DGHT HIV Case-Based Surveillance Systems Assessment

HIV Case-Based Surveillance

Definition: **HIV case-based surveillance (CBS)** is the systematic reporting of **newly diagnosed persons living with HIV (PLHIV)** at the time of diagnosis and if applicable subsequent reporting of key clinical events (sentinel events) for that individual during the course of the disease. CBS data are **individual-level data** that is **de-duplicated** across healthcare facilities and over time using a set of **identifiable variables or a unique ID**.

Key surveillance events along the course of HIV disease

HIV infection   **Advanced HIV**   **Death**

HIV Case-based Surveillance ⟶

*Diagnosis can occur at any point along the continuum

CBS System Overview

1. Is there a HIV CBS system in your country, where individual-level information on diagnosed HIV cases are reported for surveillance purposes?

☐Yes   ☐No   ☐Don't Know

2. **If "Yes" to Q1,** when did the CBS system start in the country?

Year:__ __ __ __   ☐Don't Know

3. **If "No" or "Don't Know" to Q1**, does the country currently have plans to implement CBS?

☐Yes   ☐No   ☐Don't Know

4. **If "No" to Q3**, what barriers exist for establishing CBS? (**check all that apply**)

☐Lack of national surveillance guidelines or policies   ☐Lack of funding
☐Lack of national guidelines or policies on data security and confidentiality
☐Lack of human resources   ☐No need for CBS   ☐Not a current priority
☐Other (specify):

If "No" to Q3, skip to Policy, Planning, and Legislation Section (Q27).

5. Does or will the CBS system capture the date of diagnosis?

☐Yes   ☐No   ☐Don't Know

6. Does or will the CBS system capture only new diagnoses or existing cases as well?

☐New diagnoses only   ☐Existing and new diagnoses   ☐Don't know

7. Does or will the system capture data longitudinally on subsequent clinical events (sentinel events) including date of event for persons living with HIV?

☐Yes   ☐No   ☐Don't Know

8. If yes, please attach the case report form or data dictionary of events that are captured at diagnosis and follow-up, and any SOP for completing the case report.

9. If death data are or will be captured, where do death data come from? (**Check all that apply**)
☐Vital Statistics   ☐Hospital death reports   ☐ART clinical record
☐Mortality surveillance system ☐Other (specify):   ☐Don't Know

10. Do, or will, non-governmental sites, including private and faith-based, participate in case reporting?
☐Yes   ☐No   ☐Don't Know

Geographic Coverage of CBS
11. What is the approximate geographic coverage of CBS currently in your country (ie, what percentage of public health facilities in your country are participating in CBS)?
☐Currently in planning   ☐100%   ☐99% - 75%   ☐74% to 50%   ☐49% to 25%
☐24% to 1%   ☐0%

Data Reporting and Submission
12. What sites report (or will report) initial reports of newly infected HIV individuals to the above-site level? **(Check all that apply)**
☐HTS Site   ☐ANC facility   ☐L&D   ☐ART Facility   ☐Community
☐VMMC   ☐TB facility   ☐Other (specify):   ☐Don't Know   ☐None of the above

13. What sites report (or will report) data longitudinally on clinical events for PLHIV to the above-site level? **(Check all that apply)**
☐HTS Site   ☐ANC facility   ☐L&D   ☐ART Facility   ☐Community
☐VMMC   ☐TB facility   ☐Other (specify):   ☐Don't Know   ☐None of the above

14. How are, or will, individual HIV case data be abstracted at the site-level? (**Check all that apply**)
☐Paper form   ☐Electronic form   ☐Don't Know

15. How are individual HIV case data reported (or will be reported) from the site-level to an above-site repository? (**Check all that apply—may depend on facility**)
☐Paper report (e.g. courier)   ☐Automated transmission from existing electronic health information systems
☐Manual entry of CRF and electronic transmission   ☐Other (specify):
☐Don't Know

16. **If "Paper report" or "Manual entry of CRF" in Q15,** how often are paper reports entered at the site-level or above-site level?

☐Daily ☐Weekly ☐Monthly ☐Quarterly

☐Annually ☐Ad hoc ☐Other (specify): ☐Don't Know

17. How often are or will data be transmitted from the site-level to the above-site data repository? (**Check all that apply—may depend on facility**)

☐Automatically (real-time) ☐Daily ☐Weekly ☐Monthly

☐Quarterly ☐Annually ☐Ad hoc ☐Other (specify):

☐Don't Know

CBS Data Use

18. Are HIV CBS data used to generate summary reports (eg, quarterly, annually, etc.)?

☐Yes ☐No ☐Don't Know

19. **If "Yes" to Q18**, what is the frequency of reports? (**Check all that apply**)

☐Weekly ☐Monthly ☐Quarterly ☐Annually ☐Other(specify):

20. **If "Yes" to Q18**, how often are the reports reviewed by MOH and stakeholders?

