?

t. In carrying out health reviews? Other? Specify _____

u. Is there evidence that use of data has improved programme outcomes? How?

SA-2. Data needs for HIV surveillance and reporting: national and subnational levels

a. What data are used for HIV strategic planning? What data are currently used for measuring HIV prevalence and the care cascade (such as the number diagnosed, number in care, on ART, virally suppressed)?

b. How could case-based reporting assist in your surveillance activities?

SA-3. Leadership for HIV surveillance and reporting: national and subnational levels

a. Is there an identified person responsible for disease/HIV notification?

b. Is there investment/interest from any leader to support case surveillance? Who are the appropriate leaders to engage?

c. Is there a technical working group (HIV, disease surveillance)?

d. Is there a national strategy for collecting and using HIV data? (Prompt: is case surveillance a part of the HIV national strategy?)

SA-4. Human resources for HIV surveillance and reporting: national, subnational and facility levels (in relation to levels below respondent's position)

a. National level

i. What surveillance staff report to either the HIV SI director or infectious disease notification director? (Prompt: surveillance coordinator, data manager, epidemiologist/data analyst?)

b. Subnational level

i. Is there a surveillance director or someone who can serve as the director (e.g. an HIV programme manager, surveillance director for other notifiable diseases)?

ii. Is there a data manager? Who is responsible for checking data quality? At which levels?

c. Facility level

i. Is there a site director (e.g. director of voluntary counselling and testing [VCT] or PMTCT)?

ii. Are there persons on site who can systematically report cases or does the system need additional surveillance officers to report cases?

iii. Is there a data manager? Who is responsible for checking data quality?

iv. What training is required to collect, clean and/or interpret data?

SA-5. Other case-based notifiable diseases: national and subnational levels

a. Is case-based notification used for any other disease reporting?

b. Is there integrated disease surveillance (IDS), is HIV or AIDS included? Describe how it works and performance of the IDS.

If answer to the question above is yes then please proceed to Question 5A-5c; if the answer is no then proceed to Question 5A-6

c. What diseases are reported on a case basis and why are they case-based?

d. Does notification include patient name?

e. What is the reporting process (by whom; frequency; format; variables; data use)?

f. Has there been any evaluation of the surveillance system and, if so, what were the findings?

SA-6. HIV diagnosis: national and subnational levels and HIV testing facilities

a. Where are HIV tests conducted? (e.g. within health-care facilities that provide HIV care, facilities that do not provide HIV care, home-based or self-testing, as part of surveys?)

b. Are HIV tests conducted outside of facilities recorded? If so, how?

c. Following a positive HIV test result, are people referred into care and tracked to see whether they access HIV care/treatment facilities? If yes, then what is the process for referral and tracking, and what information is collected?

SA-7. Clinical care: national and subnational levels and HIV care facilities

a. At enrolment into care and initiation of ART, are CD4 and VL testing conducted? Is it routine for patient monitoring or done only to confirm the need to change medications?

b. Are there plans to expand VL testing? If so, what are these and what is the timeline for implementation? Where is VL testing done (local or regional laboratories)? Where are VL results recorded? How are these results reported to district and national levels?

c. How are laboratory specimens collected/requested? Do clinical laboratories currently provide results to the MoH and, if so, in what format (e.g. line listed, aggregate)?

d. Within laboratories, are quality control/quality assessment practices systematically run to ensure Good Laboratory Practice? (Prompts: conducted as per standard operating procedures [SOPs]; participation in external quality assessment; validation of results by additional staff members)?

e. What records/registers are kept by the pharmacy? Does the pharmacy also report patient-level/related results upwards to the district and national levels?

