Using Routine Data to Improve Antiretroviral Treatment Retention:
Examples and Lessons Learned from the Literature and Experts in the Field

MEASURE Evaluation
Nena do Nascimento, Palladium
Catherine Barker, Palladium
Michelle Li, Palladium

USAID
FROM THE AMERICAN PEOPLE
PEPFAR
MEASURE
Evaluation

Contents

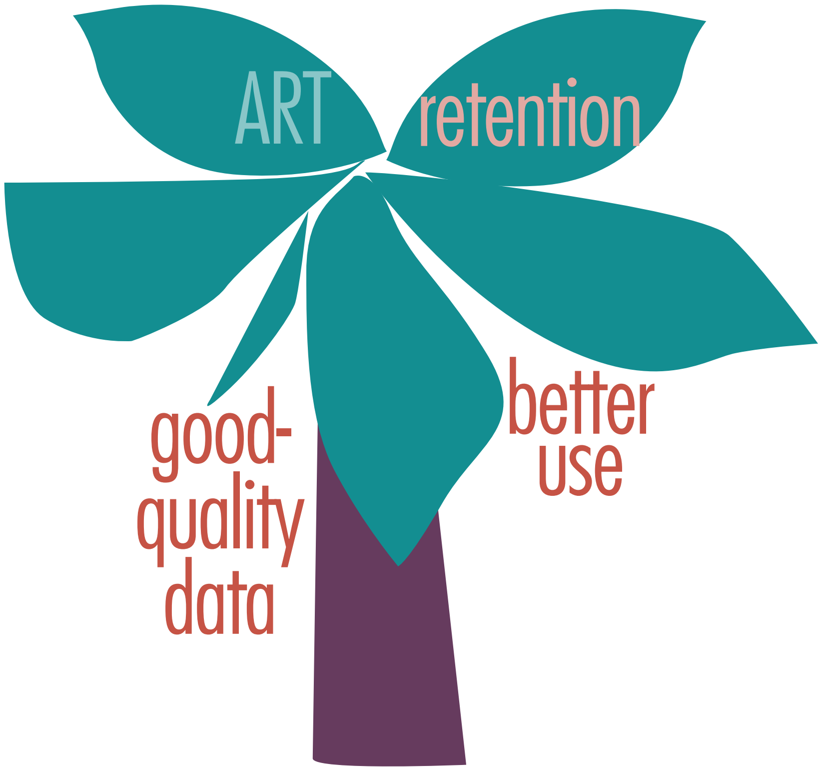
Cover photo credits: Left: United States Centers for Disease Control and Prevention, http://africaunchained.blogspot.com/2014/08/malawis-national-electronic-medical.html; Center: Riccardo Lennart Niels Mayer, iStock Photo, 2015; Right: Paul Jeffrey

01

Introduction

As is almost always the case, the key to **helping people be healthy** lies with people. In the case of increasing retention in antiretroviral therapy (ART), one key is a strong cadre of community health workers, empowered by a staff of data managers who provide quality data and good data analysis.

Good-quality data and better use of them are the low-hanging fruit to achieve retention on ART (antiretroviral treatment) — because we can do that now.



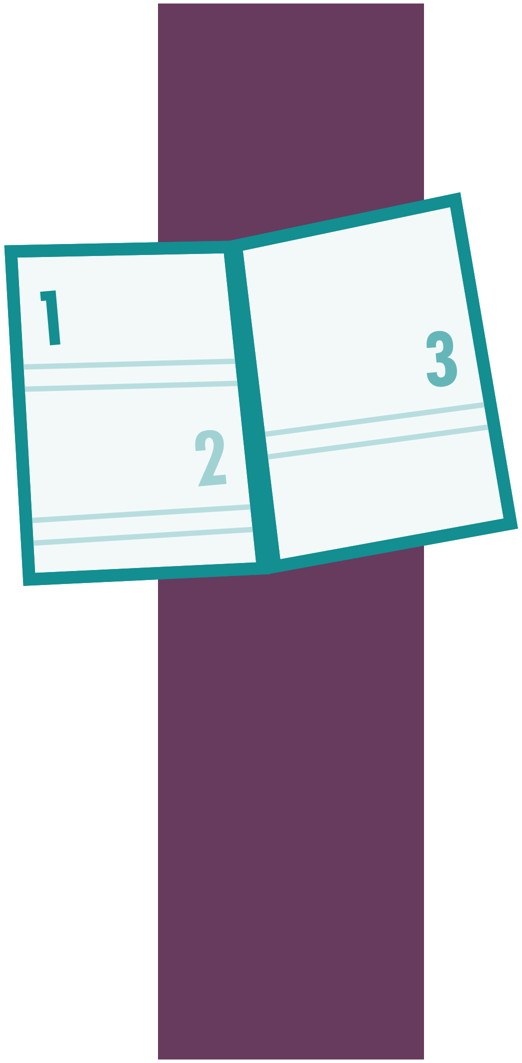
The importance? Retention in care is important if we want to curtail transmission of HIV and achieve an AIDS-free generation. Retention in care is the cornerstone of the UNAIDS 90 90 90 strategy.

