Report of a Technical Consultation on Information Systems for Community-Based HIV Programs

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Acknowledgments

Over 50 people representing international coordinating bodies, international profit and nonprofit organizations supporting community-based HIV programs, and in-country organizations implementing community-based HIV programs participated in this technical consultation. We would like to take this opportunity to thank them for taking time out of their busy lives and schedules to share their expertise with us, particularly our colleagues who traveled internationally.

This meeting would not have been possible without the help of several people including (in alphabetical order): Silvia Alayon, Erin Balch, Joni Bowling, Jeannine Bratts, Sian Curtis, Leah Gordon, Katy Handley, Shea Henson, Nash Herndon, Wayne Hoover, Phill Lyons, Svetlana Negroustoueva, John Novak, Dorina Maris, Susan Post, Heidi Reynolds, Hugh Rigby, Rebecca Teer, and Krista Stewart. Finally, thank you to the many participants who reviewed and provided comments to this report

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List of Acronyms

AIN-C	Atención Integral a la Niñez
ART	antiretroviral therapy
CAC	Community Action Cycle
CBIO	Census-Based Impact Oriented
CBIS	Community-Based Information System
CBO	community-based organization
CLPIR	Community-Level Program Information Reporting
CSHGP	Child Survival and Health Grants Program
CSI	Child Status Index
CSO	civil society organization
E2G	Excel to Google Earth
FHI	Family Health International
FOSREF	La Fondation pour la Santé Reproductrice et l'Education Familiale
GHARP	Guyana HIV/AIDS Reduction and Prevention Project
GIS	geographic information systems
HBC	home-based care
HIS	health information systems
HSDU	Health Sector Development Unit
IATT	interagency task team
IMCI	integrated management of childhood illness
IP	implementing partner
KPC	knowledge, practices, and coverage
KYE	Know Your Epidemic
LQAS	Lot Quality Assurance Sampling
M&E	monitoring and evaluation
MARP	most-at-risk population
MCHIP	Maternal Child Health Integrated Project
MERG	Monitoring and Evaluation Reference Group
MESI	Monitoring, Evaluation and Surveillance Interface
MNCH	maternal, neonatal, and child health
MVC	most-vulnerable children
MVCC	most-vulnerable children committee
NAC	national AIDS council, national AIDS commission
NAP	national action plan
NAPS	National AIDS Programme Secretariat
NGO	nongovernmental organization
OWT	Orphan and Vulnerable Children Well-being Tool
OVC	orphans and vulnerable children
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
PVVIH	people living with HIV (French)
QIVC	Quality Improvements and Verification Checklists

RED	Reaching Every District
RHINO	Routine Health Information Network
SAVVY	Sample Vital Registration with Verbal Autopsy
TB	tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USAID	U.S. Agency for International Development
VA	verbal autopsy
WHO	World Health Organization

Executive Summary

Rationale and Objectives

For the purposes of this meeting, community-based HIV programs were defined as non-facility-based programs, which include those that provide services for children orphaned or made vulnerable by HIV, home-based care (HBC) and support services for people living with HIV, and prevention programs for the general population such as youth or high-risk populations such as sex workers.

Information systems exist to track program and organizational efficiency. In the last six years or so, health information systems (HIS) for facility-based HIV programs have been strengthened considerably, partly as a result of increased investments in HIV/AIDS programs. However, development of the information systems for community-based HIV programs has lagged behind. Community-based programs are diverse in terms of their capacity and resources, and they are often multisectoral, such as programs for orphans and vulnerable children (OVC). Frontline providers and volunteers delivering community-based services are faced with a significant data collection burden due to lack of resources, capacity, and streamlined indicators.

There is increasing acknowledgement of the important role of community-based programs, communities, and civil society in the fight against HIV. To advance monitoring and evaluation systems for community-based HIV programs, MEASURE Evaluation invited experts to review the tools and experiences in this area and to identify gaps and prioritize recommendations to strengthen information systems for community-based HIV programs. On July 21-22, 2009, in Washington, DC, more than 50 people came together representing multinational agencies, international profit and nonprofit organizations, and local implementing partners.

The purpose of the technical consultation was to obtain consensus on a way forward to strengthen information systems for community-based HIV programs so that the information systems provide high quality data that are used to improve programs and facilitate reporting and use throughout the health system and beyond.

The objectives for the two days of the meeting were:

- **Day 1:** to acquaint participants with some existing tools, resources, and experiences of information systems for community-based programs; and
- **Day 2:** to identify gaps in existing information systems and to come to a consensus about how to fill these gaps.

Consultation Proceedings

The consultation consisted of presentations and small group work. On the first day, participants presented on a variety of resources and experiences from community-based programs. First, several community-based information system tools were presented:

- Community-level Program Information Reporting (CLPIR) tool kit

- Child Status Index (CSI)
- Orphan and Vulnerable Children Well-being Tool (OWT)
- Draft operational guidelines for the monitoring and evaluation (M&E) of most-at-risk populations
- Excel to Google Earth (E2G) tool
- Sample Vital Registration with Verbal Autopsy (SAVVY)

Participants also heard from programs' perspectives in implementing and carrying out community-based information and monitoring systems. Two programs' experiences were represented:

- Salvation Army's (Tanzania) Most Vulnerable Children Program
- Fondation pour la Santé Reproductrice et l'Education Familiale's (FOSREF) (Haiti) prevention programs and services for adults of reproductive age, youth, and commercial sex workers.

Four presentations of experiences with nationalizing information systems were made. These are experiences in taking the information systems from the program level making them consistent across programs, implementing partners, or donors at the national level:

- Zimbabwe's system to monitor the National Action Plan for OVCs;
- Guyana's national monitoring system for community-based HIV programs;
- Haiti's common community-based information system among programs supported by the U.S. Agency for International Development (USAID); and
- South Africa's home-based care program information system, supported by Family Health International (FHI).

Three presentations focused on specific efforts to engage the community and to strengthen the community voice in the monitoring process:

- Scale up Hope in Mozambique, which built the capacity of the community to deliver and monitor services;
- World Bank's plans for a two-year evaluation of the community response to HIV; and
- USAID's concept for a cross-sector program support model to bring multisector data into a community hub for community use.

Experiences of information systems and methods from non-HIV programs wrapped up the first day's presentations:

- Census-Based Impact Oriented (CBIO) information systems, which have been implemented in Haiti, Bolivia, and Liberia to track vital events and health service provision;
- the Care Group system, which has been implemented in Liberia, Mozambique,

and Honduras where each Care Group member (a community member) visits 10-15 households on a regular basis to deliver health care messages and to collect information; and

- ❒ M&E tools used by programs supported by Food for the Hungry.

Vision, Challenges, Gaps, and Next Steps

The second day focused on identifying the vision, challenges, and next steps. The group articulated a future vision for the field:

> *Information systems for community-based HIV programs are based on evidence and have the capacity and resources to effectively collect data on harmonized indicators, report those data to an interoperable reporting system, and use data generated by this system to make programmatic decisions to meet community-defined needs and to communicate with the community beneficiaries.*

The group discussed challenges and next steps along five themes: community ownership, most-at-risk populations, harmonization, capacity building, and data collection for outcome monitoring. A number of important challenges and gaps were listed by participants, reflecting themes reiterated throughout the meeting:

- ❒ There are varying perceptions and definition of "community" or "community-based."
- ❒ The purpose, audience, and user of the information system are not always articulated.
- ❒ Information gathering requirements pose a burden for frontline providers.
- ❒ Human resource capacity varies widely and often depends on volunteer or low-literate frontline staff.
- ❒ Expectations for community-based staff and volunteers are not defined, nor do we understand their capacity and needs.
- ❒ There are few linkages among different health information systems.
- ❒ National systems are not fully functional.
- ❒ Data quality and use are weak.

Three main areas for next steps in information systems for community-based HIV programs were defined:

1. Foster a culture of using data at the community-based program and community level where data are linked with action. Conduct systematic inquiries to understand what communities and community-based programs want and need to know. Map this information to what is currently being collected. Raise awareness of the purpose and rationale for the data that are being collected. Explore incentives for community-level data use. Adapt data-use tools with a focus on the community and

community-based program level.

2. Research and develop a framework for information systems for community-based HIV programs at the international level. The framework would aim to reduce unnecessary data collection while keeping in mind the continuum of data needs from the community to the donor level.
3. Promote the available resources and experiences related to information systems for community-based HIV programs, while at the same time work to raise awareness about the remaining challenges, gaps, and priorities. Advocate for this agenda via a wide range of fora.

Conclusion

The tools and experiences presented during the two-day meeting highlight a variety of users and stakeholders at different levels of the health system, from the community to the national level. Recommendations emerging from the meeting underscore the fundamental need to strengthen monitoring and data use at the community-based program level by implementing M&E systems that are tailored to the skills and capacity of, and meet the data needs of, programs, and building systems that yield quality, complete, relevant, and timely data.

We urge groups desiring to improve information systems for community-based HIV programs to place their work in the context of the meeting recommendations and coordinate and collaborate with the people and organizations identified in this meeting. The Global Fund to Fight AIDS, Tuberculosis, and Malaria; World Bank; Joint United Nations Programme on HIV/AIDS (UNAIDS); World Health Organization (WHO); MEASURE Evaluation; USAID; and many others have ongoing efforts in this area.

Introduction and Consultation Rationale

Background and Rationale

Over the last six years, significant strides have been made in the development of information systems for HIV services. These efforts have primarily focused on information systems for facility-based HIV programs. Non-facility based, or community-based HIV program information systems, where they exist, are much weaker. Community-based HIV programs cover all levels of primary, secondary, and tertiary prevention and include services for children orphaned or made vulnerable by HIV, home-based care (HBC) and support services for people living with HIV, and prevention programs for the general population such as youth or high risk populations, such as sex workers. Prevention programs can also include prevention of mother-to-child transmission (PMTCT) programs, non-facility based counseling, and testing and prevention with positives.

Information systems exist to track program and organizational efficiency. Information systems include resource inputs; indicator, data source, and data management processes; and products that communicate the information and facilitate data use (Figure 1). In the last six years or so, health information systems (HIS) for facility-based HIV programs have been strengthened

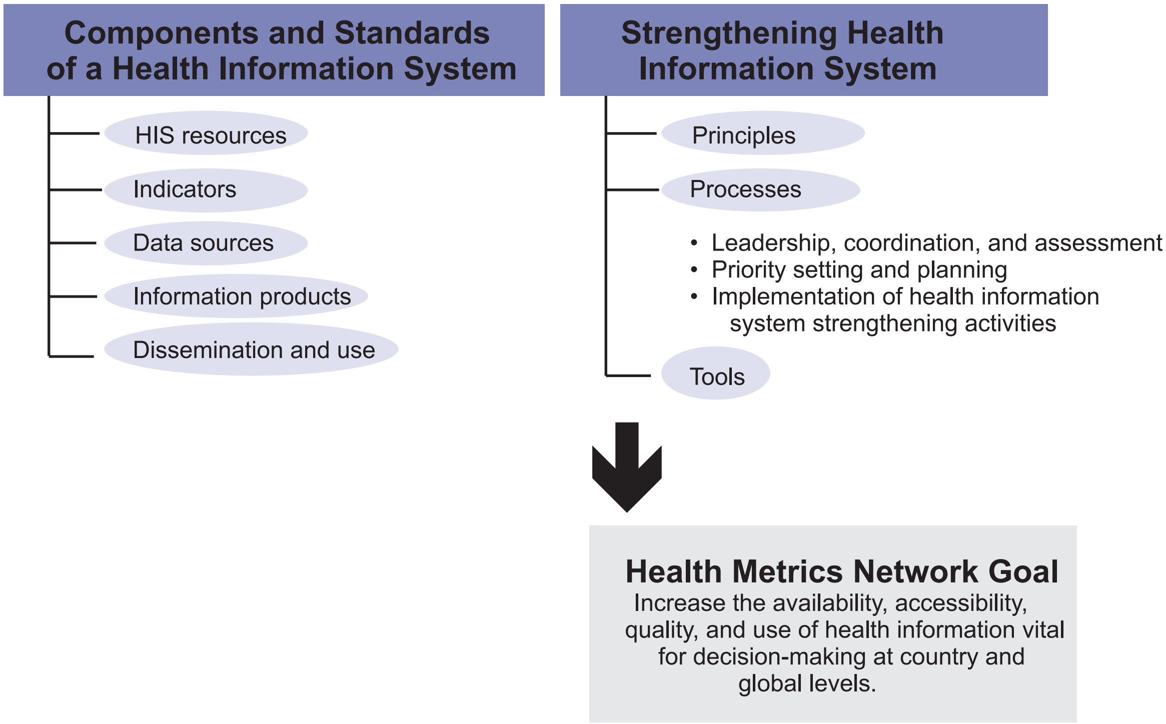


Figure 1. Health Metrics Network.

Source: Adapted from Health Metrics Network, World Health Organization (WHO). *Framework and standards for country health information systems.* 2nd ed. Geneva: WHO, 2008; 4.

considerably, but there is growing emphasis on the need for strengthening information systems for community-based HIV programs. Under the emergency paradigm characterizing the first phase of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), information systems for HIV programs were established with the primary goal to facilitate reporting to program managers, implementing partners, and ultimately the donors. Less attention has focused on how to get information back to the program or beneficiaries of services and on program capacity to make use of that information. HIV HIS exist largely in parallel with other health information systems or national informational systems. In other words, there is little integration or interoperability of HIV information systems with other information systems. Despite efforts to build systems and capacity, issues such as data quality, double-counting, and capacity and systems for data analysis and use remain.

Information systems for community-based HIV programs face the same issues as facility-based HIV programs, as well as their own unique set of challenges. Because community-based programs are more diverse in terms of their capacity and resources compared with facility-based programs, their needs are more diverse. Also, the multisectoral response of community-based HIV programs, such as programs for orphans and vulnerable children (OVC), means that information systems need to be coordinated across several ministries (e.g., health and social affairs); yet, in most contexts, no ministry is specifically mandated to coordinate information systems. A lack of harmonized indicators is a problem throughout a country, but is compounded at the community level. The lack of resources, streamlined indicators, and capacity of volunteers to collect data create a significant burden on frontline providers and volunteers (which, in turn, affects data completeness, quality, etc.).

Although there are a number of tools for community-based information systems and the experiences in this field are increasing, there is no common repository for this information. There is a need to take stock of what tools and experiences we can draw from, but also to identify the gaps so that subsequent activities can be defined and prioritized. In order to do this in a systematic manner with input from a variety of stakeholders working in this area, on July 21-22, 2009, MEASURE Evaluation convened a technical consultation in information systems for community-based HIV programs.

Meeting Objectives

The purpose of the technical consultation was to obtain consensus on a way forward to strengthen information systems for community-based HIV programs so that the information systems provide high quality data that are used to improve programs and facilitate reporting and use throughout the health system. The objectives for the two days of the meetings were to:

- acquaint participants with some existing tools, resources, and experiences of information systems for community-based programs, and
- identify gaps in existing information systems and to come to consensus about how to fill these gaps.

Consultation Proceedings

Session 1. Opening Remarks

The objective of the first day (July 21, 2009) of the two-day meeting was to acquaint participants with existing tools, resources, and experiences of information systems for community-based HIV programs. Presentations focused on the tools and methodologies used in community-based information systems and on the various experiences to strengthen these systems in countries.

Sian Curtis, director of MEASURE Evaluation, opened the meeting with a welcome to participants and other remarks. She described how MEASURE Evaluation's interest in this topic stems from some of the project's work in recent years. Several of MEASURE Evaluation's activities address aspects of strengthening information for community-based HIV programs. At the same time, because many organizations are working in this area, there was broad recognition of the need to share experiences more formally, and there was great interest and support for this meeting. This meeting draws on the expertise of people both in and outside the HIV arena. Experiences from other program areas, such as child health, are relevant and have a longer history.

Curtis called attention to a few overarching issues. First, there exists tension among the approaches to community-based information systems because there are different kinds of data needs and philosophies for information systems for community-based programs. At one end of the spectrum is the "bottom up" perspective, where the community defines what information it needs to make its own decisions. Different communities can have different needs, and define different information to collect accordingly. A more "top down" approach is when information is needed at district, national, or global levels to monitor programs, advocate for resources, and make high-level policy decisions. In this case, the ability to compare information across sites and over time is important. Can the needs of both approaches be addressed, or at least respected and balanced?

Another area of tension exists between parallel information systems and national systems. This tension is not unique to community-based HIV programs. The reason for parallel systems is to address the need for information, to be able to report against programs for global initiatives, such as PEPFAR and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, and to support ongoing funding for programs. At the same time, fragmented health information systems and the proliferation of parallel reporting systems strains limited resources in countries and creates duplication. Building national systems is a slow process, however, and it is challenging enough to balance different information needs of different programs under a single donor much less under a national system.

Thus, community-based HIV programs are faced with the following struggle: How can short-term reporting needs be met that are required to sustain program funding while also building the foundation for longer-term national systems and systems that take into account the voice of the community?

Curtis raised two other important issues for participants to consider. First, language is important in communication. The term "community-based information systems" means different things to different people. To some, it can mean that the information is contained in the community served by the program. To others, it means that the system is based in a program that is not in a facility. Productive discussions can be derailed by the terminology that may be used related to the different philosophical approaches mentioned earlier. This issue was addressed later in the meeting.

