# Standards for Integration of HIV/AIDS Information Systems into Routine Health Information Systems

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October 2015





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# Systems into Routine Health Information Systems

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This guide has been supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) through the U.S. Agency for International Development (USAID) under the terms of MEASURE Evaluation cooperative agreement GHA-A-00-08-00003-00, which is implemented by the Carolina Population Center, University of North Carolina at Chapel Hill, with Palladium (formerly Futures Group), ICF International, John Snow, Inc., Management Sciences for Health, and Tulane University. Views expressed are not necessarily those of PEPFAR, USAID, or the United States government.

October 2015

MS-15-103

## **Acknowledgments**

The authors would like to thank the following contributors and reviewers of the guidelines for integration of HIV/AIDS information systems into RHIS: Stephanie Mullen DrPH, Theo Lippeveld MD DTMH MPH, Michael Edwards PhD, Tariq Azim MD, Kola Oyedrian PhD, and Jessica Posner MPH, from MEASURE Evaluation; Dr. Aderemi Najim Azeez, head of Health Research and Statistics, Federal of Ministry of Health; Wubshet Denboba Midekssa, Health System Strengthening Advisor, National Alliance of State & Territorial AIDS Directors (NASTAD), Ethiopia; and Dr. Alemayehu Belayneh, technical expert, Ethiopian Federal Ministry of Health.

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# ACRONYMS

ANC	antenatal care
ART	anti-retroviral therapy
CBIS	community-based information systems for prevention and care
СВО	community-based organization
DHIS	district health information system
EHR	electronic health record
EMR	electronic medical records
FBO	faith-based organization
HIMSS	Healthcare Information and Management Systems Society
HIS	health information system
HMIS	health management information system
HMN	Health Metrics Network
ICD	International Classification of Diseases
ICT	information and communication technology
IT	information technology
KePMS	Kenya PEPFAR Program Monitoring System (KePMS)
MDG	Millennium Development Goals
МОН	ministry of health
NAC	national AIDS commission
NGO	nongovernmental organization
OVC	orphans and vulnerable children
PEPFAR	United States President's Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission of HIV
PRISM	Performance of Routine Information System Management
RHINO	Routine Health Information Network
RHIS	routine health information system
SDMX	Statistical Data and Metadata Exchange
SNNPR	Southern Nations Nationalities and Peoples Region
SOP	standard operating procedure
SWAps	sector-wide approaches
ТВ	Tuberculosis
TWG	technical working groups
USAID	U.S. Agency for International Development
VCT	voluntary counseling and testing
WHO	World Health Organization

# Introduction

In recent years, there has been a strong push to strengthen national health systems in developing countries. In its framework for action, the World Health Organization (WHO) describes a health system as consisting of "all organizations, people and actions whose *primary intent* is to promote, restore or maintain health." It further elaborates on the six building blocks that comprise a health system: health service delivery; health workforce; health information; medical products, vaccines and technologies; health financing; and leadership and governance.<sup>1</sup> These building blocks are interdependent and must interact synergistically to produce a positive impact on health outcomes. There is widespread agreement that, unfortunately, national health systems are not performing at an optimal level and that improved health outcomes cannot be realized without strengthening the health system.

Likewise, the achievement of the United Nation's health-related Millennium Development Goals (MDGs) and other related health goals rely heavily on a functional health information system (HIS), since quality health information is required to measure progress towards these goals. What constitutes an HIS? WHO defines a health information system as "a set of components and procedures organized with the objective of generating information that will improve health care management decisions at all levels of the health system."2 Taking it a step further, the Health Metrics Network (HMN) framework describes six components of a health information system:

- 1. HIS resources, such as coordination and leadership, information policies, financial and human resources, and infrastructure;
- 2. a core set of indicators and associated targets for health determinants, health system performance (inputs, outputs, and outcomes), and health status;
- 3. data sources;
- 4. data management, which consists of procedures to collect, store, analyze and distribute data, as well as provide quality assurance;

 <sup>&</sup>lt;sup>1</sup> World Health Organization. Everybody's Business: Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action. Geneva, Switzerland: World Health Organization; 2007.
<sup>2</sup> Lippeveld T, Sauerborn R., Bodart C. Design and Implementation of Health Information Systems. Geneva, Switzerland: World Health Organization; 2000.

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- 5. information products that are formatted/packaged for planners and stakeholders; and
- 6. dissemination and use of health information in the management of health system planning and delivery at all levels of the health system.<sup>3</sup>

One of the main data sources of an HIS is a routine health information system (RHIS), which is a health facility and/or community-based system to collect, analyze, and use relevant information for decision making on priority health services.

According to WHO, "a well-functioning health information system is one that ensures the production, analysis, dissemination, and use of reliable and timely information on health determinants, health system performance and health status."<sup>4</sup> However, attainment of sustainable population health in many developing countries is made increasingly challenging given the current weaknesses of many national HIS.

# Fragmentation

With the unprecedented levels of funding made available for disease control and prevention in the past decade through the advent of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis, and Malaria many countries have greatly expanded programs to combat infectious disease like AIDS, tuberculosis (TB), and malaria. Concurrently, the Global Polio Eradication Initiative has increased the amount of funding available to national immunization programs for routine and supplemental immunization, and surveillance for vaccine preventable conditions. This increased funding is naturally accompanied by increased scrutiny by donors with a desire to know the return on their investments. Disease-specific information systems have been developed in response to donor reporting requirements, and to track progress against ambitious objectives for disease control and prevention. These disease-specific (or 'parallel' or 'vertical') systems create data flows that are separate from established country routine health information systems since existing country systems often do not offer performance commensurate to the needs in information of the donors. Moreover, these

<sup>&</sup>lt;sup>3</sup> Framework and Standards for Country Health Information Systems. Second Edition. HMN, WHO. June 2008. <sup>4</sup> WHO, 2007.