Photo credit: Hammond, JSI, Liberia

All this may sound simple. It's not. Harnessing data to increase ART retention involves a diverse set of skilled practitioners, motivated to **collect**, **analyze**, and **use** **routine health facility data**. It also requires quality controls for data, sharing data across systems, and the support of country health-program managers and facility staff to sustain achievements.

This document **summarizes** the three main ways that routine data are currently used to improve adult ART retention in low-resource settings, **challenges** to their use, and **recommendations** on how to strengthen data use for improved HIV outcomes.

(Study conducted by MEASURE Evaluation from December 2015–October 2016.)

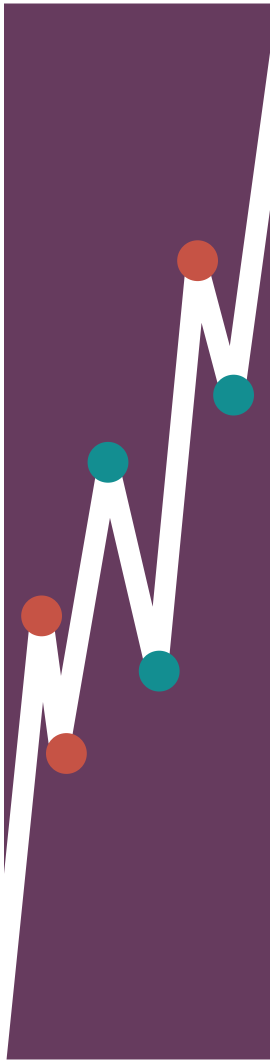


We identified three types of interventions to support retention: **data capture**, **data review**, and **client tracing**. Almost all of them ultimately rely on community health workers (CHWs) to support clients, and every one of them relies on good-quality data that are USED in programs, not just reported.

Photo credits: Partners In Health, http://www.pih.org/blog/remembering-ti-joseph-patient-friend-and-hiv-advocate

So, we know that data are really important. But data are not created in a vacuum:

- National, district, facility, and community health system staff collect, aggregate, and analyze routine data for trends and achievements.
- Funders — governments, agencies, and foundations — pay for HIV interventions to increase ART retention and they have their own data reporting streams.



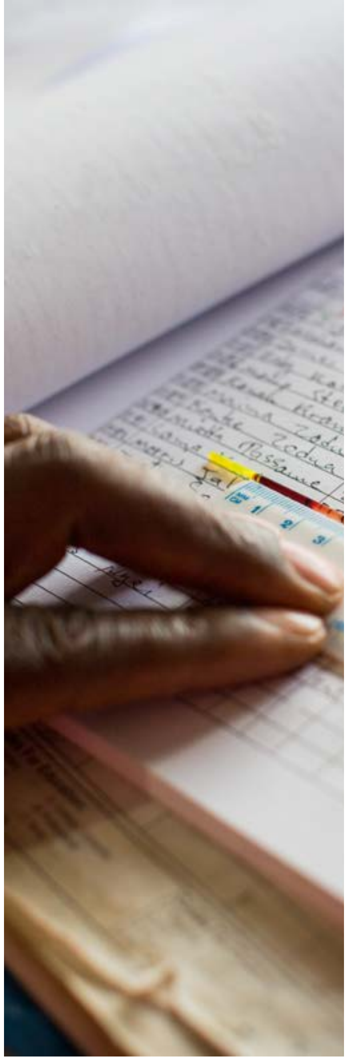
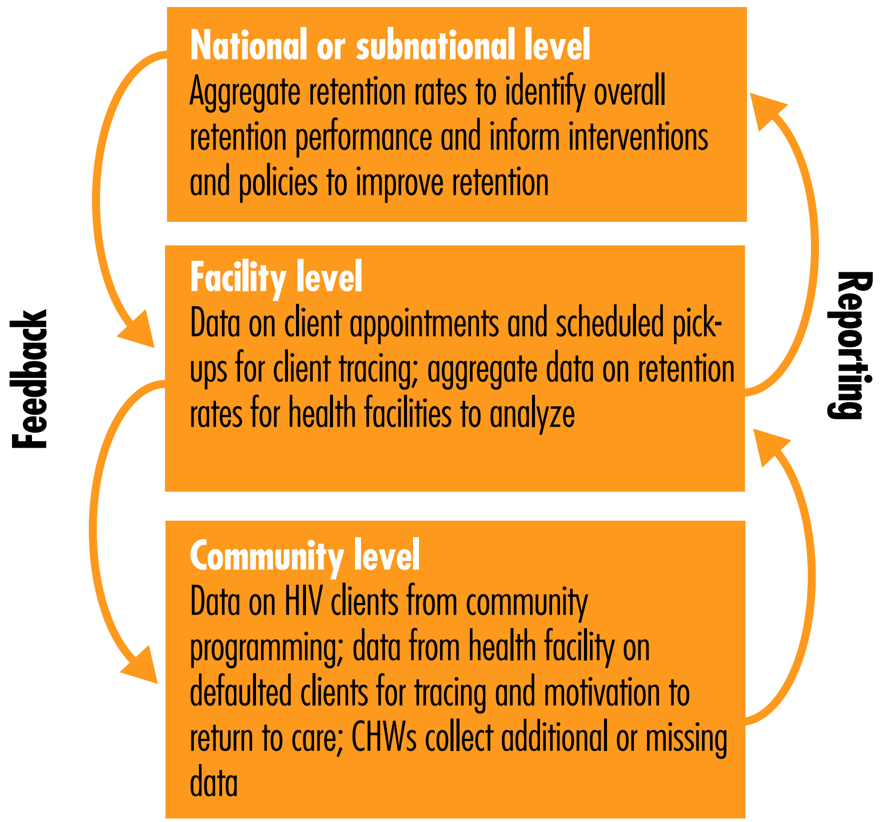