A final issue is one of capacity. Are the existing monitoring and evaluation (M&E) tools and approaches proposed realistic to implement in the field? Some of the M&E technical issues are quite complex, but M&E capacity on the ground is often very limited, especially in small community-based organizations (CBOs) that do not have much exposure to data and information.

Curtis closed her comments by once again welcoming participants and challenging participants to have a productive two-day meeting.

Krista Stewart of the U.S. Agency for International Development (USAID) followed with her own opening remarks and welcome on behalf of the Office of HIV/AIDS at USAID and the MEASURE Evaluation management team at USAID. Stewart acknowledged that she had only recently taken on the role as head of the MEASURE Evaluation management team, although she was a technical advisor for 12 years earlier in the project's history. She acknowledged Katy Handley, who was in the team leader role for the previous two years, and who originally conceptualized this meeting. She also recognized Erin Balch and Dorina Maris, who are on the USAID management team and help to oversee some of the community-based information systems work done by MEASURE Evaluation.

Stewart continued by pointing to how the use of high-quality data to monitor, manage, and improve programs is of great importance to USAID, PEPFAR, and President Obama's new Global Health Initiative. The technical consultation is important as it focuses on filling a niche that currently is unfilled. While progress has been made in developing facility-based information systems, we have less experience in dealing with the diverse situations of community-based programs.

Many HIV programs focus on providing services close to the people who need them — that is, people in the community. The proximity to the community emphasizes the need for having good systems for collecting simple but high quality data and information at the community level to help understand the effectiveness of these programs. However, nongovernmental organizations (NGOs) or civil society organizations conduct many of these programs and may not have people skilled in M&E. Having data available at the community level that can be used by the community helps to build community ownership of the problems and the solutions.

Stewart closed her comments by underscoring how the technical consultation provides an opportunity to learn about approaches currently being used and to think about what else is needed, and by thanking participants for coming to the meeting, for their willingness to contribute their ideas, and to the MEASURE Evaluation project for organizing the meeting.

Session 2. Overview of Community-Based Information System Tools

The CLPIR Tool Kit

Presenter: Upama Khatri, MEASURE Evaluation

The Community-Level Program Information Reporting (CLPIR) tool kit was developed to address key challenges associated with information systems for community-based HIV/AIDS programs, including weak coordination, standardization, and capacity. Community-based HIV/AIDS programs are defined as programs operating primarily at the community level that are not dependant upon a medical facility. The tool kit contains a collection of generic, illustrative tools and resources to help countries strengthen information systems for community-based HIV/AIDS programs (i.e., community-based OVC, HBC, and prevention programs). The tools, which include illustrative minimum data sets for OVC, HBC, and prevention; indicator reference sheets; primary data collection and aggregation tools; and user's guide for tools, are generic and are intended for adaptation prior to use, to suit specific challenges and contexts.

Components of the tool kit were field tested in Tanzania, Nigeria, Lesotho, and Kenya in 2008 and 2009. The kit also underwent a peer review during a moderated Routine Health Information Network (RHINO) discussion forum. Recommendations from the field tests and the RHINO forum can be classified into two categories: recommendations to strengthen community-based information systems in general and recommendations to improve the tool kit. Illustrative recommendations to strengthen community-based information systems include:

- involving community members and organizations in the design of community-level interventions and information systems;
- designing simple and user friendly information systems to match the capacity of data collectors (limiting the number of required indicators to a minimum);
- improving communication and coordination among different sectors and community-based programs;
- supporting the formation of coordination structures at the sub-national levels to manage and coordinate community-based activities and information systems;
- investing in human resources, including hiring sufficient staff at the supervisor/manager levels to support the needs of frontline staff like volunteers; and
- developing and implementing capacity building plans for volunteers and staff, including training workshops, in-service training, regular feedback, and supportive supervision, to improve the quality of data that are collected, reported, and used.

Illustrative recommendations to improve CLPIR include:

- streamlining the tool kit to reduce bulkiness and to improve navigation;
- creating an adaptation guide for the generic tools; and
- identifying local partners that can implement the tool kit to provide countries with technical

assistance that address specific local challenges.

A report of the RHINO forum proceedings is available at:

> http://www.rhinonet.org/Docs/CLPIR%20Toolkit%20Email%20Summary_v.7%20FINAL%208.12.09.pdf

A summary of CLPIR modules is available at:

> http://www.cpc.unc.edu/measure/networks/CLPIR%20Toolkit%20Module%20Summaries.doc/view

Next steps include getting CLPIR to a point that it can be made publically available for wider use.

Discussion

> *One concern that was raised was about the reporting burden on frontline volunteers providing services to vulnerable children and their families. The comment/question was whether illiterate volunteers could use the type of data collection tools that are in the tool kit and would the reporting burden take away from their primary responsibility of taking care of the children?*

Khatri acknowledged that data collection tools should reflect the level of capacity of the data collectors, and described how the generic tools in the tool kit were designed with simplicity and ease of use in mind, while still being capable of generating a minimum set of indicators. Further simplification can be made when the generic tools are adapted.

> *How and when was input sought into the CLIPR development process?*

Before developing the tool kit, the MEASURE Evaluation team conducted a literature review; interviewed representatives of several community-based programs in Zambia, Nigeria, and Tanzania; and reviewed indicators, data collection tools, and systems. The team synthesized this information, which fed into the process of developing the draft indicators and tools in the tool kit. An experts' meeting was conducted in 2007, where the draft indicators and tools were shared with and vetted by partners at various levels before developing the current draft of the tool kit.

A Community-Based Approach to Monitor Child Well-being: The Child Status Index

Presenter: Florence Nyangara, MEASURE Evaluation

The Child Status Index (CSI) has been developed so that caregivers and providers of services for children orphaned and made vulnerable by HIV/AIDS can collect and use data to help them understand whether the needs of the children are being met. Moreover, emerging experiences suggest that data collected about individual children can be aggregated at the program level to provide information to monitor programs and, ideally, inform management decisions to improve programs. Use of the CSI across programs will also harmonize the processes and information being collected.

MEASURE Evaluation and Duke University's Center for Child and Family Health worked in partnership and through a participatory approach with NGOs, community leaders, community workers, guardians, and children to get their buy-in and input to develop a user-friendly tool. Specifically, local program staff and community members in Kenya and Tanzania participated in concept, design, content, and field testing of the tool. In addition, consultations with experts and use of existing OVC frameworks, PEPFAR OVC guidance, and previous research on child development in resource poor countries affected by HIV/AIDS guided its format. The CSI was developed using the guiding principles that the CSI should:

- be child focused
- be simple, reliable, and intuitive
- be measurable and changeable
- capture keys dimensions of child well-being
- reflect both positive and negative outcomes
- be adaptable across ages and cultures

The tool collects information about the child mainly from caregivers and the child herself, and from other sources such as community leaders, teachers, and relatives. The information is then used to rate the child on 12 identified key CSI domains of child well-being, using a rating system of 1 to 4, where a high score means better child well-being or child is doing well in each outcome area (4=good [no problem]; 3=fair [a little problem]; 2=bad [serious problem]; 1=very bad [critical problem, emergency situation]). Data are gathered across 12 outcome areas that are organized into six themes:

- food and nutrition: food security and nutrition, and growth
- shelter and care: shelter and care
- protection: abuse and exploitation, and legal protection
- health: wellness and health care services
- psychosocial: emotional health and social behavior
- education and training: performance and education/work

Data are gathered via an informal discussion with the people identified above and they begin the conversation with general discussions (as culturally appropriate) and a general inquiry as to "how is the family and how are the children?" The discussion is supposed to be informal and open-ended and, through observations, ensure that each of the 12 outcome areas have been assessed.

CSI can be used as part of a home visit as a basis for an individual care plan for a child, monitor changes in outcomes over time, or used periodically to establish a baseline of need for children in the program (or where to target services or which services) and to monitor programs for program improvement or to document effectiveness.

The CSI manual, field guide, and "made easy" tools are available at:

> http://www.cpc.unc.edu/measure/tools/child-health/child-status-index

Discussion

> *How do you use the CSI to gather information at the local level and have information to aggregate on multiple levels (national, global)? How can tools be used on the ground to make programs better?*

Nyangara clarified that CSI was originally designed to assess and monitor individual child outcomes and needs but can also be used to monitor children as a group (i.e., program monitoring). As a result, there are efforts to develop a guideline that will address the issue of aggregating individual child information and analyzing it for program monitoring and evaluation.

A Self-Report Tool for Monitoring OVC Well-being

> *Presenter: Shannon Senefeld, Catholic Relief Services*

The Orphan and Vulnerable Children Well-being Tool (OWT) was developed because there was a need for a comprehensive measure of OVC well-being. The goal of the effort was to create an instrument that can be used internationally to monitor holistic OVC programming from a child's perspective that is valid, reliable, and practical to administer. The tool is used to monitor OVC programs at an aggregate level and to identify patterns of change in OVC well-being within projects. It is not intended to be used as an in-depth assessment tool at the individual level. The guiding principles in tool development were the following:

- ❒ capture well-being from the child's perspective
- ❒ a valid and reliable measure of well-being
- ❒ age-appropriate
- ❒ applicable to multiple settings
- ❒ ease of use
- ❒ repeated measure

OWT relies on self reports of well-being across 10 domains, from youth aged 13-18. There are 36 questions in the tool and they are measured using a 3-point Likert scale. The tool is unique in that it obtains information from the youth's perspective. It creates a holistic picture of the child's well-being. It is relatively low cost, can be done quickly, and can be used across programs and contexts. Because it is intended to be used across contexts, some context-specific information that would be useful at the local level is not included. Translation accuracy is also a challenge. Finally, the tool collects information on sensitive topics.

In the development of the tool, feedback was obtained and it was pilot-tested. The initial feedback was crucial in the adaptation of the tool; for example, some questions were eliminated based on this feedback. In general, people are enthusiastic about the product. Children are pleased to give their opinion on matters relating to themselves. There have been no reported problems understanding the questions.

A total of 890 children aged 13-18 years participated in the pilot test of the validity of the OWT. The information collected by OWT was compared with information collected during a large evaluation survey and alongside a standardized tool, the Children's Hope Scale. In general, a strong correlation between the sources was found, although some categories (e.g., mental health and spirituality) were harder to validate against the larger survey, as the larger survey did not include information on these domains. Against the Children's Hope Scale, OWT showed a Spearman rank correlation (rho) of $\rho<.01$ for both the original long version and the shortened version.

The OWT has been used in CRS programs in Ethiopia, Haiti, India, Kenya, Malawi, Rwanda, Tanzania, Vietnam, and Zambia, but use was not being mandated. Programs use the tool only if the program managers feel it would be useful. CRS is conducting research on longitudinal changes in well-being to understand the predictive value of the OWT. CRS will continue to use the tool, and wants to develop a similar tool for younger age groups.

The CRS OWT is available at:

> http://crs.org/publications/ovc-wellbeing-tool/

Discussion

> *Can the tool be used with younger children, especially for those under one year (who cannot respond to the questions)?*

Senefeld clarified that there are currently no self-reported tools for children under age five. There had been a recent OVC meeting in Tanzania with the goal to advance the early childhood development agenda and identify ways to determine what early interventions services children need, since it is important to screen for delays as early as possible so that they can be addressed. One option is to design a tool for the caregiver to be able to assess for delays. One limitation with caregiver assessment would be lack of caregiver education. A search was underway for tools to assist with addressing this.

> *How do we use information at a local level and have information to aggregate on multiple levels (national, global)? How can tools be used on the ground to make programs better?*

Senefeld responded with a couple of examples: In one country, they used the assessment tool and identified economic issues were priorities. They used this information to respond programmatically. In another country, they found that psychosocial issues were a priority, so they addressed this by creating support groups.

> *Have attempts been made to institutionalize the tool?*

Senefeld clarified that there is no mandate to use the tool in CRS programs; it is available for countries and programs to use if they wish. Five countries have tested it; and they liked it, but there is no requirement to use it.

How does this tool related to the Child Status Index?

Senefeld explained that they knew about the CSI pilot in Kenya when they were developing the OWT tool, and they have been working closely together over the last three year. CSI focuses on ages 0-18 and obtains information from caregivers, etc. CRS decided to focus on a self-reporting tool, so CRS obtains the information directly from OVCs. There are big differences in the type of information that can be obtained between self-reports and caregiver reports, although there is not much research comparing self-reports vs. caregiver reports. They hypothesized the main differences would be in some of the "softer" domains, such as psychological health, which may be difficult to measure objectively.

Session 2 General Discussion

There was general discussion about the definition of vulnerability when it comes to children who are orphaned and made vulnerable by HIV/AIDS. The definition of vulnerability varies by the local context. The community may be the best body to identify who is vulnerable, but then the criteria for who is considered vulnerable will vary across contexts. The field is at a critical stage of defining vulnerability at national levels for comparative purposes. There are still questions of how to evaluate OVC programs, there are issues of inter-rater reliability across different methods, and there are different attempts to assess reliability by characteristics. The question facing the group is how we harmonize our methods so as not to confuse things at a country level.

Operational Guidelines for the M&E of Most-at-Risk Populations

Presenter: Sharon Weir, MEASURE Evaluation

In 2008, *A Framework for Monitoring and Evaluation of HIV Programs for Most-at-Risk Populations* (MARP) was produced, available at:

http://data.unaids.org/pub/Manual/2007/JC1519_me_Framework_en.pdf.

However, the framework provides insufficient guidance about how to implement the concepts, since that was not its objective. To build on the framework, the UNAIDS Monitoring and Evaluation Reference Group (MERG) asked the MARP Technical Working Group to develop operational guidelines to extend the framework. At the time of this presentation, the guidelines were still under development (scheduled to be submitted to MERG in October 2009).

The guidelines will build on the eight organizing steps in the 2008 framework. These steps are outlined in Figure 2. In the guidelines, these questions are adapted for HIV prevention and mapped to M&E activities. These M&E activities are also organized by national, sub-national, and service-delivery levels, as show in Table 1.

Table 1. M&E Activities Organized by Levels

National level	Sub-national level	Service-delivery level
• Set national level definition(s)	• Estimate HIV prevalence among key population and size	• Review description of epidemic from sub-national level
• Estimate HIV prevalence among key populations and size	• Identify sub-national contributing factors	• Conduct resource analysis, identify activities, targets, indicators, request funding
• Identify modes of transmission and contributing factors	• Identify which components of national package are necessary	• Implement activities & monitor inputs, quality, outputs
• Identify sub-national areas for focused prevention	• Specify and monitor quality, output, and coverage	• Provide outputs to sub-national level for coverage estimates
• Identify national intervention package and quality indicators	• Set sub-national level targets	• Discuss gaps in coverage with sub-national level
• Specify and monitor quality, output, outcome, impact indicators	• Produce sub-national coverage estimates and maps	• Participate in any sub-national outcome evaluation
• Set national level targets	• Estimate outcomes at sub-national level	
• Produce national coverage estimates and maps	• Use findings to adapt sub-national program	
• Estimate outcomes and impact of prevention interventions		
• Use findings to adapt national program		

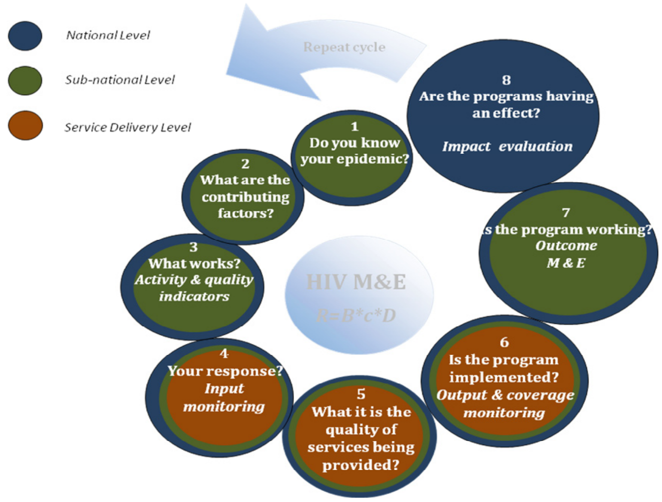


Figure 2. The eight organizing steps in the 2008 MARP framework.

Discussion

What tools are there to assess the steps in the HIV M&E cycle (Figure 2)?

Weir explained that the guidelines will contain "sign posts" and refer to other tools that are available. More feedback is needed about what tools should be included.

Mapping and GIS Tools for Community Reports

Presenter: John Spencer, MEASURE Evaluation

Geography is a common denominator. Everything happens somewhere, and understanding the "where" can help with understanding the "why." Spatial tools such as geographic information systems (GIS) and mapping can provide added value to community-based data in two ways: by using geography to facilitate linking multiple data sets; and through the creation of analytical tools, such as maps.