SA-8. Patient monitoring: national and subnational levels and any facility where HIV care is being provided (Annex 2.6.2 provides a checklist for rapid assessment of the patient monitoring system, which covers some of these issues.)

a. Does a minimum dataset for patient monitoring exist? If so, when was it last updated?

b. What are the national HIV indicators related to the HIV care and treatment cascade, and what are their data sources?

c. At what stage in the transition to "treat all" is the country (by facility)?

d. What is the flow of data (including laboratory, pharmacy, back of card, when are registers filled, reports filled)?

e. Is there task-shifting – lay health workers who fill out non-clinical information?

f. Who completes clinical patient information?

g. What is the role of community-based health workers in monitoring patients? Tools?

h. Who fills the registers (pre-ART/ART), when and how long does it take?

i. Who fills the reports (cross-sectional/cohort), when and how long does it take?

j. What is the patient flow (including laboratory, pharmacy)?

k. Integration of services (clinical care) (TB/ANC/noncommunicable diseases [NCDs]), integration of patient monitoring and linkages between services and patient monitoring systems

i. Where do pregnant patients on ART receive care and for how long?

ii. Where do TB patients on ART receive care and for how long?

iii. How are exposed infants monitored and followed up?

iv. Are there linkages between HIV and other service delivery points (e.g. NCD care)? If so, please explain.

l. How are patients referred or transferred (within HIV and between HIV and other programmes (e.g. MCH, TB, other NCDs)?

m. Who completes patient information (registration)?

n. At what point does the system become electronic?

i. If electronic, is it parallel?

ii. Data entry clerks?

iii. Satellite sites?

iv. Tiered system (which sites have which systems based on what capacity/resource level?)

v. Link to HMIS or district health information software 2 (DHIS 2)?

o. Supervision – when/how/what/by whom?

p. When and how is data quality assessed?

q. How are data used, and by whom?

r. What are the feedback systems in place for using data for patient care and programme management?

For case surveillance and patient monitoring:

s. Are patients in care able to be tracked over time (i.e. is the registry longitudinal)? If so, what is the follow-up process? What updated information is collected? Are data sources linked (e.g. pharmacy, laboratory and clinic records/EMRs)?

t. Do clinic staff conduct specific activities to track patients who have missed appointments or who are lost to follow up to determine whether they are no longer accessing care, are receiving care elsewhere, have migrated out of the area, or if they have died? If so, what criteria are used to determine if a patient should be tracked, who does the tracking, what is the tracking process, and how is the information recorded?

u. Is there a set protocol for following up patients? If so, is the protocol strictly adhered to? If not, what are the reasons for not following the protocol? Are follow-up efforts documented (e.g. the number of attempts to call a patient, or number of visits to the patient's home)?

v. Among patients diagnosed with HIV, how are deaths ascertained? If a death occurs in the hospital, is this information recorded in the clinic record? Is there a process for reporting and recording deaths in the community?

SA-9. Individual-level (disaggregate) data sources: national and subnational levels and relevant facilities

a. What data systems are in place that could be utilized for case surveillance (i.e. they collect and can report individual-level/line-listed data) (case surveillance only)? Do these systems include EMRs?

If EMR systems are in place then please proceed to Q9.b below; if the answer is no, then proceed to Q9.i

For patient monitoring and case surveillance:

b. Where are EMRs in use and how many different EMRs are in use?

c. Are the EMRs open source (what are the approximate costs)? Is there interoperability between EMRs?

d. Are EMRs used only for HIV or are other infectious diseases recorded? If yes, which ones?

e. What types of EMR hardware and software are being used?

f. Is EMR information completed in real time without the need for paper records or are data initially collected on paper forms and later entered? What is the time interval between collection of the data on the paper form and entry of these data into the EMR?

g. What features of the EMRs work well and what are the limitations? Are there issues relating to data quality and timeliness? If so, what can be done to improve the system?

h. Have the EMRs been evaluated? What were the findings? Any corrective action taken?

i. Are there other digital systems for recording HIV clinical data such as SmartCare?

j. What data are collected and reported at the individual level? Are behavioural risks coded and reported? What patient identifiers are collected?

k. How comprehensive are the systems (i.e. what proportion of all people diagnosed with HIV is captured)? Does this vary geographically or by key populations? Has this been evaluated?

l. Have the data collection systems been evaluated for completeness and accuracy? If so, what were the results and when was the evaluation conducted? What were the main findings?