Photo credit: Hammond, JSI, Liberia

These players (health system staff and funders) use **routine health information systems (RHIS)**, in which people record information at regular intervals to meet predictable information needs. Data collected on health status, health interventions, or health resources may be captured in these systems.

- **As countries work toward 90-90-90 goals, they must be able to assess how well their RHIS are able to track clients and monitor their visits to facilities and clinical data effectively.**

RHIS and ART Retention Data



Collection and Use of Routine Data for ART Retention

National or subnational level
Aggregate retention rates to identify overall retention performance and inform interventions and policies to improve retention

Facility level
Data on client appointments and scheduled pick-ups for client tracing; aggregate data on retention rates for health facilities to analyze

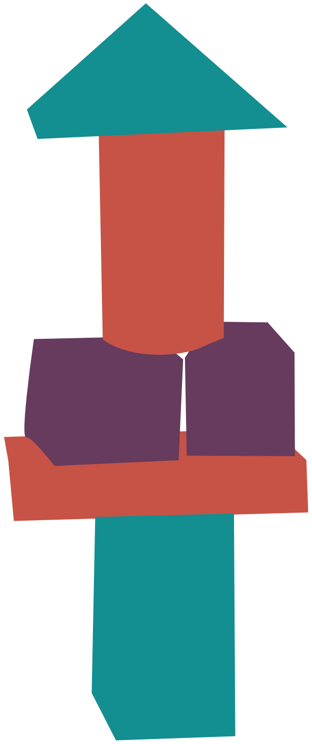
Community level
Data on HIV clients from community programming; data from health facility on defaulted clients for tracing and motivation to return to care; CHWs collect additional or missing data

An RHIS may store data on ART retention at the community, facility, subnational, and national levels.

Data on retention from multiple sources are stored at each of these levels.

Data are normally reported up through the system, and feedback ideally flows down through the system in a continuous process.

We studied how routine data are being used and what would be needed to use them more effectively to increase ART retention. Here's how we constructed our review:



3 We **interviewed** key informants to learn more about specific programs, interventions, or experiences that respondents identified in the online survey.

2 We **conducted** an online survey to fill in the gaps in the literature, by asking 63 practitioners and experts in the field about their knowledge of how routine data are being used to improve ART retention.

1 We **examined** almost 4,700 documents to summarize how facilities and programs use client data to retain adults on ART* in low- and middle-income countries and the effect of these interventions on retention in care.

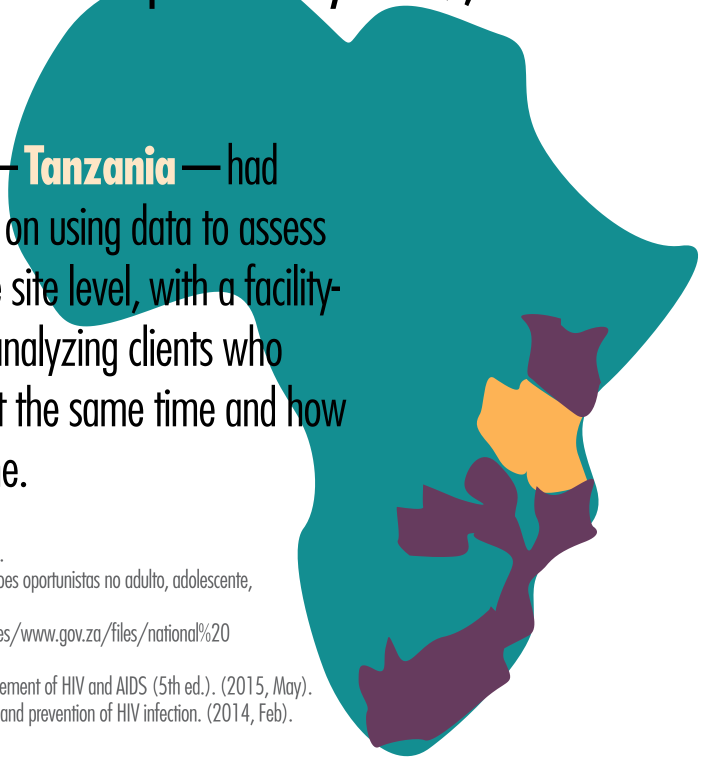
*Excluding pre-ART clients and clients receiving services to prevent mother-to-child transmision of HIV