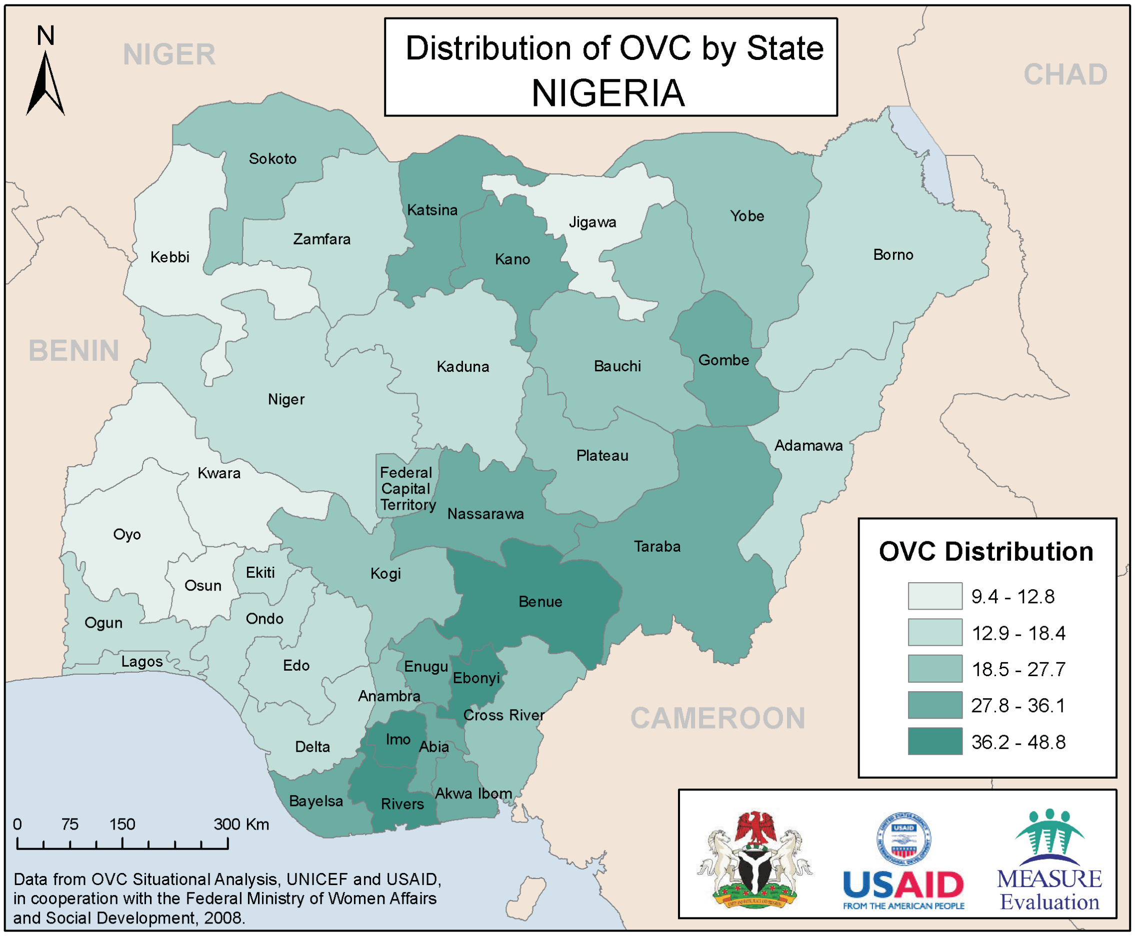
In the context of a community, maps can be a valuable decision support tool for community-based program. While community-based data may focus on one specific aspect, such as OVC, such activity does not exist in a vacuum. Additional contextual data, such as poverty or education, can be useful to consider. This multi-dimensional approach to analyzing community data can be facilitated by using geography as the common link between data sets. Figure 3, an example from Nigeria, geographically compares concentrations of children orphaned or made vulnerable by HIV/AIDS with levels of poverty. The map was produced by joining two different datasets, collected independently of each other. Such multi-dimensional analysis maximizes the value of both data sets. Information such as this can help target resources for programs or to formulate research questions to understand why there are such different levels by region.

There are a number of challenges, such as ensuring that mapping software is available and that there is the capacity to use and interpret maps. The main challenge for mapping is the data. The data must be well formed and have a geographic identifier. Additionally, the availability of affordable, easy-to-use mapping software can be a hurdle. To overcome this challenge, MEASURE Evaluation has developed the Excel to Google Earth (E2G) Tool. The target audience includes decision-makers, data processing and M&E staff, and anyone with Microsoft Excel data that they would like to use in a map.

Compared with GIS software, E2G permits quick mapping of data and draws on Microsoft Excel and Google Earth, which are widely used and available (Google Earth is free). The disadvantages are that this does require Internet access, and Google Earth lacks certain cartographic advantages (e.g., it is currently limited to 16 countries and data need to be in a particular format). E2G is not a GIS because it cannot do spatial analysis and it cannot manage layers. E2G is a display tool.

The E2G "beta" version is currently available by request. Feedback, experiences, and suggestions are being solicited. Improvements in the tool are expected in 2010. The E2G tool is available at:

http://www.cpc.unc.edu/measure/e2g.



Data from OVC Situational Analysis, UNICEF and USAID, in cooperation with the Federal Ministry of Women Affairs and Social Development, 2008.

Figure 3. OVC distribution in Nigeria.

Discussion

To overcome the challenges associated with data quality and inclusion of geographic identifiers, it is important that community data are part of national spatial data infrastructure efforts. During an April 2009 meeting in Addis Ababa, Ethiopia, (a pre-meeting associated with the UN CODIST Group [see http://www.uneca.org/codist/codist1.asp]), representatives from both the health and mapping sectors met to discuss opportunities for increasing the collaboration on mapping efforts to support public health efforts. Reporting requirements can mean that there is a proliferation of multiple data sets, some of which are suitable for mapping, some of which are not. In order to produce maps of this or any other data set, data need to have geographic identifiers. It takes a coordinated effort for managing spatial data, and traditionally the health sector has not been involved in national efforts to produce, maintain, and distribute spatial data. Awareness of the other sector's needs, skill sets, and resources is necessary to ensure that both sectors collaborate effectively. The Addis Ababa meeting was the first of its kind, a meeting to bring people together from ministries of health and mapping agencies to explore such collaborations.

> *How are biases of data collection in conflict states, in the cases of migration, wars, etc. handled?*

Spencer responded that the geographic component makes it sensitive. Political events and humanitarian events can all have implications that can make data especially sensitive and can limit the availability of that data. Effective use of the data means that a balance needs to be struck between these issues and data use requirements.

Vital Events: Measuring and Monitoring HIV-Related Mortality in the Community

Presenter: Robert Mswia, MEASURE Evaluation

In most developing countries, systems to document vital or civil events (births, deaths and their causes, and migration) are weak or non-existent. Specifically for mortality, the majority of deaths do not take place in health facilities but in communities, and these deaths are never recorded. Until complete and universal vital and civil registration is available, there are other methods used to document these events. With mortality, there are methods to enumerate and register deaths in communities, to determine likely causes of death, and to create and use mortality statistics derived from all available information.

The purpose of the Sample Vital Registration with Verbal Autopsy (SAVVY) tool is to provide improved monitoring and measurement of vital events. This is done by complete enumeration at the household level (baseline) in a nationally representative sample (national sentinel) of community areas. Then periodic updates of vital events (demographic: births, deaths, migration, parental survival, marriages, divorces; social-economic: occupation, education, household wealth) are conducted, by household interviews. Specifically for causes of death, verbal autopsy (VA) is conducted and international standards to determine cause of death are applied. VA is an indirect, community-based method of ascertaining cause of death. It is indirect because cause of death is ascertained through interviews or records and not through direct methods, such as an autopsy. It is community-based because the data collection is done at the household level.

Several examples of results from studies were presented to demonstrate the type of information that VA produces. Further, validation studies have shown that VAs perform well in identifying some specific causes of death, including AIDS deaths, although misclassification of HIV/AIDS into other immediate causes (e.g., diarrhea, chronic respiratory illness) is possible, likely resulting in an under-estimated AIDS-related mortality.

Until there is a functioning civil/vital registration with proper medical certification of causes of death, alternative means to document the burden of mortality and their causes are necessary. Many bilateral and multilateral donors and agencies are adopting and endorsing country efforts to improve the measurement of vital events. Community-based VA monitoring tools available from MEASURE Evaluation are meant to be adopted and adapted to fit with country settings and implementation platforms.

Documents related to SAVVY (field and training manuals, VA questionnaires, and data entry and processing systems) are available at:

> http://www.cpc.unc.edu/measure/tools/monitoring-evaluation-systems/savvy.

Discussion

> *Is there a problem of misclassification in verbal autopsy of events, and how do we classify them?*

Mswia responded that the information is captured in verbal autopsy questionnaires. The interviewers ask respondents questions about symptoms and diseases, and a medical doctor reviews the answers and assigns cause of death. Information is also used from the death certificate or medical records, if there are any. Consequently, the accuracy of the classification is dependent upon the ability of the interviewer to get good information and the training of the doctor who assigns cause of death.

> *Are there issues of reliability about the information provided, including cultural sensitivities?*

Mswia clarified that reliability is an issue, but the tool is not designed for individual diagnosis. Studies have compared causes of death from community and death records, and sensitivity and specificity were high at the community level. It is currently a suitable solution in the absence of anything else at this level to document vital events, including deaths and their causes.

Session 3. Program Case Studies of Community-Based Services Information and Monitoring Systems

Monitoring and Information System for Most Vulnerable Children Program

Presenter: Herbert Nsauye, The Salvation Army, Tanzania

The objectives of the Most Vulnerable Children Program are to strengthen communities to construct community-based responses to meet the needs of most-vulnerable children (MVC) and others affected by HIV/AIDS, to provide psychosocial support for MVC, and to improve the economic security of MVC. To date, the program has been implemented in 21 districts in Tanzania and has served 15,962 MVC for the reporting period of October 2008 to March 2009. The program has two main components, Mama Mkubwa and WORTH. Mama Mkubwa consists of community groups with 10 to 20 members who are responsible for providing care and psychosocial support to MVC. WORTH consists of community groups of 20 to 25 women who do village banking, macro enterprises, and literacy activities.

The Salvation Army MVC program identified a number of program monitoring challenges: limited volunteer capacity to collect data and prepare reports; too many forms and indicators; and no standards to guide how to fill out forms. The Salvation Army implemented the CLPIR tool kit to address these issues. Following the piloting of CLPIR, the overall monitoring and system was streamlined (Figures 4 and 5), the number of indicators was reduced from 23 to 15, data collection forms and the register were simplified, a user guide was developed with clear definitions of each term, and data quality and data use improved.

Data quality is assessed by a data reviewer at each reporting level, who reviews the data before submitting them to high levels. The data reviewer examines completeness and accuracy of the data and provides feedback on these dimensions to lower levels of the system where the data are collected (volunteer or field staff). They have also implemented some activities to examine double-counting and to increase use of the data collected.

The Salvation Army team found the use of CLPIR was practical and simple, and that it provided clear guidelines to help programs improve monitoring and information systems and to streamline indicators and data collection tools. The team felt that the tool was particularly useful for organizations with integrated program components (e.g., HBC, prevention, awareness, etc.) to come up with indicators that cut across program components.

Discussion

> *Can you provide examples of how data are rolled back into the system to be used for decision-making, or are data mostly used for counting and accountabil*ity?

Nsauye replied that The Salvation Army is working in two communities in one district to make decisions using the data instead of just reporting. MEASURE Evaluation will be helping to roll out data use to the rest of the Salvation Army project in Tanzania.

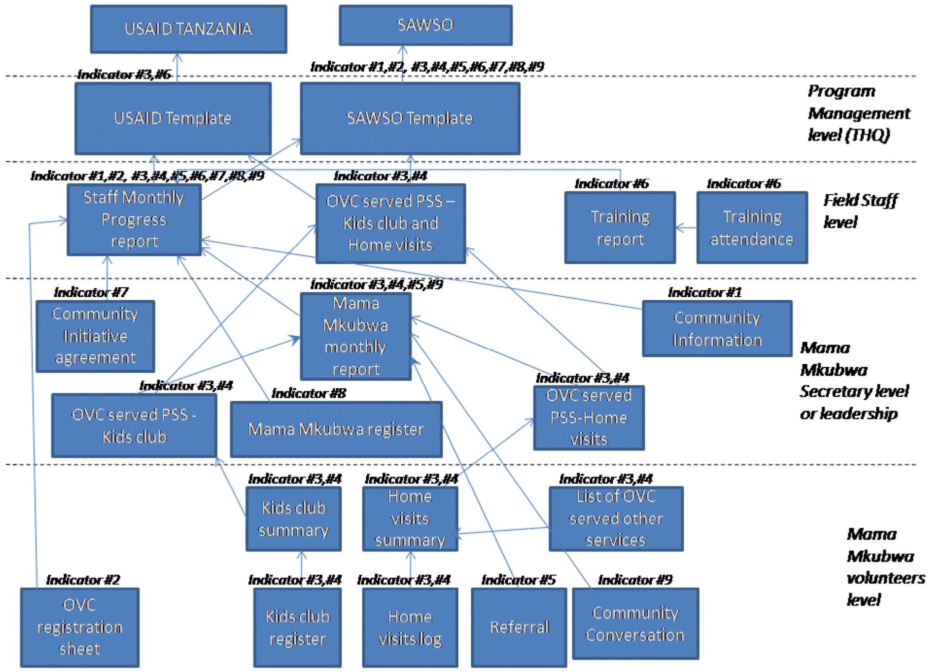


Figure 4. The Salvation Army's (Tanzania) monitoring and information system *before* the implementation of CLPIR.

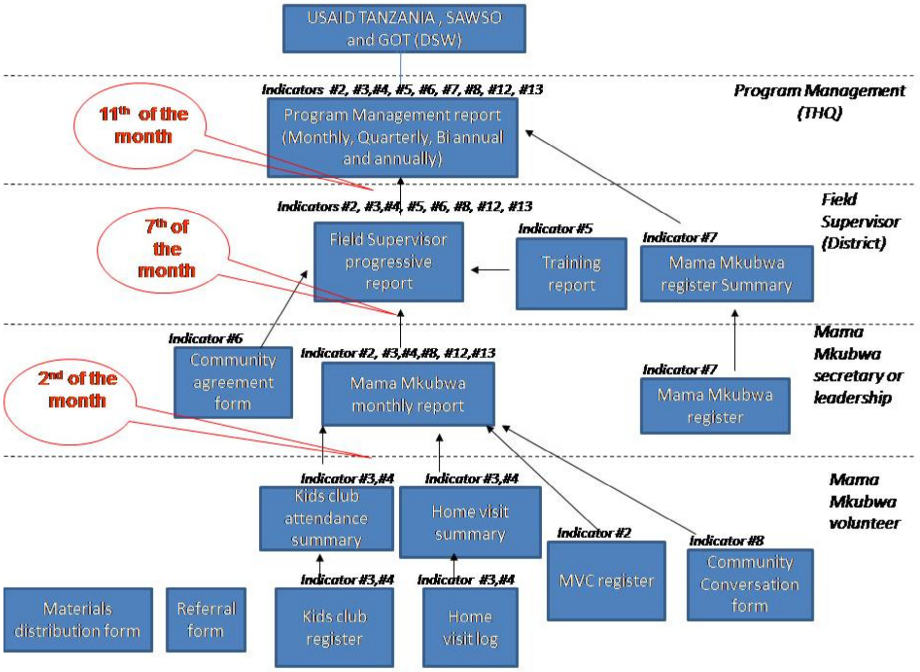


Figure 5. The Salvation Army's (Tanzania) monitoring and information system *after* the implementation of CLPIR.

(Additional responses are presented in the following section because the questions were asked of both The Salvation Army and FOSREF programs.)

The Steps Taken by FOSREF to Put in Place the New Community-Based Information System

Presenter: Marc Philippe Depestre, FOSREF, Haiti

La Fondation pour la Santé Reproductrice et l'Education Familiale (FOSREF) has one of the strongest community networks in Haiti consisting of programs specializing in family planning, reproductive health, and sexually transmitted infection/HIV/AIDS prevention with a focus on three main target groups: adults of reproductive age, youth, and commercial sex workers. FOSREF and other programs implementing PEPFAR-funded programs were led by MEASURE Evaluation to develop and implement a harmonized community-based information system. The process consisted of a series of partner meetings facilitated by MEASURE Evaluation, the development of data collection forms and registers, and training trainers.

Implementation of this system began with training of trainer activities across all of Haiti's departements. About FOSREF 50 staff were trained in the use of the harmonized forms. However, there was no funding to reproduce the harmonized forms, so use of the forms was delayed. FOSREF eventually paid out of their own funds to reproduce the forms. This allowed FOSREF to pilot the forms in 12 of their centers. FOSREF trainers oriented 220 staff to the new forms. The register was also modified but instead of having each provider fill out the register (as intended), the forms were transmitted to the supervisor who filled out the register. A system of continuous coaching was implemented to ensure the correct use of tools and to verify and validate data. Monthly reports are submitted to MEASURE Evaluation from FOSREF and other organization and the reports are uploaded into the Monitoring, Evaluation and Surveillance Interface (MESI) program. MESI is being used at the national level to store all organizations' data.

The advantage of the harmonized community-based information system is that it facilitates common understanding and provides the same detailed information across the organizations implementing PEPFAR programs. The data are readily available in MESI to facilitate analysis and planning. However, the system is complicated and tedious for field teams to implement. There are no tools to capture people reached through the mass events and drama presentations (a key feature of FOSREF's programs). Some of the data required in the monthly report do not correspond to how the program is carried out.