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vertical systems typically do not communicate with each other, or with the established national systems.

This 'fragmentation' of the health information system weakens the government's capacity to assume its stewardship and coordination roles, since health programs look to the donors to set priorities for planning. The traditional health information architecture in the country withers as funding that might have gone towards health system strengthening is rather poured into efforts to combat single diseases. Moreover, it creates inefficiencies throughout the health system, whereby in certain health facilities, 50% of the funding spent on health information systems is devoted to a single disease which affects 5% of the population, while everything else has to share an increasingly small share of the pie. Fragmentation also places a heavy burden on health care personnel at the periphery as reporting requirements swell with the proliferation of vertical reporting systems.

## **Benefits of Integration**

The PEPFAR M&E, HIS, and Surveys and Surveillance Technical Working Groups (TWGs) held a conference on the keys to HIS integration, sustainability, and country ownership in 2010. The participants identified several benefits that they expected from HIS integration:<sup>5</sup>

- standard data definitions
- uniform recording and reporting forms
- protocols for electronic medical records (EMR)
- protocols for training
- greater data use at all levels for day to day management and strategic planning
- comprehensive view of health activities nationally
- better collaboration among stakeholders
- increased efficiencies and reduced costs
- Improved service delivery quality
- Better health outcomes

<sup>&</sup>lt;sup>5</sup> Keys to Health Systems Integration, Sustainability, and Country Ownership: 2010 PEPFAR Conference. Conference themes and key findings. Held 9-13 August 2010, The Westin Grand Cape Town Arabella Quays, Cape Town, South Africa.

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The last three items listed above emphasize the relationship between integrated service delivery and integrated HIS, which is crucial in the effort to strengthen health systems. Integrated services need integrated tools, such as RHIS. Just as there is no one approach to service integration and many models exist depending on the context, the same is true for RHIS integration. As the approach to service delivery becomes more integrated, data collection tools also need to be adapted to facilitate the recording and reporting of integrated or linked services. Tools such as patient cards/records, registers, family folders, EMR, databases, etc. that gather client level information are often the primary data source and are an integral component of the RHIS at the service delivery level, as are the tools used to report data within the service units of a facility and/or from a facility to higher levels.

This guide describes approaches and standards for integration of vertical information systems with the RHIS. It uses HIV/AIDS information systems primarily, as examples of best practices and what is required for achieving integration with RHIS. These principals are cross-cutting, however, and can be applied to nearly any disease or program-specific information system. General aspects of information system integration are first presented, followed by the case of HIV/AIDS integration. The concept of interoperability as a method for achieving the goals of integration is then presented, with generic models and country examples of different types of integration.

# Integration

### **RHIS Integration Definition**

In July 2009, the Routine Health Information Network (RHINO) hosted an online discussion forum titled Is Integration of Health Information Systems Possible? Some Issues and Considerations. Although the goal of the forum was to develop an operational definition of HIS integration, in the end there was no consensus among participants on how to define HIS integration. Various perspectives were represented and it was clear that integration meant different things to different people.

Some participants viewed integration from a systems perspective in which the relationship between an HIS and the health system was emphasized. The systems perspective views the HIS as composed of two entities: the information generating process where data are transformed into information for use in planning and management; and the HIS management structure consisting of resources and the organizational rules for the efficient use of those resources.<sup>6</sup> HIS integration, therefore, encompasses more than information processing. It requires stewardship, coordination, and partnerships to ensure the appropriate resources are in place to support integrated data use for day to day management and strategic decision making.

From a technological perspective, integration is focused on the information generating process and can be addressed via various information and communication technology (ICT) models, standards, and technologies. The Healthcare Information and Management Systems Society (HIMSS) defines integration as "the arrangement of an organization's information systems in a way that allows them to communicate efficiently and effectively and brings together related parts into a single system."<sup>7</sup> A key mechanism to achieve integration is interoperability, defined by HIMSS as "the ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities."<sup>8</sup> Thus, from this perspective, integration implies that there is one consolidated

<sup>&</sup>lt;sup>6</sup> Lippeveld, Sauerborn & Bodart, 2000.

<sup>&</sup>lt;sup>7</sup> www.himss.org/asp/topics\_integration.asp, accessed April 2011.

<sup>&</sup>lt;sup>8</sup> www.himss.org/asp/topics\_integration.asp, accessed April 2011.

information system to meet all information needs; whereas, interoperability takes advantage of powerful ICT capabilities to allow subsystems to work together seamlessly, to give the appearance of one system. (Refer to the section on Interoperability for a description of an interoperability maturity model.)

An essential feature of an integrated HIS is the integration of data. The challenge is to consolidate data from a variety of sources for a diverse group of users with very different information needs. At the center of the HMN's process for building an integrated HIS is an integrated data repository, which merges and manages data from disparate data sources.<sup>9</sup> Although it requires the use of ICT to maximize its potential, it is important to note that ICT is just a tool; a means to an end. What matters to users of health information is that they receive information in a way that is useful to them, regardless of how it is accomplished technically.

With that in mind, the following working definition of RHIS integration is offered:

RHIS integration develops or enhances RHIS to overcome the fragmentation in healthcare services by organizing information (via mechanisms such as ICT, coordination, stewardship, etc.) from diverse service delivery areas in a way that gives users at all levels timely access to information that is meaningful to them and supports their decision making process.

