SPOTLIGHT ON DATA

Sub-group of the UNAIDS Advisory Group on Science

Meeting Report

October 8th, 2020

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Background

The UNAIDS Advisory Group (UAG) provides the UNAIDS Executive Director with strategic guidance to support the repositioning of UNAIDS during the transition, and strategy development period from 2020 to mid-2021. More specifically the UAG advises UNAIDS on the development of strategic priorities for the UNAIDS Joint Programme; UNAIDS' institutional transformation and internal culture; and the next UNAIDS strategy.

In order to inform the next global AIDS strategy a specialized sub-group of the UAG on Science, data and innovation has been established.

A technical consultation on strategic information ("Spotlight on data") was held on 8 October to a) explore UNAIDS short and long term programmatic priorities in HIV surveillance and monitoring as the HIV response moves towards 2025, and b) to make recommendations on HIV surveillance and monitoring for the upcoming UNAIDS Strategy 2022-2026 (proposals can be further elaborated with support from the UNAIDS Monitoring Technical Advisory Group (MTAG), the UNAIDS/WHO Working Group on HIV/AIDS/STI surveillance and the UNAIDS Reference Group on Estimates, Modelling, and Projections, among others.

Summary of Breakout Discussions

Participants were divided into 4 groups to cover the following topics a) Surveillance Data b) Monitoring of programmatic and policy data c) Systems and d) Community monitoring

Surveillance data:

The first questions addressed by this group was "What additional input data will be needed to better inform the current trajectory of the epidemic in the next decade?". The following key recommendations were proposed:

- Better understand where new HIV infections are coming from given infections are declining globally. As we reach 90 90 90 we need to identify new HIV infections quickly, and need data metrics for this and the rapid evolution in the ability of data systems to capture this information in many countries
- Transition from collecting data that monitors HIV risk and treatment to capturing data on new HIV diagnoses. This will require robust, high quality systems for monitoring new diagnoses, and case surveillance acknowledging that they are complex and there are challenges in maximizing their use of systems for surveillance
- Data and surveillance for key populations will increasingly be important to understand the epidemic across different settings. Priority for case surveillance and risk surveillance data to be used alongside risk data from molecular surveillance, social media data.
- Improve the measurement of use of preventive services (e.g. PrEP), using routine data systems like insurance claims
- Need for high quality data on pathways to care, loss to follow up, and return to care including why people were lost and why they returned to care
- Need to understand where (location) people live and seek services

The second question addressed by the group was "What systems need to be set up to generate those additional data?". The following key recommendations were proposed:

- Surveys could become efficient if integrated into routine data systems (use of rapid tests and transport and lab network used for VL to conduct household survey)
- Molecular surveillance using phylogenetic analysis has potential to identify recent infections and clusters of transmission

Monitoring of programmatic and policy data

The first question addressed by this group was "What input data will be needed to better inform adoption and implementation of guidelines in the next decade?". The group recognized that global adoption of guidelines is reported on through the GAM although there are existing challenges with receiving complete/timely information. The following key recommendations were proposed:

- Invest in routine information systems and national systems to allow a higher degree of country-ownership. For example, monitoring systems for KPs are largely created by donors and therefore not sustainable.
- Implement unique identifiers so patients can be followed through the various services
- Increase harmonization of required data among donors
- Focus on implementation of guidelines

The second question addressed by the group was "How to best monitor guideline adoption?". The following key recommendations were proposed:

- Efforts to provide real-time feedback to countries are needed (ie: from GAM reporting on guideline adoption)
- Emphasize implementation, rather than adoption of guidelines
- Strengthen users of guidelines to share their data
- Incorporate end user feedback to improve monitoring (at national and sub-national levels)
- Ensure monitoring at sub-national level as well as national level

Systems

The first question addressed by this group was "What should be done in the next 5 years to reduce duplication in data collection, analysis, visualization?". The following key recommendations were proposed:

- At the global level:
  - Build on existing measurements to reduce asking for duplicate reports and data
  - Bring learnings from COVID to better collect and use data
- At the regional level
  - Focus on regional analysis and country comparisons which facilitate healthy capacity leveraging so that countries start learning from each other. As an example, Africa CDC can play a key role here
- At the country and subnational level
  - Setup oversight bodies to look at data collection and systems mechanisms, (eg: Zambia eHealth Coordination Mechanism)
  - Moving towards open data, anonymised, synthesized datasets.
  - Establish data repositories at national level.
  - Push for real time data use agenda and sharing for programmatic change (real time varies by country/data), "Health situation rooms" is an example.
  - Investments should be made by governments in surveys and move towards multi-disease, multi-sectoral surveys and better utilization of surveys using AI and machine learning.
  - Promote Electronic Medical Records and Unique IDs in an effort to reduce the burden of data collection and de-duplication of data. Prioritise high-volume facilities
  - Establish laws and policies on unique ID and data safety and security

- o Collect data on people who are not being reached by services
- o Understand mortality and morbidity data and ensure link between vital statistics and ministry of health statistics to allow triangulation with data coming facilities.