This three-step process found limited availability of high-quality evidence. Nevertheless, survey respondents were confident that good RHIS data can and do improve ART retention.

That conviction is something to build on.

We also reviewed government HIV guidance documents from Kenya,[1] Mozambique,[2] South Africa,[3] Tanzania,[4] and Zambia.[5] These provided instructions on how to define clients as defaulted based on length of time since an expected encounter (e.g., appointment or pharmacy visit), and how to report on their status.

- Data sources to identify defaulters were patient appointment books, pharmacy records, and community programming records.
- Only one country — **Tanzania** — had national guidelines on using data to assess performance at the site level, with a facility-based register for analyzing clients who began treatment at the same time and how they fared over time.



[1] National AIDS & STI Control Program. Guidelines on Use of Antiretroviral Drugs for Treating and Preventing HIV Infection in Kenya (2016 ed.).

[2] Republica de Mozambique, Ministerio da Saude, Direccao National de Assistencia Medica. (2014). Guia de Tratamento antiretroviral e infeccoes oportunistas no adulto, adolescente, gravida e crianca 2014. http://www.who.int/hiv/pub/guidelines/mozambique_art.pdf.

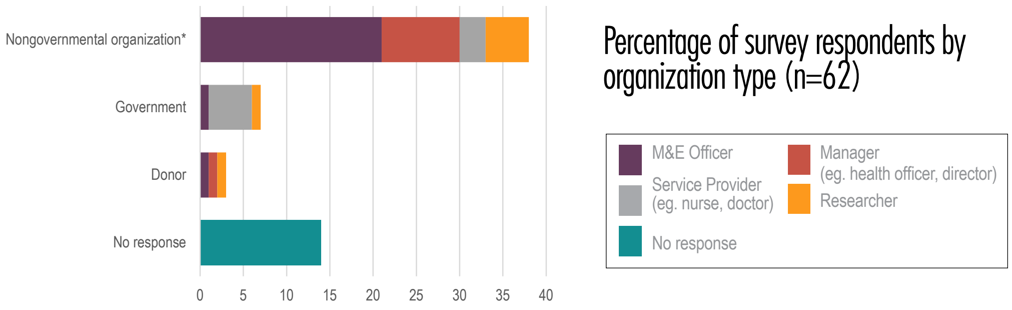
[3] South African National AIDS Council (SANAC). National Strategic Plan for HIV, STIs, and TB. (2012–2016). 2011. http://www.gov.za/sites/www.gov.za/files/national%20strategic%20plan%20on%20hiv%20stis%20and%20tb_0.pdf.

[4] The United Republic of Tanzania, Ministry of Health and Social Welfare, National AIDS Control Programme. National Guidelines for the Management of HIV and AIDS (5th ed.). (2015, May).

[5] Ministry of Health and Ministry of Community Development, Mother and Child Health. (2014). Zambia consolidated guidelines for treatment and prevention of HIV infection. (2014, Feb). Retrieved from http://www.hivpolicywatch.org/duremaps/data/guidelines/ZambiaARTguidelines2013.pdf.

Characteristics of Online Respondents and Key Informants

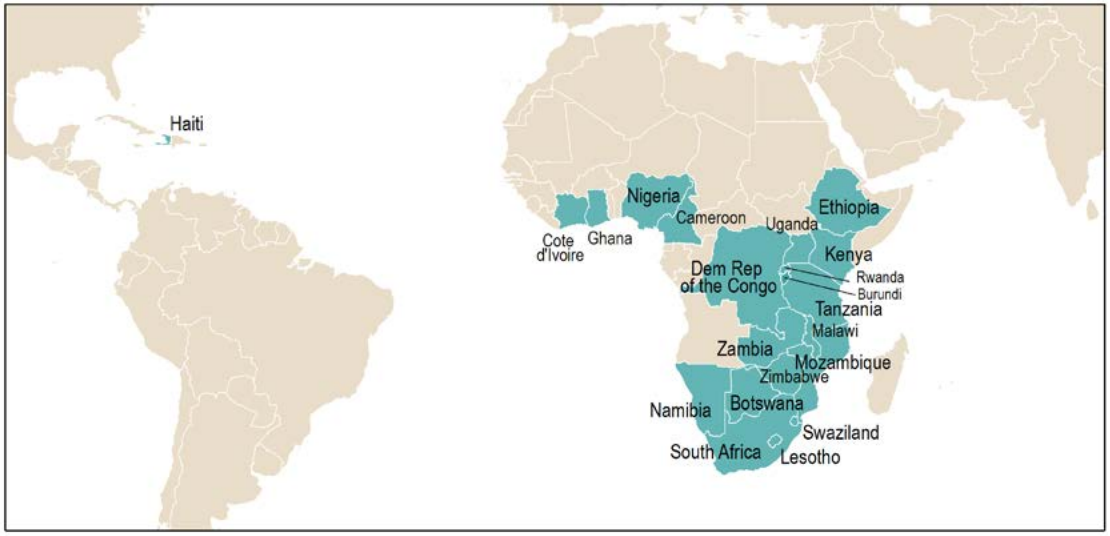
Key informants (N=7): Most key informants interviewed were M&E specialists and described their experiences working in Bangladesh, Chad, Democratic Republic of the Congo, Ethiopia, Kenya, Liberia, Madagascar, Mexico, Nigeria, Rwanda, Tanzania, Uganda, Zambia, and Zimbabwe.