FOSREF has the following recommendations for the system:

- ❒ Create an electronic version of the registers and design a program to generate monthly reports from registers automatically.
- ❒ A manual is needed to help make data collection more user-friendly.
- ❒ More work is needed to reduce double counting across organizations.

- ❒ Work with the ministry of health to have the ministry define organizational intervention zones.

Discussion

> *Bottlenecks in reporting were mentioned in both the Haiti and Tanzania programs. Have the new systems resulted in improved timeliness of the data being reported?*

Nsauye responded that, in Tanzania, reporting has improved and that implementing deadlines and facilitating with transportation (funding) has specifically helped. Depestre answered that reporting timeliness in Haiti has improved for some, but for others the result is the opposite. However, generally, people who send reports later provide better data.

> *How do these efforts contribute to building national system capacity? Is the program focusing on the national level reporting or is it just PEPFAR? How will the systems strengthen the national level system?*

Nsauye responded that there is a most-vulnerable children committee (MVCC) at the community level. This was an initiative of the government started two or three years ago. The MVCC is supposed to be supervised by a government social welfare officer whose role it is to share information from the MVC data collection form to the district social welfare office. If this system functioned as it should, this would help strengthen the national system, but the challenge is that some officers do not understand their role. Another difficulty is with sharing information across organizations (harmonization) because different organizations collect different information and there is a weak mechanism to share information. Depestre reported that the government in Haiti has access to the reports produced by the PEPFAR system. There is currently a multisectoral plan being developed by the government, which should facilitate national system strengthening.

> *How is the issue of double-counting of children who move addressed?*

Nsauye replied that it is easier to identify a child who moves between two Salvation Army areas; otherwise, it is very difficult to identify them when they move from or to other implementing partners. Depestre confirmed that is very difficult to identify children who move.

> *How are data used? Is there lack of skills for programmatic decisions?*

Depestre stated that the MEASURE Evaluation training module in data use has been helpful, but it is still an issue at community provider level. When relating the data to the targets that have been set, providers can see where there are gaps. Nsauye confirmed that CLPIR contains a module that uses the targets to serve as goals for the volunteers.

Session 4. Case Studies of National Operationalization of Community-Based Monitoring Systems

The Challenges of Building a System to Monitor the National Action Plan for Orphans and Vulnerable Children in Zimbabwe

Presenter: Sue Laver, UNICEF Zimbabwe

The HIV prevalence and estimates of the number of people living with HIV suggest that the worst is yet to come in terms of the number of children orphaned and made vulnerable by the epidemic. Similar to other countries, the OVC response in Zimbabwe is characterized by multiple donors funding multiple organizations and interventions, and these efforts are uncoordinated.

In response to the OVC situation in Zimbabwe, a national action plan (NAP) for OVC was developed in order to have predictable, sustained funding for organizations assisting children. The NAP has developed a funding pool that is managed by the United Nations Children's Fund (UNICEF). In order to receive funds, registered civil societies apply to the competitive process. UNICEF signs contracts with individual organizations and disburses funds. Funded organizations report through a NAP secretariat, the National AIDS Council (NAC), and UNICEF.

There were several challenges implementing this program. There was a need to acknowledge an approach that embraced many government sectors, donors, and civil society organizations and to be sensitive to a rapidly changing political and economic environment. In terms of reporting, across organizations there are a variety of definitions of vulnerability; there were different donor reporting cycles, requirements, and expectations; and there were problems with over-reporting, meaningless indicators, data quality, and double-counting. For data entry, there were different systems competing for the same data and there was a limited culture of data use.

Some of the challenges faced include a weak M&E capacity. There is a need to develop capacity at two levels, the partner and the sub-grantee level. More evidence is needed to inform interventions. Data collection was hampered by variation in how to interpret indicators, lack of harmonization across indicator guides, low data quality, and high attrition. Reporting was improved by creating a consistent data flow in the system, reporting timeliness, decreased monthly data queries, increase in data submission rates. Finally, an electronic Microsoft Excel-based data entry and storage system was developed.

After two years, the following issues are considered central to a functioning system:

- inclusive approach with all stakeholders;
- possibility and importance of adherence and harmonization with national system;
- linking conceptual framework to M&E process;
- simple, user-friendly system mechanics;

- ❐ continued technical support to enhance capacity and regular and timely feedback;
- ❐ heightened awareness of the value of an evidence-base to expand implementation knowledge; and
- ❐ importance of getting the story behind the numbers (develop culture of data use, need to capture "most significant change," importance of triangulation).

In 2009, the following activities were ongoing: a two-tiered operational research agenda was initiated and capacity building for data use and capture of "most significant changes" was initiated. This activity has been initiated through partners, whereby routine data captured through implementation is triangulated with "key question/most significant change" data collected directly from beneficiaries, caregivers and, key leaders at community level.

Monitoring Community HIV Services in Guyana

Presenter: Mary Freyder, MEASURE Evaluation
(presenting work of the CAPACITY Project)

The presentation focused on the planning and capacity building needed to establish a national program monitoring system for community HIV programs, based on the work that the CAPACITY Project team did between September 2007 and October 2008. The team worked with the Health Sector Development Unit (HSDU) and the National AIDS Programme Secretariat (NAPS), in collaboration with Family Health International (FHI)'s Guyana HIV/AIDS Reduction and Prevention Project (GHARP) to identify, adapt, and implement a monitoring system for CBOs and line ministries.

There are three types of communities — those joined together by geography, by issue, or by institution. Community organizations are made up of volunteers who, as individuals, do not have power, but together have the goal to generate a power base collectively. Because community or faith-based organizations are formed by, for, and within the community, creating a culture of local or internal M&E is important.

In Guyana, the PEPFAR M&E system for community HIV programs was identified as a strong system that could be adapted and used as a national system. It was believed that adapting the PEPFAR system would facilitate stronger reporting to the HSDU and would initiate civil sector reporting to the NAPS (which was not happening before), regardless of funding stream. Steps taken to create the national system were to:

- ❐ pilot the system in a subset of high-functioning CBOs;
- ❐ conduct inventory and document organizational structures, technical guidelines, and data reporting flows at the national level (Figure 6);
- ❐ operationalize the system in phases with initial focus on restructuring the NAPS; and
- ❐ identify the capacity of the remaining CBOs, introducing the system in phases with the appropriate capacity building activities for each phase.

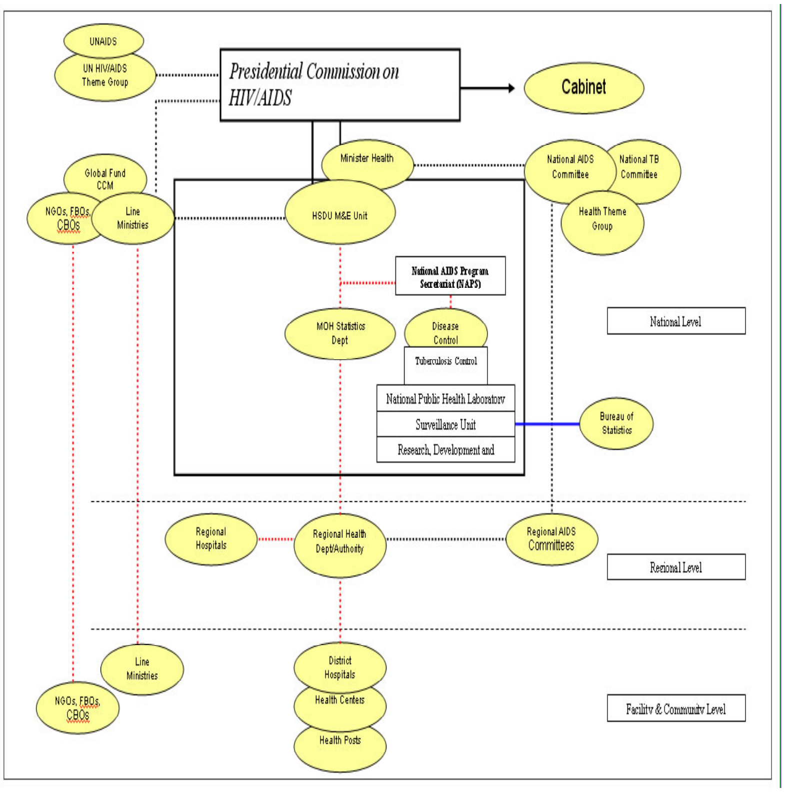


Figure 6. HIV data flow within Guyana's health ministry.

Several challenges to community-based information system development were identified in the process. Reporting cycles differed by donor. Program area definitions were not consistent. Criteria varied among donors and the national program (for example, the definition of OVC, and the emphasis of care and support vs. prevention). Due to disparities in NGO capacities, there was a need for sustained field monitoring, field testing of tools, and regular feedback.

Based on the experience adapting the PEPFAR community-based information system to the national system in Guyana, the following recommendations were made:

- In order to pilot an information system, it is important to have the strongest program management environment possible, which can be accomplished by choosing the strongest community organizations available.
- Significant resources should be spent to document the program design and have technical guidelines for community HIV services.
- Technical guidelines are a backbone of a community services monitoring system. They standardize information; for example, they define the interventions and the clients, they contain job descriptions within the organization, etc. Having this information documented in guidelines facilitates design and implementing the data flow within the organizations and up to the next level.

- ❐ A strong culture of M&E must also be developed at the community level as the top-down approach won't be effective. Communities organize out of a common interest: tracking a decrease in the number of clients reported lost to follow up or recording the number children who are now in school within your case load are great examples of effective team work and positive reinforcement.

Overview of the Community-Based Information System in Haiti

Presenter: Moussa Ly, MEASURE Evaluation Haiti

Establishing a common Community-Based Information System (CBIS) among community-based HIV programs supported by USAID was driven by the fact that there were numerous reporting systems. This was a USAID initiative to get all partners to use a common reporting system. The process has involved 15 partner institutions and all 10 *departements* are covered.

MEASURE Evaluation led the harmonized community-based information system process. The process began by developing and harmonizing the data collection tools. This took place during stakeholder consensus meetings between June and September, 2007. The CLPIR tool kit served as a reference tool, and the partners' indicators and tools were also considered. Tools were pilot tested in five sites. Staff members were oriented to use the forms, and close monitoring of use took place. Following the pilot test, the forms were modified. Specific tools were developed for prevention, OVC, and palliative care programs, and included several different types of forms (Table 2).

Since March 2008, training of trainers has been ongoing. Those trainers then orient providers and other program staff to use the new forms. So far, 261 volunteers and community workers in charge of service delivery and data collection have been trained. Various organizations have paid to have the forms printed and used at their sites, but one limitation has been that no official body was responsible for printing the new forms and tools. The health ministry is responsible

Table 2. Tools Developed for Prevention, OVC, and Palliative Care Programs

Prevention	**OVC and Palliative Care**
• referral card • condom distribution point monitoring tool • information education, communication material distribution monitoring tool • field staff monthly activity report • consolidated prevention monthly report • community group sporting and cultural events monitoring tool • community meeting report • community activity register • condom distribution site register	• support to community service providers monitoring tool • household visit tool • referrals monitoring tool • condom distribution monitoring tool • service provision to infected and affected persons monitoring tool • OVC care and support monthly report/community level • HIV/AIDS palliative care monthly report/community level • community palliative care register • OVC community register • support group/post test club register support group/post test club activity monitoring tool

for and coordinates data storage and provision of data. A data quality assessment has been carried out and resulted in a supervision manual and increased supervision. The community level data are integrated into the Web-based data warehouse for monitoring HIV/AIDS at health facility level. In January 2009, there was also a training of PEPFAR partners for data entry and processing.

It was found that data were used at the community, partner, and donor levels for such purposes as planning for a Haitian national network for people living with HIV and OVC services support, identifying strategies to undertake household visits and developing methods to avoid duplications of service provisions, as well as reorganizing funds in relation to program priorities.

There were a number of challenges in establishing CBIS, such as double-counting of beneficiaries, low literacy levels of community staff, shift from old tools to standardized tools, and difficulty in integrating PEPFAR CBIS with information systems of other donors and organizations. However, there was strong commitment and ownership from the partners contributing to the process and to the training of trainers.

Several lessons were learned in the process of establishing CBIS. While it is a long process, it is important to involve partners from the beginning and to obtain commitment and ownership of PEPFAR partner organizations. Regular contact between partner organizations and community sites through formative supervision was critical. Successful involvement of a new M&E local NGO to provide assistance continually with data quality control was seen as an important step in sustainability of the data quality. The monthly feedback meetings allowed partners to develop a strong network and benefited data quality. In one instance, double-counting between partners may have been reduced as they defined their intervention areas.

Recommendations coming from establishing CBIS in Haiti focused on improving M&E officers' orientation to the tools (ensuring consistent replication of training), improving supervision of data collection, and joint strategies to avoid double-counting. Health ministry leadership is critical to a successful CBIS, as is integrating CBIS into the ministry's existing HIS. This approach should be expanded to other community interventions implemented by other donors (global fund, WHO, etc.).

Discussion

> *Why was government not involved from the very beginning? Why were donors left out?*

Ly replied that the government was involved from beginning in meetings on indicator harmonization, but was not a leader in the process. It was an assignment by USAID for PEPFAR reporting. Training was paid for by implementing partners, not the government. WHO, Management Science for Health (the USAID bilateral in Haiti), and Canadian International Development Agency are being brought into the process to try to harmonize the routine health information system, which will benefit everyone.

Program-Specific Case Studies of Community-Based Services, Information, and Monitoring Systems: FHI's Support to the Home-Based Care Program in South Africa

Presenter: Chiho Suzuki, Family Health International

FHI's work with HBC programs in South Africa focuses on supporting the existing HBC programs through implementing partners (IPs). HBC programs, operated by these IPs, are comprised of community volunteers who provide services and collect and record service data. HBC programs provide a wide range of services from adherence support for tuberculosis (TB) and antiretroviral therapy (ART) and home-based HIV counseling and testing to will preparation and future planning and household chores. Examples of the program indicators tracked include number of HBC organizations and projects providing services, number of individuals receiving HIV-related palliative care services including TB, number of family members of HIV infected individuals receiving palliative care, and number of individuals trained to provide palliative care.

Service data are collected and recorded on forms by HBC caregivers (volunteers) as services are provided. The information documented include the type of services provided and the number of clients provided with services (disaggregated by sex, geographic location, and marital status). Data are summarized by the HBC supervisors every Friday and sent to IPs monthly. Data beyond PEPFAR requirements are also collected to improve service delivery and program implementation. Data flows in the following manner: from caregivers to HBC supervisor, then to HBC manager, to IP program officer/M&E officer, to FHI South African program officer, and finally to FHI South Africa office. Data are collected, compiled, and aggregated at the community level by hand. After each HBC program submits data to IPs, the IPs aggregate data electronically. The FHI South Africa office submits data to Khulisa (a USAID contractor) and to FHI's headquarters global database.

Both external (USAID/Khulisa) and internal (FHI South Africa/IPs) data audits are conducted as part of data quality, and the results of the assessments are documented in the form of reports. Reports include action items to improve data quality. Each HBC program was assigned to a certain geographic area to avoid overlap with others, and thus double-counting is prevented.

The M&E system is designed to allow for the ability to adjust with the course of the HIV epidemic and the program content. For example, HBC programs initially focused on support to the very sick and terminally ill, but now they provide assistance to those on ART to adhere and to live positively. Data collected are used to inform program implementation and decision-making.

Despite the successes, there are a number of remaining and emerging challenges. HBC programs are often funded by multiple donors with varying reporting requirements. This places a heavy burden particularly on the volunteers, who are responsible for providing services as well as recording service data in severely resource-constrained environments. Furthermore, volunteers' capacity and infrastructure/systems at the community-level remain a challenge (i.e., low literacy among volunteers and limited or unavailability of computer systems), as well as volunteer fatigue and staff turnover. There is an overall weak understanding of M&E principles, including indicator definitions, which call for training and retraining of IPs' staff and their volunteers. There is a need to establish a balance between data collection, recording, reporting efforts, and program implementation efforts. Finally, additional efforts should be put on ensuring and assessing quality of services, rather than just counting services provided.

Discussion

> *I was waiting to hear about challenges related to stigma and discrimination, but this was not addressed in the presentation. Is stigma and discrimination a barrier to delivering home-based care?*

Suzuki responded that it was not raised by her colleagues as one of the major problems they faced, but she acknowledged that stigma and discrimination are widespread problems.

Session 4 General Discussion

The various issues raised by the presentations in this session sparked a general discussion among participants about where the development of harmonized and nationalized routine health information systems ends (and other issues, such as those related to referral between services) and service quality begins. HIV programs and their information systems have been developed vertically and in response to PEPFAR. This vertical orientation has resulted in weak follow up between the community-based HIV program and the facility. Existing information systems are unable to capture how clients move between various points of contact as well as between different services in the same point of contact. There is a need to be able to follow individuals between different points of services. For example, there is a need to be able to identify perinatally exposed HIV infants and refer them to HIV services for HIV testing and cotrimoxazole treatment. There is little understanding of what effective linkages between service delivery systems look like. There is a need to strengthen referral systems and enhance data collection forms to capture information about clients that are referred, whether they received the referral service, and whether they return to the original point of contact. Some meeting participants argued that paying attention to strengthening referral systems will dilute efforts to harmonize indicators and integrate them into the national system.