# Service Integration vs. integration of Health Information

The idea of integration in the health sector is not new; it dates back to the goals of the primary health care movement and child survival efforts of the 1980s. Today's global health budget constraints, efforts to achieve the MDGs, fragmentation in health systems, and other causes have motivated a new urgency for integration. Improved efficiencies and greater impact through strategic coordination and integration is one of the core principles of the United States government's global health strategy (Global Health Initiative or GHI). One premise of the

<sup>&</sup>lt;sup>9</sup> Components of a strong health information system: A guide to the HMN Framework. HMN, WHO.

initiative is that coordinating and integrating the delivery of health interventions is essential for achieving sustained improvements in health. <sup>10</sup>

Individual clients in the health system have many health needs that should be addressed by a package of services reflecting national health priorities. The exact content of these packages of service and what population groups they serve varies by the epidemiological context of the country or region. For example, one country may focus on infectious disease outcomes such as HIV, TB, and malaria, while another might focus on a package of essential health services for maternal and newborn health.

When a client with multiple health needs enters a health facility, the facility should be prepared to link the client with the services the client needs. This represents integrated health service delivery which can be achieved in different ways. For example, all services are offered in the same facility (primary care model), or clients may be referred to services via a referral network to other facilities offering needed services, or to different units in the same facility. Moreover, this link can be made differently depending on what level a client enters the health system – either in the community via a community health worker or at a district hospital. No matter how the link occurs, the health system should provide a continuum of quality care and possess tools and methods to facilitate the link, as well as track health system results.

Other elements of the health system may also be integrated. The extent of integration of a particular element of the health system may affect other elements. For example, training of medical personnel may need to be updated to create classifications of health workers trained to provide multiple services. Additionally, the distribution patterns of health commodities may need to be updated to reflect a broader range of services in a given service area.

An information system should be responsive to changes in service delivery as service delivery guidelines and modes of service delivery are likely to change with programmatic updates. Integrated information systems provide an understanding of how individual clients, with multiple health needs, may be accessing and utilizing services. It permits an understanding of how resources

<sup>&</sup>lt;sup>10</sup> U.S. Government Health Programs interagency Web site, Global Health Initiative, http://www.ghi.gov/index.html.

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are being used to meet the needs of clients and provides information on how programs can improve service delivery, and potentially health outcomes, at each level of the health system.

Integration of health information systems involves the data collection tools that gather information on services provided to clients, the summary reports of this information prepared by health facilities and sent regularly to higher levels of the health system, the aggregation of these data at district and higher levels, and the analysis and use of this information for program and health system monitoring, evaluation and planning. The extent to which services are integrated at the point of service delivery, the health information system should reflect the same level of integration. Moreover, integration of health information reduces burden to health workers who are required to record the delivery of service and report results.

# Examples of Integrated RHIS at the Level of Patient Management

In 2005, WHO began development and implementation of patient monitoring guidelines for HIV care and anti-retroviral therapy (ART) in a number of countries. These tools and guidelines were updated in 2009. The revised tools, called the Three Interlinked Patient Monitoring Systems for HIV care/ART, MCH/PMTCT and TB/HIV (3ILPMS), incorporate content from several interventions/program areas within a single tool and promote linkages between HIV services and other services, such as TB services and antenatal care (ANC). The 3ILPMS tools are designed to respond to the need for better integration of services across different program areas, improved and integrated information on services provided, and an improved continuity of care for patients.

Prevention of mother-to-child transmission of HIV (PMTCT) can be views as an example. The main outcome of PMTCT program performance is that HIV-positive pregnant women receive anti-retroviral prophylaxis and treatment for themselves and their children, as well as other needed health care services as dictated by their health status. In order to draw more pregnant women to ANC and eliminate vertical transmission from mother to child, there is a need for better integration of service delivery, and functional referral mechanisms and counter referrals among ANC, PMTCT, MCH, TB, and HIV care/treatment, as well as an information system that is able to link data from these different services. The 3ILPMS tools enable identification of women in ANC who are in need of PMTCT services. In addition, the tools facilitate more comprehensive

and coordinated care for those women by linking them to HIV care/treatment services, including TB, and linking the mother-infant pair allowing for follow-up of exposed infants.

Other examples of RHIS integration at the client level include Zambia's SmartCare<sup>11</sup> system, Malawi's health passport,<sup>12</sup> and Ethiopia's integrated patient folder.<sup>13</sup> In the SmartCare system, the client receives a smart card, similar to a credit card, which contains their health information and history. When clients visit a health facility, their smart card is swiped by a special reader that transfers all their data to the facility's database. Before they leave, the services received are downloaded to their smart card, so that they maintain a complete history of their health information on the card. If someone loses her smart card, she can return to the last health facility visited and have her information downloaded to a replacement card. The Malawi health passport is somewhat similar in that the client carries her health passport to every facility visited and the card is updated with all services that are rendered. In both cases, integrated health information is transported by the client to each point of service delivery. The health passport is not electronic, however, and is not replicated at the facility. If a client loses her passport, she also loses her health history. Finally, in Ethiopia, a patient folder containing the complete record of services provided to a client is kept at the health facility visited. As long as patients receive all their health services at a specific facility, their complete health history will be available.

Of course, in health facilities with adequate infrastructure, the best example of integrated health information at the client level is an electronic health record (EHR). In this model, data are entered at the point of service delivery (e.g. in a treatment ward) for a variety of services and pulled together in a patient record identified by a unique patient identifier. Data can be aggregated from EHRs automatically to compile indicators for routine reporting for program monitoring and evaluation. While EHRs offer a host of advantages over paper-based systems, most health facilities in developing countries lack the essential infrastructural elements necessary for full functionality (see more on EHRs in the section on Interoperability).

<sup>11</sup> More information is available at: http://www.smartcare.org.zm/.
<sup>12</sup> More information is available at: HMN Malawi HMIS Assessment, 2009.

<sup>(</sup>http://www.who.int/healthmetrics/library/countries/2HMN MWI Assess Final 2009 07 en.pdf, p. 26) 13 More information is available at:

http://www.jsi.com/JSIInternet/Features/article/display.cfm?txtGeoArea=INTL&id=296&thisSection=Features &ctid=1030&cid=232&tid=20.