Percentage of survey respondents by organization type (n=62)

*Includes implementing partners, universities, associations, and local civil society

Countries with PEPFAR funding where respondents had relevant work experience



02

Key Findings

We found **three main ways data are used** to improve ART retention:

DATA CAPTURE:

Health facilities improve the systems used to collect routine data, by introducing an appointment book or electronic medical record system that alerts staff when patients default

In Western Cape, **South Africa,** a longitudinal paper-based ART register system was introduced to track cohorts of patients by month of ART initiation, making it easier to track patient outcomes, including retention*

*South African National Department of Health (SANDOH). (2010)

DATA REVIEW:

Reviewing facility data with clinic staff, community workers, and other to discuss how ART retention can be improved using techniques already established or identifying new methods

AIDSRelief in **Kenya** held patient care audit meetings with a multidisciplinary team, using data to identify areas of improvement and strategizING ways to close gaps, including enforcing use of clinic diaries*

*Wandina, et al., (2011)

CLIENT TRACING:

Clients who miss a pharmacy, clinical, or laboratory appointment are identified using health facility records and contacted to determine status and/or bring them back to care

In Nhamatanda district in **Mozambique,** community workers phone or make home visits to ART patients who are overdue for pharmacy pickups or needed consultations*

*do Nascimento, N.& Joao, F. (2013)

Most studies focused on the third way: client tracing. Few described data reviews and improved data capture. Our literature review showed few instances of using data specifically to increase ART retention. More often, data were used to determine the existing rate of retention.*

The quality of evidence in the studies we found was weak. Most assessed pilot or small-scale programs and did not use comparison groups. Most also assessed greatly differing interventions—meaning there was no opportunity to generalize any one approach.

*e.g., McMahon, et al., (2015); Dalal, et al., (2008); Scheibe, et al., (2013); Forster, et al., (2008).

Techniques for locating or learning the status of defaulted clients are:

- Phone calls, home visits, reaching out to a treatment buddy or emergency contacts, and SMS reminders
- Consultation with community-based programs regarding the status of a client.

"The **use of this data has increased adult ART retention**. This data [ART clinic-register data] has been used to reduce loss-to-follow-up through the use of mHealth interventions and increase ART client education through real-time call center consultations with doctors."

– Respondent working in Uganda, Kenya, and Nigeria

> "…use of these data increased patient retention, by ensuring that regularly, a list of defaulting patients was printed and given to community health workers/case managers to go either call the defaulting patient or go into the community to trace the individuals. By doing this regularly, the program could account for those who were lost to follow-up and those who were defaulting but returned to care. In addition, this data helped the program to collect reasons why the patients were defaulting and had them addressed to increase retention."
>
> —Survey respondent with experience in Ghana

Photo credits: Partners In Health, http://www.pih.org/blog/remembering-ti-joseph-patient-friend-and-hiv-advocate

Survey respondents and interviewees report multiple challenges that affect their ability to use data effectively:

- Inaccurate data and errors on client forms, especially for elements such as client locator information, appointment dates, or client IDs
- Lack of timely data entry, leading to missing data and misclassification of clients

"In many facilities, the **quality of available records is poor**, and it is difficult to link client records into a longitudinal history. Sometimes unique identifier numbers do not match, or are not captured, and it can be difficult to differentiate between holes in the data and actual missed visits."

—Respondent working in Zimbabwe

And there are structural challenges:

- Informants said community-based interventions and their data are not linked with health facility activities and their data.

- Connection between pharmacy data and health facility data is often weak

- While CHWs are a key component to finding defaulted clients, they are often given additional ad hoc or even formal duties at health facilities (e.g., data entry because of inadequate staffing), limiting the amount of time they can trace and counsel patients.