m. Is there ongoing data quality improvement/data quality assessment? If so, what were the findings? How are the data cleaned? What data quality controls are in place?

n. How frequently is data quality assessed? What are methods or tools used?

o. Is data quality assessed at facility level? At district level? At national level?

p. What are the key data quality issues?

q. Are there data security systems and policies for patient-level data? How are records archived and disposed of?

r. Have changes been made to the system (including EMRs) in the past (new variables, new technology)? Was the system easy to change or did problems arise? When did these changes occur?

s. Have there been times when the system has been down (i.e. was not functioning either because of a problem with the system, electricity or lack of staff)?

t. Has there been a process to standardize and simplify reporting tools? In what area is this particularly needed?

u. What reports are generated from the data and at what frequency and for whom? What is the timeliness of the data reported?

v. Are the reports individual level or aggregate? If aggregate data, where does aggregation occur and have there been data queries/questions that have been difficult to answer due to reporting data in aggregate?

w. How are data currently used (cohort analysis, cascade, etc.)? Is there an analytic team? Are dashboards, reports, etc. being produced and distributed to decision-makers?

x. Is there a process to systematically use the information to inform relevant policies, strategies, update HIV/AIDS control and treatment programmes?

y. Is information shared among facilities to enhance continuity of care across facilities and to reduce duplication of records?

z. Is there interest in using, or a vision of how to use, patient monitoring data for case surveillance?

SA-10. Unique identifiers: national and subnational levels and at all facilities

a. Are unique identifiers in use for labelling individual records? If not, is there any plan to develop health or national unique identifiers? Investments planned?

b. What types of patient or client identifiers (full names, national identification cards) are being used in the country? (There are likely to be different responses for different regions of the country.)

i. Facility-level identifiers

ii. Programme- or service-level identifiers

iii. National-level identifiers

c. Are unique identifiers in use at facility, programme or national level, or by insurance or other systems that could be expanded for use in case surveillance or as unique identifiers for the HIV programme data and across health programmes (e.g. ANC, TB, NCDs)? Would their use be acceptable to the public?

d. If unique identifiers are in use, are they being used to de-duplicate reporting of cases (at diagnosis or in care) and to link information relating to a single individual over time, across programmes and across facilities? If so, which ones and how?

e. Where there are multiple different information systems and different unique identifier systems, do these systems interoperate?

f. What privacy, confidentiality and data security laws, policies and guidelines are in place? This applies to data collection, data standards, information access, data ownership, storage, transfer, use, disposal and stewardship. What is the current status of their implementation and enforcement?

g. What physical and human resources are available to develop and run electronic health information and medical record systems? (There are likely to be different responses for different regions of the country.)

i. What is the availability of electricity, telephone and Internet connectivity at health facility, district, subnational and central levels?

ii. What is the availability of computers, staff with computer skills, and facilities with electronic medical or health records?

h. Have the unique identifier systems for health been evaluated for quality? If yes, which system(s), when, by whom and with what results? Have recommendations coming from these evaluations been implemented to improve the quality of the systems?

i. Is the information linked to uniquely identified health records being analysed and used to track and improve the quality of:

(i) individual prevention, diagnosis, care and treatment at facility and programme levels?

(ii) programme overview and management at the programme, district, subnational and country levels?

j. Are any identifiers collected but not used? If yes, what can be done to have them included in case surveillance or patient monitoring systems?

k. Are names and dates of birth collected at HIV testing sites/services or HIV care/treatment sites? If names are not currently collected, will it be possible to do so in the future? How would patients and communities currently view the collection of identifiers among people diagnosed with HIV?

l. Have biometrics been used in relation to HIV? Have biometrics been used in any other setting? If so, describe these.