Another issue the group grappled with is how to harmonize indicators so that those indicators are still useful to monitor and manage programs. For example, if indicators are limited to counting service numbers, then nothing can be said about the quality or comprehensiveness of services. One participant voiced that there was a WHO and global fund group working on quality, and these issues were relevant to that group.

There seemed to be some consensus from the group, however, that community-based HIV programs, particularly the frontline volunteers, are overburdened with data collecting responsibilities. There is a need to proceed in this area of information systems for community-based HIV programs with caution to alleviate that burden rather than adding to it. One suggestion was to do an assessment of what is being collected and examine why each indicator is useful. The rule should be "when in doubt, throw it out" ("it" being an indicator). Another suggestion was for agencies to put coordination and harmonization into their work plans.

Session 5. Community-Oriented Activities

Scale Up Hope, Mozambique

Presenter: Kendra Blackett Dibinga, Save the Children

The OVC Service Delivery Model is based on OVC committees selected by the communities and consists of HBC and OVC volunteers who assess the needs of children and link households to services or provide material support across a range of services including education, food support, and psychosocial support. While the model is heavily based on the Community Action Cycle (CAC), a community participatory approach (Figure 7), some of the steps are not always followed due to the fact that OVC response was viewed as an emergency.

In the Scale Up Hope project in Mozambique, the CAC was implemented to build the capacity of the OVC committees that were responsible for delivering support services to OVC in Gaza Province. The committee had a president, secretary, community leaders (secretary of the area, chief of the village), and community members (volunteers). Some volunteers were literate, although most were not. The secretary was often the only literate member of the committee. Community members conducted household visits to check in on children. These community volunteers were responsible for sharing data from the visits for monthly reporting.

For monthly reporting, all communities had experience with the data collection forms. Some of the forms were pictorial and most were in Portuguese. Committees worked with the

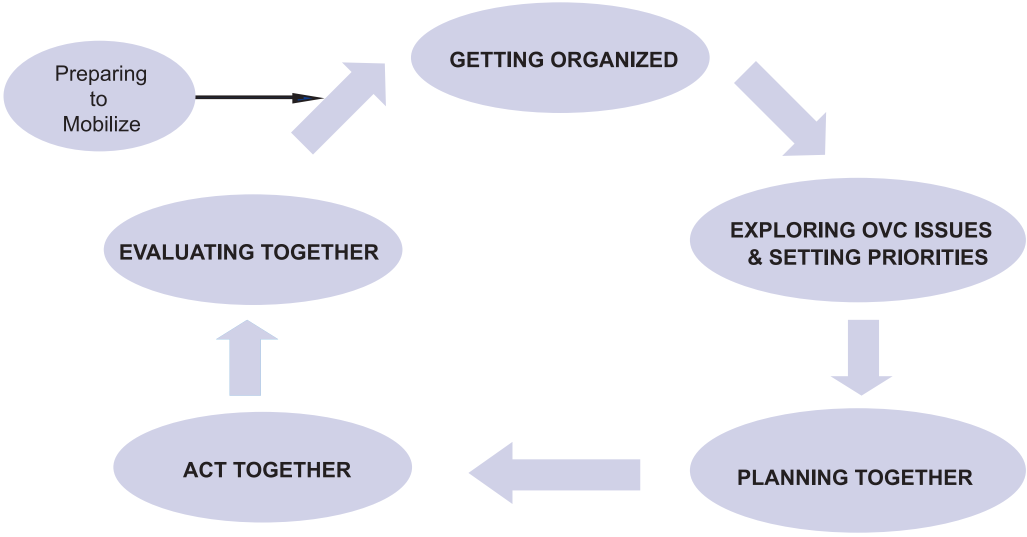


Figure 7. The Community Acton Cycle.

community mobilizer (a Save the Children employee but who was also a community member) who trained them on data collection using forms provided by Save the Children. Volunteers provided information orally with the secretary taking notes. Because information that was gathered relies on recall, information may not be entirely reliable. The community mobilizer was often present at these meetings.

The key findings from data collection include that gathering data by communities takes place primarily for reporting to donors, as opposed to being used in the community. Communities did not systematically make decisions based on the data they collected for reporting. The forms capture quantitative information and not qualitative information on OVC overall well-being. The provision of "soft" support services, such as psychosocial support, was more difficult to track compared to such the provision of material items.

There were several challenges identified with the data collection forms. The forms require certain level of literacy, and the majority of volunteers were illiterate. The terminology used in the forms was confusing for volunteers and sometimes also to the secretary. The forms did not contain information on the quality of services or on child outcomes. Finally, there were frequent changes of the data collection form formats due to donor requirements, which created additional confusion.

There were also several challenges associated with data storage, reporting, and use. The climate and lack of computers often negatively affected the ability to store data. The data that were collected were not reported to the district, provincial, and national levels; they were only reported to the implementing partner and donor. There was insufficient time for the communities to analyze the data due to the sheer volume of OVCs.

There were efforts to use data at the community levels. Monthly meetings were held between the community mobilizer and OVC committees to discuss activities and challenges. However, it is unclear whether these discussions were informed by the actual data collected. The mobilizer often served as the key liaison in terms of reporting data between the OVC committee and district/provincial services. After monitoring reports were submitted to the implementing partner, there was rarely feedback or planning sessions by communities.

In general, there were disconnections in data use, despite training on the CAC. Data were primarily used for reporting with few examples of groups using the data to advocate for additional funding. In general, communities had weak capacity to use the data to advocate for additional services to supplement existing donor resources. At the same time, the community members had their own opinions about what they needed to improve lives. For example, one community's leadership reported that if they had farming tools and skills, they could make money and provide for the needs of their OVCs without relying on donors to purchase items such as school bags, clothing, or even food.

While community-based monitoring and information systems do hold the promise to improve OVC well-being, community leadership is essential. Programs must involve communities in the development of data collection systems if they are to be community owned and managed. It is also important to recognize what assets a community has and to support the community in its ability to care for the children, but also to listen to its specific requests for support. There is a need to involve stakeholders inside and outside the community and to link community systems with other data systems. Data need to be presented in simple language and formats. There needs to be a better balance between donor accountability and community ownership.

To support community ownership at the global level, donors need to create a balance between reporting for the purposes of accountability and contributing to improved efforts at community level, this will lead to increased sustainability of community-based programs.

Discussion

Blackett Dibinga reminded participants the study report is available to participants, and that there are case-study reports that are also available. She also clarified that the goal of the CAC for health and OVC programs is to look into how communities mobilize and to help harmonize the community's response on a larger scale. They are currently advocating for indicators for OVC programs.

Evaluation of Community Response to HIV

Presenter: Rosalía Rodríguez García, World Bank

Rodríguez García explained that the World Bank is undertaking a two-year evaluation exercise to document and assess the added value of the community response to national HIV/AIDS programs. The consultative process had just begun. The rationale for wanting to evaluate the community response to HIV is that the results achieved by community-based interventions need to be documented in a systemic and robust way. Also, there is substantial donor funding being funneled to community and civil society organizations because the argument is that the community response is best. There is also an epidemiological argument: Exposure to infection can be modified by peers, the community, and leaders. There is a capacity argument: People in the community are best placed to reach others at high risk of HIV transmission or acquisition. Knowledge is another advantage: The community can customize activities. Finally, there are efficiencies: The community and civil society organizations can deliver services quickly and in a timely manner. These beliefs about the community are widespread, but they have not been fully substantiated.

The critical questions are: What has been the flow of funds from national to community levels? What are the outcomes of the community response-changes in coverage, behavior, practices, and utilization of services? Has the community response led to social change related to prevention, treatment, care, and support? The working hypothesis is that the community response adds value to the national program and multisectoral response. A related issue is what works for specific population groups, and under what conditions?

Rodríguez García stressed that the evaluation exercise is in the early stages, so what is presented may evolve over time. However, they are looking for input and ideas to help focus the evaluation in critical areas and to make the evaluation as robust as possible. She distributed a two-page summary to participants.

Discussion

In response to the question about whether the evaluation is limited to World Bank programs only, she clarified that it was not. The unit of analysis is the community and the results achieved with funds received from many sources. The World Bank is working with partners and civil society networks.

The Health Intersect in Community-Based Information Systems

Presenter: Steve Settimi, Senior Advisor, USAID Bureau of Global Health

Communities are the front line of development. It is the place where sustainable growth can happen. It is where people first meet with the "people issues," including health. It is where data are drawn. It is where the evidence suggests that HIV/AIDS and other health matters intersect with other areas of interest for other sectors.

A community has the following attributes among others: ever-changing demography; varied in social, economic, and political structures, as well as ethnic, religious, and political affiliations; extended geographic boundaries that can reach from rural to urban as a diaspora; and changing priorities sensitive to internal and external factors. Each community has different sets of attributes and these attributes change over time.

It is important to understand community priorities. As an example, the Peace Corps does a good job at this when they engage a community in participatory analysis for community action. The United Nations Development Programme has assisted communities to undertake similar self-assessments producing community council action plans, as in Lesotho. If community needs are well-articulated, a better understanding of the development issues is easier for CBOs to understand, and outreach workers and volunteers are then better informed on how to engage with the community. Community data and information is important for that understanding. One can imagine how more accurately development might reflect the need and voice of the community if this process were repeated among multiple communities. Communities sensing responsiveness to their own development needs are more readily inclined to buy-in to program activities and become actively engaged in their own development.

The principle challenge from the health sector is to identify the health intersects in communities where health is not always ranked at the top of a community's needs and to capture data that illustrate how health intersects with other domains. Education, jobs, water, and nutrition may all out rank interest in health or HIV/AIDS. In such cases, it is incumbent on health development partners to find the health interest link with other interest areas and make a case to the community why health, even if it is no more than prevention measures, is worth the community's consideration. If, for example, a community ranks a new school and education as most important, then looking at how health can be part of the curricula or training of educators or peer counselors may be the intersect that provides the rationale for health interventions in that community. In a worse case, a community totally void of a health-aspect interest may indicate a need for social messaging, behavior change communication, and advocacy of health.

For PEPFAR resource expenditures in non-health or allied sectors, a case must be made on how program funds positively impact HIV/AIDS outcomes if they are to be expended in ways that also support other sectors in addition to health, such as education, economic growth, transportation, sanitation, or nutrition. More specifically, for community health information systems, how can PEPFAR funds be used in ways to support a broader data and information platform open to a variety of development activities, all of which require data and information, and which, at the same time, positively impact on HIV/AIDS program areas?

The "business as usual" model as we know it plops down some health-centric data and M&E solutions into a community as an extension of a high-level vertical silo system. This approach is not sustainable. A single sector approach to community-information systems, whether health, education, or agriculture, is unrealistic; it is myopic to what factors impact development. Loss of funding in one cycle or constant staff and worker turn over make for an impossible situation in communities that are highly fragmented and fragile. This is analogous to a three-legged stool: As soon as one leg of support is withdrawn, the stool falls over. We need to look more at three- or four-legged stools, one leg for each development sector, if we want long-term scalable development, a multiple-sector approach. In that way, single-sector program fluctuations would not dismantle the entirety of the effort; there would be a protection of assets.

How much more sustainable and what efficiencies could we gain if a centralized community resource center might be installed that serves the back-end support services of data collection, aggregation, information sharing, and dissemination of multiple development interventions in addition to health? How would development partners align and behave differently in communities where data gathering and use at the community level suggest a more holistic approach to development, one that meets community needs, one in which sharing of common knowledge is common practice? Why would a community not buy into development activities reflective of their own personally expressed interests?

As a cross-sector program support model, a community data and information resource center or hub can support a health worker as well as an agriculture worker, education/tutor, or other outreach worker. Data brought to a community center could be shared and discussed within a community forum. Those same data, now enriched with community understanding and knowledge, can be enveloped in a package of community needs that may be multi-sector. The "envelope" disassembled could readily be funneled upstream to respective data centers of the various development partners at the district or next level up. Suppose, in this scenario, community-based organizations and volunteers serve as intermediaries between community leaders and development partners as the interface to the more formal development programs, including health, as extensions of the community voice as their advocates? Sufficiently resourced community centers that can serve as hubs to the collection and understanding of data gathered in the community will contribute to the knowledge base at the community level and provide sufficient and detailed data for development partners needing to report on program indicators.

A multi-sector approach to community-based information systems is an element of USAID country ownership strategies: an approved PEPFAR-funded activity, supported by USAID's

Office of HIV/AIDS and Bureau of Global Health, consistent with the Paris Declaration and Accra Agenda for Action.

Session 5 General Discussion

A participant observed that the meeting was lacking on perspectives from low and concentrated epidemics. Information systems in concentrated epidemics would work differently than for generalized epidemics. It was acknowledged that there was a focus on information systems in generalized epidemics, and particularly for OVC, but this is a function of the proliferation of these types of programs rather than any oversight or exclusion criterion.

A participant commented that there is a tendency to think of the community-based health worker volunteer as a temporary measure until the health systems get stronger. There is a need to change that attitude and embrace the idea that the community health worker is an asset and to stop thinking of them as temporary. This type of change in thinking will help us more effectively tap into, strengthen, and support this community resource.

Session 6. Experiences from non-HIV Community-Based Information Systems

Experiences from Non-HIV Community-Based Information Systems: Overview of Methods (What, How, and Who)

Presenter: Jim Ricca, Maternal Child Health Integrated Project (MCHIP), ICF Macro

The purpose of this presentation was to describe the technical and organizational characteristics of several community-based information systems, especially those used by international NGO projects for maternal, neonatal, and child health (MNCH) programming at the district level and beyond. Such community-based health information systems have been used for vital events registration, disease surveillance, routine monitoring of program activities, collection of administrative data, and client tracking. The examples cited here are mainly from USAID's Child Survival and Health Grants Program (CSHGP), an NGO granting mechanism for MNCH programming that has delivered more than 400 grants over the past 24 years. Probably in the neighborhood of one-third to one-half these projects have instituted some form of community-based information system.

The role of the community in community-based health information systems can be viewed on a continuum of involvement. It can be advisory, in which the community provides information on perceived problems and expectations of health services. It can be involved in implementation of the system, in which community members collect information. Finally, community members can even be involved as decision-makers, helping design the health information system and advising on the use of the data for decision-making.

The Census-Based Impact Oriented (CBIO) information system is an example of a community-based information system implemented by several NGOs in conjunction with health ministries at the district level (more information and resources at: http://www.coregroup.org/index.php?option=com_content&view=article&id=51). There are standard forms and reporting protocols to track vital events. First, a census of the district is done to establish a firm denominator. Then there are forms and protocols for tracking of births and deaths, verbal autopsy protocols and forms, mortality review meetings, and data forms for health status and health service provision. CBIO systems have been implemented in various manners. A CBIO system was implemented in Haiti by professional nurses; Curamericas Bolivia relied on community health workers to collect the information; and in Curamericas Liberia, it is now being implemented by care group mothers (non-professional community health volunteers).

The last example of care groups illustrates the importance not just of what information is collected or how it is collected, but on who collects the information (that is, the community structures used). In the care group system, mothers of preschool children are eligible to be in a care group. Each group member has under her responsibility 10 to 15 households around her with pre-school children, identified through an initial census. The care group mother visits each of her households every two weeks to deliver simple health messages and to collect the information needed for the CBIO. The mothers (10 to 12 of them per group) meet biweekly with their supervisor. At these meetings, health information is shared and training and supervision occurs. Care groups are facilitated and supervised by paid promoters or other health staff. An example of this care group structure from Food for the Hungry's Mozambique project is shown in Figure 8.

The care group structure has been implemented by many NGOs, mainly at district levels and sometimes at multi-district levels. An example of a similar community-based platform that has been implemented by a health ministry at near national scale, for both implementation and data gathering, is the Honduras Ministry of Health nutrition monitoring program known as Atención Integral a la Niñez (AIN-C). This program is carried out by groups of three local mothers with minimal training to perform monthly community-based growth monitoring and promotion for children under two years of age in 25 surrounding households. It aims for 100% population coverage in selected villages within a facility catchment area. Information on "growth tendency" (whether weight gain has occurred the previous month) and other key child health information (such as vaccination status and intercurrent illness) are reported to the associated health center. This system has now been scaled up to cover over half the country. The information system is not without problems, especially in terms of the community-based information communicating with the facility-based information. On the other hand, this example shows that high-volume volunteer systems can work at scale when implemented by ministries, not just with NGO facilitation at a district level.