- The reliance on donor support for much of community programming and tracer programs raised questions about the long-term commitment of the government to support community programs to strengthen retention in care for people living with HIV.

Larger concerns have more to do with culture and management:

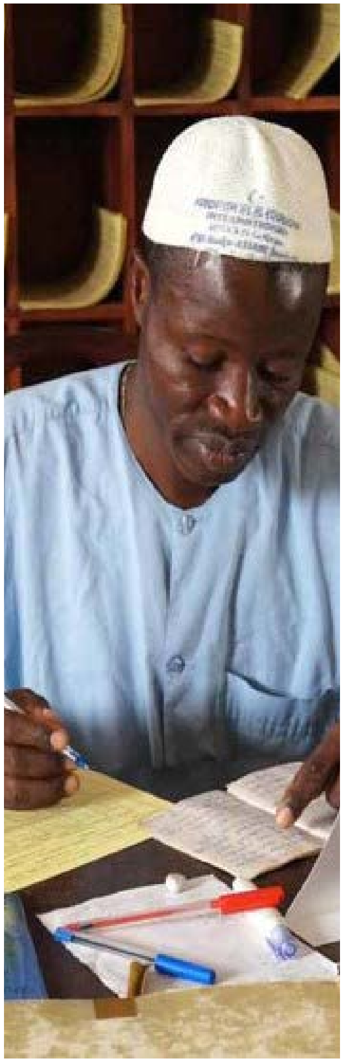
- Data-use culture at health facilities was described as poor. While many respondents described the existence of data review forums, they report that client data were rarely or improperly analyzed for trends and visualization tools did not exist to help staff understand their data.
- Others described a lack of motivation and ownership among healthcare providers to capture accurate client data, because roles and responsibilities between clinicians and M&E staff were not clear.
- Patients provide false information because of stigma and privacy concerns.

"**[We] lack proper tools for analyzing** routine data—e.g., trend analysis, dashboards, and visualizations, which make it easy to interpret performance."

—Respondent with experience in Kenya

Larger concerns have more to do with culture and management:

- Many existing systems are geared for national or donor data collection and reporting, not program or client monitoring at the facility level. Disparate information in different databases is hard to use and often not useful for analyzing needs at the facility level.
- Many clinic staff feel overworked, overwhelmed with competing duties, and under compensated. Thus, they delay their data capture and reporting responsibilities.
- Staff at health facilities lack the capacity and time to conduct routine data analysis. They need additional training on analysis and use, and tools for interpretation and communication of data. This would strengthen data quality and use, mentioned by many key informant respondents as essential.



> “The great challenge with daily data collection is that there is use of a lot of registers and also patient files and therefore the staffs may get overwhelmed with the duty… Power fluctuations also may delay the electronic process of data entry.”
>
> —Respondent working in Kenya

Photo credit: https://static1.squarespace.com/static/5412c0dfe4b0a1dd950e3cdb/t/570db4994d088ed2c69f3ab1/1460516007710/

03

Conclusions & Recommendations

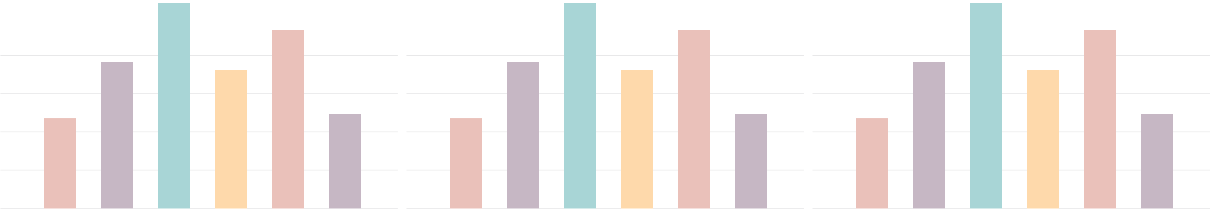
Conclusions:

- We found many examples and evidence of patient tracing to improve ART retention –in the literature, national guidelines, survey and key informant interviews – but using data to hold data review meetings and improving data capture systems were cited much less frequently.

- Human resource constraints – at the facility and in the community – are a major barrier to improving ART retention in low-resource settings, in terms of data quality as well as data use. Human resource constraints are compounded by the complexity of multiple parallel reporting structures.

- Community health workers are an integral part of most retention-in-care efforts because they are best placed to find clients in the community and counsel them to continue treatment.

- Evidence we have on ART retention interventions using available data could be strengthened.