☐Weekly ☐Monthly ☐Quarterly ☐Annually ☐Other(specify):

21. How are HIV CBS data used? (**Check all that apply**)

☐Monitoring of trends of new cases and sentinel events

☐Identification of signals for public health action

☐Intervention at the site-level, regional-level, and/or national-level

☐Patient management at the site-level ☐Commodities forecasting ☐Other (specify):

Security Measures

22. If **"Automated electronic transmission" or "Manual electronic transmission" to Q15,** are any of the following security measures in place for the electronic transmission of HIV case data? **(Check all that apply)**

☐Encryption of data ☐Software barrier ☐Limited personnel access to data

☐Multifactor authentication ☐Require periodic password changes and/or complex passwords

☐Laws, policies, SOPs, or guidelines mandating security measures

☐Other (specify): ☐None of the above

23. Are (or will) any of the following security measures in place for the electronic storage of HIV case data? **(Check all that apply)**

☐Encryption of data ☐Software barrier ☐Limited personnel access to data

☐Multifactor authentication ☐Require periodic password changes and/or complex passwords

☐Laws, policies, SOPS, or guidelines mandating security measures

☐Other (specify): ☐None of the above

24. **If "Paper report" or "Manual entry of CRF" in Q15,** are any of the following security measures in place?

☐Kept in secure and locked location   ☐Record retention policies   ☐Other (specify):

Funding and Management

25. What entity is responsible for managing the CBS system for HIV (**check all that apply**)?
☐MoH   ☐UN Organizations (WHO, UNAIDS, GF)   ☐Implementing partners of USG agencies   ☐Other (specify):   ☐Don't Know

26. What entity funds the CBS system (**check all that apply**)?
☐National Government   ☐Global Fund ☐PEPFAR   ☐Gates Foundation   ☐Other (specify):

Policy, Planning, and Legislation

27. Is HIV a nationally notifiable condition by law?
☐Yes ☐No   ☐Don't Know

28. **If "Yes" to Q27**, does the country mandate the subsequent sentinel events for diagnosed HIV cases—such as date and result of first CD4 cell count, date of antiretroviral initiation, and dates and results of first and follow-up viral load tests—be reported?
☐Yes ☐No   ☐Don't Know

29. Are there guidelines or policies mandating the reporting of HIV to a public health surveillance system?
☐Yes ☐No   ☐Don't Know

30. **If "Yes" to Q27, Q28 and/or Q29**, please attach the guidelines, policies, or SOPs.

31. Are there currently MoH personnel or staff in country dedicated to the public health response and use of CBS data?
☐Yes ☐No   ☐Don't Know

32. Are there currently MoH surveillance personnel or staff in country dedicated to maintaining a CBS system?
☐Yes ☐No   ☐Don't Know

33. Are there any of the following policy-related barriers to data submission? These may include non-surveillance-specific policies or laws that pertain to persons living with HIV or key populations. **(Check all that apply)**
☐No national policy/guidance for case surveillance
☐No policies for data security, confidentiality, and privacy of HIV information
☐HIV criminalization laws
☐Stigmatization/criminalization of key populations
☐Other (specify):
☐Don't Know

Health Information Systems (HIS) for HIV Information
Definition: HIV **Health Information System (HIS)** is an information system designed to capture, store, process, or transmit information related to the health of persons accessing HIV services and programs providing HIV services in the health sector. A country may have multiple HIS (e.g., EMR, LIS, HMIS, etc.)

34. Is there an HIS or multiple HIS in your country for HIV information?
☐Yes ☐No ☐Don't Know

35. Which of the following systems are in the country's current HIS infrastructure? (**check all that apply**)
☐EMR/EHR ☐Laboratory Information System (LIS) ☐Pharmacy Information System
☐National Health Management Information System ☐National Aggregate Disease Monitoring System (e.g., DHIS)
☐National Individual-level Disease Monitoring System (e.g. REDCap, DHIS-2 Tracker)
☐National/sub-national repository (e.g., surveillance information system, disease register, etc.)
☐Client Registry/Master Patient Index ☐Community health information systems (eg, KP)
☐Civil Registration and Vital Statistics ☐Other (specify): ☐Don't Know

36. If you checked yes to EMR/EHR, are there components for any of the following programs? **(Check all that apply)**
☐HIV Testing Services (HTS) ☐ART Program ☐LIS/Lab ☐Mortality ☐Pharmacy ☐Don't Know

37. Are the HIS proprietary or open-source?
☐Proprietary ☐Open-Source ☐Both, depends on system ☐Don't Know

38. What is/are the HIS used for (**check all that apply**)?
☐HIV CBS ☐HIV Patient Monitoring ☐ Clinical Care
☐HIV Program Evaluation ☐Other (specify):

39. Does the HIS have the capability to connect and de-duplicate HIV patient data within facilities?
☐Yes ☐No ☐Don't Know

40. Does the HIS have the capability to connect and de-duplicate HIV patient data across facilities?
☐Yes ☐No ☐Don't Know

41. **If "Yes" to Q39 and/or Q40**, what unique identification method is used to connect and de-duplicate HIV patient data within/across facilities? **(Check all that apply)**
☐Health ID ☐Passport Number ☐Driver License ☐Biometrics ☐Program specific identifier (eg, ART number) ☐Civil Identity card (e.g, national unique ID or some other *non-health* specific identity document)
☐Matching algorithm/pseudo-ID (combination of demographics) ☐Other (specify):
☐Don't Know

42. Does your HIS have the following data in patient records? (**Check all that apply**)
☐First Name ☐Last Name ☐Mother's Name ☐DOB ☐Place of Birth
☐Civil Identity card (e.g, national unique ID or some other *non-health* specific identity document)

43. Does your country have an electronic central data repository for individual HIV client data?
☐Yes   ☐No   ☐Don't Know

44. **If "Yes" to Q43**, does the electronic central data repository have the ability to connect individual HIV client data that are uniquely identified?
☐Yes   ☐No   ☐Don't Know