At the intra-facility level, integration can be facilitated by an effective referral system between health services, including counter referrals to provide feedback to the referring site about the outcome of the referral. At a community level, integrated information could be collected by a single health care worker, who is trained to meet all the client's health care needs. Alternatively, India maintains a village health record in which information on selected health issues are updated every month for families and individuals. It includes demographics and provides a comprehensive health profile for the village.

At higher levels, e.g. district and national, data warehouses are often mentioned as a mechanism for integrating health data. To achieve this level of integration, however, requires stewardship, coordination, partnerships (public/private), as well as the use of sophisticated ICT tools. In developing countries, this may be possible only at the national level, leaving subnational systems to supply data to the data warehouse, but not necessarily have direct access to it (see more on data warehouses in the section on Interoperability).

It is important to note that the quantity of data required at each higher management level is less than the data requirements at lower levels. The HMN framework describes the information needs and tools at different levels of data collection. The household/community and facility level needs a wide variety of patient level data to understand the burden of disease, risk factors, treatment outcomes, as well as for monitoring and evaluation. Patient-level data need to be detailed because they are used by service providers, both at the community and facility levels, to manage the care of individual patients. At the facility level, these data are aggregated to support program management, audits, planning, and drug procurement. At the district level, data are aggregated in district summary reports to provide information on indicators for district and national reporting and planning. At the national level, further aggregation provides indicators that address national needs, such as strategic planning and resource allocation. At the highest level, global/regional reports contain summary indicators for global reporting<sup>14</sup> (figure 1).

<sup>&</sup>lt;sup>14</sup> Health Metrics Network. *Framework and Standards for Country Health Information Systems* [2<sup>nd</sup> ed]. Geneva, Switzerland: World Health Organization; 2008.

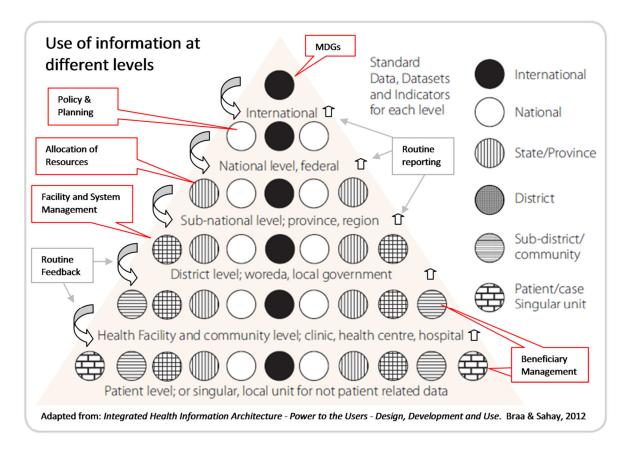


Figure 1. Use of information at different levels of the health system.

# **RHIS Integration Challenges**

While integration of health information systems is desirable from the standpoint of efficiency and reduction of burden in information collection and reporting, it is not without its challenges. The participants in the 2009 RHINO online forum,<sup>15</sup> an advocacy group for RHIS reform and strengthening led by MEASURE Evaluation and John Snow, Inc., identified current factors related to health information systems that limit their ability to meet their objectives and move toward integration. Below are key barriers to integration cited by participants:

• Fragmented health systems as a result of donor-specific funding and reporting demands are barriers.

<sup>&</sup>lt;sup>15</sup> More information is available at http://rhinonet.org/files/2013/04/forum\_integrating\_his.pdf.

- Existing information systems, which were developed to meet an organization's unique needs, cannot be easily replaced with an integrated information system that may not be as functional.
- A top down design approach does not adequately meet the needs of subnational levels.
- Without standardized data definitions, it is difficult to link patient, facility, and other administrative records across databases.
- Lack of, or inadequate, leadership and political will from a country's health ministry, including lack of an organizational culture toward data use, can be a key barrier.
- Other organizational issues, such as lack of a strong collegial relationship between the HIS unit and program managers, donors, etc., as well as between divisions within the health ministry, are barriers.
- Tendency for an HIS unit to be reactive rather than proactive in responding to changing health information needs can be challenging.
- Limited resources for capacity building in the collection, analysis, and use of quality data or integrated tools, as well as insufficient resources (technical, human, financial, etc.) for the maintenance of an HIS are problems.
- Integrated data collection via integrated tools is a burden on healthcare workers.
- Inadequate understanding of the role of RHIS or the benefits of an integrated HIS is a problem.

# Integration and Interoperability

Due to the above cited challenges (and others) it may not be possible or even desirable to integrate routine health information systems fully. In an era of well-financed disease-specific care, treatment and prevention programs, high performing health information systems have been developed for vertical programs in many countries. Tremendous resources have been expended to design, implement, and train users for these systems. While many studies have shown that the existence of vertical systems weakens the country RHIS,<sup>16</sup> many disease programs and countries are unwilling to pull the plug on these systems due to the substantial investments made in

<sup>&</sup>lt;sup>16</sup> For more information, see: http://www.who.int/management/district/services/WhenDoVerticalProgrammesPlaceHealthSystems.pdf.

implementing them. Moreover, information is power and disease programs in some countries are not willing to diminish the influence they may wield as a result of a proprietary information system.

A disadvantage to integrated health information systems is the potential loss of detail in health information for disease programs. Typically, it is the responsibility of a medical provider to collect and report health data. Most often in developing countries there are not sufficient resources available for dedicated data management staff, so this responsibility falls to the staff which is present, such as nurses and doctors. This staff, of course, has other pressing duties, such as patient care. Therefore, there is a limit to the amount of data that can be reasonably collected in the health information system. In an integrated HIS, the limitations in what data are collected and reported would likely be greater for individual health programs.