SA-11. Ascertainment of recent HIV infections/incidence: national and subnational levels – case surveillance only

a. Do you/have you ever/do you have plans to apply a test to blood (liquid serum or plasma) specimens to distinguish recent HIV infections from those that are long-standing (e.g. the limiting antigen (LAg)-Avidity enzyme immunoassay [EIA])? If yes, then please provide further information (e.g. how samples are taken and stored, whether the incidence test was conducted on the same specimen as VL and CD4 cell count, and what standard testing algorithm is used to ensure that the sensitivity of their screening test fits with the mean duration of recent infection of the incidence assay).

b. To calculate the recent rate of false test results (applied now or in the future) certain information on the person diagnosed with HIV is required. Which of the following information is collected on people newly diagnosed with HIV?

i. CD4 cell count at, or within 3 months of, HIV diagnosis:	YES/NO
ii. Viral load at, or within 3 months of, HIV diagnosis:	YES/NO
iii. AIDS-defining illness at, or within 3 months of HIV diagnosis:	YES/NO
iv. In receipt of antiretroviral therapy:	YES/NO
v. HIV subtype:	YES/NO

Comments:

SA-12. Ascertainment of death: national and subnational levels and at all facilities – case surveillance only

a. Are deaths routinely recorded in the country? (Prompt: Are there laws or regulatory issues that result in complete recording of deaths [e.g. are death certificates required for burial]?)

b. How are deaths recorded? (Prompts: Who is responsible for recording deaths? Is there a death certificate? What information is included on the death certificate? If a cause of death is recorded how is that determined?)

c. Where and in what format are death records stored? Which personal identifiers are stored?

d. Are there any health and demographic surveillance sites?

e. Are there death records available for linking with HIV case records? If yes, then have death records been linked to HIV case records and how successful was this?

Assessment of feasibility, barriers and needs (FBN)
For case surveillance (CS) only:

FBN-CS-1. What are the resources/costs of operating current systems?

FBN-CS-2. What are the funding sources for surveillance, including EMRs? What is the potential for further funding?

FBN-CS-3. Can staff at clinical facilities report HIV cases? Do they have the time and motivation?

FBN-CS-4. Is there someone within clinical settings who reports other infectious diseases? Can that system be expanded to include HIV case surveillance? How might that be done?

FBN-CS-5. How could implementing partners assist in developing case surveillance? Which partners?

FBN-CS-6. Are data security and patient privacy measures of sufficient strength to support and instil confidence in an HIV case reporting system?

FBN-CS-7. Does the MoH have the capacity to receive and process electronic reports?

FBN-8. Does the capacity exist for electronic reporting from sites and clinical laboratories?

FBN-CS-9. What are the technological limitations within the country that might affect case surveillance?

FBN-CS-10. What barriers do you foresee to developing case surveillance?

FBN-CS-11. Can the system evaluated be expanded or adapted for national HIV case surveillance? What would this require? What steps can be taken to move this system forward? Are there elements that can be pilot-tested?

FBN-CS-12. Is there anything else you would like to add?

For patient monitoring (PM) only:

FBN-PM-1. What are the resources/costs of operating the current patient monitoring system?

FBN-PM-2. What are the funding sources for patient monitoring, including electronic systems? What is the potential for further funding?

FBN-PM-3. Are staff at the facility able to fill patient records (card), register and reports adequately? Do they have the time and motivation? How do district- or regional-level staff support patient monitoring, and how often?

FBN-PM-4. How does joint programme reporting work at the facility level (e.g. for TB/HIV or HIV/MNCH indicators)? How do district- or regional-level staff support joint reporting requirements by facilities?

FBN-PM-5. How could implementing partners assist in improving patient monitoring? Which partners?

FBN-PM-6. Are data security and patient privacy measures of sufficient strength to support and instil confidence in an HIV patient monitoring system?

FBN-PM-7. Does the MoH have the capacity to receive and process electronic reports?

FBN-PM-8. Does the capacity exist for electronic reporting from sites (and clinical laboratories)?

FBN-PM-9. What are the technological limitations within the country that might affect patient monitoring?

FBN-PM-10. What barriers do you foresee to improving patient monitoring – for patient management and for programme monitoring?

FBN-PM-11. Does the current patient monitoring system need to be adapted per the new *Guidelines* or expanded or improved? What would this require? What steps can be taken to move this system forward? Are there elements that can be pilot-tested?

FBN-PM-12. Is there anything else you would like to add?

Thank you for your participation!