The second question addressed by this group was "What should be done in the next 5 years to further integrate HIV surveillance and monitoring with surveillance and monitoring for other diseases/conditions?". The following key recommendations were proposed:

- Establish a role of regional bodies like Africa CDC or Euro CDC for region-specific needs
- Address under-utilisation of DHIS and other survey-based data
- Use the opportunity provided by UHC for integration of multi-diseases
- Move towards epidemic control and transition creates opportunity for HIV surveillance to be integrated into disease surveillance
- Ensure structures in the Ministry of Health reflect this integration
- National AIDS Councils/Commissions need to expand their mandate to other diseases such as NCDs and multi-disease screening, and mental health

Community monitoring

The break out group on community monitoring discussed both community-led monitoring data and community data recognizing that community monitoring data is very specific, collected formally, and repeatedly over time. The group proposed the following recommendations:

- GAM could incorporate more textured stories, surveys and photos which are broader than data currently monitored
- Currently, there are many forms of community led data which need strengthening in terms of quality and scope. In the future opportunities could be created for community data to come into monitoring side-by side existing monitoring activities.
- There is an urgent need to differentiate community delivery of services from community-led monitoring which is routine, systematic collection by communities of information on the quality and accessibility of HIV treatment and prevention services & broader health services. Quantitative and qualitative data about services are needed, whether they are government provided or community-provided.
- Communities can monitor the 5As: affordability, availability, accessibility, accommodation, and acceptability as a framework
- Community data can validate and triangulate data collected through other channels. For example when coverage levels do not match the epidemiological data on key populations. This includes information on:

  - Coverage levels: e.g. ART numbers, people on PrEP, etc.
  - Loss to follow up vs. silent transfers
  - Stock outs
  - Legal barriers, human rights, enforcement of the law, implementation of the law
  - MMD
  - % of service delivery that is "community" led (& KP led)
  - Turnaround time for Viral Load & use. TAT-R to patient.
  - Availability & integration of services beyond HIV—TB, SRH, etc

- Community data can collect information that's not collected elsewhere
  - Quality of treatment & prevention services they receive
  - Size estimates missing from prevention scorecards

- User fees
- Stigma
- "Adverse events" including IPV
- Community level treatment & prevention literacy
- Quality of community-led services
- Sustainability of community services, programs, organizations including Implementation of social contracting
- What is being provided at community level, tracking innovation, etc.
- Create ties into a broader accountability system such as budget monitoring (e.g. govt investment in PrEP), and political engagement (Are we talking to the right ministries?)
- Bring back shadow reports which may be a useful opportunity for community data to be incorporated into GAM. What does a useful shadow reporting look like in 2020? GAM could incorporate community-generated data, elevate it, let it sit alongside official reported data.
- Community data collection & validation can be a key indicator of "community systems strengthening"—if communities are not, cannot generate—then we know community system is not strong.
- A suggestion was made for UNAIDS to look into the HIV Policy Lab's website at https://www.hivpolicylab.org/ which provides a comprehensive overview of the adoption and implementation of different HIV-related policies.

Conclusions

The meeting chairs acknowledged the quality of discussions and reports and opened the floor for discussion. Participants noted commonalities between recommendations from group 1 on surveillance and group 3 on systems and need to ensure quality of data collection by ensuring infrastructure, and capacity challenges are addressed ("brain drain"). Participants also noted importance of social enablers to enable communities to do their work.

Annexes

- Agenda
- LoP

Technical Consultation

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Meeting Agenda

08 October 2020

Objectives:

- To explore UNAIDS short and longterm programmatic priorities on HIV surveillance and monitoring as the HIV response moves towards 2025
- To make recommendations on HIV surveillance and monitoring for the upcoming UNAIDS Strategy 2022-2026 which will be elaborated with support from the UNAIDS Monitoring Technical Advisory Group (MTAG) and the UNAIDS Reference Group on Estimates, Modelling, and Projections

Time (CET)	Session	Presenter
14:00-14:05	Welcome and overview of agenda	Adeeba Kamarulzaman Peter Ghys
14:05-14:30	Plenary session: • Background and Objectives of technical consultation • Methodology • Discussion and Q&A	Peter Ghys Adeeba Kamarulzaman
14:30-15:30	Breakout Groups: 1. Surveillance Data 2. Monitoring of programmatic and policy data 3. Systems 4. Community monitoring	Participants
15:30-16:30	Plenary session: • Report back from groups (20 minutes) • Discussion and Q&A (30 minutes) • Summary and next steps (10 minutes)	Adeeba Kamarulzaman / Peter Ghys

List of Participants

<u>Co-chairs of the UNAIDS Advisory Group (UAG) breakout-group on science</u>

GHYS, Peter (UNAIDS)
KAMARULZAMAN, Adeeba (IAS President; University of Malaya)

<u>Participants:</u>

1. BAPTISTE, Solange (ITPC)
2. DABIS, Francois (ANRS)
3. EATON, Jeff (co-chair of the Reference Group on Estimates, Modelling and Projections; and Imperial College, UK)
4. GREEN, Kimberley
5. KAUR, Anjali (BMGF)
6. KIRUNGI, Wilford (MoH Uganda)
7. KUMAR, Pradeep (MoH (NACO) India)
8. MHANGARA, Mutsa (MoH Zimbabwe)
9. NKENGANSONG, John (ACDC)
10. PASCOM, Ana Roberta (MoH Brazil)
11. STEGLING, Christine (Frontline AIDS)
12. STOVER, John (Avenir Health)
13. ZHAO, Jinkou (GFATM)

<u>UNAIDS Secretariat:</u>
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8. SABIN, Keith
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