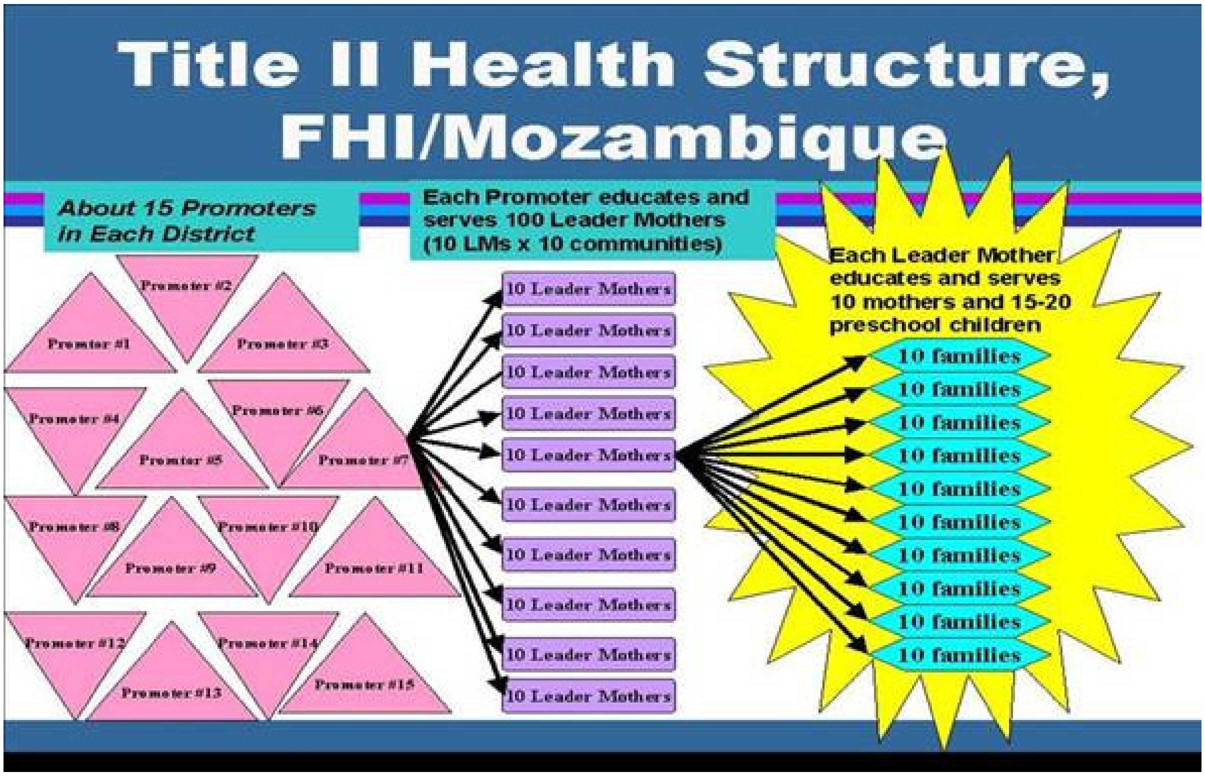


Figure 8. Example of a care group structure from Mozambique.

There are many other CSHGP examples of local community-based information systems for MNCH projects that were implemented by NGOs in conjunction with health ministries. These include CARE in Peru, Kenya, Nepal, and other locations; Save the Children in Bolivia and elsewhere; and Catholic Relief Services in Honduras and the Philippines. These programs were highlighted as case studies in the USAID/Child Survival Technical Support consultation in February 2003 on community-based health information systems (*On the Design of Community-Based Health Information Systems*, by Child Survival Technical Support Project and USAID, February 2003, available by e-mail request at csts@macrointernational.com).

This discussion has highlighted some of the key issues relating to who collects community-based information and how this can affect feasibility and sustainability of implementation of the system. In summary, the key lessons for community-based health information systems are the following:

- The "software" (organization) is at least as important as the "hardware" (forms, indicators, etc.).
- An intensive data collector to population ratio is desirable so as not to overburden workers.
- It is advisable to involve lay workers/volunteers in data collection (and preferably data use, as well) in order to achieve an intensive data collector to population ratio.
- Community-based information systems should be simple and feed into facility-based health information systems, in order to give the most useful information. This is not without difficulty, as shown by the Honduras AIN-C example.
- There should be a short "feedback loop" (i.e., as little time as possible passes from data collection to sharing it with the community). This keeps community members motivated to continue collecting the information, thus increasing the chance of sustainably maintaining the system.

Making Impact. Tested Examples of Monitoring and Evaluation Tools that Can Increase a Program's Impact

Presenter: Carolyn Wetzel, Food for the Hungry

This presentation described M&E tools used by programs supported by Food for the Hungry. The first was the Care Group Model of Program Implementation. In the model, there are staff (such as the program director, supervisors, and promoters), volunteers (such as the mother-leaders), and beneficiaries (the mothers themselves). There are a number of monitoring systems in place to ensure program quality. Monitoring consists of documenting care group attendance, provision of vitamin A and deworming medicine, post-training tests, and quality assurance checklists. Deaths, births, and integrated management of childhood illness (IMCI) data are also monitored. To evaluate the program's progress, staff members rely on a mini-KPC (knowledge, practices, and coverage) process. Surveys using Lot Quality Assurance Sampling (LQAS) are taken and compared with health ministry data in designated child-survival districts, along with other districts that are not so designated. More information about LQAS is available at:

http://www.cpc.unc.edu/measure/publications/html/ms-00-08-tool09.html

http://207.226.255.123/working_groups/LQAS_Protocol_for_Parallel_Sampling.pdf.

The presentation focused on discussing the mini-KPC surveys and barrier analysis methods to monitor programs. Mini-KPCs are short (12-20 questions) surveys used every four to six months. LQAS is used to obtain information on a small sample. LQAS identifies whether programs are exceeding performance or not, as determined by pre-set "threshold" or "decision rule." Performance is improved by targeting those indicators that do not meet the thresholds. Mini-KPC data can be easily analyzed by field offices and the results can easily be used to inform program decisions. Frequent and regular monitoring by supervision area allows program managers to identify slow moving indicators and tailor programming to focus on problem areas, both technically and geographically.

An example of how programs improved using mini-KPC data: Program managers in Mozambique realized that unless feeding frequency was increased the project goal of decreasing malnutrition would not be reached. The child-survival team decided that more health promotion and skill-building needed to be done in promoting snacks for children. The team created snack recipes and shared them with mothers. A year later, another mini-KPC demonstrated that all programs exceeded the pre-determined threshold.

Barrier analysis is a rapid assessment tool used to identify the important behavioral determinants associated with particular behaviors (http://barrieranalysis.fhi.net). This information is used to develop more effective behavior change communication messages and activities. It was developed in 1990 by Tom Davis of Food for the Hungry and modified based on the Academy for Educational Development's BEHAVE Framework and Doer/NonDoer Analysis. The following behavioral determinants are examined with barrier analysis (based on health belief and theory of reasoned action models): perceived severity, perceived action efficacy, cues for action, perceived self-efficacy, perceived susceptibility, perception of divine will, perceived social acceptability, and positive and negative attributes.

For example, a baseline KPC survey found that only 17% of infants five months of age or younger were exclusively breastfed within the last 24 hours. A barrier analysis was conducted to help project staff and community members (especially promoters) to discover behavioral determinants of exclusive breastfeeding through interviews with mothers of infants in five districts of Sofala Province, Mozambique. The barrier analysis helped identify whom the program should target (i.e., who approves of early breastfeeding and thus would support women's efforts to breastfeed), document the perceived benefits of breastfeeding, and identify things that make it easier to breastfeed. In response, wrap-around skirts with key messages confronting the barriers to exclusive breastfeeding were given to mother-leaders as an incentive, and the benefits of exclusive breastfeeding were discussed in educational sessions.

Quality Improvements and Verification Checklists (QIVC) have three purposes: to encourage, to monitor, and to improve a development worker and the work that she or he does. QIVC should be used for the processes repeated over and over within a project (not just in problem areas), such as weight monitoring or breastfeeding education. QIVC provides management information on system-wide problems, such as what problems workers have with the process, and information on people problems, such as which workers need more supervision or support.

An example of implementation of the QIVC in a Mothers 2 Mothers program found that community health workers spoke loud enough, sat at the same levels as the mothers, and spoke slowly and clearly; but community health workers did not give a complete message on why oral rehydration solution is helpful, and they sometimes gave different instructions about the preparation of oral rehydration solution.

In summary, headquarter-based staff need to dedicate the time and skills to assist field staff in creating M&E tools, applying the tools, and analyzing the results. In terms of data storage, a file sharing program (Grove) has prevented data loss because it enables field staff to backup their files online, preserving data when computers fail or there are changes in staff. Verbal or paper-based data collections are used in Mozambique at the provincial level, but in Bolivia staff are using handheld computers to collect monitoring data. Field staff who collect data need to be involved in the analysis and interpretation of results and they need to be convinced that the practices that they were hired to promote were effective.

Session 6 General Discussion

One participant highlighted the experience of the successful Reaching Every District (RED) management strategy that was started by UNICEF and WHO to improve immunization coverage (http://www.who.int/immunization_delivery/systems_policy/RED-FactSheet.pdf), and now is in 60 countries. In 2006, WHO conducted an impact evaluation (http://www.afro.who.int/ddc/vpd/routine/red-2007.pdf). There are five basic components to RED: establish immunization outreach services, supportive supervision, linking health facilities with communities, data for decision-making, and planning and management of resources.

Session 7. Community-Based Information Systems: Terminology and Information Users

With Session 7, the first session of the second day, the group moved away from presentations related to information systems and tools experiences. The group worked to take those experiences and information from previous sessions to help identify gaps in existing information systems and to come to consensus about how to fill these gaps.

Presenter and discussant: Cyril Pervilhac, World Health Organization

There is a rich history and knowledge in the measurement of community-based programs. Principles and fundamentals from primary health care in the 1980s and 1990s still apply. These principles identify whom the information is for, what the information is for, how to do this process in such a way that is minimally burdensome, and how to make indicators clear; and these principles already provide normative guidance. This guidance for the measurement of community-based primary health care programs comes from various sources, including those developed by the Aga Khan Foundation, WHO, and others (e.g., faith-based organizations, bi-laterals). See how these principles apply to M&E systems for HIV/AIDS at:

http://www.pactworld.org/galleries/default-file/building_mer_systems.pdf.

A report of the sixth meeting of the Strategic and Technical Advisory Committee for HIV/AIDS, a 2009 internal WHO document, describes how community-based HIV programs are at the core of primary health care. Prevention and treatment are best handled through a primary health care approach by "intensifying efforts to decentralize the AIDS response to primary care level, and strengthen links with communities, updating, and widening treatment activism and literacy towards health activism and literacy."

For the period 2010-2011, WHO has the following priorities, all of which respond to current gaps and touch on community interventions and their measurement: testing and counseling, adult and pediatric treatment, PMTCT, TB/HIV, harm reduction (injecting drug users), and health sector HIV response for men who have sex with men and sex workers. These interventions are prioritized because they align with regional and UNAIDS priorities, they are focused and results-oriented, and they will have an impact on the epidemic. WHO's core functions include monitoring health, providing leadership and engaging in partnerships, shaping the research agenda and disseminating knowledge, and setting norms and standards (including strategic information with M&E aspects).

Regarding terminology in this area (based on the various session presentations), it is important to identify who are the information users. These include program providers, service providers, community health workers, volunteers, health ministries, national AIDS commissions (NACs), and other ministries such as social affairs and education. Then we must consider what the information is for and the systems that are supporting these various data collection sources (i.e., health infrastructures from the health ministry, community specific from various ministries and NGOs, and various sources and interests with special studies or research).

Figure 9 provides an example of upcoming guidelines for PMTCT services that encompass strong community-level monitoring (linking facility to patient), but where the role of the community health worker may need further specification in this regard.

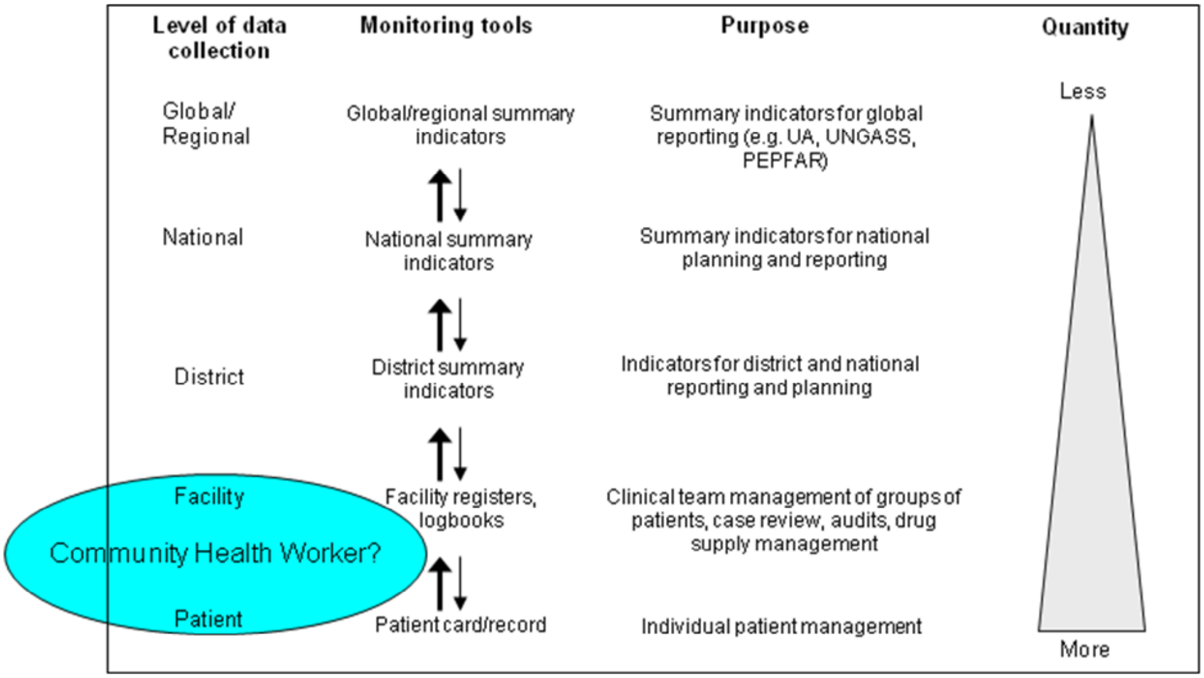


Figure 9. The limitation of normative M&E guides: monitoring at lower level of the health-care systems.

Source: Monitoring and evaluating prevention of mother-to-child transmission of HIV. a guide for national programs. [Unpublished, June 2009 draft.]

Examples are provided of measuring services at a community level using WHO's Three Interlinked Patient Monitoring System for HIV care/ART, MCH/PMTCT, and TB/HIV. The CLPIR tool kit could be revised to become a step towards providing good guidance for strengthening community-level reporting.

Session 7 General Discussion

The idea for organizing this session grew out of the observation that we have trouble defining this area we want to address. When discussing the "community," there is not a common understanding of what is meant by "community." In the context of HIV services, there is a distinction made between health facility-based services and non-facility-based services, or community-based services. There are the activities that happen in the context of a geographically defined community; for example, the types of activities conducted by community health workers or lay health workers. There are the members of the geographically defined communities themselves, the residents and representatives of the community (e.g., group leaders). For MARPs, such as sex workers or injecting drug users, their communities are defined by behaviors that put them at risk for HIV. Members of geographically defined communities are likely to self-identify as members of the community, and they are likely to identify other members who also self-identify. MARPs are defined mostly by people external to those groups, and members of those groups may or may not self-identify (either publicly or privately) as members, and they may not be able to name other members of their community.

This distinction in terminology has implications for the approaches to community-based information systems. One view is that community members are the sources, users, and decisions-makers of information and they should have the skills and resources to assess their own problems and demand services that meet their needs. From a service delivery perspective, the program is based in closer proximity to the community it serves compared with a health facility. The information collected by a community-based program is used for reporting and, ideally, for improving programs. Another view is that information is community-based because the information is extracted by a community member (in the case of a community health worker) and transmitted elsewhere, usually to other levels such as the district, national or donor. Consensus around terminology related to how to refer to users and uses of the data is needed, but should be kept simple. Regardless of the interpretation of "community-based" there is consensus that the communication loop among the community residents, community-based program, community health worker, and higher levels of the health system (district, national, donor) is weak or non-existent.

For our purposes, when discussing an information system associated with non-facility based HIV programs, "community-based" is better than "community" ("community" means something different to each person, and it is being used loosely as a catchall term). Greater delineation in language is needed between who are the individuals or units who have a need for information and why they need that information; but at the same time, do not forget individual clients and what they need to know. The language used needs to distinguish the "user" from the "uses" of data.

While consensus on terminology in defining the users was difficult, several important points were raised during the discussion:

- ❐ There is no need for HIV service providers or program policy-makers to reinvent the wheel. We can learn from community-based information system experiences in other fields, such as maternal and child health, and where the emphasis has been on health services from the community, for the community, by the community.
- ❐ There are many examples of data collected at the community level. The data in general are not being collected for the community, but rather for reporting higher up. There is a need to figure out how to make the community response to HIV fit into the national effort. Currently, there is tension between local and outside levels because the information needs of the community and how to respond to the epidemic are not necessarily the same as the information needs required at the national or donor levels. We cannot ignore the fact that most of the reporting requirements are being imposed on the community and those requirements place high expectations for lay volunteers.

- The ultimate goal is for communities to be able to collect and use their own data and also to report up this information. Communities are ultimately responsible for capturing information related to civil society concerns and health services. In order to do this, collaboration, not dictation, is needed and national systems need to be empowered.