SWOT analysis of results

The strengths, weaknesses, opportunities and threats (SWOT) analysis table below provides a summary of the high-level results from the document review and interviews that comprise the *Assessment tool for person-centred HIV patient monitoring and surveillance*. Based on the result, complete the grid below by giving **no more than three to five high-priority elements** for each SWOT category.

SWOT analysis derived from the rapid assessment of responses with the *Assessment* tool

Strengths	Weaknesses
Opportunities	Threats

Reference table and results scorecard

The analysis of the results of the desk review of documents, interviews and discussions is facilitated by using the reference table to identify the status of each of the 15 major recommendation categories.

1. **SWOT analysis.** Based on this summary, the SWOT analysis matrix can be completed to identify no more than five priority elements for action in each SWOT category.
2. **Priority action plan scorecard.** This scorecard is a summary of the assessment findings and provides a summary of the analysis. It also identifies priority costed improvement actions and support needs to implement them.

Due to lack of uniformity within most countries, it is useful to assess the stage of development and define the priority improvement actions by subnational jurisdictions. After an assessment has been carried out of the developmental status of the major subnational jurisdictions, a consolidated national description can be produced, together with prioritized key improvement actions, a medium-term investment estimate and the support required.

The completed scorecard can be used as a specific, evidence-based tool for planning improvements to modernize HIV patient monitoring, case surveillance and using unique identifiers. The costed priorities are especially useful for explaining and justifying requests for domestic financial support as well as for seeking financial and technical support from development and financing agencies. The toolkit and the scorecard can be filled in repeatedly over time. In this way, the results can be used to monitor progress and evaluate the outcome of interventions to improve the HIV information system.

Using the definitions in the reference table, the country teams can determine the current developmental stage for the 15 major recommendation categories.

Priority action plan

Major area for HIV information improvement	Assessed developmental stage	Top 5–10 priority actions		Support requests	Comment
		Key improvement actions and priority[a]	Cost estimate		
1. Minimum dataset for patient care	☐ Early ☐ Middle ☐ Advanced	1.	1.	1.	1.
2. Transitioning to "treat all"	☐ Early ☐ Middle ☐ Advanced	2.	2.	2.	2.
3. Simplification of tools	☐ Early ☐ Middle ☐ Advanced	3.	3.	3.	3.
4. Integration and linkages	☐ Early ☐ Middle ☐ Advanced	4.	4.	4.	4.
5. Data quality (DQ) review and use for quality of care	☐ Early ☐ Middle ☐ Advanced	5.	5.	5.	5.
6. Standardization of sentinel events and indicators	☐ Early ☐ Middle ☐ Advanced				

Major area for HIV information improvement	Assessed developmental stage	Top 5–10 priority actions		Support requests	Comment
		Key improvement actions and priority[a]	Cost estimate		
7. De-duplication of records to support facilities and improve data quality	☐ Early ☐ Middle ☐ Advanced				
8. Country situation analysis	☐ Early ☐ Middle ☐ Advanced				
9. HIV diagnosis and building on patient monitoring	☐ Early ☐ Middle ☐ Advanced				
10. Key population data	☐ Early ☐ Middle ☐ Advanced				
11. Promote and use an anonymous code	☐ Early ☐ Middle ☐ Advanced				
12. Transition progressively from paper-based to electronic patient information systems	☐ Early ☐ Middle ☐ Advanced				
13. Strengthen and establish different data security levels	☐ Early ☐ Middle ☐ Advanced				

Major area for HIV information improvement	Assessed developmental stage	Top 5–10 priority actions		Support requests	Comment
		Key improvement actions and priority[a]	Cost estimate		
14. Invest in data systems and interoperability	☐ Early ☐ Middle ☐ Advanced				
15. Use individual data to improve programmes and long-term chronic health care	☐ Early ☐ Middle ☐ Advanced				

[a] Priority: 1 = Lowest and 5 = Highest

Reference table for scorecard analysis

These categories are derived from the document and are summarized in Table 1.1 Major recommendations in the guidelines that appears on page 8.