An alternative approach to integration, which still yields the valued goals of improved access to information that cuts across the health program landscape, is system interoperability. Interoperability describes the extent to which systems and devices can exchange data and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.<sup>17</sup>

Interoperability permits different information systems to work together and provides, from the user's perspective, the appearance and functionality of an integrated system. Interoperability is primarily a property of electronic systems, where sharing data is a matter of electronic transmission, data formats and coding schemes.

Making information systems interoperable is a complicated process which involves the creation of data translation layers, or gateways, which permit two systems to understand one another. Creating and maintaining such gateways is time consuming and laborious since each gateway may need to accommodate (translate) hundreds (or even thousands) of data elements. Each successive system added to the mix requires a separate, customized gateway to ensure accurate data transfer between systems. Since each new system will need to connect with the other systems, and in total

<sup>&</sup>lt;sup>17</sup> For more information, see http://www.himss.org/library/interoperability-standards/what-is.

requires  $n^{(n-1)/2}$  connecting gateways to be established and maintained,<sup>18</sup> the management of these gateways soon becomes unmanageable as the number of interoperable systems increases.

Ultimately, the likely solution in many countries will be a mix of integration, interoperability and standardization of data, indicators and reporting protocols. This is discussed further in the section on Interoperability.

## Integration of HIV/AIDS Information Systems into RHIS – Best Practices

#### Intra-Program Integration

In order to integrate disease-specific information systems into the RHIS, first the diverse systems within that program area should be harmonized. With the increase in disease-specific funding in the past decade through the PEPFAR and the Global Fund to Fight AIDS, Tuberculosis, and Malaria, many new implementing partners have appeared on the scene as sub-grantees, or implementers of donor-specific country operational plans. Nongovernmental organizations (NGOs), community-based organizations (CBOs), and faith-based organizations (FBOs) have received funding to conduct activities geared towards disease control and prevention, and care and treatment of affected individuals. Many of these erected proprietary information systems to satisfy the information needs of their donors. The result was a plethora of indicators attempting to measure similar health processes and results, but with different definitions, which led to incompatible data and incomparable results.

In an attempt to reduce the proliferation of unique organization based systems and harmonize data that are collected within a program, donors sought to develop standardized information systems for specific program areas. This resulted in the creation of separate national information systems for ART, PMTCT, voluntary counseling and testing (VCT) community-based information systems for prevention and care (CBIS), and orphans and vulnerable children (OVC).

<sup>&</sup>lt;sup>18</sup> Integrated Health Information Architecture: Power to the User, P. 66s. Jorn Braa & Sundeep Sahay, 2012. http://www.mn.uio.no/ifi/english/research/networks/hisp/integrated-health-information-architecture/prelims.pdf

As a first step towards integrating HIV into RHIS, diverse information systems within HIV/AIDS should be standardized and integrated. For this to occur, information across the diverse systems should be harmonized.

#### Minimum Package of Service

What constitutes a client being served? How many of what types of services should a client receive before they are counted as being served? What constitutes a person 'in care' for HIV? In order for the provision of services by different providers (or different HIV/AIDS programs in the same country) to be comparable, such standards need to be developed. For example, for community-based HIV prevention and care activities there are many services offered to meet many needs, ranging from the provision of school supplies, food/nutrition supplementation, health and psychosocial services, and the provision of shelter and/or protection. What level of services or how many of the above services constitutes service?

#### Minimum National Data Set for HIV/AIDS

An agreed-upon national minimum data set of essential indicators for HIV/AIDS should be developed through a consultative process with stakeholders. The indicators should be organized by level of the health system, have standard definitions and data elements, and be linked to objectives within the national strategic plan. The minimum data set, so called because it represents a parsimonious, bare minimum required to monitor progress toward goals and objectives outlined in national planning documentation, should be published online to ensure widespread access. If need be, lower levels of the health system can add indicators according to locally prevailing priorities. But the indicators in the national minimum data set should be required from health facilities and community-based programs through the different levels of the health system up to the national level.

#### CASE STUDY

#### Community-Based Information System for HIV/AIDS in Haiti

In 2006, MEASURE Evaluation in Haiti began a process of integration of diverse information systems reporting on community-based HIV/AIDS prevention and palliative care activities. This was no easy task: there were 17 PEPFAR implementing partners, all with proprietary information systems collecting data on 200 indicators across three program areas (prevention, home-based palliative care, and support to OVC).

MEASURE Evaluation began with consultations with the implementing partners to share the vision of a unified, integrated system for reporting on community-based HIV/AIDS prevention and care activities. This was followedup by a series of workshops to map indicators across systems, identify ways to harmonize the indicators and arrive at common definitions. A 'minimum package of service' was defined for each program area, which allowed different service providers to compare "apples to apples".

Following the identification of a parsimonious list of harmonized indicators and definitions, MEASURE Evaluation, along with implementing partner stakeholders and donors, began the process of developing a harmonized set of data collection tools, in both English and Creole, to capture the data. Following an intensive workshop that brought all the stakeholders together, a draft set of tools were produced which were then pilot tested in a number of communities. The data were reported from CBOs (sub-grantees) to umbrella institutions (primary grantees), which then entered the data into an online data repository, which combined facility data with the community-based data. All the data were available from this online data repository for analysis and results dissemination.

The system went live in 2008 and was used to inform PEPFAR indicators for community-based prevention, palliative care and OVC.

Challenges, successes, and lessons learned cited by MEASURE Evaluation include the following.