Session 8. Vision for the Field of Information Systems for Community-Based Programs

Before working to identify challenges, gaps, and next steps, it is important to articulate a five-year vision of what we want this field of information systems for community-based HIV programs to become. This was the exercise posed to the group during this session. The group articulated seven principles that described this vision with implications at global and country levels:

Global level

- ❒ **Harmonize indicators at the global level:** Donors should agree on simple indicators for collection at the community-based HIV program level.
- ❒ **Generate an evidence base:** Generate evidence about what are the characteristics of effective information systems and use this evidence to inform and improve community-based information systems.
- ❒ **Make tools, guides, and indicators available but adaptable:** Generic guides, indicators, and tools that are simple but help collect and use data, including data about quality as well as coverage at each level are needed. For example, explain how the community-based HIV program gets information to the national level. At the same time, help community-based HIV programs use their information to improve programs.

Country level

- ❒ **Harmonize systems:** Government, NGO, and donor reporting systems and those relevant systems outside the health system, e.g., education, agriculture, etc., should be merged into one system or should be able to communicate (interoperability).
- ❒ **Strengthening information linkages throughout the system:** Strengthen the links among data collection, reporting, and use so that data for reporting can go up to the national level and data for program management and use can go back to the community-level program.
- ❒ **Communities determine their needs:** Help communities, i.e., the beneficiaries of community-based HIV programs, to articulate their information needs and to demand the systems so that they can get that information.
- ❒ **Strengthen community-based HIV program capacity:** Strengthen community-based HIV program capacity to be able to generate and use data through standards that are defined, operationalized, and adequately resourced.

Taking these principles together, the vision for the field of information systems for community-based HIV programs can be synthesized as follows:

> *Information systems for community-based HIV programs are based on evidence and have the capacity and resources to collect data effectively on harmonized indictors, report those data to an interoperable reporting system, and use data generated by this system to make programmatic decisions to meet community-defined needs and to communicate with the community beneficiaries.*

Session 9. Thematic Working Group Reports

Following the session about a five-year vision, the group identified five themes related to community-based information systems that they wanted to discuss in depth. These themes were:

1. harmonization
2. capacity building
3. data collection for outcome monitoring
4. community ownership
5. MARPs

Each small group spent time discussing the definition, meaning, and elements of its topic and identifying gaps in its area. Some groups went a step further to identify how gaps could be addressed considering a wide range of possibilities, including policies, formal and informal agreements, resources (human, financial, technical, material, etc.), tools, technical competencies, etc. Finally, some groups identified things that were working especially well in this theme area today, and how that success could contribute to overcoming some of the challenges and gaps.

1. Harmonization

Harmonization refers to the extent to which indicators and M&E processes and approaches are consistent across community-based programs, across implementing partners, across donors, and within countries. The lack of harmonized or standardized indicators is consistently pointed to as a cause of over-burdened frontline providers and as a limitation to monitoring community-based HIV programs.

Gaps include the following:

- ❐ Lack of harmonization is a problem at the global level and at the national level through all layers of the system or sector, including at the community level.
- ❐ There are no standardized approaches, guidelines, or tools to community-based information systems.
- ❐ There is a need for a small, agreed upon set of core indicators to guide a framework approach that would trickle down to the community.
- ❐ Emphasis was placed on the need for community representation at the global level dialogue, to articulate their needs.
- ❐ Even in terms of data use, there is little harmonization. Data are not used, shared, or disseminated between and across levels.
- ❐ At the global level, donor requirements result in non-harmonized community-level information systems.
- ❐ Despite the parallel and fragmented approaches, there was recognition of ongoing

partner efforts at the global level to try and address this problem.

- Routine systems, such as the health management information systems, shoulder much of the data collection burden. There is a need to focus on what can appropriately and realistically be collected in the routine system and what would be better collected by other methods, such as surveys.
- At the national level, there is a lack of committed leadership; roles and responsibilities are not defined; there is friction between health ministries and NACs (NACs are not typically under health ministries, and NACs are multisectoral, not limited to health); and there is little coordination between sectors. Despite this, a few country "best practices" can be identified.

What is working well includes the following:

- The example of the Uganda AIDS Commission Civil Society Fund was raised as a potential best practice. The Civil Society Fund is working to coordinate donor resources for grants to civil society organizations. More information is available at www.csf.or.ug, including a report titled, *Increasing Civil Society Participation in the National Reponse to HIV/AIDS, OVC, TB and Malaria in Uganda. Governance, Management and Operations Manual.*
- There is community and civil society representation at the global level (e.g., United Nations General Assembly Special Session).
- The UNAIDS MERGs and interagency task teams (IATTs) could be useful resources for strengthening coordination at the international level. International resources are pooled to support these groups.

A series of steps were suggested to address the gaps related to harmonization:

- International partners come to specific agreement about existing tools and approaches to promote at international level. A resource database of existing tools, approaches, and experiences (including lessons learned) should be developed.
- International partners develop a framework where standards and guidelines are developed and used by global partners. The role of how the global partners promote funding of and training on harmonized information systems at the country level would be defined in the framework and guidelines.
- Further dialogue on harmonization, promotional partnerships (e.g., PEPFAR Partnership Framework) should be taken to the country level and tools agreed on within these discussions (e.g., promote CLPIR at a national level).
- Leadership/champions should be identified at all levels, especially in communities and at national levels.
- Monitoring data from community-based HIV programs are reported to a common level (such as the district), then that information is reported uniformly to donors (in contrast to the more typical situation, where each donor makes a request for different information from community-based programs).

- Shift some of the burden on frontline community workers by complementary routine systems with surveys.

2. *Capacity Building for Community-Based Information Systems*

Since a lack of capacity for monitoring and evaluation has been identified as a limitation of community-based information systems, this group focused on how to build capacity. The group identified the following gaps:

- Within the community-based program, there are technical, financial, human resource, and, material limitations.
- The current culture is to report up the reporting system.
- There is a need to enhance responsiveness of systems to community needs.
- There is a need to increase documentation of the value of data. Document best practices in data collection, use and decision-making, and disseminate success stories.
- There is a need to establish a mechanism for feeding back information to community-based programs and to communities.

The main players are community volunteers (unpaid), community workers (paid), community mobilizers (organizers), organizations supporting volunteers (faith-based organizations, CBOs, etc.), and national systems (cross sectors).

Specifically, capacity is needed to improve the data collection of required indicators for reporting. Reporting can be improved if the data collection systems are designed so that they match the providers' and volunteers' capacity. On the other hand, the community and the community-based HIV program need to define their own information needs. Capacity building will help the community-based HIV program and the community itself to be able to identify information gaps and articulate a way forward to close those gaps.

The following outlines steps needed to address capacity gaps at various levels:

National level

- Conduct assessments of national information systems to yield recommendations for enhancing the community response.
- Develop a partnership framework that contains leadership and strategic recommendations for supporting and improving national level information systems coordination.
- Build capacity at the national level about appropriate involvement of volunteers to meet government data needs (e.g., volunteers may be ideal for identifying and registering OVC). In general, national level policies should provide more guidance regarding human resources for community-based programs and information systems.

System level

- Develop guidelines that address how data are collected, who reports the data, when data are reported, etc.
- Develop or adapt tools so that they are appropriate for different literacy skills (e.g., oral, paper-based, diagrams).
- Conduct research and/or document methods that result in the collection of complete and accurate data by non-literate or low-literate frontline providers or volunteers.
- More training at the organizational level (NGO, faith-based organization, CBO) on M&E and data quality, in general, is needed; and with volunteers, to increase awareness of the importance of and process of data collection.
- Expand the pool of and capacity of community-based HIV program supervisors and managers. Implement supportive supervision methods that are sensitive to community-based programs, including training on strengthening information systems.
- Involve peer-driven approaches, e.g., youth, in data collection.

Individual level

- Develop clear guidelines on the roles and responsibility of volunteers. Develop these guidelines with community participation and government involvement. Articulate standards about what are realistic expectations for volunteers (unrealistic expectations have negative effect on data quality).
- Create incentives to use data at the community level.

3. Collection of Data for Outcome Monitoring and Lessons Learned

Data for decision-making for both programmers and community members is needed at the level of outcomes and impact, although activity and output monitoring can be highly relevant for community activities in terms of monitoring day-to-day activity, self-reporting, and tracking. A focus on outcomes impact is for decision-making purposes at multiple levels including policy and evidence-based programming. Program-level data include data on inputs, activities, and outputs. The community and community-based program is the source of and user of those data.

There are several considerations if we are to move feasibly and sustainably in the direction of collecting and analyzing such outcome data:

- In each context, we need to consider whether we expect unpaid volunteers with low literacy skills to collect the data or whether this is the responsibility of the organization implementing the program.
- We should define the level of outcomes: community, individual, or other. Ultimately, we want to support collection of data that answers the question: Are we doing the right thing?

- The level and complexity of data to be collected will vary with the context (e.g., emergency vs. development).
- We should employ a variety of methods to understand what works and what does not in community programs. We can combine routine output monitoring with qualitative inquiries of the data and with more rigorous surveys and special studies for more robust M&E.
- Consider rapid assessment methods, such as LQAS, that community-based programs could use to monitor outcomes and program quality.
- When denominators are not available, they should be estimated in order to understand population coverage of key services. Having denominators, estimated or otherwise, gets us closer to outcomes.
- Conduct research to see if the measurement of program outcomes affects the sense of community ownership more than the measurement of activities and outputs. Does the documentation of outcomes improve the sustainability of community-based information systems compared with the measurement of activities and outputs?
- Circulate data and findings back to the community.

4. Community Ownership

Community ownership refers to the community involvement in information systems, either through a community's participation in implementing an HIV program or as beneficiaries and users of HIV programs. The group identified the following gaps in community ownership of information systems:

- Communities rarely define their data needs.
- Communities commonly lack an understanding of the value of data and of when data are valuable.
- There are a lot of data that are collected but are not being used at the donor or the community levels, leading to data fatigue at the community level.
- There are few "bottom-up indicators." Indicators are often determined by the donor or implementing partner, but are collected by the community volunteer.
- In general, there is a lack of systems and services to respond to community needs.
- There is rarely a feedback loop to the communities about the data that have been collected.
- In general, community-based information systems are characterized by an inherent ladder structure of the system, with communities at the bottom.
- Fear and privacy issues associated with data collection, particularly when related to HIV, persist and need be addressed before data accuracy and completeness can improve.
- The community lacks a full understanding of benefits of intangible services (for

example, such as psychosocial support services), especially when basic needs, such as food and shelter, are so apparently lacking.

- Communities and volunteers are often overburdened with implementation of services and data requirements.
- There are inadequate resources to address and to respond to the needs identified by data that are collected.

5. Most-at-Risk Populations

The MARP group decided to tackle the issue of community-based information systems from the perspective of an issue-defined population (rather than geographically defined). This group identified the following gaps in community-based information systems as they relate MARPs:

- There is a lack of information about the characteristics of MARPs, such as sex, location, mobility, and turnover (in and out of the group), which is necessary for a response based on "knowing your epidemic."
- There is a lack of definitions about MARP groups, particularly how MARP group members self-identify.
- Compared to other areas related to the HIV epidemic (e.g., OVC, pregnant women), addressing MARP needs requires a different paradigm, since one is dealing with hidden and stigmatized networks such as sex workers, injecting drug users, and men who have sex with men.
- There are leadership gaps among those responsible for structural interventions. Some of those gaps are rooted in a lack of understanding about how addressing MARP needs advances a national agenda to combat HIV.
- There is no well-defined package of services for injecting drug users, either at the structural or individual level. Interventions have to tackle combination prevention and they need quality indicators, evidence for effectiveness, and to consider the intensity of messages and services.

The group identified the following main players who have roles in addressing the gaps:

- **Individual level**: Interventions need to scale up.
- **Community level:** There is a need for structural level interventions to enable environments to strengthen the capacity of MARP networks. There is a need to distinguish between the information that can be collected in surveys versus routine monitoring. Finally, more work is needed to understand what "they'" really want to know (which means we have to understand who "they" are).
- **Civil society:** Civil society, government, and MARPs need to develop partnerships
- **Health services:** There is a need to create an environment in the health care system

to enable MARP-friendly services.

- ❐ **Government:** Civil society can only go so far before government has to show leadership. The government needs to know how to enable environments for programs to work, including knowing how to remove barriers, decriminalize behaviors, bring groups in and work with them, and take a lead in empowerment of marginalized groups.

Those main players interact at multiple levels: within the MARP peer group; at the civil society, implementing partner, and facility level; at the community (geographically defined) level; and at the national level.

Cross cutting

There is a need to distinguish types of information that can be collected through community-based information systems for players at different levels. In other words, there is a need to determine what indicators are needed for program monitoring at the individual, MARP peer-group level (such as number of people reached); and at the community, facility, and national levels. Further, information that can be collected via surveys at the community and national levels needs to be defined. More information is needed to understand the effectiveness of peer-driven information collection approaches. Table 3 provides an example of the different type of information needed at the national and community levels.

Table 3. Information Needs at the National and Community Levels

National level	Community level
• Number of high risk areas • Number of commodities distributed • Number of individuals getting the intervention package	• Enumerate MARPs in the area (denominator) • Condom stockouts • Unique identifier • Mortality

Session 10. Challenges and Next Steps

In the final two sessions, participants were asked to identify the most urgent and important challenges that should be addressed over the next three to five years, the most important steps or actions to take to surmount them, the resources currently available, and other resources that are needed. Several common themes were raised by the three groups, which are summarized here.

A number of important challenges were listed by participants, reflecting themes articulated earlier in the meeting:

- ☐ **"Community" lacks definition:** There are varying definitions and perceptions of what "community" or "community-based" means. How is "community" different than the facility? Are facilities in the communities considered part of the discussion? Is a community only a geographic entity or a group of people with a common interest?
- ☐ **The purpose of the information system is not always articulated:** There is a need to keep in mind what is the goal of these efforts to strengthen information systems. If it is important to establish and maintain an information system for community-based HIV programs, then that purpose must be clearly articulated. The lack of explicit purpose also fuels the confusion between whether community-based information systems exist to serve the donors' needs or the communities' or programs' needs.
- ☐ **Information gathering requirements pose a burden for frontline providers:** This challenge has been articulated repeatedly. The information gathering burden is heavy on the frontline providers and volunteers, partially because of a lack of harmonized indicators at the donor and national levels. Existing tools used by frontline volunteers should be also reviewed to assess whether they need to be simplified.
- ☐ **Capacity and quantity of human resources vary widely in community-based programs, but is rarely considered:** Personnel at the front lines collecting data often have low literacy skills or are volunteers. The expectations of frontline personnel should be defined after an assessment of their capacity and needs. In addition, local and implementing partners can implement capacity building activities so that personnel can meet stated expectations. In general, the sustainability of relying on volunteers should be assessed.
- ☐ **Linkages are weak:** There is a lack of linkages at a number of different levels. Health services, and many HIV services, are often delivered vertically, which in turn means there are no links between those health information systems. There is a lack of linkages between non-health and health sectors and systems. To strengthen linkages, first one must define what is being linked. Then there must be advocacy about the need to link information systems across sectors. Ultimately, partners work to create those linkages.

- **Data use is weak:** Data use has been traditionally a weak point for information systems and this is especially true at the community program level. There is a general lack of understanding of how to use data, why to use data, and why the data are being collected in the first place. However, this needs to be complemented by processes that feedback data to programs in a timely and efficient manner.
- **Data quality is weak:** There are consistent issues with the quality of data coming from communities that can be traced to the reporting burden on frontline volunteers, lack of capacity, lack of harmonization, and lack of orientation to the usefulness of data being collected. Lack of orientation to forms and concepts, supervision, and mechanisms for data quality control also contribute to this problem.
- **National systems are weak:** Weak national systems means that there is no central coordination or guidance about information systems for community-based HIV programs, and that void is filled by multiple donors and implementing partners. Moreover, there is no leadership at the national level to recommend how to coordinate. This in turn means that there are significant duplication of efforts between implementing partners and donors in terms of programs and services delivered, population bases served, and information system tools.
- **Double-counting is a problem:** The lack of national coordination and duplication of efforts by programs means that there are limited mechanisms to distinguish which clients have received services elsewhere. Programs lack unique identifiers for clients and mechanisms to communicate with other programs.

From those challenges, the groups defined the following main areas for next steps:

From Data Collection to Use for Program Management

One of the main challenges facing this field is to foster a culture of using data at the community-based program and community level, where data are linked with action. A first step is to conduct systematic inquiries to understand what communities and community-based programs want and need to know. This information can be used to map what communities want to know with what is currently being collected. At the same time, explaining to communities or community-based programs what the purpose is of the data being collected may help identify some information that is superfluous and could be excluded, and generate an appreciation for why and how the information is useful. Incentives to use data at the community level should also be explored.

Tools need to be adapted for data use with a focus on the community and community-based program level. Tools should be developed and adapted respecting the following principles:

- Obtain user input (community, frontline providers, etc.) when developing tools.
- Explain the value of data, using language and approaches appropriate for low literacy audiences.
- Draw upon existing tools (e.g., microplanning, a technique used by the Bill &

Melinda Gates Foundation, to support the Avahan Project (see http://web.mit.edu/urbanupgrading/upgrading/issues-tools/tools/Micro-Planning.html).

- ❒ Carefully define who is responsible for capturing information and user groups.

A specific idea was to create a bibliography of resources for donors or implementing partners for use at the community-based program level that includes tools and best practices for how data can be used to inform community advocacy initiatives.

