

Using Data for Programmatic Decision-Making: AIDSRelief Rwanda

Data Demand and Information Use
Case Study Series

MEASURE Evaluation
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Point of Entry

The MEASURE Evaluation framework is represented as a cycle that connects data demand, data collection and analysis, information availability, and information use. DDIU activities are designed to enter the cycle at any of these points, depending on the particular situation. The first step in influencing data demand and information use is to determine where to enter the cycle. In the case of AIDSRelief in Rwanda, the point of entry was data utilization.

Data Utilization

AIDSRelief began in Rwanda in January 2004, and by September 2008 was assisting 12 service sites, called local partner treatment facilities (LPTFs), to provide antiretroviral therapy (ART). According to program service statistics, the program had tested 103,685 individuals for HIV, had enrolled more than 7,840 people in care, and had started 3,852 clients on ART as of the end of September 2008.

Each site provides services at a health facility (either a hospital or health center) and supports community outreach. Facility staff include clinicians, administrators, data entry clerks, and a community coordinator. The community coordinator is responsible for the community support team, which involves approximately 40 community support volunteers for each health center and 80 volunteers for each hospital. Most volunteers are themselves PLWHA.

AIDSRelief/Rwanda utilizes a system known as IQChart (International Quality Clinical HIV/AIDS Registry tool) to collect patient data necessary for its ART programs.* IQChart is an electronic patient management and monitoring system that allows service sites to collect, store, and analyze patient-level data. The system assists providers in making informed decisions about patient care, and monitoring and evaluating programs at all levels.

AIDSRelief/Rwanda uses this system to create an individual medical history on every person tested for HIV. The medical history includes contact information (name, place of residence, etc.) socio-demographic characteristics (sex, date of birth, etc.) and clinical information (test dates and results, laboratory tests, clinic visits, pharmacy pick-ups, etc.). Data clerks, under the supervision of strategic information staff, enter key clinical data from the patients' files into the IQChart management system. The data can be aggregated by patient characteristic (age, sex, etc.) and can track individual clients by such factors as lymphocyte blood tests for CD4 cell counts, prescribed ART regimens, and dates of clinic visits. These data are also used to generate reports for government organizations and donors on a variety of indicators.

AIDSRelief is fully committed to enhancing data management and reporting and fostering a culture of information use at all levels of the program. In May 2008, an IQChart report showed that a large number of clients were missing their scheduled appointments to receive antiretroviral (ARV) drugs. The AIDSRelief/Rwanda central office discussed the findings with each site's clinical team. Initially, the clinical teams did not believe so many patients had missed their ARV appointments, suspecting instead that the number of missed appointments was inflated.

* The IQChart has also been adopted by other implementing partners, including the International Center for AIDS Care and Treatment Programs at Columbia University's Mailman School of Public Health, the Elizabeth Glaser Pediatric AIDS Foundation, and IntraHealth International. Together, these implementing partners support approximately 77 local clinics and hospitals.

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Data Demand

The results of the IQChart report surprised the clinical teams and created a demand for further information to determine if this was a data quality issue or whether many patients were, in fact, missing appointments. Factors that could have compromised data quality included clinician error (failure to update the medical record at each visit), data entry clerk error (failure to upload the medical records to IQChart), or medical record errors (such as patient transfers and patient deaths).

AIDSRelief/Rwanda had a multi-faceted problem to resolve. If the quality of data was poor, they needed to reinvest in training service site staff; if the data quality was sufficient, they needed to collect data that would substantiate that, in fact, many people were missing their appointments. Clearly, there was a demand for additional data and improved data quality. AIDSRelief/Rwanda identified the data that would be needed to answer the question about missed client appointments, and set out to collect these data for analysis.

Data Collection and Analysis

The central office devised a plan to address the clinical teams' concerns that the number of missed appointments reported by IQChart was inaccurate. Using patient data already collected and stored, the office generated a list of names and addresses of every patient listed as more than 20 days overdue for an ARV pickup appointment. The list was given to clinicians and community coordinators for individual follow-up and verification at both the facility and the patient's home. Patient records were updated as appropriate and the entire IQChart database was cleaned. This resolved the issue of data quality of existing medical records.

Next, AIDSRelief/Rwanda took steps to ensure that future data would be entered correctly and completely. The majority of AIDSRelief/Rwanda sites are health centers located in remote rural areas. This makes it difficult and expensive to train and retain qualified staff (especially data clerks) and to supervise program operations directly. Clinicians were given refresher training to remind them to record every visit and the visit's details in the client's medical record, and to advise clinic management when a patient was transferred to another site. Data entry clerks were given refresher training on updating database records on a timely basis.

Information Availability

AIDSRelief/Rwanda instituted new procedures to strengthen routine client monitoring and facility-community collaboration, which in turn improved the accuracy and availability of data. Roles and responsibilities of the community support team were specified in greater detail and activities were scheduled and more closely supervised. Each community volunteer was assigned eight ART clients and was expected to visit each of them weekly. New forms were designed for the volunteers to report on their clients, and monthly meetings were scheduled with the community coordinators to share and discuss the information collected and their experiences supporting clients.

With improved data quality and increased availability, it was possible to provide a higher standard of care. Every site now monitors weekly ARV pickup, CD4 cell counts, and care support. With

improved data available at the service sites, clinicians now use the reports to identify problematic patients and, in turn, pass that information to community coordinators. At monthly community support team meeting, coordinators present the site reports and give the volunteers the names and contact information of clients who are overdue for clinic appointments. The volunteers turn in their weekly client visit reports and inform coordinators of any clients who have died. This information is fed back into the medical records and IQChart.

Not only have the program innovations improved data quality and reporting, they have also improved patient management and the quality of life of program beneficiaries. The number of patients who were more than 90 days overdue in collecting their medications dropped by 95 percent in only three months, as shown in Figure 1. The number of patients lost to follow-up also dropped significantly.

Anecdotal reports suggest that community support volunteers have become more visible in their communities, which has encouraged other PLWHA to join the program and helped reduce

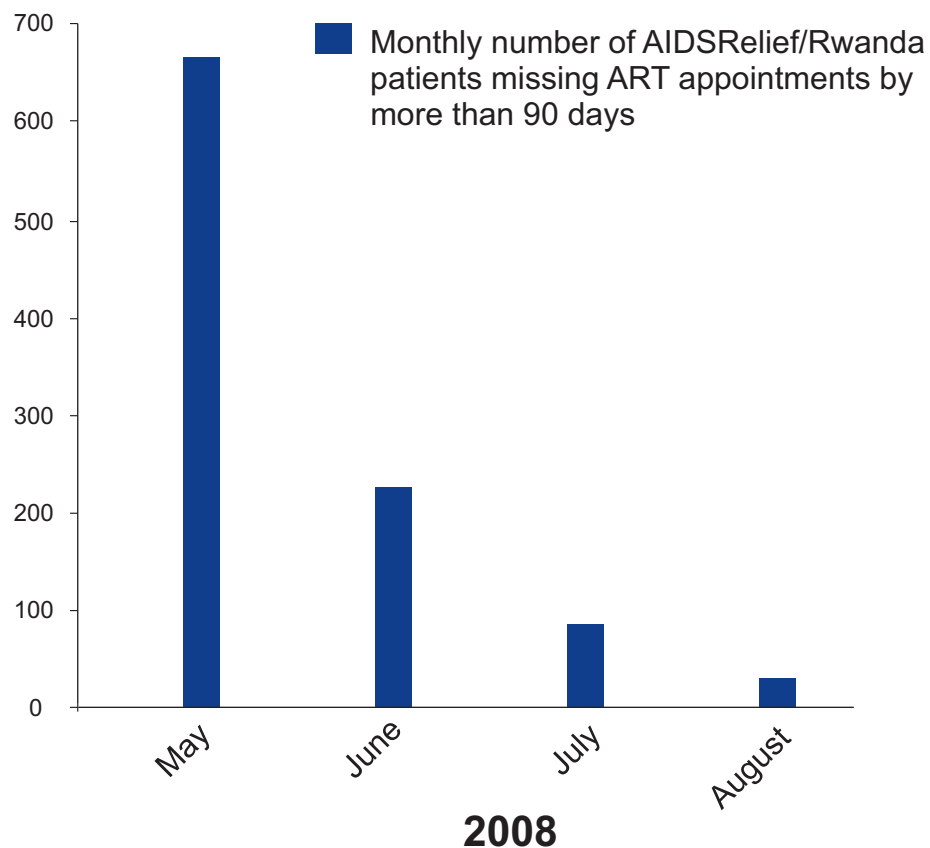


Figure 1. The number of patients more than 90 days overdue in collecting their medication dropped by 95 percent in only three months.

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the stigma associated with HIV. Regular home visits by volunteers provide the opportunity for continuous health education and promote client behavior change. Volunteers encourage partner testing and condom use among discordant couples, adequate nutrition and rest, and refer clients to other important programs, such as those that address prevention of mother-to-child transmission and family planning. What began with examination of routinely-collected data led to decisions to improve both data quality and program performance.