Challenges:

- double counting of beneficiaries
- low level of literacy of community staff to use data collection tools
- shift from previous tools to the standardized tools
- integration of the PEPFAR CBIS with other donors' and organizations' information systems

Successes:

- commitment and ownership of umbrella institutes
- participation of other partners in the training of trainers of newly funded institutes
- involvement of a new monitoring and evaluation local NGO to provide assistance on data quality control

Lessons learned:

- good ownership with involvement of the partners from the beginning is a must
- regular contacts between umbrella institutes and community sites through formative supervision are needed
- better understanding of tools by monitoring and evaluation officers during replication of the training and supervision of the use of data collection tools
- good network among partners during the monthly feed-back meetings
- collaboration between partners to avoid double counting by developing joint strategies

#### **Indicators and Definitions**

Indicators are the corner stone of monitoring and evaluation of health sector performance. Indicators permit comparisons of different countries, regions within the same country, or districts from one point in time to the next. Indicators and their definitions should be standardized across an HIV/AIDS program. The same indicator, from two different reporting systems, can have drastically different results if the definitions are not the same. *Harmonizing indicators* — Coordination at a high level, and national consensus on a standard set of indicators, indicator definitions, reporting tools and timelines for HIV/AIDS indicators, can help standardize the reporting system. Standardization and coordination help streamline data collection, ease the reporting burden, improve data quality, and pave the way for more effective and consistent use of data at the program and service delivery levels. This process of standardizing indicators and indicator definitions is called indicator harmonization.

In an integrated information system, indicators and the data elements and definitions that inform them need to be harmonized. Stakeholders from the information systems to be integrated should be brought together to discuss and arrive at a consensus on priority indicators, their definitions and disaggregation. The priority should be on the information needs of the health program as defined by current program strategic plans. In the interest of minimizing burden to those who collect and report the data, parsimony in indicator selection and in particular, disaggregation of indicators, should be paramount. Harmonizing indicators is an iterative process and sufficient time and resources should be budgeted to ensure consensus is achieved.

In summary, a successful indicator harmonization process:

- engages stakeholders to determine what are the common information needs across stakeholders and develop a standardized way to collect and report on that information;
- strengthens national or sub-national coordination of community-level programs and information reporting, and
- sets the stage for developing standardized routine reporting tools.

Guidelines for conducting indicator harmonization for community-based HIV/AIDS programs are available from MEASURE Evaluation:

Community-Level Program Information Reporting for HIV/AIDS Programs. Tools and Processes for Engaging Stakeholders. Module 3: Indicator Harmonization.

Available at: <u>https://www.cpc.unc.edu/measure/publications/ms-10-40-m3</u>.

Although these guidelines are focused on HIV/AIDS community-based programs, the methods are applicable to harmonization of indicators for any program area.

#### **Data Collection Tools**

*Reporting patient-level data* — Tools are required to input data at the point of service. Typically these tools are registers, tally sheets, and client-held forms. Often, integration amounts to adding columns in one register to create a link to another set of forms with information on another service being provided. For example, an ANC register can be updated to include information on services typically provided by PMTCT, such as HIV testing, ART prophylaxis, and prophylaxis for opportunistic infections. If the services are not integrated (i.e., they are provided by different wards in the same facility or in different facilities), then the client can be linked to those services via a unique client identification number.

The 3ILPMS from WHO is a good example of an integrated patient level information system linking three distinct services: HIV Care/ART Patient Monitoring System; Maternal and Child Health (MCH)/PMTCT Patient Monitoring System; and TB Patient Monitoring System. In this system, there is a bi-directional link between the HIV Care/ART patient monitoring system and ANC. In ANC, when a pregnant women tests positive for HIV she is referred to the HIV Care/ART program. Likewise if a woman in HIV care/ART becomes pregnant she is referred to ANC. There are links in both data systems to identify the woman and the care she receives.

Similarly, when a patient in HIV care/ART tests positive for TB s/he is referred to the TB Program to begin treatment and a link is established in the HIV care/ART register on TB status and treatment. If tested HIV positive in the TB Program the patient is referred to HIV care/ART and similarly, the TB register is updated with the HIV status and ART unique ID. In this system, staff from the different services co-manage and co-supervise clients of HIV, TB and Pregnancy Services leading to improved continuity of care.

*Reporting aggregate data* — The periodic reporting of aggregated program results requires a standardized form. For the majority of countries, this information is still communicated to the higher levels of the health system using paper-based forms. The forms should contain all the relevant information required by the higher levels of the health system for program monitoring, evaluation and planning. The different disease program results, along with commodities management and health facility administrative data (e.g., staff levels, health unit capacity, and financial inputs/outputs) can also be included.

An integrated form implies that all these data are reported together on the same form or set of forms. Care should be taken that only the most essential data are reported to minimize the burden to staff compiling and transmitting the data.

*Referral systems* — A sound system to refer clients from one service to another is required to integrate services adequately at the patient level and to achieve an integrated health information system to monitor performance. Referrals can be from one service to another in the same health facility or between services in separate health facilities. A system of counter-referral, whereby a return note is sent to the referring service (or facility) with the results of the referred service, is an important component of a functional referral network and enhances the continuity of patient care.

MEASURE Evaluation has developed tools to measure the effectiveness of referral systems. The Referral Assessment and Monitoring (RSAM) tools<sup>19</sup> consists of guidelines for establishing a routine monitoring system of referrals and assessing overall functioning of a referral system, which can be adapted to any type of referral system.

#### **Reporting Protocols**

Similarly, the protocols of reporting, that is the reporting deadlines, what to report, and where to report, should be standardized across the information systems to be integrated. In many countries reporting on HIV/AIDS treatment, care, and prevention, facility-based indicators (ART, VCT, PMTCT) are being reported through one system with defined reporting protocols, and another system for community-based indicators (OVC, home-based care, prevention) with different reporting protocols is used. In one system, the reporting may be monthly; while in the other reporting system, it may be quarterly. The data flow model for reporting may also be different. For example, it may be from facility to district to national in the facility-based system; and from community-based implementer to NGO sub-grantee to the national AIDS commission (NAC) in the community-based system. Having different protocols and channels of reporting can result in the same data being reported separately through the different systems creating double counting of results and confusion at higher levels.