Framework for Information Systems for Community-Based HIV Programs

At the international level, there is a need to research and develop a framework for information systems for community-based HIV programs. The framework would aim to reduce unnecessary data collection while keeping in mind the continuum of data needs from the community to donor level. Specifically for PEPFAR, such a framework could be useful to the partnership frameworks and provide guidance on how to work within national level systems and to improve coordination. Identified as essential components for the framework were:

- ❒ a review of existing information systems to describe strengthens and weaknesses and to provide information about how to decrease system redundancies and increase synergies;
- ❒ a data-flow map from the community level to donor level, and back again;
- ❒ a description of the continuum of data needs and definitions of the information needs of donors, countries, and their communities (districts, etc.);
- ❒ a list of a critical minimum of indicators that can be captured by community-based information systems;
- ❒ a description of information that should be captured at other levels by other data sources (to reduce burden on frontline providers);
- ❒ guidelines to outline clear roles for community workers and volunteers;
- ❒ guidelines to develop and describe mechanisms to facilitate feedback to communities and community-based HIV programs, including identifying responsible people at all level for collecting and using data;
- ❒ guidance on how to facilitate linkages across sectors and programs; and
- ❒ information on existing resources.

To launch the development of such a framework, it was proposed that the idea should be brought to the attention of the UNAIDS HIV/AIDS MERG. Consultancies and working groups could be convened and involve all partners. Civil society representation at the international level is important so that they can articulate their own needs.

Two other suggestions could be done in parallel with the development of a framework that would subsequently facilitate implementing partners' abilities to achieve the recommendations in the framework. First, work to change the minds of donors about target setting. Some donors require that targets, such as number of people reached by the program, be set at the proposal stage. Typically, this means that programs have not had a reasonable opportunity to take into account input from community-based programs when setting targets. Second, request for proposals or applications should require that the implementing partner demonstrate how it would implement data use at the community level, and how it would monitor the data use efforts and evaluate the changes that result from data use.

Increase Awareness of Existing Tools and Experiences and of the Remaining Gaps and Challenges

Promote the available resources and experiences related to information systems for community-based HIV programs, while at the same time work to raise awareness about the remaining challenges, gaps, and priorities. Advocate for this agenda via a wide range of forums, including:

- the Global Health Council and the annual meeting;
- the CORE group, a private voluntary organization dedicated to working with organizations and sharing best practices around community level programs and data collection (a consultative process could be initiated online and during the next partner meeting; for more about CORE group, see http://www.coregroup.org/about/about_core.cfm);
- the World Bank portal at http://gametlibrary.worldbank.org/;
- the Global HIV M&E portal at http://www.globalhivmeinfo.org/Pages/HomePage.aspx;
- the UNAIDS portal at www.unaids.org;
- the HIV/AIDS M&E Listserv at http://www.cpc.unc.edu/measure/networks/aimenet/;
- a Web-based mechanism to be developed, to centralize discussion via a single portal, e.g., such as Kayak is to travel (the challenge is to brand the site as "the one to go to" for information related to community-based information systems; one idea is to maximize visibility via the Google search engine);
- UNAIDS MERGs, to take on community-based information systems as an agenda item in their 2009 meetings (the issue is bigger than HIV, so also take it to non-HIV MERGs, such as those for malaria, nutrition, etc., and work with colleagues from other fields); and
- a Web-based forum for community-based information systems, such as a community of practice (first determining that it is needed and would fill a gap; then calling for program examples and online experiences sharing; with outputs made available via this forum and other outlets).

Other Promising Opportunities and Ideas to Follow Up

Other promising ideas included the following:

1. Document and evaluate existing experiences in information systems for community-

based HIV programs, for example, a community or community-based HIV program which has successfully implemented several data collection tools. Another idea is to document the experiences of a national system such as Community-Based Programme Activity Reporting (COBPAR) in Kenya. Document experiences, data collections methods, training models, analysis tools, guidelines, success stories, etc. Explore experiences of more participatory information systems such as peer-based monitoring and information systems.

2. Apply lessons from non-HIV field experiences, such as IMCI experiences, with integrated information systems or other more participatory evaluation methods (e.g., Marie Therese Feuerstein), by documenting in a bibliography or other thought piece for the literature.
3. Identify and keep list of people who have expertise in community systems. Consider forming an expert review panel to guide future work, including framework development.
4. Create a "road map" of related and available community-based information systems tools and describe how they complement each other (could be part of the framework described above or as separate activity).
5. At the international level, work to review existing periodic population based surveys (while also defining what we need to know about community-based HIV programs) to assess whether some M&E data could be gathered via these resources (or by implementing new surveys) as a way of shifting the data gathering burden away from volunteers and frontline providers allowing them to focus their attention on gathering monitoring data that cannot be collected otherwise.
6. Seek innovative solutions to the issue of individual identifiers as a way to be able to more accurately count beneficiaries (reduce double counting) and for being able to track data over time. For example, investigate the feasibility of portable medical records and projects, such as the Bill & Melinda Gates Foundation's Avahan project in India, which may provide lessons learned.

Conclusion

The two-day technical consultation shared a wide range of information and generated several ideas about how to improve information systems for community-based HIV programs. A number of tools and experiences were presented, and links to those resources are available in Annex 1. Tools and experiences presented during the meeting highlighted variety of users and stakeholders at different levels of the health system, from the community to the national levels.

Recommendations emerging from the meeting underscore the fundamental need to strengthen monitoring and data use at the community-based program level. This can be facilitated by ensuring that indicators are harmonized, forms are appropriately tailored for literacy levels, the information collected serves a key function in M&E, and other sources are tapped to filling monitoring and evaluation needs to alleviate the burden on frontline providers. At the community-based program level, expectations for data collection procedures should be aligned with the skills and capacity of community-based providers and volunteers. To improve use of data, programs should ensure that the data collected map to data that programs need for decision making, and also that the data are quality, complete, relevant, and timely. Other recommendations focus on coordination at the national and international levels to promulgate a common understanding of information systems for community-based services, the resources available, the evidence of "what works;" to facilitate interoperability and linkages between information systems; and to advocate for improving community-based information systems.

Although a number of gaps, challenges, and potential solutions were identified, participants noted that the meeting was largely influenced by perspectives from generalized HIV epidemics. Future initiatives should also work to address issues related to how information systems needs are different for concentrated epidemics.

The ideas and solutions defined here are not expected to be implemented by any one group or organization; rather, different groups and organizations should identify what they can do to move this agenda forward. It is recommended that groups desiring to improve information system for community-based HIV programs place their work in the context of the meeting recommendations and that they coordinate and collaborate with the people and organizations identified in this meeting.

Specifically, there are a few activities that are being implemented. The Global Fund has begun a consultative process with the goal of defining a community systems strengthening framework and a framework for M&E of community systems. As part of this process, the fund will also be documenting best practices in community systems. The World Bank is developing a plan to evaluate the community responses to HIV/AIDS and lessons learnt to inform the way forward (see presentation). UNAIDS and WHO are both working with civil society to build capacity including M&E. MEASURE Evaluation and USAID have initiated a consultative process to define a parsimonious set of indictors for community-based HIV programs that hopefully will lead to harmonized indicators at the international and national levels. Finally, groups and organizations will continue to develop, test, and refine the various tools and systems presented during the technical consultation.

Annex 1: Resources

Barrier Analysis

Barrier analysis is a rapid assessment tool used to identify the important behavioral determinants associated with particular behaviors (http://barrieranalysis.fhi.net).

Census-Based Impact Oriented

Census-Based Impact Oriented (CBIO) information system is available at:

http://www.coregroup.org/index.php?option=com_content&view=article&id=51.

Child Status Index

The Child Status Index manual, field guide, and "made easy" tools are available at:

http://www.cpc.unc.edu/measure/tools/child-health/child-status-index.

Civil Society Fund, Uganda

The Civil Society Fund is working to coordinate donor resources for grants to civil society organizations. More information is available at www.csf.or.ug including a report titled, Increasing Civil Society Participation in the National Reponse to HIV/AIDS, OVC, TB and Malaria in Uganda. Governance, Management and Operations Manual.

Community-Based Programme Activity Reporting (COBPAR)

COBPAR began in 2006 in Kenya and captures health and community information from HIV/AIDS program implementers including civil society, CBOs, NGOs and FBOs. More information about COBPAR is available in the 2008 United National General Assembly Special Session (UNGASS) country report for Kenya available at:

http://data.unaids.org/pub/Report/2008/kenya_2008_country_progress_report_en.pdf.

Community-Level Program Information Reporting (CLPIR) Toolkit

A report of the RHINO forum proceedings is available at:

http://www.rhinonet.org/Docs/CLPIR%20Toolkit%20Email%20Summary_v.7%20FINAL%208.12.09.pdf.

A summary of CLPIR modules is available at:

http://www.cpc.unc.edu/measure/networks/CLPIR%20Toolkit%20Module%20Summaries.doc/view.

The CORE group

The CORE group is a private voluntary organization dedicated to working with organizations and sharing best practices around community level programs and data collection:

http://www.coregroup.org/about/about_core.cfm.

Excel to Google Earth (Mapping)

Excel to Google Earth (E2G) public "beta" version is available by request. Feedback, experiences, and suggestions are being solicited. Improvements in the tool are expected in 2010. The E2G tool is available at:

http://www.cpc.unc.edu/measure/e2g.

Framework for Health Information Systems

Health Metrics Network, World Health Organization (WHO). *Framework and Sandards for Country Health Information Systems*. 2nd edition. Geneva: WHO; 2008.

Framework for M&E of Programs for MARPs

In 2008, A Framework for Monitoring and Evaluation of HIV Programs for Most-at-Risk Populations (MARP) was produced, available at:

http://data.unaids.org/pub/Manual/2007/JC1519_me_Framework_en.pdf.

Lot Quality Assurance Sampling (LQAS)

LQAS is a sampling method that is used to obtain reliable information on a small geographic or administrative unit using a small sample. LQAS can be used to accurately detect the extremes of performance; those which are exceeding an "upper threshold" of performance and those fail to meet a "lower threshold" of performance. LQAS cannot detect performance levels between those arbitrarily set upper and lower thresholds. Studies will be descriptive and cross sectional. More information and resources about LQAS are available at:

http://www.cpc.unc.edu/measure/publications/html/ms-00-08-tool09.html; or

http://207.226.255.123/working_groups/LQAS_Protocol_for_Parallel_Sampling.pdf.

Microplanning

Microplanning is a technique used by the Bill & Melinda Gates Foundation to support the Avahan Project in Indai:

http://web.mit.edu/urbanupgrading/upgrading/issues-tools/tools/Micro-Planning.html.

M&E and Reporting Systems for HIV/AIDS Programs

This workbook from PACT aims to present monitoring, evaluation, and reporting systems in its most basic and useable form. It is geared particularly toward those local NGOs implementing HIV programs, though not necessarily based in the community:

> K. Lynn McCoy, Patricia Njeri Ngari, Edwin E. Krumpe. *Building Monitoring, Evaluation and Reporting Systems for HIV/AIDS Programs*. Washington: Pact; 2005. Available at:
>
> http://www.pactworld.org/galleries/default-file/building_mer_systems.pdf.

Orphan and Vulnerable Children Well-being Tool

The Catholic Relief Services Orphan and Vulnerable Children Well-being Tool is available at:

> http://crs.org/publications/ovc-wellbeing-tool/

Reaching Every District

Reaching Every District (RED) is a management strategy that was started by UNICEF and WHO to improve immunization coverage (http://www.who.int/immunization_delivery/systems_policy/RED-FactSheet.pdf), and now is in 60 countries. In 2006, WHO conducted an impact evaluation (http://www.afro.who.int/ddc/vpd/routine/red-2007.pdf).

Scale up Hope, Mozambique

> Blackett-Dibinga K, Sussman L. *Strengthening the Response for Children Affected by HIV and AIDS through Community-Based Management Information Systems*. Westport, CT: Save the Children; 2008. Title page and executive summary available at:
>
> http://www.jlica.org/userfiles/file/Cover%20Page,%20TOC,%20Executive%20Summary.pdf; full text available at: http://www.jlica.org/userfiles/file/Body%20of%20Document.pdf.

Training for Community Groups to Challenge Stigma and Discrimination

This tool kit is designed to help trainers work with community groups to challenge HIV stigma and discrimination:

> Academy for Educational Development, International Center for Research on Women, International HIV/AIDS Alliance. Understanding and challenging HIV stigma. A toolkit for action. Available at:
>
> http://www.icrw.org/docs/stigma-toolkit/intro-a.pdf.

Annex 2: Meeting Agenda

Technical Consultation on Information Systems
for Community-based HIV Programs
July 21-22, 2009, Washington Plaza Hotel, Washington, DC, USA

Meeting purpose : The purpose of this meeting is to obtain consensus on a way forward to strengthen information systems for community-based HIV programs so that the information systems 1) provide high quality data that are used to improve programs and 2) facilitate reporting and use throughout the health system .

Day 1 objective : To acquaint participants with existing tools, resources and experiences of information systems for community-based HIV programs.

Day 2 objectives : 1) To identify gaps in existing information systems and 2) to come to consensus about how to fill these gaps.

Day 1 – Tuesday, July 21, 2009		Susan Post, MEASURE Facilitator
7.30-8.30	**Breakfast & Registration** *(Jefferson-Monroe Rooms, aka National Hall)*	
8.30-8.45	**Opening remarks**	Sian Curtis, MEASURE Evaluation
8.45-8.50	**Welcome**	Krista Stewart, USAID
8.50-9.10	**Introductions**	Participants
9.10-9.30	**Meeting overview**	Heidi Reynolds, MEASURE Evaluation
9.30-10.30	**Community-based Information System Tools**	
	The CLPIR Toolkit	Upama Khatri, MEASURE Evaluation
	A community-based approach to monitor child well-being: The Child Status Index (CSI) Tool	Florence Nyangara, MEASURE Evaluation
	A self-report tool for monitoring OVC wellbeing	Shannon Senefeld, Catholic Relief Services
10.30-10.50	**Tea and coffee break**	
10.50-11.50	**Community-based Information System Tools** (con't.)	
	Operational guidelines for M&E of MARP	Sharon Weir, MEASURE Evaluation
	Mapping and GIS tools for community reports	John Spencer, MEASURE Evaluation
	Vital events: Measuring and monitoring HIV-related mortality in the communities	Robert Mswia, MEASURE Evaluation
11.50-12.50	**Lunch** (*Hotel restaurant*)	
12.50-1.30	**Program Case Studies of Community-based Services Information and Monitoring Systems**	
	Monitoring and information system for MVC program	Herbert Nsauye (OVC) Salvation Army, Tanzania
	The steps taken by FOSREF to put in place the new CBIS	Marc Philippe Depestre, FOSREF, Haiti
1.30-2.50	**Case Studies of National Operationalization of Community-based Monitoring Systems**	
	The challenges of building a system to monitor the national action plan for orphans and vulnerable children in Zimbabwe	Sue Laver, UNICEF Zimbabwe
	Monitoring community HIV services in Guyana	Mary Freyder, MEASURE Evaluation (presenting work of CAPACITY Project)
	Overview of the community-based information system (CBIS) in Haiti	Moussa Ly, MEASURE Evaluation Haiti
	Program-specific case studies of community-based services, information and monitoring systems ~FHI's support to HBC program in South Africa~	Chiho Suzuki, Family Health International
2.50-3.10	**Coffee/Tea Break**	
3.10-4.10	**Community Oriented Activities**	
	Scale up Hope, Mozambique	Kendra Blackett Dibinga, Save the Children/US
	Evaluation of community response to HIV	Rosalía Rodriquez García, World Bank
	Health data intersects in multi-sector community-based development: The case for information systems	Steve Settimi, USAID
4.10-4.55	**Experiences from non-HIV Community-based Information Systems**	
	Experiences from non-HIV community-based information systems: Overview of methods	Jim Ricca, MCHIP, Macro International
	Making impact	Carolyn Wetzel, Food for the Hungry
4.55-5.00	**Wrap up**	Heidi Reynolds, MEASURE Evaluation

Day 2 Wednesday, July 22, 2009	Susan Post, MEA SURE Facilitator	
7.30-8.30	**Breakfast** *(Jefferson-Monroe Rooms, aka National Hall)*	
8.30-8.45	**Review of Day 1 an overview of Day 2**	Susan Post, MEASURE Facilitator
8:45-9:15	**Community-based Information systems: Discussion about the Terminology and Inform ation Users**	Cyril Pervilhac, WHO
9:15-9:45	**Where do we want to go in this field?**	Susan Post, MEASURE Facilitator
9:45-10:00	**Introduction to Group Work**	Susan Post, MEASURE Facilitator
10.00-10.15	**Coffee/Tea break**	
10:15-12.15	**Group Discussions** (Rooms: *National Hall, Senate Room, Diplomat Room [2nd level], Cabinet Room, Congressional Room, Executive Boardroom, Lincoln Room*)	All
12.15-1.15	**Lunch** (*Hotel restaurant*)	
1.15-2.30	**Presentation of Group Findings**	All
2.30-2.45	**Tea/coffee break**	
2.45–4.00	**Discussion about Next Steps** (*Of rooms above, 3 TBD*)	Sian Curtis, Heidi Reynolds, & Silvia Alayon, Facilitators
4.00-4.45	**Report out about Next Steps**	All
4.45-5.00	**Closure**	Heidi Reynolds

Annex 3: Meeting Participants

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