Major categories for improving HIV information	Reference to questionnaire[a]	Suggested criteria for developmental stages (tick assessed stage)			Comment
		Early	Middle	Advanced	
1. Minimum dataset for patient care	SA-8	☐ Standardized indicator list	☐ Data sources identified for key indicators	☐ Simplified, standardized minimum dataset for patient management and monitoring at national, district and facility levels	
2. Transitioning to "treat all"	DRvC-1 SA-8	☐ Treat all policy approved	☐ Pre-ART register maintained	☐ Single ART register	
3. Simplification of tools	DRvC-1 DRqC-2 SA-8,9	☐ No standardized patient monitoring tools	☐ Standardized patient monitoring tools in use	☐ Standardized patient monitoring tools in use across all facilities	
4. Integration and linkages	SA-8	☐ HIV-positive patients referred from TB or MNCH	☐ HIV-positive patients followed in TB and MNCH settings, using HIV patient card. TB or ANC registration number recorded in HIV patient card and ART register	☐ HIV patient card as part of patient folder or passport, electronic register interlinks patients between programmes (HIV, TB, MNCH, other)	
5. Data quality (DQ) review and use for quality of care	DRvC-2 DRqC-3 IG-1 SA-1,4,7,8,9,10	☐ DQ assessment undertaken	☐ DQ audits carried out at facility, district and national levels	☐ Periodic review of patient monitoring system assessing/ improving data quality and quality of care at facilities	
6. Standardization of sentinel events and indicators	SA-1	☐ Standardized indicators collected	☐ WHO sentinel events are collected from HIV diagnosis to death	☐ There is a single system for collecting and sharing key sentinel events – the six key cascade events	

Major categories for improving HIV information	Reference to questionnaire[a]	Suggested criteria for developmental stages (tick assessed stage)			Comment
		Early	Middle	Advanced	
7. De-duplication of records to support facilities and improve data quality	SA-1	☐ No de-duplication is being carried out	☐ De-duplication of records at national level only	☐ De-duplicated counts of HIV-diagnosed persons on treatment used to adjust reporting and shared with facilities	
8. Country situation analysis	All	☐ No recent situation analysis available	☐ Situation analysis completed	☐ Costed action plan developed	
9. HIV diagnosis and building on patient monitoring	DRvC-1,3,4 DRqC-2,3 IG-1 SA-1,7,8,9,10 FBN-4,5,6,9,10	☐ HIV diagnosis incorporated in the case surveillance system	☐ Case surveillance built on patient monitoring systems running in parallel	☐ Consolidated and linked single system of PMCS	
10. Key population data	SA-1,9	☐ Key population data assessed at time of HIV diagnosis or during care and treatment	☐ Periodic assessment of access to services by key population groups	☐ Strong data access, security and confidentiality policies protect key population rights	
11. Promote and use unique identifiers	SA-9	☐ Name-based records, aggregate data based on summary sheets	☐ Unique identifiers at facility level	☐ Programme or national unique identifiers and people-centred health record systems	
12. Transition progressively from paper-based to electronic patient information systems	DRvC-1,2,3 DRqC-1,3,5 SA-1,9	☐ Paper-based record system with records retained at facility or by individual	☐ Offline electronic upload of data with on- or offline data access (electronic registers, reports or records)	☐ Fully online systems used across facilities and in community care; Services linked within a facility and across facilities	
13. Strengthen and establish different data security levels	DRvC-1,6,9 SA-10 FBN-CBS-6 FBN-PM-6	☐ Name labelled paper files used by individual and facility	☐ Records coded with unique identifiers	☐ National system with health record data protected by law with limited and enforced data access control	