<sup>&</sup>lt;sup>19</sup> These tools are available at <u>http://www.cpc.unc.edu/measure/publications/ms-13-60/at\_download/document</u>.

In integrated systems, the reporting protocols should be well defined and published. Standard operating procedures should be developed and made available for all data management staff in the integrated system which describes when reports are due, where they should be sent, and what should be reported. As much as possible, data from the national minimum data set should be reported through a single channel of the national RHIS. Parastatals such as a country's NAC should harmonize reporting protocols within the health ministry. If data for community-based programs or non-health sector HIV/AIDS interventions continue to be reported in parallel to the RHIS, these data should have adequate geographic attribute data (i.e. standardized place names, facility or unit ID codes) so that results can be aggregated by geographic administrative unit.

#### **Flexibility of Design**

While the content of the integrated system should be well-considered and meet the needs of all stakeholders, the system should be flexible enough in design to accommodate changes which reflect the evolving nature of epidemics and the nation's response. While continual changes to data collection and reporting tools are burdensome for data management staff, printing 10 years' worth of ART registers for the entire country locks the system into what will in two years be an outdated system. A periodic system of review, such as a routine RHIS performance assessment (e.g., Performance of Routine Information System Management or PRISM) is a good way to gauge how well the information system meets the needs of the health system in information for monitoring, evaluation and planning. RHIS managers should anticipate updates to the information system on a cycle of no more than every two or three years, and plan for training of staff on the updated system accordingly.

#### **Donor Needs in M&E**

Donors such as PEPFAR and the Global Fund often have separate information systems in countries to ensure timely reporting of results to their constituents. Often, these parallel systems create burden at the point of service delivery and pose the risk of double-counting of results at higher levels of the reporting system. Donors should be involved in the integration of HIV/AIDS systems in country and their needs in information considered in the identification of the national minimum data set.

Increasingly, these donors are recognizing the value of sector-wide approaches (SWAps). SWAps are approaches to international development that "brings together governments, donors and other stakeholders within any sector. It is characterized by a set of operating principles rather than a specific package of policies or activities. The approach involves movement over time under government leadership towards: broadening policy dialogue; developing a single sector policy (that addresses private and public sector issues) and a common realistic expenditure program; common monitoring arrangements; and more coordinated procedures for funding and procurement."<sup>20</sup> (World Health Organization, World Health Report, 2000.)

#### Key Stakeholder Buy-in and Governance/Oversight of Integration

Integration of information systems can only happen effectively with buy-in from key stakeholders. Kanjo and colleagues assert that stakeholder involvement is one of the crucial factors in the strategies for developing support of the implementation of an integrated HIS and describe a consensus building approach resulting in strong stakeholder buy-in.<sup>21</sup>

Examples of key stakeholders in a country are the minister of health, director general of the NAC, directors of infectious disease control divisions, monitoring and evaluation officers from the NAC and health ministry, and directors and managers of the RHIS. Each country will have its own variety of influential stakeholders that will need convincing of the benefits of integration. Integrating information systems often changes the dynamics of workplaces and workflows, and disrupts the status quo. People tend to be resistant to change, so convincing important stakeholders to buy-in to the integration process is important. Advocates for integration should be prepared with evidence of the benefits of integration (e.g., peer-review journal articles, testimonials from countries or systems that have achieved integration, etc.) for when the opportunity arises to convince key stakeholders.

An integration oversight committee can help plan, source resources for, and implement the information system integration. Such a committee, or governance board, should be made up of

<sup>&</sup>lt;sup>20</sup> WHO, 2000.

<sup>&</sup>lt;sup>21</sup> Kanjo C, Moyo C, Muyepa A. Institutionalising the Integration of Health Information Systems through Stakeholder Buy-in: The Case of Malawi, IST Africa 2008, Namibia. NC: NP; 2008.

interested stakeholders from both government and NGOs, donors, and the private sector. Members should be influential in the health sector and committed to the integration process.

# Summary of Standards for Integration

Standards for integration include:

- standard minimum package of service
- minimum national HIV/AIDS data set
- standardized indicators
- standard data collection and reporting tools
- functional (and evaluated) referral systems
- harmonized reporting protocol
- harmonized data flow models
- flexibility in RHIS design
- routine RHIS performance assessment
- donor support for integration (e.g. through a sector-wide approach)
- key stakeholder buy-in
- governance/oversight of RHIS integration

#### A Proposed Method for Integration When Existing Vertical Programs Prefer the Status Quo

Nyella and Mndeme\* argue that integration of health information systems requires the building of shared meaning of the integration process through communication approaches (e.g. holding workshops to articulate and share the vision of health information system integration) and for the need to distribute the control of the integrated HIS using a modularization approach which facilitates leveraging resources from well-endowed, donor-funded vertical programs for the strengthening of the country RHIS.

A modularization approach, or allowing vertical programs to maintain legacy health information systems devoted to a particular health program and linking these to the country RHIS (i.e. making them interoperable with the RHIS), rather than fully integrating them, is one way to ensure that powerful vertical programs buy-in to the integrated RHIS.

Nyella E, Mathew Mndeme M. Power Tensions in health information system integration in developing countries: the need for distributed control. *Electronic J Info Systems Devel Countries*. (2010) 43(4):1-19.