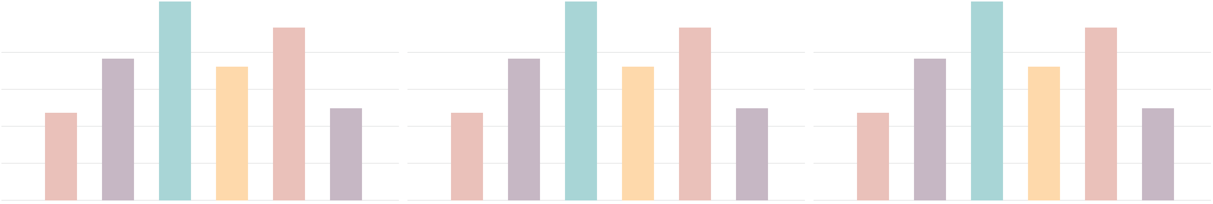


Recommendations:

1. More **emphasis should be placed on data use** as part of retention interventions at the community and facility level.

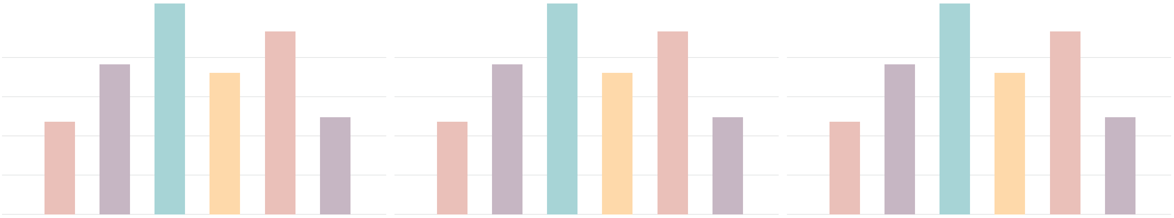
Use of simple data analysis and data visualization tools, such as longitudinal cohort analysis registers and templates that visually show retention trends using Microsoft Excel or pen and paper could strengthen data use during data review meetings and other ad hoc forums at the health facility level.

2. **Supportive supervision, mentoring, and training** of health facility workers on data collection and data use would strengthen data quality and use of data to improve retention. It could also ease the burden on community workers who are called on to support health facility staff. This would be reinforced through routine data quality assessments that focus on learning.



3. **Strengthen and invest in community programming** and community information systems, and strengthen their linkages to facility systems. The use of unique client identifiers could improve linkages and enable more accurate measurement of retention. Ensuring sustainable government-led community HIV interventions could also strengthen connections to facility systems and ensure greater sustainability. Community information systems and their staff offer the potential to find defaulters and prevent patients from defaulting.

4. **More evidence is needed** on which approaches work best to improve retention in care, particularly with interventions that include data review meetings and improved data capture systems. Operations research, as well as quasi-experimental studies that use combinations of approaches (eg., client tracing and data reviews; data review and improved data capture systems) could increase our understanding of what interventions are most effective to improve retention. Research can also focus on differences in approaches based on type of HIV epidemic (concentrated or generalized).



04

References

AIDS Info. (2016). HIV medication adherence [Fact sheet]. Retrieved from https://aidsinfo.nih.gov/education materials/fact-sheets/21/54/hiv-medication-adherence

Dalal, R.P., MacPhail, C., Mqhayi, M., Wing, J., Feldman, C., Chersich, M.F., Venter, W.D.(2008). Characteristics and outcomes of adult patients lost to follow-up at an antiretroviral treatment clinic in Johannesburg, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 47(1), 101–107.

do Nascimento, N., & de Jesus Joao, F. (2013). Formative assessment of a future mHealth site in Nhamatanda, Mozambique. MEASURE Evaluation: Working Paper Series. Retrieved from https://www.measureevaluation.org/resources/publications/wp-13-139.

Forster, M., Bailey, C., Brinkhofl, Ma.W.G., Graber, C., Boulle, A., Spohr, M., Balestre, E… Egger, M. (2008). Electronic medical record systems, data quality and loss to follow-up: Survey of antiretroviral therapy programmes in resource-limited settings. *Bulletin of the World Health Organization*, 86 (12).

Fox, M.P., & Rosen, S. (2010). Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: Systematic review. *Tropical Medicine & International Health*, 15(s1), 1-15.

Geng, E.H., Nash, D., Kambugu, A., Zhang Y., Braitstein P., Christopoulos K.A… Martin J.N.. (2010). Retention in care among HIV-infected patients in resource-limited settings: Emerging insights and new directions. *Current HIV/AIDS Reports*, 7(4), 234–244.

Hotchkiss, D.R, Diana, M.L., & Foreit, K.G. (2012). How can routine health information systems improve health systems functioning in low-and middle-income countries? Assessing the evidence base. *Advanced Health Care Management*, 12, 25–58.

Massaquoi, M., Zachariah, R., Manzi, M., Pasulani O., Misindi D., Mwagomba B… Harries A.D.. (2009). Patient retention and attrition on antiretroviral treatment at district level in rural Malawi. *Transaction of the Royal Society of Tropical Medicine and Hygiene*, 103, 594–600.

Ministry of Health and Ministry of Community Development, Mother and Child Health. (2014). Zambia consolidated guidelines for treatment and prevention of HIV infection. (2014, Feb). Retrieved from http://www.hivpolicywatch.org/duremaps/data/guidelines/ZambiaARTguidelines2013.pdf.