Major categories for improving HIV information	Reference to questionnaire[a]	Suggested criteria for developmental stages (tick assessed stage)			Comment
		Early	Middle	Advanced	
14. Invest in data systems and interoperability	DRvC-6 SA-9	☐ Separate data systems that cannot share data	☐ Electronic data systems that can extract and share data on non-routine basis	☐ Fully interoperable data system with routine links to health data, vital statistics, migration data, etc. Useful for tracking individuals lost to follow up, etc.	
15. Use individual data to improve programmes and long-term chronic health care	DRvC-4 SA-1,2,5,8,9,10	☐ Data officer uploads data from paper record to electronic health record; regular data quality reviews	☐ Programme- or central-level analysis of data, and creation of management dashboards and other data analysis and reporting tools	☐ Local analyses of care and programmatic capacity; standardized dashboards, data visualization and reports; regular use of data for decision-making at individual, facility, programme and national levels	

[a] DRvC = Document review checklist; DRqC = Document request checklist; IG = Interview guide; FBN = Assessment of feasibility, barriers and needs

Site visit checklist

Travel logistics

- ☐ At least three weeks prior to the visit, coordinate with the MoH/Centers for Disease Control and Prevention (CDC) regarding potential places for site visits
  - ☐ Sites in the capital area and a high-prevalence area that is geographically different
  - ☐ Sites varying in size (e.g. hospital, health centre, HIV testing only [case surveillance only])
  - ☐ Sites varying by partner support (e.g. MoH, United States Agency for International Development [USAID], nongovernmental organizations [NGOs])
  - ☐ Sites varying by patient monitoring system and EMR type
  - ☐ Laboratory sites performing VL/CD4/EID (case surveillance only)
  - ☐ Sites with innovative systems (e.g. integrated programmes for patient monitoring) or surveillance (case surveillance only) methods
- ☐ Plan agenda for the visit and review with MoH/CDC contact
- ☐ Schedule date and time to allow someone from MoH/CDC to attend
- ☐ MoH/partner lets facility know ahead of time about the proposed visit
- ☐ Obtain point-of-contact information
- ☐ Schedule transport/travel if overnight

Sample agenda

- Welcome and introductions (meet in charge)
- Overview of the project
- Facility tour
- Observe HIV surveillance process/patient monitoring system
- Interview a few key surveillance/patient monitoring staff, as necessary

Sites

Site	Name & location	Visit date & time	Reason site selected
1			
2			
3			
4			
5			
6			

General information

Site visitor: _____ **Date of visit:** _____

Site: _____ **Type of site:** _____

- Greet the person in charge. Introduce yourself if you have not had previous personal contact with him/her.
- Thank them for taking the time to let you visit their facility to observe HIV surveillance/ patient monitoring. Provide a brief overview of the SWOT assessment.

Assess:

- ☐ Existing infrastructure
- ☐ Human resources and need for training
- ☐ Reporting mechanisms
- ☐ Technology capacity and interoperability of systems
- ☐ Data standards/MoH and implementing partners collect same information
- ☐ MoH and implementing partners' use of the information produced by case surveillance or patient monitoring system
- ☐ Feasibility of capturing pharmaceutical data
- ☐ Feasibility of capturing laboratory data
- ☐ Feasibility of linking vital statistics data to patient monitoring/case surveillance
- ☐ Integration/linkages between services/programmes/patient monitoring systems

Observe:

- ☐ Ability to uniquely identify patients
- ☐ Demographic variables collected
- ☐ Clinical information/care continuum measures collected
- ☐ Flow and transfer of data
- ☐ Availability and completeness of vital statistics (especially cause of death) (case surveillance only)
- ☐ Data quality and use of data, including data from laboratories
- ☐ Innovative ways to capture diagnosis to reduce paper-based data collection (case surveillance only)
- ☐ Patient flow (including to laboratory/pharmacy) and experience (how, when, time taken, by whom and in what data are recorded, movement of facility-held patient record, reasons why data might not be recorded)

Debrief form for stakeholders

1. Present highlights of the findings from the SWOT analysis and Priority action plan

2. Summary of data available for case surveillance measures:

Yes	No	
☐	☐	HIV diagnosis date
☐	☐	Entry to care date
☐	☐	CD4 results and date (first and follow up)
☐	☐	Viral load results and date (first and follow up)
☐	☐	Initiation of ART date and regimen
☐	☐	Advanced HIV diagnosis date (WHO stage III or IV)
☐	☐	Death date

Additional comments: