

Data Demand and Information Use in the Health Sector

Case Study Series



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Acknowledgments

The information use case study series documents the work of numerous MEASURE Evaluation staff members, including Gustavo Angeles, Yusuf Hemed, Ani Hyslop, Alan Johnston, Andrew Koleros, Peter Lance, Shannon Salentine, Philip Setel, Ifeoma Udoh, Sharon Weir, and Dan Williams. In addition, several in-country agencies and organizations were the driving forces behind producing and using data and information as described in these case studies.

The cases studies were compiled and reviewed by MEASURE Evaluation staff members and consultants, especially Ed Abel, Jenifer Chapman, Karen Foreit, Teresa Harrison, Nicole Judice, Elizabeth Miller, Scott Moreland, Tara Nutley, Philip Setel, and Sylvana Smith.

About MEASURE Evaluation

MEASURE Evaluation strengthens the capacity of host-country programs to collect and use population and health data. The project is a key component of the U.S. Agency for International Development (USAID) program, Monitoring and Evaluation to Assess and Use Results (MEASURE) framework, and promotes a continuous cycle of data demand, collection, analysis and utilization to improve population health conditions.

MEASURE Evaluation fosters demand for effective program monitoring and evaluation. We seek to empower our partners as they improve family planning, maternal and child health, and nutrition, and prevent HIV/AIDS, sexually transmitted diseases, and other infectious diseases worldwide.

For more information about MEASURE Evaluation, visit us on the Web at:

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Case Study Series of Data Demand and Information Use in the Health Sector

The MEASURE Evaluation project has a major focus on data demand and information use (DDIU). As part of this effort, we have developed a series of related documents. In part one of this series, *Data Demand and Information Use in the Health Sector, Conceptual Framework*,¹ we provide a conceptual framework for evidence-based decision making in the public health arena. Part two of this series, *Data Demand and Information Use in the Health Sector, Strategies and Tools*,² provides detailed strategies and tools for taking concrete next steps in implementing DDIU activities. This publication, which presents part three, is a series of case studies that illustrate, from a variety of settings, cases where data and information have been used, as well as examples of how interventions have successfully facilitated data demand and changed how information is used within the MEASURE Evaluation project. It is expected that other DDIU experiences — inside and outside of the project — will eventually be added to these case studies.

Background

Health data and information lack value unless they are used to inform decisions. Interventions that increase local demand for information and facilitate its use enhance evidence-based decision making. Activities that foster DDIU, therefore, are critical to improving health system effectiveness.

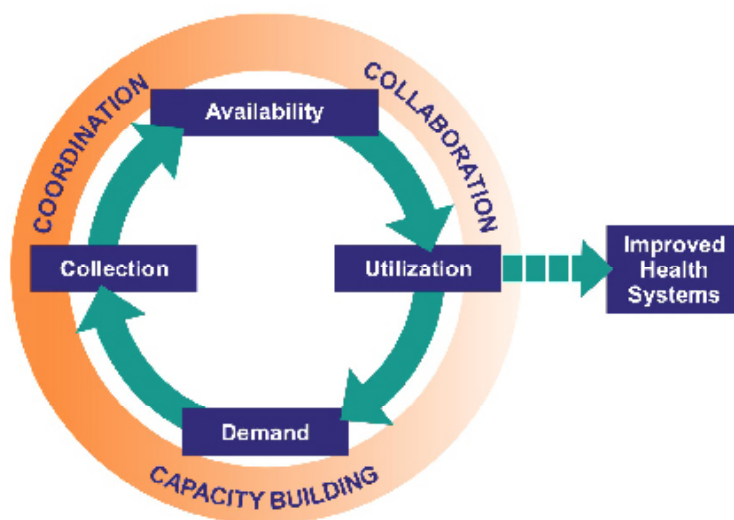


Figure 1. Conceptual framework for improving health systems.

The MEASURE Evaluation DDIU conceptual framework (figure 1) is a cycle connecting data demand, data collection/analysis, information availability, and data and information use. This cycle is supported by collaboration, coordination, and capacity building. In this framework, there is a clear and consistent link between the use of health information and the commitment to improving the quality and availability of data. In this cyclic process, increased information use stimulates greater demand for data which, in turn, leads to more information use, leading to more demand, and so on.

For each case study presented in the series, we begin by identifying the “point of entry” for promoting data demand and information use interventions. The entry point depends upon understanding how data supply, information demand, and capacities for use all interrelate within a given context. We then present each element of the data demand and information use continuum with evidence from MEASURE Evaluation projects. “Data demand” describes the information stakeholders are actively and openly requesting; “data collection/analysis” describes the various methods and tools used to address data and information gaps; “information availability” illustrates ways that data and information are disseminated and made publicly available in a format that is understandable and useful to the user; “information use” provides examples of key actionable research findings that have been used in the process of evidence-based decision-making, as well as examples of how interventions have successfully changed how information is used. We hope that others might be able to draw upon the examples in these case studies and apply these approaches and tools to increase the demand for data and use of information in the settings in which they work.



Using GIS Information to Target Health Services in Slum Areas in Bangladesh

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Point of Entry

As noted previously, 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 use is to determine where to enter the cycle. In Bangladesh, the entry point was data demand (figure 2).

Data Demand

The pronounced trend toward urbanization in lower-income countries is likely to continue for decades to come. This growth is largely driven by rural to urban migration, with many of the migrants settling in densely populated areas of concentrated poverty and environmental vulnerability (i.e., slums) within cities. Bangladesh is typical in this respect. Its urban population is projected to more than double in the next quarter century. Slum formation and growth has been, and is anticipated to be, central to this process.

Bangladeshi cities, and particularly the slums within, will become increasingly important arenas for health policy. There will soon need to be a fundamental policy shift away from programs traditionally focused on the rural poor to address expanding and worsening poverty within impoverished and crowded cities. Unfortunately, very little is known about the implications of slum life for health or broader human welfare. The lack of such information had made it very difficult for stakeholders interested in targeting health- and human welfare-related programs to slum populations to do so efficiently. To help rectify this, the U.S. Agency for International Development (USAID) and the government of Bangladesh requested technical guidance for a survey of health in urban areas in which slums were to receive particular attention.

Data Collection and Analysis

To resolve the information deficit, an effort was made to map the location of, obtain a population estimate for, and collect basic socio-economic characteristics of each slum in the six city corporations of Bangladesh. The outputs of the activity needed to serve the purposes of a range of stakeholders and, therefore, multiple stakeholders were involved in the process.

The Centre for Urban Studies (CUS), an independent research nongovernmental organization (NGO) implemented the census of slums. Technical assistance was provided by the International Centre for Diarrhoeal Disease, Bangladesh (ICDDR, B), the National Institute of Population Research and Training (NIPORT), USAID, and the MEASURE Evaluation project.

The 2005 census and mapping of slums (CMS) had three phases. The first phase involved the development of baseline maps of the city corporations (which serve as administrative seats for the six main divisions of the country) that would identify suspected slum settlements and provide an accurate overall organizing framework for later field investigation. This was done using official maps and satellite photographs, which were geo-referenced and used to visually identify the suspected slums. During the second phase, teams assessed conditions on the ground in each ward of the city

corporations. In the final phase, the information from the checklists gathered in the course of field operations was entered into a geographic database containing a list of slums and their attributes in each of the six city corporations. The integrated maps and database were then made publicly available.

Information Availability

This activity produced a number of valuable outputs, including:

- highly accurate, detailed ward-level maps of slum settlements in the six city corporations;
- a database describing the exact location of the settlements visited by field teams, as well as their social and economic characteristics (information in the database is integrated with that contained in the maps, allowing, for instance, maps based on alternative slum designations to be generated quickly and easily);
- a detailed report published in 2006 summarizing the findings of the survey; and
- a Web site through which these materials were made public.

The results of the project were presented at a meeting held in Dhaka in May 2006. Over 125 stakeholders were present at the dissemination, including over 30 news media representatives. The event received wide coverage in major Bangladeshi daily newspapers and television news programs. Afterward, city- and ward-level slum maps and a slum database were made available on the MEASURE Evaluation Web site. Results have been presented by CUS staff at different meetings on urban issues in Bangladesh.

Information Use

Health services are being targeted to those in need. The tools and information developed under this activity have proven extremely popular, and are being used to help provide health services to those in need. A few major examples include the following:

- The Bangladesh Rural Advancement Committee (BRAC) is using the maps to place birthing huts in slums and will use the information to target expansion of their health program for the urban poor.
- The Bangladesh AIDS Program is using the information to plan the future location of counseling and treatment centers for most-at-risk populations (e.g. sex workers, drug users, truck drivers, rickshaw pullers, etc.), who disproportionately reside in slums.
- The USAID-funded NGO Service Delivery Program is using the maps to identify locations for its main and satellite clinics for its next five-year phase.
- Family Health International (FHI)/Bangladesh intends to use the maps to track its own intervention sites and areas of program coverage for various programs.

Other human welfare services are being targeted to those in need. In addition to improving the targeting of health services to those in need, organizations involved in other development initiatives are using the information to improve the delivery of their services. Two examples include the following:

- The United Nations Development Programme (UNDP)-funded Local Partnership for Urban Poverty Alleviation has requested the maps for use in targeting its efforts during its next seven-year phase.
- The World Bank, which is currently working with the water and sewer authorities of the city corporations to extend water and sanitation to the urban poor, has requested the maps of Dhaka and Chittagong to help identify slums not serviced by the present grid. The maps are being used to redirect the allocation of water and sanitation lines.

The CMS generated detailed and accessible slum maps integrated with a database of slum characteristics, allowing one to identify and locate slums exhibiting certain combinations of circumstances. The database is proving to be immediately useful for those engaged in the practice of public health and other human welfare services.

Further information on the Bangladesh Slums Project:

http://www.cpc.unc.edu/measure/research/bang_slums

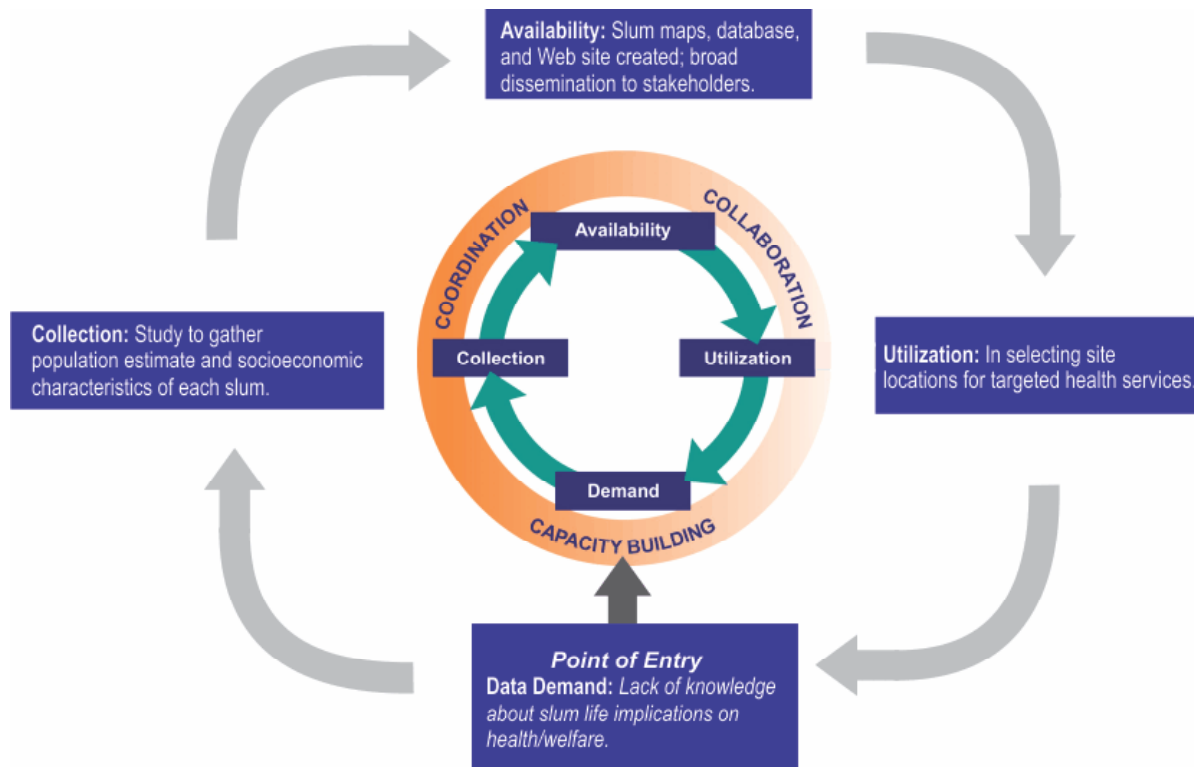


Figure 2. Socioeconomic characteristics of slums in six city corporations were gathered and disseminated, leading to the selection of sites for targeted health services.



Using Routine Health Information to Improve Voluntary Counseling and Testing in Cote d'Ivoire

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Point of Entry: Data Demand

The MEASURE Evaluation framework consists of a cycle connecting data demand, data collection and analysis, information availability, and information use. Data demand and use 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 the Cote d'Ivoire Ministry of Health (MoH), the point of entry was data demand.

Data Demand

In 2004, MEASURE Evaluation began working with the MoH to improve its routine health information system (RHIS). At the beginning of the partnership, MEASURE Evaluation's technical assistance focused on addressing weaknesses of the national RHIS, as identified in an RHIS evaluation report prepared by MEASURE Evaluation. The study found three major weaknesses in the system:

- the absence of harmonized health indicators that included HIV services (at that time, HIV indicator data were only reported by the implementing partners);
- the absence of standardized HIV data collection tools; and
- data collection forms existed, but were often unavailable at the decentralized level.

In response to the identified weaknesses, the MoH and MEASURE Evaluation focused on building a consensus on priority HIV indicators, developing HIV data collection tools, and revising existing RHIS data reporting forms to include HIV. In early 2005, the MoH began rolling out HIV data collection tools and the revised RHIS data collection forms to support data collection on HIV services at the health facility level. The rollout was supported by training providers how to complete the forms accurately. Before the rollout was complete however, the MoH needed information about current service delivery to determine if national targets for HIV services were being met. Moreover, the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) program, which was supporting the RHIS improvement activities, also needed information on the activities it was supporting in Cote d'Ivoire. Because the rollout was not yet complete, the MoH and PEPFAR lacked the data they needed in the short term to report to PEPFAR, to monitor program progress in the country, and to make data-based planning decisions. In response to this data gap, a targeted data collection activity was launched to collect specific data needed for reporting and decision making. Data were collected for selected indicators involving prevention of mother-to-child transmission (PMTCT), voluntary counseling and testing (VCT), and care and treatment.

Data Collection and Analysis

Data were collected in two phases, to capture the period from October 2004 through December 2005. A technical committee was created by the MoH, PEPFAR, the Global Fund to Fight AIDS (Global Fund), Tuberculosis and Malaria, as well as other key stakeholders such as the National HIV Care and Treatment program, the U.S. Centers for Disease Control and Prevention (CDC), and the Elizabeth

Glaser Pediatric AIDS Foundation to oversee the data collection process, with a sub-committee in charge of the actual data collection. Specially appointed data collection teams went to 183 facility-level care and treatment sites to gather data from the various HIV/AIDS data sources, including consultation registers, quarterly reports, and client records. Specific client record databases used by implementing partners were reviewed in all units where they were available. The teams used data from the review of the data sources to create a VCT, PMTCT and a care and treatment assessment sheet, including a section on drug management. The initial data collection revealed that the early assessment sheets were too complex. The technical committee developed new assessment sheets especially for this intermediate round of data collection, but based them on the newly created permanent HIV data collection tools.

Information Availability

Results from the data collection effort were compiled in a 2005 national HIV report and in April 2006 were disseminated and reviewed at a data use workshop in Abidjan. The MoH distributed the data to key partners, including the Ministry of the Fight Against AIDS, PEPFAR, PEPFAR implementing partners, Global Fund, World Health Organization, United Nations Children's Fund, Joint United Nations Programme on HIV/AIDS, and a few Cote d'Ivoire districts.

The data review highlighted that, without major improvements in service delivery coverage, it was unlikely that Cote d'Ivoire would achieve its national objectives of treating 77,000 people with antiretroviral (ARV) drugs and preventing 265,000 new infections. In particular, it was evident that VCT services were not available in all regions of the country and were inadequately distributed. This resulted in a low uptake of VCT services and an inability of the program to increase coverage rates.

Information Use

The National HIV Care and Treatment program managers, who were a part of the technical committee for the special data collection effort, discussed with donors and partners the findings highlighted in the 2005 national HIV report. The discussion focused on the failure to meet the national target for people on antiretroviral therapy (ART) from 2004 to 2008. In response to the findings, the National HIV Care and Treatment Program decided to implement multiple strategies to address VCT coverage caps. The strategies included the development of a national policy that encouraged health providers to initiate discussion of VCT as part of routine health visits, community based VCT through mobile units and home based door-to-door visits, and mass HIV screening campaigns. The implementation of these interventions began in 2006.

The national policy, which targeted providers, required all public sector health providers to either offer or refer clients to VCT services. All providers who cared for individuals of reproductive age were required to inform the client of VCT services, regardless of the health services they were providing. In addition, mobile clinic and door-to-door visit strategies were implemented by the National Support Agency for Rural Development (ANADER) among rural residents working in 10 of the 64 administrative departments. The mass community screening campaigns were supported by ANADER.

In 2008, the MoH was interested in learning the effect of the activities implemented in 2006 to expand VCT coverage as a result of the short-term data collection. By this time, nearly all the

originally planned RHIS improvement strategies were in place and HIV data were being regularly collected by the integrated system. The synthesis of these routine data and a 2007–2008 national HIV report indicated that by 2008 all 18 health regions were offering VCT and only three regions reported fewer than 4,000 people tested for HIV. Moreover, the total number of people counseled and tested increased from 127,044 counseled and 111,417 tested in 2005 to 218,684 counseled and 197,428 tested in 2008, with a 90% acceptance rate. These increases were noteworthy, with the number of people counseled increasing by 72% and the number tested increasing by 77% in a three-year period. Figure 3 and 4 highlight the improvements in VCT.

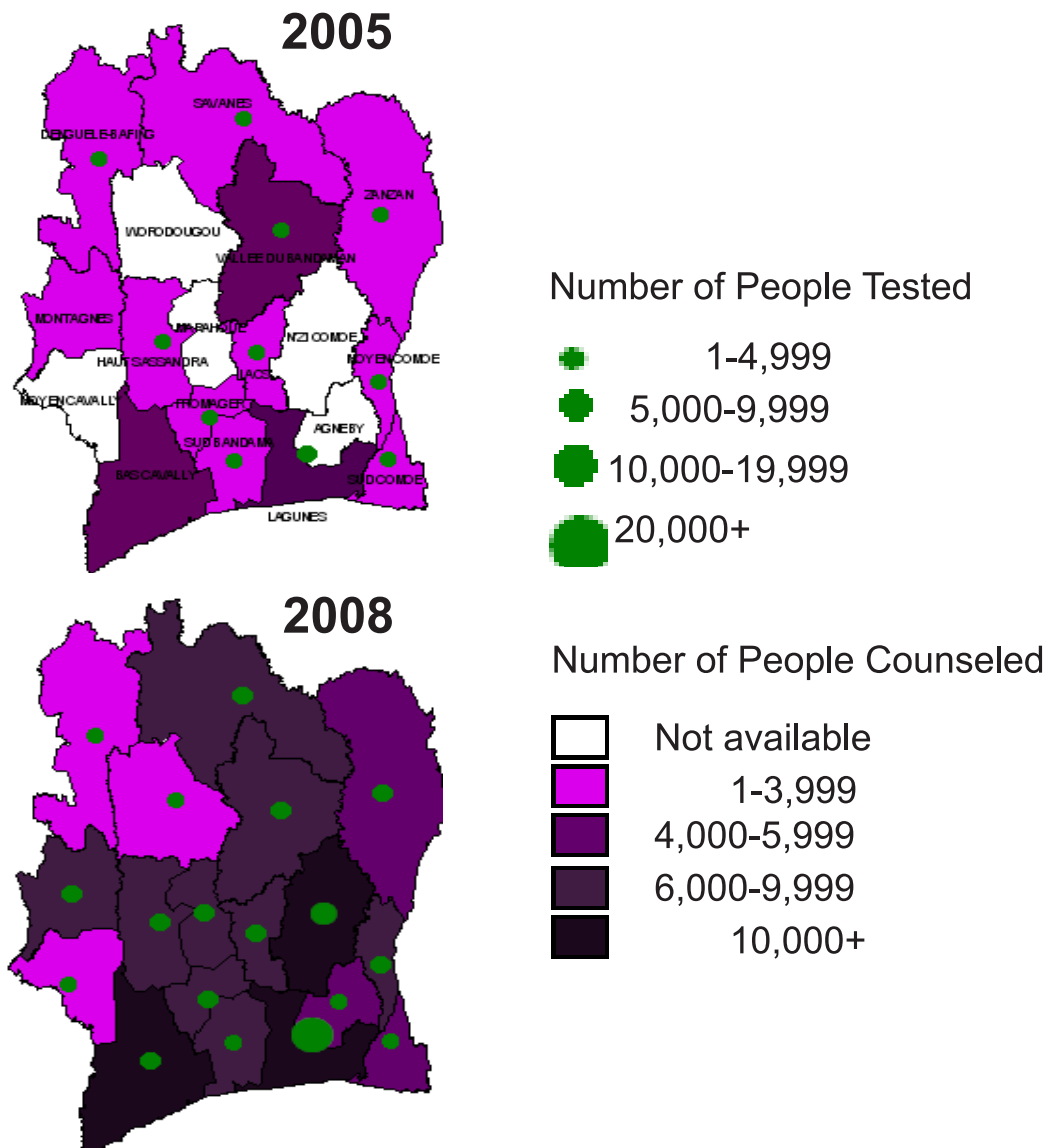


Figure 3. VCT service availability: number of people tested and number counseled, 2005 and 2008, Cote d'Ivoire.

The analysis of the 2008 data strongly suggests that the data-informed interventions put in place by the National HIV Care and Treatment Program were successful in bringing about program improvements, meeting the established targets, and reaching more people in need of HIV/AIDS services.

Several important factors contributed to the use of data in the decision-making process in Cote d'Ivoire. The first factor was that the MoH and the larger technical stakeholder group, including the National HIV Care and Treatment Program, valued quality data to assist in the management of their programs, and demanded quality data regularly. At the organizational level, the MoH committed planning efforts and resources to strengthen the monitoring and evaluation system, and was also willing to collect additional data while waiting for the monitoring and evaluation system strengthening process to roll out. An additional contributing factor was the extensive stakeholder involvement. The stakeholders involved, such as the MoH, Elisabeth Glazer Pediatric AIDS Foundation, and CDC, ensured data were gathered, and used these data to make important changes to VCT programs. Figure 5 outlines the process MoH used in achieving data-informed decision making.

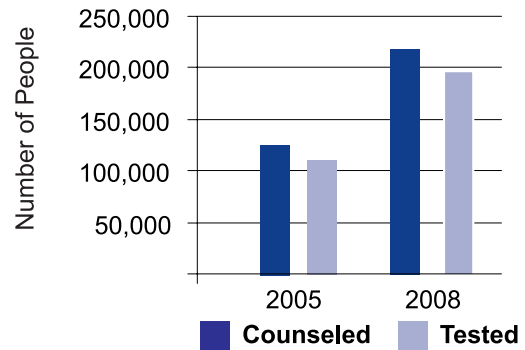


Figure 4. Number of people counseled and tested for HIV in 2005 and 2008.

Sources: 2005 and 2008 national HIV reports.

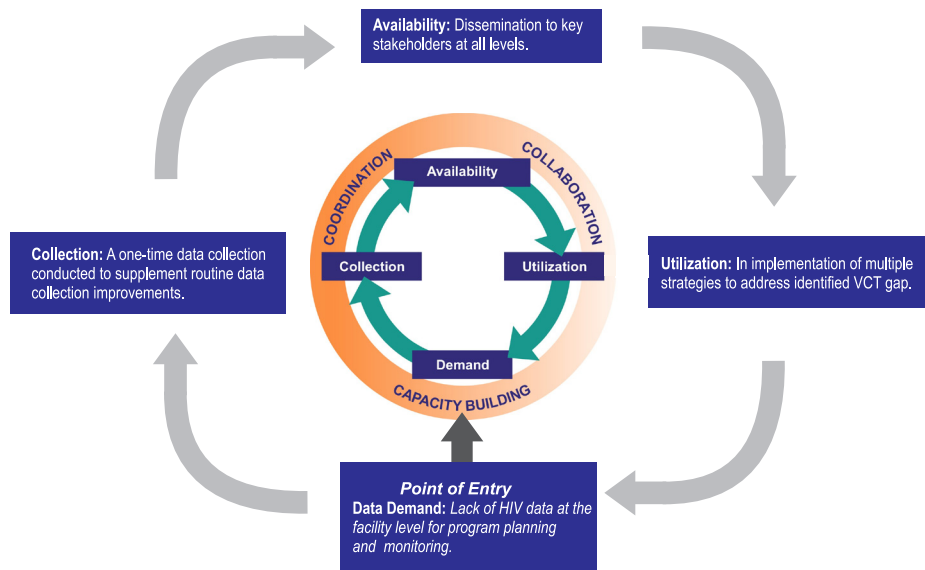


Figure 5. A lack of HIV data at the facility level led to a one-time data collection, dissemination to stakeholders, and strategies identified to reduce the VCT gap in Cote d'Ivoire.



Using HIV/AIDS Information to Improve Local HIV/AIDS Programs — PLACE in Ghana

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Point of Entry

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Data Demand

About 3% of adults in Ghana are currently living with HIV/AIDS. This level of prevalence is indicative of a generalized epidemic and, as a result, has earned national and international attention. It has also spurred data collection efforts to better understand the disease and efforts to address it. Specifically, there was inadequate information for districts to use in developing their strategic plans. Every district is required to develop a three- to five-year composite strategic plan for HIV/AIDS.

To address this gap in knowledge, USAID/Ghana and the Ghana AIDS Commission requested technical assistance from MEASURE Evaluation in the collection and use of information for district-level HIV/AIDS interventions in Ghana.

Data Collection and Analysis

The Priorities for Local AIDS Control Efforts (PLACE) methodology developed by MEASURE Evaluation was adopted by the Ghana AIDS Commission to collect data on knowledge, attitudes, and practices of persons at risk of HIV infection. The Ghana AIDS Commission piloted and then adapted the PLACE protocol for the Ghanaian context, trained interviewers to conduct the three surveys that are the key data collection activities in the protocol, and identified criteria for selecting districts to participate in the PLACE assessments. These criteria included high HIV prevalence among antenatal clients and having a main transportation route in the district, an indication that there were many mobile persons in the district. Interviewer training, data collection, and data entry were all conducted by the Ghana AIDS Commission. For each local area within a district where PLACE was implemented, PLACE provided the following outputs:

- list and map of public venues where people meet new sexual partners and whether these venues have any current HIV prevention services on-site;
- description of the characteristics of the patrons of these venues;
- summary of major gaps in program coverage; and
- comparison of local PLACE findings with selected national indicators.

Information Availability

In 2004 and 2005, with assistance from MEASURE Evaluation, the Ghana AIDS Commission conducted PLACE surveys in 14 districts in Ghana. Following the surveys, three targeted data use workshops were held to train district teams comprised of staff responsible for coordinating the HIV/AIDS response. The teams consisted of district planning officers, district budget analysts, district HIV/AIDS committee members, and others. The Ghana AIDS Commission, the USAID-funded, bilateral Strengthening HIV/AIDS Response Partnerships (SHARP) project, and a local monitoring and evaluation officer also participated in the data use workshops. These activities built the capacity of teams to analyze the survey data and prepare their own district PLACE reports, and to plan for district action planning workshops where a broad group of shareholders would translate PLACE findings into prioritized HIV/AIDS interventions.

The workshops generated three outputs:

- **Targeted district action plans** — Following the workshops, participating districts successfully completed district PLACE reports and conducted planning workshops to use their PLACE results to produce targeted district action plans.
- **Training materials for future data use workshops** — The activity delivered session plans; training modules on data use, communication and facilitation skills; ethics training modules; training modules on data analysis skills; computer programs for data quality checks and statistical analysis (Epi-Info, STATA, SPSS); guidelines for report preparation and presentations; and guidelines on participatory planning to facilitate use of the data for policy and program decision-making.
- **Local capacity to conduct future workshops** — The local SHARP project has adopted the curriculum and can conduct targeted data use workshops without external assistance. Furthermore, SHARP can adapt the workshop curriculum and materials to hold targeted data use workshops related to other studies as well.

Information Use

As a result of the planning workshops among stakeholders, district teams identified priority interventions. A wide cross section of stakeholders provided input through focus group discussions. Stakeholders included chiefs, opinion leaders, people living with HIV/AIDS (PLWHA) and other community members. As a result of this consultative DDIU process, PLACE study data were expanded to include such information as the level of awareness of PLWHA, myths about HIV/AIDS, and how people relate to PLWHA. Based on this information, priority interventions were identified, including:

- providing care and support to PLWHA;
- monitoring of activities of NGOs; and
- preventing new HIV/AIDS transmission.

Reliable district-level HIV/AIDS information is now available and being used. The reliable, rapid assessment of high transmission areas in the districts serves as a baseline in monitoring and evaluating

local HIV/AIDS programs. The Districts Response Initiative (DRI) also drew on the PLACE information to design the strategic plans, which are mandated by district assemblies in Ghana.

Action plans are now based on district evidence. Several district action plans offer a statistical basis to justify program interventions and funding requests. For example, a proposal to increase funding for voluntary counseling and testing (VCT) cited district-level PLACE statistics that showed that 85.8% of respondents had never been tested for HIV/AIDS, 42.8% were not interested in being tested, and 39.6% did not know where to go for testing. A proposal to increase funding for educational programs showed that only one-third of respondents had been involved in any HIV/AIDS education program in the period under study.

Districts identified, implemented, and funded the HIV/AIDS action plans. In three districts (Jomoro, Wasswa West, and New Juaben), NGOs were identified and given grants by SHARP to implement interventions with commercial sex workers. On their own, these districts have also undertaken HIV/AIDS education and promotion of condom use among the general population with their own resources.

The PLACE method has provided Ghana with valuable district-level information about locations at high risk of HIV/AIDS transmission and gaps in prevention programs among most-at-risk populations. Targeted data use workshops have enabled local stakeholders to make use of this information to identify locally appropriate, workable approaches to address the problem: designing and targeting acceptable and effective local HIV/AIDS programs and interventions.

Further information on PLACE method: <http://www.cpc.unc.edu/measure/leadership/place.html>

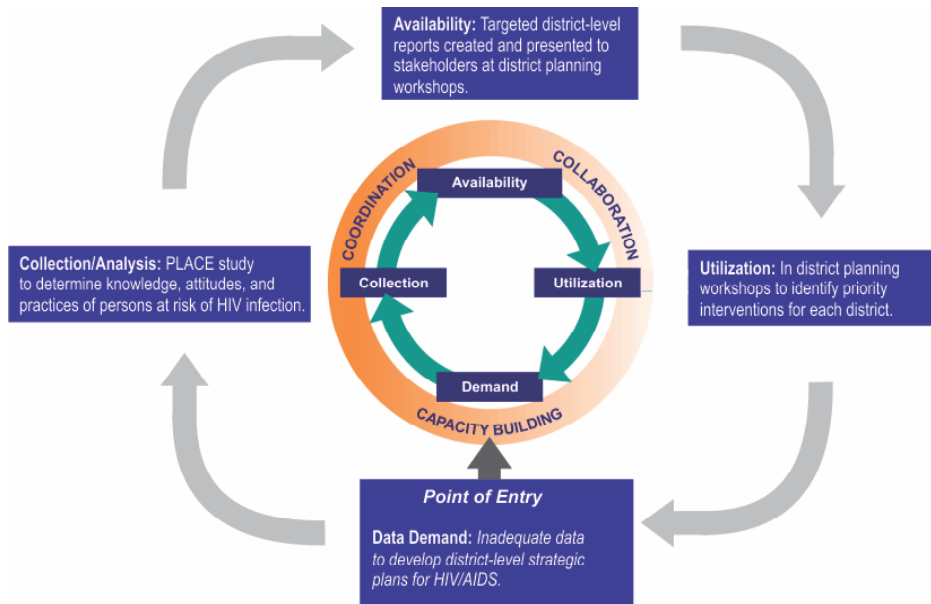


Figure 6. A PLACE study determined knowledge, attitudes, and practices among people at risk of HIV infection, providing information for planning workshops to identify priority interventions.



Using Information to Reposition Family Planning in Kenya

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Point of Entry

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Data Demand

In 1980, Kenya had the highest fertility rate in the world — on average, every woman was giving birth to eight children. Between 1980 and 2000, the rate dropped to 4.7 children per woman. In 2003, however, the Kenya Demographic and Health Survey (KDHS) showed that the 20-year pattern of sustained fertility decline had stalled, and that a plateau in the contraceptive prevalence rate had been reached. The Ministry of Planning and National Development, which was troubled by these trends and their potential implications for economic development, began looking into the issue more closely. Information was needed to help explain the causes of the stall and to help develop strategies to reposition family planning as a cornerstone issue for national development strategies.

In order to develop an informed approach to addressing this situation, the Kenyan government sought answers to the following questions:

- What had caused the plateau in contraceptive prevalence?
- What strategies could be used to increase the contraceptive prevalence rate and reverse the stagnation in fertility decline?
- How could the government generate awareness and support for corrective actions?

Officials in the Ministry of Planning and National Development, including the permanent secretary and other senior officials, lent their support to the effort and endorsed a large stakeholders' meeting organized by the National Coordinating Agency for Population and Development (NCAPD) and supported by MEASURE Evaluation. The goal of the meeting was to identify priority research topics and generate support to reposition family planning. Nearly 100 delegates from the Ministry of Planning and National Development, Central Bureau of Statistics, Ministry of Health (including representatives from the central, provincial, and district levels), local NGOs, cooperating agencies, the donor community, and the private sector attended the meeting. Representatives from sub-national agencies, and particularly the private sector, are not often involved in the design of national evaluation efforts.

Data Collection and Analysis

Following the initial stakeholders' meeting, a technical working group designed and commissioned secondary data analyses of KDHS data to address six major areas:

- demographic change and contraceptive use dynamics;
- socioeconomic correlates of contraceptive use;

- effects of infant and child mortality on fertility;
- impact of HIV on fertility and contraceptive use;
- trends in community-based family planning services; and
- effect of declining educational and counseling efforts on contraceptive use.

Six teams of Kenyan researchers conducted the analyses, prepared reports, and submitted the reports to NCAPD. Throughout this process, the 16 Kenyan researchers received technical support in research design, analysis of DHS data, and presentation of findings from MEASURE Evaluation and MEASURE DHS staff.

Information Availability

Promoting publicly available data and information was a major focus of Kenya's efforts to address the flattened contraceptive prevalence rate and stalled fertility decline. For example, the initial stakeholders' meeting was covered by several major news outlets, both print and television. This media coverage helped raise the profile of contraceptive prevalence and fertility issues and reinvigorated public discussion around family planning issues which have significant social and economic implications.

CAPD presented the results of the analyses at a second stakeholders meeting and a summary report of the KDHS Further Analyses were published in a NCAPD Working Paper Series. The final reports were made publicly available on the NCAPD website and shorter versions were printed for distribution.

Information Use

The second stakeholders' meeting provided the opportunity to review the conclusions of the analyses and to prepare a 'Decision Calendar.' The Decision Calendar tool is used to identify key decisions that need to be made and the information necessary to support those decisions. The use of this decision calendar tool helped the NCAPD to: identify what types of secondary data analyses were required for evidence-based decision making; create a time table for developing and implementing corrective actions; and monitor the progress towards developing and implementing these corrective actions.

As a result of these efforts, the following achievements were realized:

- **National reproductive health policy drafted** — The NCAPD and Ministry of Health/ Division of Reproductive Health used the secondary data analyses and a decision calendar to revise the draft reproductive health policy to incorporate a much stronger emphasis on information, education, and communication (IEC) activities, which had been shown by the secondary analyses to have been significantly reduced over the previous five years.
- **Baseline indicators produced** — The Ministry of Health used indicators from both the KDHS and the secondary analyses as a baseline for the 2005-2009 National Health Sector Strategic Plan, including knowledge and support for family planning, inter-spousal communication regarding family planning, and resource allocation for IEC efforts.
- **Evidence used to argue for new services and resource mobilization** — The NCAPD used information from the secondary analyses to initiate public debate on the issue, which appeared in newspapers throughout the country and in World Population Day celebrations

in Coast Province; sensitize politicians about the need to re-emphasize the importance of family planning (a meeting for interested members of parliament led to the formation of a parliamentary caucus on reproductive health); and engage members of parliament in a discussion about using constituency development funds to establish youth-friendly reproductive health centers in each constituency.

- **National concern translated into commodities line item in national budget** — Evidence-based advocacy helped influence the Kenyan government to allocate approximately U.S. \$2.8 million to the 2005-2006 budget line item for family planning supplies. This allocation was in addition to the support from donors.

In addition to the results mentioned above, there were several other accomplishments of this activity. For example:

- The process helped the NCAPD develop a clear framework for data use. A decision calendar showed specific decisions that needed to be made, and linked those decisions to the data required to make evidence-based decisions — plus responsibility and timelines for data use. The calendar continues to be used to monitor the follow-up steps in the process, and to help ensure that the results of the analysis are actively used in guiding decisions on corrective actions to revitalize family planning and reproductive health services in Kenya.
- The process helped strengthen cross-organization collaboration. The stakeholders' meetings included groups that often have competing interests or priorities. By collaborating on this activity, all contributors recognized the necessity to combine their efforts to successfully reverse the plateau.
- The process provided a framework for ongoing stakeholder involvement. A stakeholder engagement tool was used to identify stakeholders in family planning activities including contributors and beneficiaries; to define their roles and resources, and to identify their information needs. This process helped ensure that cross-organization cooperation was not a one-time event, but rather that it represented ongoing involvement in the cycle of data demand, production, and use.
- Causes of the slowing fertility decline were assessed. Secondary research helped identify the causes of the contraceptive prevalence rate plateau and the stall in the fertility decline. It became clear that several factors needed to be acted upon, requiring action on a range of fronts.

Further information on the PLACE method is available at:

<http://www.cpc.unc.edu/measure/leadership/place.html>

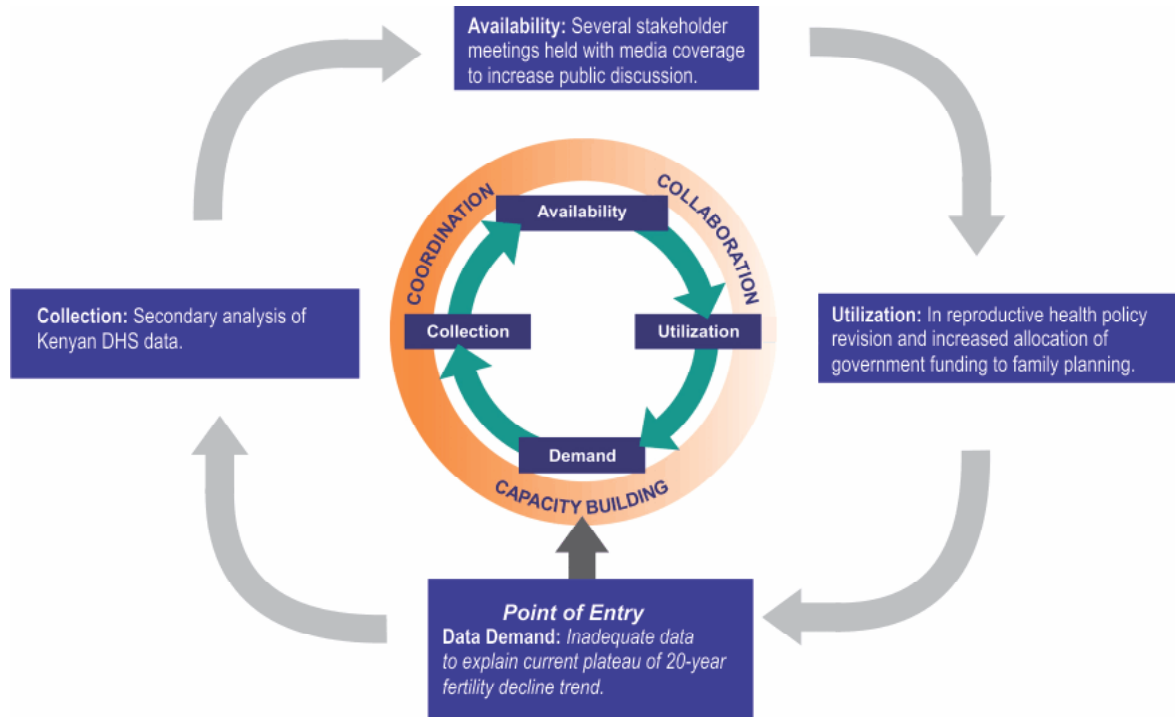


Figure 7. Secondary analysis of DHS data helped to increase public discussion about a plateau in fertility decline, which led to increased allocation of government funding to family planning.



Using Data for Programmatic Decision-Making: AIDSRelief in Rwanda

Data Demand and Information Use
Case Study Series

MEASURE Evaluation
www.cpc.unc.edu/measure

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.

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 8. 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

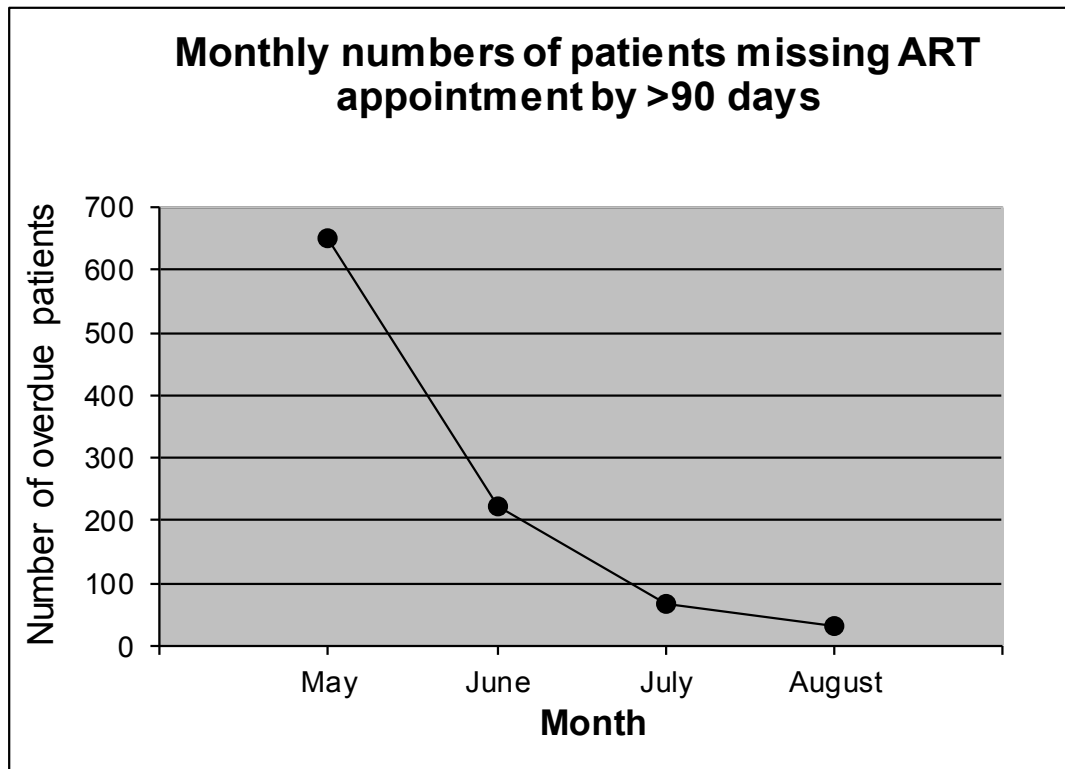


Figure 8. Improvement in treatment attendance following changes in program management practices.

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 9). AIDSRelief Rwanda successfully navigated this potential problem because of high demand for data, appropriate stakeholders involvement, and data-based decision-making.

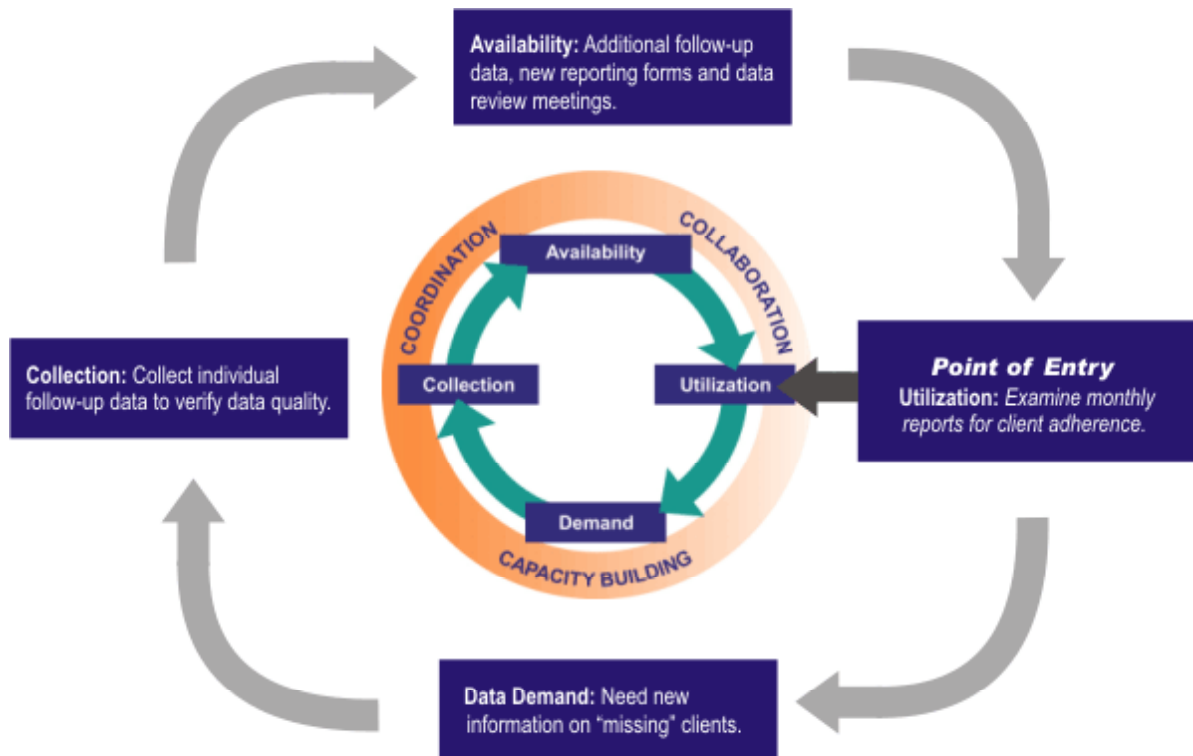


Figure 9. Once additional data were collected and a problem was identified, decisions were made to address the findings, resulting in better data use and a higher standard of care.



Using MSM Data in Rwanda for Program Creation and Policy Change

Data Demand and Information Use
Case Study Series

MEASURE Evaluation
www.cpc.unc.edu/measure

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. Activities intending to promote data demand and use 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 understanding the HIV risk among men who have sex with men (MSM)* in Rwanda, the point of entry was data demand (figure 10).

Data Demand

In 2009, the National AIDS Control Commission of Rwanda (CNLS) and partners conducted several analytic reviews and exercises in order to inform the development of a new national strategic plan on HIV/AIDS. In support of this, a modes of transmission (MOT) HIV incidence modeling exercise was conducted. MOT modeling estimates the distribution of new HIV infections in Rwanda across different HIV-risk groups. According to the model, three groups emerged as the primary contributors to HIV incidence — HIV sero-discordant couples, female sex workers, and MSM. In order to inform the model, detailed demographic, epidemiologic, and behavioral data were required for each potential risk group in the country. As local data were not available for all risk groups, the exercise used regional data from sub-Saharan Africa for some risk groups. As such, when the results were presented at the national level, many were skeptical of their relevance, and some decision makers questioned the existence of MSM in Rwanda.

As there were no data about the existence, practices, or HIV risk of MSM in Rwanda to support the model results, it was clear that, if the strategic plan was to be based on evidence, concrete data were needed. Consequently, CNLS commissioned a study to determine the HIV risk of MSM in Rwanda.

Data Collection and Analysis

A study was designed to investigate the MSM population in Kigali. The study was led by CNLS, with technical assistance from MEASURE Evaluation and financial assistance from the Joint United Nations Programme on HIV/AIDS (UNAIDS) and USAID. The purpose of the study was to describe the MSM population in Kigali, the capital of Rwanda, to explore the nature of sexual/risk activity among the MSM population, to establish men's opinions regarding potential HIV prevention activities, and to explore the feasibility of a more comprehensive bio-behavioral surveillance study of MSM nationwide. The study was designed to inform both program managers and policy-makers.

A study steering committee comprised of national-level stakeholders from government and civil society, including representatives of the MSM community, was established to guide the study from inception to dissemination. Kigali was chosen as the site of the study due to the higher HIV prevalence in the general population, study feasibility, and the reality that an urban environment

* We use the term “men who have sex with men” to describe homosexual or bisexual males who have anal or oral sex with other males, regardless of whether or not they ascribe to a personal or social identity associated with that behavior, such as being “gay” or bisexual.

provides greater opportunity for MSM partnerships. In light of the stigma around MSM in Rwanda, two important decisions were made. First, a member of the MSM community was chosen as peer coordinator to oversee study participant recruitment and interviewing. This helped put participants at ease and to assure them that participant confidentiality would be maintained. Secondly, CNLS acted as the principal investigator of the study. The establishment of local study leadership increased government and stakeholder acceptability of the study results. This heightened acceptability facilitated the use of study results in programmatic decision-making.

The study utilized a “snowball sampling” strategy involving peer recruiters, using a double-incentive structure. That is, men completing the questionnaire were asked to recruit their friends, acquaintances, or sexual partners into the study. Study participants received a small incentive for completing the study and for each eligible respondent that they recruited. The questionnaire was interviewer-administered. Ninety-eight MSM, aged 18 to 52 years, participated in the study.

Information Availability

The study produced a number of valuable outputs, including:

- evidence of MSM networks in Kigali;
- description of HIV risk behavior among MSM in Kigali; and
- recommendations for HIV prevention activities.

The information from the study was disseminated in four ways. The first was a dissemination meeting held in July 2009 with 40 MSM in Kigali, including some who had participated in the study, to inform the study population of the primary findings and to verify what was found. The study results were also presented at an international research conference in Rwanda. The peer coordinator from the study presented the abstract in a session that included three other studies. In the 45 minutes allocated to discuss all four abstracts presented, the discussion centered on the existence of homosexuality in Rwanda. Clearly, the study provided a catalyst for intense debate. In October 2009, a MEASURE Evaluation staff member was interviewed in Rwanda by BBC radio. This allowed a wider audience to learn about the study findings, and furthered the discussion of homosexuality in Rwanda at an international level. Finally, in December of 2009, a study dissemination meeting was held that included representatives from CNLS; the Rwanda Ministry of Health; U.S. Centers for Disease Control and Prevention (CDC); USAID; the Global Fund to Fight AIDS, Tuberculosis, and Malaria; and civil society groups. Meeting participants were invited based on their institutions’ potential to use the results of the study. Members of Parliament involved in the national dialogue on the criminalization of homosexuality were invited, as were other government officials involved in HIV policy issues. Donors with an ability to fund MSM HIV prevention programs and civil society groups advocating better health services were also invited.

Data Utilization

Data from the study were used in several key ways. After the 2009 dissemination meeting, MSM were identified as a priority group within the HIV/AIDS national strategic plan. This not only recognized them as a priority group in need of services, but validated their existence. As a result, a costed plan

was developed and used to secure global fund support for MSM programming in Rwanda. CDC also used the data to support a budget allocation to two organizations — one to provide health services, preventative care, and support to MSM in Rwanda; and the other to reach MSM through community outreach and behavior change communication. In addition, USAID decided to fund a follow-up qualitative study to understand better the determinants of HIV risk behavior among MSM and to explore issues of acceptability of HIV prevention services.

The study also played a key role in an historic policy decision. In 2007, the government began the process of revising the nation's penal code, which was originally drafted in the 1960s. The original code, while outlawing same-sex marriage, did not specifically mention homosexuality. Proposed revisions to the code, however, would have criminalized same-sex behaviors and those who encouraged or incited these behaviors, as well as mandating fines and jail time for individuals convicted of practicing homosexuality. In 2009, the peer coordinator of the MSM study was contacted because a proposed code provision would double fines and jail time compared with those originally proposed. In addition, any person or organization supporting homosexual behavior could also receive fines and jail time.

Civil society groups in Rwanda fought the revisions and drafted a position paper that was submitted to the president and to Parliament. The study conducted by CNLS was the only information available on the HIV risks faced by MSM in Rwanda, as well as providing information about men's experiences of stigma and discrimination, including sexual violence. This information was used in the position paper to support an argument that MSM require appropriate health care services and protection from further discrimination. Global advocacy groups and the media also used the study data to shift the discussion from one of ideology involving homosexuality to a discussion of public health needs. This shift allowed the discussion to focus on the constitutional right of all Rwandans to public health services. Through this widespread advocacy, the position paper circulated among all levels of government. As of mid-2010, a bill to de-criminalize homosexuality in Rwanda had passed through three levels of government and was expected to be signed into law.

Several factors promoted the use of the study data. Evidence gathering was an accepted part of the national HIV strategic plan process. This data use culture prompted the initiation of the modeling exercise. Furthermore, when the modeling exercise revealed unexpected results, there was a commitment to seek additional data to prove or disprove the findings. There was also an influential government stakeholder willing to support and lead the research effort. In terms of local buy-in of the MSM population, the study, which could have been seen as unwelcomed outsider involvement, was designed in coordination with MSM, and had a strong MSM stakeholder advisory group throughout the study and dissemination of results. Local ownership of the study by government and the study population ensured not just local buy-in for and ownership of the research process, but it also ensured that the study questions were closely linked to the data that would be necessary to support decision making around MSM services and national policy. As a result, when presented with data, key leaders were willing to support the inclusion of the MSM population in the strategic plan despite a cultural history of stigma surrounding homosexuality. Finally, civil society groups used the data to oppose criminalization of homosexuality.

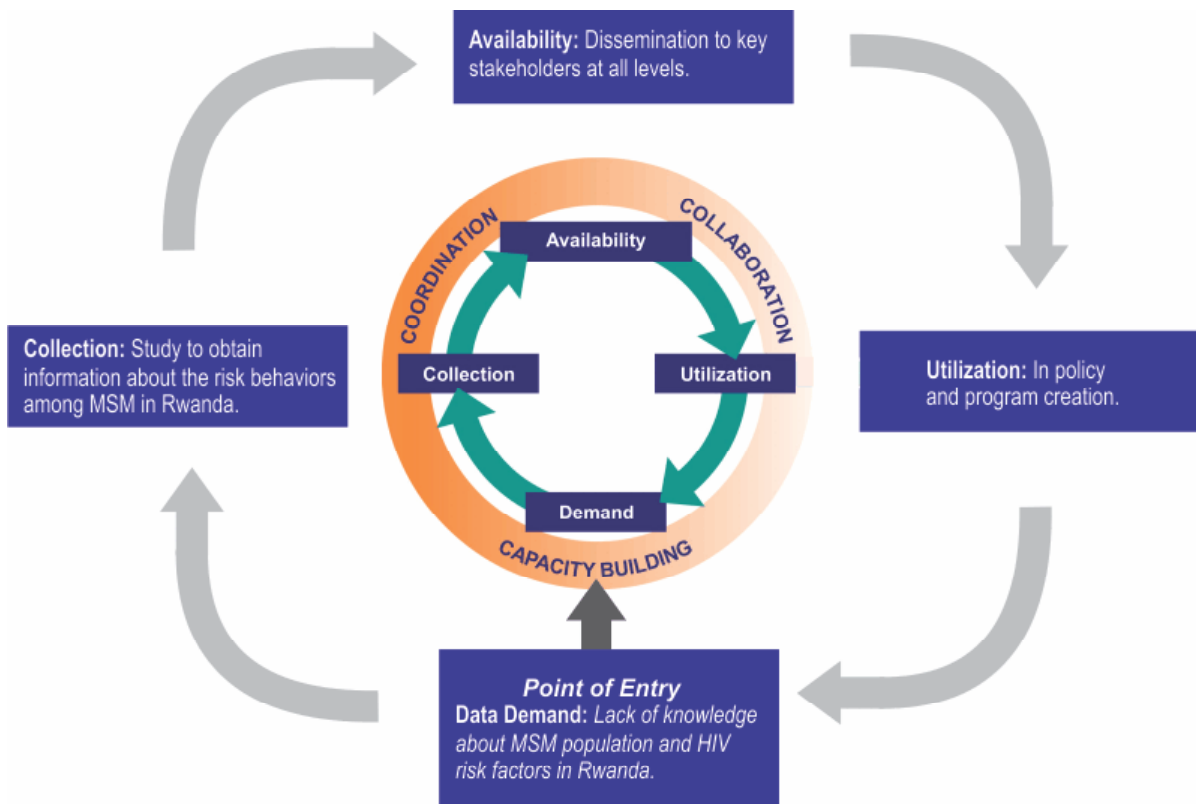


Figure 10. As there were no data on practices or risks among MSM in Rwanda, a study was designed to examine the MSM population in Kigali. The resulting information helped policy-makers shape the HIV/AIDS national strategic plan and the nation's penal code.



Using Vital Registration
Information to Improve Local
Malaria Programs — Malaria
Mortality Surveillance in
Tanzania

Data Demand and Information Use
Case Study Series

MEASURE Evaluation
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Point of Entry

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Data Demand

In Tanzania, community-based information on cause of death and use of health services was needed for health sector planning and priority setting. There was a paucity of information to help guide district-level resource allocation decisions to reduce malaria-attributable mortality. This information was needed by districts to help develop evidence-based decisions, target malaria interventions and influence malaria treatment policy at the national level.

One of the most common problems facing districts in Tanzania is the lack of resources to address major public health problems: The magnitude of the burden of disease is always larger than the resources available to respond adequately. To compound the situation, the information required to make decisions about allocating those limited resources is not available in many instances. Because of the lack of available and reliable information, districts are oftentimes faced with the problem of attempting to make choices based on common sense, last year's budget allocations, or donor preferences.

In addition to needing affordable health information systems that would track infections at the national level, Tanzania also needed information systems that would provide comprehensive, annual data to support fiscal decisions at the district level. Such systems were required to monitor the effectiveness of implementing new community intervention policies, and to inform resource allocation decisions. In Tanzania, as in most parts of Africa, vital event registration or cause of death data in any routine information system is rare.

Unfortunately, traditional health management information systems were not capable of providing the necessary information to address the inequitable distribution of district-level health resources in Tanzania. In 1996, for example, in one sentinel district, malaria was responsible for 30% of years of life lost (YLLs), but received just 5% of the district's budget. Top childhood diseases such as diarrhea, pneumonia, and malnutrition were responsible for 28% of YLLs, but received just 13% of the budget. Tuberculosis, on the other hand, at 4% of the YLL burden, received 22% of the funds.

Data Collection and Analysis

To address the information gap, MEASURE Evaluation assisted the district council's health management team (CHMT) to analyze and use information from sentinel vital registration. The vital registration and mortality surveillance method, designed to monitor cause-specific mortality, was used to collect information in five districts. "Verbal autopsy" methods were used to ascertain the underlying causes of death at the community level. The analysis was done at the district level; comparing the burden of disease profiles with the budgetary allocations to proven interventions that address the cause-specific burden.

Technical assistance was also provided by Canadian- and British-funded projects to increase the capacity of district councils (including the district health management team) in sentinel areas to carry out health management and administration activities. Health management training workshops were designed to increase the levels of confidence and skills among CHMT members. These workshops included a step-by-step training in using vital registration data for district planning.

Finally, a series of tailored data use workshops were used to train district-level representatives on how to organize, analyze, and report their district-level malaria mortality data in ways that would help guide priorities and inform operational decisions.

Information Availability

Following data collection and analysis, the vital registration information was disseminated to wider audiences, including the Ministry of Health, national health programs (e.g. national malaria program), district health management teams, district planners, and the communities where the data were collected. Annual mortality burden profiles for each district/sentinel area were developed to assist the CHMT in the production of comprehensive council health plans. These profiles included:

- leading causes of deaths by age group and sex for each area;
- tables and diagrams of use of health services before death;
- intervention-addressable shares of mortality burden (percent of YLLs);
- distribution of causes (e.g. malaria, perinatal conditions, pneumonia, injuries, etc.) addressable by the essential drug program; and
- distribution of causes addressable by malaria/acute febrile illness treatment and prevention.

As part of national and district capacity-building initiatives, the district teams and selected Ministry of Health representatives worked closely with the project team to develop these outputs, which were then distributed to Ministry of Health policymakers on a periodic basis and during annual planning cycles. The communities from which data were collected received an annual newsletter containing locally relevant health news and articles.

Information Use

The information collected through the vital registration has been used at the national level to influence malaria treatment policy, and by districts to help inform evidence-based decisions and target malaria interventions. This information was disseminated through a variety of mechanisms including:

- annual district mortality profiles;
- annual health statistics profiles;
- surveillance package/open source (SPOS), a collection of open source data and analysis tools for operating demographic and mortality surveillance and poverty measurements in the form of CD-ROMs and web-based tools; and
- a report entitled *The Policy Implications of Tanzania's Mortality Burden*.

National policies — Vital registration information was used to help guide the development of the National Package of Essential Health Interventions, including interventions to prevent and treat malaria. Mortality surveillance in the districts persistently showed high malaria-attributable deaths in all ages, but especially in pregnant women and in children younger than 5 years of age. The Tanzanian Ministry of Health noted that the vast majority of malaria deaths in children occurred at home and that a significant proportion of those deaths were among children who died despite having been treated in a formal health setting. This evidence, combined with other data on drug resistance, led the Ministry of Health to review first-line treatment guidelines for malaria. In particular, a decision was made by the Ministry of Health to change its first-line anti-malarial drug from chloroquine to sulphadoxine-pyrimethamine, based on the information.

Vital events information from sentinel demographic surveillance areas continues to be widely used in monitoring, evaluating and informing national drug and treatment policies and in the evaluation of integrated management of childhood illnesses (IMCI). The Ministry of Health now requires that all systems that collect data in the country be responsive and relevant to the national health problems and the data should be made available periodically to inform decisions. Vital registration information is now regularly disseminated to various stakeholders including the Ministry of Health and the National Malaria Control Program.

District planning and resource allocation — The districts adopted and introduced IMCI in all of their health facilities, and promote the social marketing of insecticide-treated bed nets. For the first time, as a result of the information produced through the district mortality surveillance, Malaria is now given a prominence within district health plans consistent with its disease burden. The district mortality surveillance continues to be used to document how these investments and strategies operate to reduce the burden of disease attributable to malaria. CHMT members and district planning officers also are using the vital registration information to allocate scarce district resources, to design local interventions, and to prepare their action plans more effectively and efficiently. These plans include increasing budget shares to malaria interventions to correspond with malaria's associated burden; and providing insecticide-treated bed nets to children, pregnant women, and people in poorer communities. The mortality surveillance methodology has provided Tanzania with valuable district-level information about locations at high risk of malaria transmission and gaps in prevention programs among most-at-risk populations.

Because so many deaths were occurring at home or without contact with the formal health sector, planners also recognized the need for new, household-based approaches to address malaria; and made substantial investments in promoting insecticide-treated bed nets. This change in practice at the district level was largely fostered by access to new, community-based data from the sentinel/sample vital registration, or demographic surveillance system.

The measurement of births and deaths by age, sex, and cause, and the calculation of mortality levels and differentials, should be central to evidence-based health policy, monitoring, and evaluation. Countries with the highest disease burden from infectious diseases, such as malaria and HIV/AIDS, not only need affordable health information systems but they also need systems that provide comprehensive, annual data that are nationally representative with sub-national estimates.

These data, combined with targeted data use workshops (where local stakeholders are made aware of the

information and whose ideas are sought to identify locally appropriate, workable approaches to address the problems), have led to acceptable and effective local malaria programs and interventions being designed and implemented throughout Tanzania.

Further information on Tanzania's sentinel demographic and mortality surveillance:

Ministry of Health. *The Policy Implications of Tanzania's Mortality Burden: A Ten-Year Community-Based Perspective. AMMP-2 Final Report*. Volume 1. Dar es Salaam: Adult Morbidity and Mortality Project, Tanzania Ministry of Health, University of Newcastle upon Tyne, United Kingdom Department for International Development; 2004. Available at http://www.ncl.ac.uk/ammp/site_files/public_html/finrep/index.html.

de Savigny D, Kasale H, et al. *Fixing Health Systems*. Ottawa: International Development Research Centre; 2004.

Further information on Sample Vital Registration with Verbal Autopsy, a community-based demographic and mortality surveillance system developed by MEASURE Evaluation in partnership with the U.S. Census Bureau:

<https://www.cpc.unc.edu/measure/leadership/savvy.html>

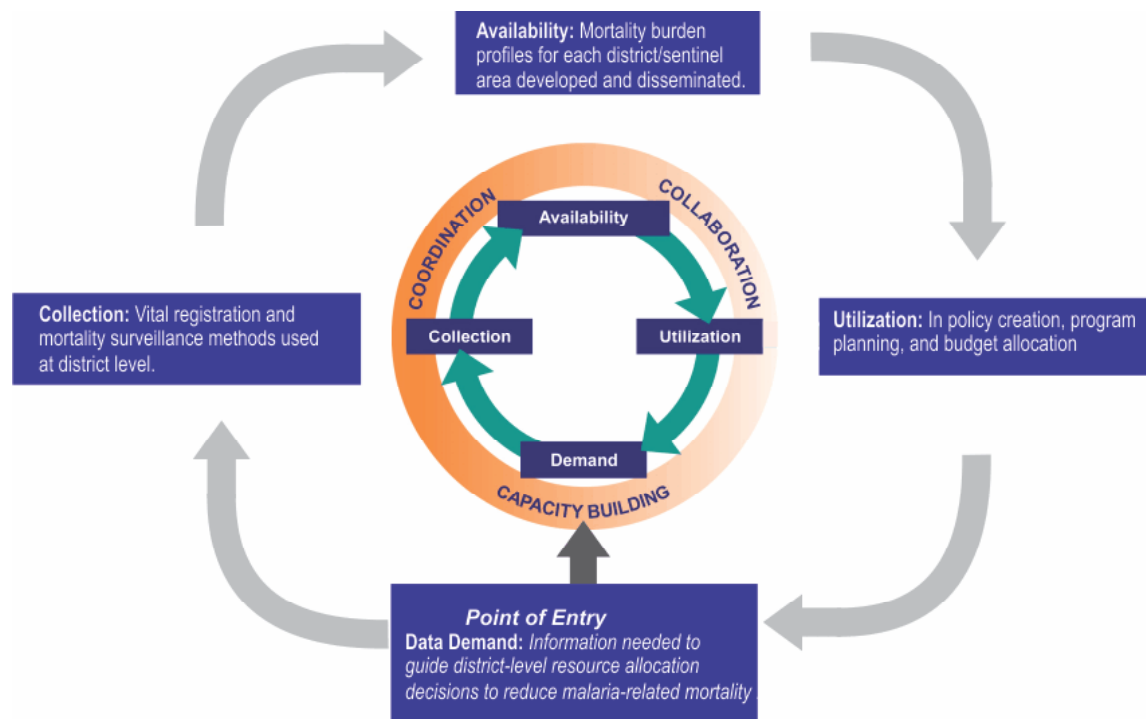


Figure 11. Vital registration and mortality surveillance at the district level provided mortality burden profiles, leading to better malaria program planning and budget allocation.



Generating Demand for HIV/AIDS Data and Information in the Eastern Caribbean Region

Data Demand and Information Use
Case Study Series

MEASURE Evaluation
www.cpc.unc.edu/measure

Point of Entry

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Data Demand

In the eastern Caribbean region, which consists of nine countries involved in this case study, public and private-sector organizations generally have limited financial and technical resources for M&E activities, yet their reporting requirements are extensive. Typically, the vast majority of M&E staff time was spent fulfilling reporting requirements, and little time was spent using that information to support decision making. Although HIV/AIDS data were being collected in the region, the information was underutilized — particularly at the country level. Local stakeholders recognized the need to base their decisions on data, yet were unsure of how to proceed. To address the gap between data collection and use, USAID/Barbados requested technical assistance from MEASURE Evaluation to support the latent demand for HIV/AIDS data and information.

First, a capacity assessment of data needs, data flows, and data constraints was conducted. This assessment was designed to answer the following questions:

- What decisions were being made at different levels?
- What were the specific information needs of community groups, health-care providers and caregivers, nongovernmental organizations, ministry officials, and international donor agencies?
- What types of data related to national HIV/AIDS programs were already being collected?
- What additional information was necessary?
- How did the information flow through the system, from collection to use?
- What constraints needed to be addressed to obtain this information?

Some of MEASURE Evaluation's DDIU tools were developed and piloted in part during the process of preparing for and conducting the capacity assessment. The DDIU Decision Calendar, Information Use Map, and Stakeholder Engagement tools were used to collect information from local stakeholders.

Following completion of the capacity assessment, country-specific briefing reports containing the findings and recommendations were shared with key stakeholders. MEASURE Evaluation also held briefings with representatives from government agencies, health-care facilities, and community-based programs to discuss the findings, which included the following priorities for further activities:

- identify and discuss informatics needs;
- develop and use consistent reporting tools across the region's states that receive support from the Global Fund to Fight AIDS, Tuberculosis, and Malaria;

- collect information about most at-risk populations (MARPs) for program design and implementation; and
- assess capacity and quality of services provided at HIV/AIDS facilities.

Data Collection/Analysis

As the nine countries started to understand their own capacity through the assessment and as they began to report to international donors, they started to demand data and an improvement in M&E structures and capacity. Simultaneously, the capacity-building activities and donor reporting requirements helped stakeholders realize the need for data and information to support strategic planning and programmatic decision-making.

To address the need for data and improved M&E systems, MEASURE Evaluation worked with the Caribbean Health Research Council (CHRC) and other stakeholders to conduct two workshops and collect information to meet those needs. The first workshop and one-on-one mentoring were focused on helping the countries report to donors. This assistance involved identifying existing data sources, training participants, and national AIDS programs in analyzing the data to respond to specific indicators, creating standardized reporting tools, and also considering how to gain ready access to data. As the countries considered how they could store and access data easily, MEASURE Evaluation, CHRC, and other partners identified the need to conduct a second workshop and provide additional technical assistance and mentoring to discuss different database systems and analysis tools, and to train the countries in the use of these systems.

In response to the need for data and information that could guide HIV/AIDS policies and programs, national AIDS programs, ministries of health, and other stakeholders, including MEASURE Evaluation, supported targeted data collection activities:

- Health Service Provision Assessments (HSPAs) were conducted in nine countries (Antigua, Barbados, Dominica, Grenada, Suriname, St. Lucia, St. Kitts and Nevis, St. Vincent and the Grenadines, and Trinidad and Tobago) across the region to assess the quality and accessibility of care and treatment services. Implementation and completion of the HSPA had the added benefit of building the capacity of a local institution, given that St. Georges University in Grenada led and completed much of the data analysis, report writing, and dissemination of the final data.
- A qualitative rapid assessment was conducted in St. Kitts and Nevis in collaboration with the Caribbean HIV/AIDS Alliance to understand the vulnerability of MARPs to HIV/AIDS infection, the community barriers to accessing HIV-specific services, and recommendations for addressing those barriers.
- The Priorities for Local AIDS Control Efforts (PLACE) methodology was used in St. Lucia as a monitoring tool to identify priority prevention areas and the specific venues within these areas where AIDS prevention programs should be focused. One clear goal of this assessment was to improve access to data by the civil society organizations that were contributing to the HIV/AIDS efforts in St. Lucia so that they could better inform their community-based programs.