Several important factors contributed to the use of data in the decision-making process. The first is that AIDSRelief regularly demands quality data to assist in the management of its programs. At the organizational level, the project is committed to a strong M&E system and also to reviewing regularly the data it produces. The second contributing factor is stakeholder involvement. The central office convened meetings to discuss information generated by the IQChart report and encouraged data-informed solutions. Both those who collect and those who use the data took an active role in these meetings. When the initial data showed a possible problem, a decision was made to collect more data to inform the decision-making process. Once the additional data were collected, decisions were made to address the findings (Figure 2). AIDSRelief Rwanda successfully navigated this potential problem because of high demand for data, appropriate stakeholders involvement, and data-based decision-making.

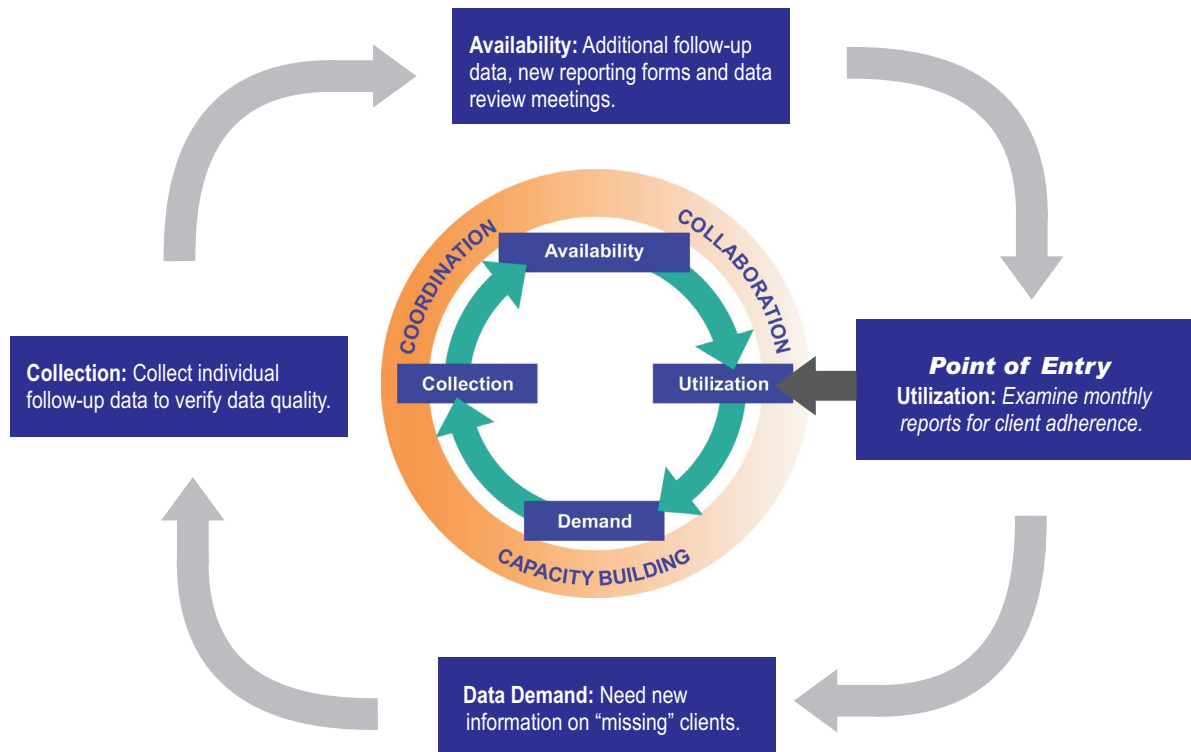


Figure 2. Once additional data were collected and a problem was identified, decisions were made to address the findings, resulting in better data use and a higher standard of care.

This case study is extracted from:

Data Demand and Information Use in the Health Sector: Case Study Series. Chapel Hill, NC: MEASURE Evaluation; 2008, revised 2010.

MEASURE Evaluation is a MEASURE program project funded by the U.S. Agency for International Development (USAID) through Cooperative Agreement GHA-A-00-08-00003-00 and is implemented by the Carolina Population Center at the University of North Carolina at Chapel Hill, in partnership with Futures Group International, John Snow, Inc., ICF Macro, Management Sciences for Health, and Tulane University. The authors' views expressed in this publication do not necessarily reflect the views of USAID or the United States government.



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