HIV case-based surveillance: From epidemiology to information needs

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HIV case-based surveillance – update on evolving perspective
Understanding the role of HIV surveillance in a national HIV program

- How does surveillance complement the national HIV program response
  - What do we need to know
    - Surveillance data needs versus program data needs
  - Who needs to know it
    - Surveillance officer versus program manager
  - When do they need to know it
    - Public health action versus program planning

- Can we still have outbreaks when a national HIV program is in place
  - Recent outbreaks (both through needle exchange)
    - Indiana, United States (2015)
    - Cambodia (2015)
  - How well did the outbreak response system work?
Why HIV presents special challenges

- **Infectious disease**
  - Different epidemiologic profile for sub-populations
    - Adults (including various priority populations)
    - Pediatric
    - Exposed Infants
  - Significant concerns around confidentiality

- **Multifaceted approach to prevention & care**
  - “Treatment as prevention”, evolving towards Test & Treat
  - Managed as life-long episode of care (chronic disease)

- **Complex/emerging issues**
  - Long term exposure to Antiretroviral treatment
  - Emerging drug resistance
  - Co-infections

- **Ongoing innovation**
  - Rapid testing assays, Laboratory assays,
  - medication, program innovations
HIV care continuum: data needs for public health decision making

- (on reporting): “A comprehensive approach is needed that accounts for all individuals identified with HIV and follows them up through the care continuum to its ultimate goal of viral suppression”
  
  De Cock and El-Sadr, From START to finish: implications of the start study, The Lancet Jan 2016

- “Weak national systems for case-based surveillance hinder the ability to report routine, localized data and for monitoring of prevention and treatment cascades. Most countries do not have systems for unique identification of individuals, which makes tracking them across prevention and treatment services difficult, leading to inaccuracies in the reported data”

  UNAIDS 2016, Prevention Gap Report
Multiple perspectives on data use

- **Indicator monitoring: count how many individuals are in each part of the cascade**
  - Balance the set of indicators against geo-spatial and attribute disaggregation.
  - If calculating performance against targets, need denominator/target values

- **Patient monitoring: track each individual through the HIV cascade**
  - Primarily a clinical activity - care providers monitor the patients that they are responsible for
  - Comprehensive data needed for clinical management and continuity of care

- **Case-based surveillance: describe (at population level) those individuals who are in the cascade (and those who are not)**
  - Who are the patients that are “leaking” from the cascade
  - Data representativeness and completeness, aim for small data set
  - Data is confidential / anonymous

- … not including exploratory data analysis or research
Data use and the role of patient identification

- **ALL data use perspectives require accurate patient identification**
  - Indicator data is more precise through linked records, eliminating double counting
  - Patient monitoring data is more complete through linked records and allows higher quality care through feedback to the care provider
  - Surveillance data is more complete through linked records

- **ONLY patient care & monitoring**
  - is about knowing the patient identity
    - subject to the strictest policy considerations

- **RECORD linkage versus DATA de-duplication**
  - Linkage: Connect clinical data over space and time
  - De-duplication: Correct double counting
  - When in doubt, do not link records.
    - Remaining un-linked records result in estimation errors during surveillance
UNAIDS & WHO guidance related to HIV Case-based surveillance

2013

2015

2017
Guidelines for second generation HIV surveillance

- HIV case reporting as part of a comprehensive system of HIV surveillance
- “Know your epidemic” vs “know your response”

UNAIDS, guidelines for second generation HIV surveillance: Know your Epidemic, 2013
WHO Consolidated strategic information guidelines

- Responds to the UNAIDS 90-90-90 targets
- Outlines critical strategic information
  - Core indicators – disaggregation levels
  - M&E framework
- Limitations of indicator monitoring
  - A role for HIV case reporting
    - Population level characteristics of individuals not in the care cascade
    - Continuous versus ordinal data
    - Temporal information
  - Epidemiology
  - Service delivery/quality
  - What do we do when we reach the targets?
Strategic Information & the HIV care cascade

- All people
- Reached by prevention activities
- Aware of HIV status
- Enrolled in HIV care
- On ART
- Viral load suppressed
WHO consolidated guidelines: Person-centered HIV patient monitoring and case surveillance

• Emphasis on
  – Patient identification scheme
  – Reporting process (events and data)
  – Confidentiality
  – Policy and governance

• Cautions
  – including Key Population category
    • considered too high of a risk in most settings

World Health Organization, Consolidated guidelines on person-centric HIV patient monitoring and case surveillance, Geneva, 2017
Tracking individuals in the HIV continuum
Analytics (1)

- Core aggregate counts (correspond to indicator definitions)
  - What proportion of people living with HIV have been diagnosed?
  - What proportion of cases diagnosed is linked to care?
  - What proportion of patients are retained in care?
  - What proportion of cases are currently on ART?
  - What proportion of cases enrolled to care are virally suppressed?
  - What is the mortality rate?

- Is there a significant change over time in these values
Analytics (2)

- Multiple variables, temporal analysis
  - What are the socio-demographics (e.g., age, sex, key/priority population group, residence, location of test) of persons newly diagnosed with HIV?
  - What is the average time between HIV diagnosis, linkage to care, and ART initiation?
  - What proportion of cases receive a viral load testing within 12 months of ART initiation?
  - What is the impact over time of ART on CD4 and viral load test results?
  - What is the time from diagnosis to any other sentinel event?
  - What is the mortality rate of PLHIV on ART?

- Is there a significant change over time in these analyses
Implementation
HIV Case Report Form (CRF)

- Establishes an approved reporting process
  - A CONTRACT on data sent from service delivery to public health

- Process
  - Develop
    - Establish a MINIMUM data set
      - Focus on making form submission easy and fast
        » Trace all data elements to any relevant data source
    - Allow both paper-based and electronic implementation
    - Build in a planned revision process
  - Prototype & test
    - Document use cases
      - to ensure all sentinel events can be tracked
    - Define the role of the surveillance officer in data abstraction/review
  - Approve
    - Initiate MOH approval process.
HIV CRF essential content

1) Administrative
   - Reporting facility, staff, date of transmission
   - Report sequence (initial, update, correction), triggers/sentinel events

2) Patient
   - Identifiers & identifying information
   - Demographics: DOB (age) & sex

3) HIV
   - Diagnostic
   - Risk factors
   - Laboratory (immunology, virology)
   - Therapy (date of initiation, regimen)
   - Clinical findings (WHO stage)

4) Other health related (optional)
   - Antenatal (female)
   - TB episode status (diagnosis + program state)

5) Loss-to-follow up

6) Death
EMR case-based surveillance
Facility workflow in BPMN

Business Process Model (BPMN 2.0) contributed by Stanley Kamocha, CDC Zambia, 2016
Coverage versus representation

Prioritize inclusion of electronic data sources
  – EMRs and LIS

  • Emphasis on geographical coverage
    – Includes larger number of persons

  • Coarser data analytics
    – Especially for missing testing locations

  • Prioritize regional completeness
    – Include all (most) data sources in a region
    – Determine how to use paper based source systems

  • Emphasis on local representativeness
    – more expensive to scale up

  • Finer grain analytics
    – But overall less data
CDC Atlanta Division of Global HIV and TB -- HIV CBS task team

- **Organization – participating branches**
  - Health informatics, data management and statistics
  - Epidemiology and surveillance
  - Monitoring and evaluation
  - Science Integrity

- **Develop guidance on**
  - Protocol development
    - Address differences in intended data use
    - Consider different requirements on confidentiality and use and management of patient level data
  - Health Information System development and review
    - Collection and processing of HIV program data with electronic and paper-to-electronic processes
Surveillance from Electronic Health Records, PHI perspective

- Tools and resources to help public health agencies access and use EHR data
- Adaptable to a wide range of conditions
- Based on
  - comprehensive planning
  - sound informatics principles
- Responds to
  - Increased uptake of EHRs
  - Requirements for data use
- Focused on the domestic USA
  - But broadly generalizable methods

phii.org/ehrtoolkit
Electronic Case Reporting

Push Model - Basic Workflow

Public Health Agency  |  Clinical Care

Author Reporting Criteria  |  Consume Reporting Criteria

Report Criteria  |  Implement Trigger Codes

Patient Meets Reporting Criteria  |  Build, Send Case Report

Add Case to Surveillance Database  |  Case Report

Case Report  |  Structured Data Capture

need more info?  |  Complete, Send Case Investigation Form

Provide Electronic Form  |  Response

Form  |  Clinical Decision Support

Adapted from PHII presentation to CDC CHIIC forum, 11 Aug 2015
See also http://www.cste.org/group/RCKMS and http://www.thephcp.org/committees/case-reporting
A pragmatic approach to architecture

• Country may have planning activities around eHealth
  – Strategic plan, policy
  – National approach to eHealth architecture

• Employ the concept of “just-in-time architecture”
  – (term inherited from ICT literature 1996)
  – Ground national level activities with respect to priority needs
    • Build only the pieces that you need, but build those the right way

• We need a MINIMAL approach to health information exchange
  – Define what is needed for CBS
  – Other program priorities may influence implementation planning

Business Process Model (BPMN 2.0) contributed by Stanley Kamocha, CDC Zambia, 2016
Pragmatic approach to implementation minimum needs

• A STANDARDIZED MESSAGE format to encode the CRF data
• AGREED upon content
  – Create a plan for adopting data standards
• A SECURE message transmission mechanism to transmit the CRF from each service delivery to the public health data store
  – Trust the messages & the communicating parties
• A ROBUST method to link records from individuals from each service point over their lifetime
  – Implementing an identification scheme is a process
A health information exchange (HE) makes the sharing of health data across information systems possible.

1. Client registry
2. Provider registry
3. Health facility registry
4. Terminology service
5. Shared health record

Health interoperability layer

Clinical systems (i.e. Open MRs)
Laboratory information systems
Hospital record systems
Community health worker systems (i.e. Rapid SMS)
Pharmacy systems

Point of service

CHW
CHW manager
Ambulance
Health Information Exchange
minimum approach for CBS

Client
  Testing
  Care
  laboratory

Trigger and dataset definitions
Control clinical data messaging

Interoperability services
Longitudinal Record

HIM
Clinical Data Store
Client registry

Secure data environment controls
access to patient identity

Surveillance data mart
Person matching
THANK YOU

For more information please contact Centers for Disease Control and Prevention

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The findings and statements in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.