Mugavero, M.J., Westfall, A.O., Zinski, A., Davila, K., Drainoni, M.L., Gardner, L…Giordano T.P. (2012). Measuring retention in HIV care: The elusive gold standard. *Journal of Acquired Immune Deficiency Syndromes* (1999), 61(5), 574.

National AIDS & STI Control Program. (2016). Guidelines on use of antiretroviral drugs for treating and preventing HIV infection in Kenya.

Republica de Mozambique, Ministerio da Saude, Direccao National de Assistencia Medica. (2014). Guia de Tratamento antiretroviral e infeccoes oportunistas no adulto, adolescente, gravida e crianca 2014. Retrieved from http://www.who.int/hiv/pub/guidelines/mozambique_art.pdf.

Rosen, S., & Ketlhapile, M. (2010). Cost of using a patient tracer to reduce loss to follow-up and ascertain patient status in a large antiretroviral therapy program in Johannesburg, South Africa. *Tropical Medicine and International Health*, 15 (I), 98-104.

Scheibe, F.J., Waiswa, P., Kadobera, D., Miller, O., Ekström, A.M., Sarker, M., Neuhann, H.W.F.. (2013). *Effective coverage for antiretroviral therapy in a Ugandan district with a decentralized model of care.* PloS One, 8(7), e69433.

South African National AIDS Council (SANAC). (2011). National strategic plan for HIV, STIs, and TB. (2012–2016). Retrieved from http://www.gov.za/sites/www.gov.za/files/national%20strategic%20plan%20on%20hiv%20stis%20and%20tb_0.pdf.

South African National Department of Health (SANDOH). (2010). Models for the scale-up of HIV prevention, treatment and care from South Africa and beyond. http://www.ihi.org/resources/Documents/TriedandTested_ModelsforScaleUpHIVPrevention_Book.pdf.

Tierney, William W.M., Sidle J.E., Diero L.O., Sudoi A., Kiplagat J., Macharia S... Wools-Kaloustian K. (2015). Assessing the impact of a primary care electronic medical record system in three Kenyan rural health centers. *Journal of the American Medical Informatics Association*, 23(3):544-52.

The United Republic of Tanzania, Ministry of Health and Social Welfare, National AIDS Control Programme. National Guidelines for the Management of HIV and AIDS (5th ed.).

Wandina D., Odhiambo F., Ojoo S., Mongare J., Ogillo G., Muriuki, J. . . .Ngethe, R. (2011, July). Strategies for reducing lost to follow-up rates in adult patients receiving antiretroviral treatment in rural services in Kenya. Poster presentation presented at the 6th International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, Rome, Italy.

World Health Organization. (2011, September). Retention in HIV programmes: Defining the challenges and identifying solutions. Meeting report, 13–15, Geneva, Switzerland. Retrieved from http://www.who.int/hiv/pub/meetingreports/retention_programmes/en/.

05

Appendix

Examples of Approaches to Track ART Retention Described by Key Informants

Approach	Description	Country	Technology
Appointment book	Appointment system split the day into three blocks; clinic knows how many people to expect in each block. If clients do not come within three days, they were noted as lost to follow-up (LTFU).	Tanzania *(and versions available in many other countries)*	Paper-based
Tickler file system	System used for continuity of care (including HIV). Each time a patient is supposed to return, the return date is written on a card, and filed in the tickler box for the month of the appointment. Health workers then can easily identify clients who do not come in and follow up with them that month.	Ethiopia (and in many other countries)	Paper-based
Electronic Card System (SmartCare)	Introduced in 2003; originally HIV-specific. Information is collected and stored digitally on a card that the client keeps, while the facility keeps an electronic record. Data clerks enter information in the system from paper forms.	Zambia	Electronic system
Open Medical Record System (OpenMRS)	An electronic database that included date from HIV care cards (in Uganda these are used in high-volume facilities). HIV care cards include client information (e.g., demographics; history of ART care) on one side and a client encounter form on the other. Appointments are entered in OpenMRS so facilities can run a daily appointment report to see who was expected at the health facility but did not arrive.	Uganda (and in many other countries)	Electronic
Retention and Audit Determination Tool (RADET)	A required reporting tool for USAID implementing partners in Nigeria to track the number and relevant information of clients on ART. The tool uses an appointment calendar to track clients LTFU.	Nigeria	Excel-based tool

Using Routine Data to Improve ART Retention

This publication was produced with the support of the United States Agency for International Development (USAID) under the terms of MEASURE Evaluation cooperative agreement AID-OAA-L-14-00004. MEASURE Evaluation is implemented by the Carolina Population Center, University of North Carolina at Chapel Hill in partnership with ICF International; John Snow, Inc.; Management Sciences for Health; Palladium; and Tulane University. Views expressed are not necessarily those of USAID or the United States government.
SR-17-141