- HIV/AIDS country profiles for St. Vincent and the Grenadines, St. Kitts and Nevis, and Dominica were drafted and provided a clear and concise tool to capture pertinent program data and contextual knowledge to support decisions about program design and improvement.

Information Availability

The various data collection activities undertaken in the region produced large amounts of information across several countries and program areas. To facilitate use of information for decision-making, this information was disseminated through a variety of mechanisms, including the following:

- Two dissemination meetings (one in St. Kitts and one in Nevis) were held in September 2007. The results of the MARPs rapid assessment were disseminated as part of a National Stakeholder's Meeting for Setting HIV/AIDS Priorities and were used, along with other relevant and recently-conducted assessments, to revise the five-year National Strategic Plan, which was drafted with support from the Joint United Nations Programme on HIV/AIDS.
- A half-day meeting was held in September 2007 in Castries, St. Lucia. About 80 stakeholders, including high-level administrators from various governmental ministries, nongovernmental and civil society organizations, regional partners, USAID, research staff, outreach workers, and the media attended the dissemination of the PLACE results. The dissemination meeting was followed by a two-day DDIU workshop where about 30 participants were led through a series of activities to help them process the results of the PLACE study, discuss existing activities and gaps in services, and identify interventions that were needed to both fill these gaps and that were appropriate, considering the PLACE study findings. Participants completed a data use plan by the end of the workshop that specified planned activities, responsible parties, general timelines, and resources needed.
- Country dissemination meetings were held in all nine countries where HSPAs were conducted. These meetings included separate meetings for the islands of Tobago and Nevis, for a total of 11 meetings. In all of these meetings, key country representatives had a chance to discuss the HSPA findings and to begin using them in country planning activities.

Information Use

The capacity assessment activities assisted stakeholders with identifying data and information needs, increased the capacity of stakeholders to collect and produce data and information, and also strengthened their commitment to building an organizational culture of M&E. More specifically, the capacity assessment process accomplished the following:

- **The process engaged stakeholders throughout the project process.** The capacity development consultation helped stakeholders see the interrelationships among all the players, their interests and roles in M&E activities, and possible synergies among them.
- **Deficiencies in information flow were identified.** The Information Use Maps were adapted to the local context and generated discussion about where data were originating, who was using the data, and how data were being used. The information from the data flow maps were used by stakeholders to make recommendations about how to address gaps between data

users and nonusers, and between public and private reporting, for example.

- **Potential opportunities to improve the information being collected were identified.** For example, the capacity matrix diagnosed and mapped several instances of duplicative reporting. This insight provided opportunities to fine-tune the timing or type of information required, to reduce the burden on those agencies, or to gain more information for national HIV/AIDS programs.
- **The importance of a system/organizational context that supports data collection and availability was communicated.** For example, as a result of this training, the M&E officer in St. Vincent and the Grenadines purchased analysis software and hired and trained staff to enter data and produce needed reports.

In addition, outcomes that resulted in the development of tools used to monitor and evaluate programs include the following:

- **HIV/AIDS data profiles.** Data profiles have been created for use in the planning process. These profiles summarize HIV/AIDS information in a format needed for decision-making; however, the countries used the final product differently. For example, Dominica has used

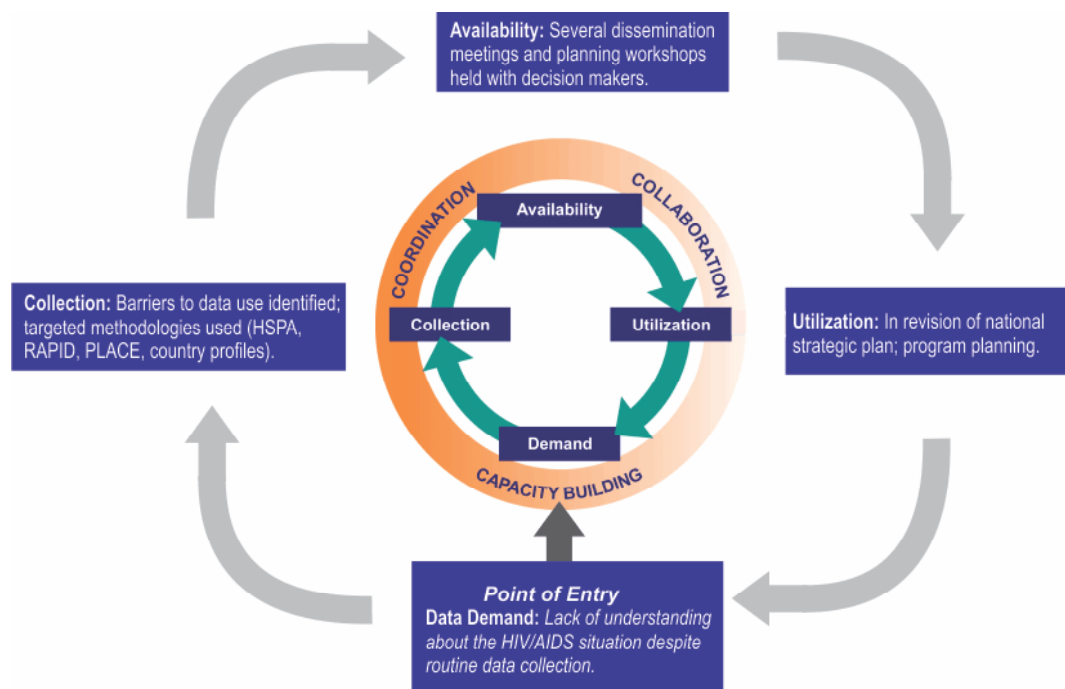


Figure 12. Information from targeted methodologies were used in workshops and dissemination meetings with decisions makers, resulting in better HIV program planning and a revised national HIV strategic plan.

the profiles as the “preface” for its revised strategy plan in reviewing the previous five years of programming to make decisions for future directions. St. Vincent planned to use its profiles to guide program improvement and monitoring.

- **Data-use plans.** National M&E plans include a section that describes how counties plan to use the information that is being collected to meet stakeholder needs and donor-funded programs.

Further information on DDIU in the Caribbean:

AID Inc., MEASURE Evaluation, St. George’s University. *Barbados Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-45]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

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MEASURE Evaluation. *An HIV and AIDS Situational Assessment: Barriers to Access to Services for Vulnerable Populations in Saint Kitts and Nevis* [TR-07-61]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, AID Inc., St. George’s University. *St. Lucia Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-47]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, AID Inc., St. George’s University. *St. Vincent and the Grenadines Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-46]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, St. George’s University. *Antigua and Barbuda Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-50]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, St. George’s University. *Grenada Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-52]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, St. George’s University. *Nevis Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-51B]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

MEASURE Evaluation, St. George’s University. *St. Kitts Caribbean Region HIV and AIDS Service Provision Assessment Survey 2005* [TR-07-51A]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

National AIDS Programme Secretariat, MEASURE Evaluation. *PLACE in St. Lucia: Identifying Gaps in HIV Prevention in Castries, Gros Islet, and Anse la Raye, 2007* [TR-07-62]. Chapel Hill, NC, USA: MEASURE Evaluation; 2007.

Conclusion

This booklet has been developed for health and information professionals to provide practical examples of approaches and tools that have been used to increase the demand for data and use of information. The examples provided here are also relevant to stakeholders at all levels of the health system — from program managers, practitioners, and policymakers to members of civil society, community groups, and patients — to encourage more strategic and effective use of health data and information in decision-making.

The aim of this document is not necessarily to promote the activities as “best” practices for evidence-based decision-making, but to illustrate data demand and information use in action. Although some tools and strategies have been adapted to the local context, there are common principles involved in facilitating information use that can be applied in other countries or circumstances, whether to guide policymaking or to improve service provision in the health sector. These principles include:

- **Participation** — Data are used more often when those involved in using the data have actively participated in data collection and analysis. Stakeholder participation fosters ownership of the data and leads to not only better decisions and more effective use of the data but can also improve data quality.
- **Collaboration** — Collaboration also fosters data use. When several stakeholders collaborate, they develop a shared understanding and vision and this enhances the use of the data.
- **Capacity building** — Technical assistance is more effective in improving data use when it also includes a capacity building component. This capacity can often only be improved through a process of continuous technical assistance and mentoring.
- **Demand-driven** — Data and information should be produced for the purpose of being used to improve health strategies and interventions. Data collection systems should be designed to collect data that will respond to demonstrated needs. Those needs should be from the beginning and should guide the entire data collection, analysis, and use cycle.

The benefits to a health program that can be gained from better use of health data have been documented in these case studies and include:

- improved health strategies that lead to improved health programs;
- improved management of programs by an increased focus on measurable results;
- improved programs by using data and information to make service delivery, programmatic and management decisions at the health facility, program site, and program management levels;
- increased awareness of emerging or existing health problems by key decision-makers and opinion leaders;
- awareness of successful interventions among policymakers and donors leading to increased support including increased funding;
- improved transparency of health programs leading to improved confidence by funding agencies that health funding is accomplishing results; and
- improved data quality when those who generate data use the data, since they have a vested interest in collecting data regularly and maintaining data quality.

The ultimate goal of evidence-based decision making is to improve health by improving the health system's ability to respond to health needs at all levels. With this goal in mind, we hope that stakeholders find the examples in these case studies useful and apply the approaches and tools to increase the demand for data and use of information in the settings in which they work.

References

1. Foreit K, Moreland S, LaFond A. *Data Demand and Information Use in the Health Sector, Conceptual Framework* [MS-06-16a]. Chapel Hill, NC: MEASURE Evaluation; 2006.
2. Foreit K, Moreland S, LaFond A. *Data Demand and Information Use in the Health Sector, Strategies and Tools* [MS-06-16b]. Chapel Hill, NC: MEASURE Evaluation, 2006.

For more information, please contact:

MEASURE Evaluation, Carolina Population Center
University of North Carolina at Chapel Hill, CB8120
Chapel Hill, NC 27516 USA

www.cpc.unc.edu/measure

Telephone: 919-966-7482 Fax: 919-966-2391 E-mail: measure@unc.edu