# Interoperability

Interoperability, as defined previously, is the extent to which systems and devices can exchange data, and interpret that shared data. For two systems to be interoperable, they must be able to exchange data and subsequently present that data such that it can be understood by a user.<sup>17</sup> Hammond and colleagues argue that many of the problems affecting RHIS, such as fragmented, unreliable, incomplete, inaccurate, cumbersome, untimely and isolated data, can be remedied by interoperability. A necessary prerequisite to interoperability is the existence of standards - agreedupon ways in which these data will be presented, stored, and transmitted.<sup>22</sup>

# Standardization in Interoperability

To arrive at standards, standards development organization members work together to build consensus around solutions informed by their personal experience and understanding of data needs and resources. Ideally, these solutions (or standards) would then be universally applied. However, not everyone is aware of the existence of the standards or of the role that standards can play. Competition can arise between standards developed for similar purposes. For these reasons (and others) standards are not always employed.

For interoperability between electronic data systems a number of standards have already been developed, such as for planning, data and information models, terminologies, defining data and attributes, data exchange, decision support, and database queries. Some standards developed for interoperability of health data systems include:

Health Level Seven (HL7)<sup>23</sup> — standards for the exchange, integration, sharing, and • retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services

Hammond WE, Bailey C, Boucher P, Spohr M, Whitaker P. Connecting information to improve health. *Health Affairs*. 2010. 29(2): 284-288. See http://www.hl7.org/.

- International Classification of Diseases, 10<sup>th</sup> revision (ICD-10)<sup>24</sup> a coding scheme for clinical diagnoses and causes of death
- Systematized Nomenclature for Medicine (SNOMED)<sup>25</sup> a clinical messaging standard
- Logical Observation Identifiers Names and Codes (LOINC)<sup>26</sup> to facilitate the exchange and pooling of results for clinical care, outcomes management, and research
- SDMX-HD<sup>27</sup> a Statistical Data and Metadata Exchange (SDMX)-based data exchange format intended to serve the needs of the Monitoring and Evaluation community

Most of the standards necessary for interoperability between electronic data systems in health care exist already through the work of these standards development organizations. These standards are universal and facilitate interoperability in developing countries as in the developed world.

# Semantic Interoperability

Semantic interoperability refers to the vocabulary of electronic data. The more that vocabulary for health message is standardized, the greater the chance that receiving systems will understand the message sent by transmitting systems and the greater the likelihood of achieving interoperability. Many vocabularies (or terminology sets) exist (more than 150 for different purposes within electronic health system data exchange), however, so the selection and universal application of the appropriate vocabulary in a given health information system is important. SNOMED for clinical data, LOINC for laboratory test names, and the WHO ICD coding system for diagnoses are examples of terminology sets, or vocabularies, that can be used to achieve semantic interoperability.

WHO has also developed the Indicator and Measurement Registry (IMR) to help standardize definitions for health indicators and data elements globally. The IMR contains:

- global indicator definitions and codelists (used for translating terms from one system to ٠ another);
- complete and well-structured metadata;
- consistency with other statistical domains;

See http://www.who.int/classifications/icd/en/. See http://www.ihtsdo.org/snomed-ct/. See http://loinc.org/background. See http://www.sdmx-hd.org/.

<sup>25</sup> 

<sup>26</sup> 

<sup>27</sup> 

- utilities for indicator and codelist harmonization and management;
- federated indicator definition and indicator set maintenance;
- promotion of interoperability through the SDMX-HD indicator exchange format; and
- Internet access to indicator definitions.

The IMR also incorporates appropriate international standards, such as:

- SDMX MCV (Metadata Common Vocabulary)
- SDMX-HD www.sdmx-hd.org
- ISO 11179 (Metadata Registry)
- DDI (Data Documentation Initiative)
- DCMES (Dublin Core)
- Organization/Program-specific metadata

# Data Interchange Standards

These standards help ensure transfer of information from one system to another through a variety of communications channels. Data interchange standards help ensure syntactic interoperability, that is the ability to recognize components of electronic transmissions and parse them appropriately. If semantic interoperability refers to what we are saying in an electronic message, syntactic interoperability refers to how we say it.

Data interchange standards are used throughout the electronic health information system, for example in the clinical setting to exchange client clinical data as part of an electronic health record, or from one level of the health system to the next for aggregate reporting of health system results.

Examples of data interchange standards are HL7 and SDMX-HD. SDMX-HD, or Statistical Data and Metadata Exchange for the Health Domain, was initiated by WHO and partners to facilitate exchange of indicator definitions and data in aggregate data systems.

# **Unique Identifiers**

*Individuals* — Critical to continuity of care for patients, unique identifiers for individuals in care also help enable interoperability by unambiguously linking services rendered to a patient to other

services rendered to the same patient in a separate system. Unique identifiers are not without controversy, as some activists feel that identifying patients by a unique code could compromise their privacy. However, health systems have used non-name codes devised from patient attributes, such as gender, age, date of birth, social security number, etc. for many years to help ensure confidentiality. This system is not perfect, however, and algorithms based on these attributes only achieve roughly 80% disambiguation.

Biometric markers, such as fingerprints or retina scans, have also been attempted with some success, but the technology to make this work is often inappropriate for developing country settings, or the cost for implementation prohibitive. Moreover, often when the data are meant to be transferred, or shared, the patient is not physically where she or he seeks care in the health system.

The Joint United Nations Programme on AIDS/HIV has published technical guidance on the development of national unique identifiers, as have other organizations. The American Society for Testing and Materials publishes the ASTM E1714 standard, which describes the properties of a correct identifier scheme without specifying the scheme, allowing organizations to design identification schemes to suit their needs.

*Health facilities* — Health facilities also need to be identified uniquely in order to attribute results correctly to facilities and ensure that patient data are shared appropriately between facilities providing care to the same patients. Ideally, the health system in a country maintains a master list of facilities, a master facility index, along with information about capacity and what services are offered.

A master facilities list is a complete listing of all unique public, private, and faith-based health service delivery sites in a country, with information about capacity and services available. It is usually a searchable, referential, electronic database maintained at a central location (e.g., the national-level offices of the RHIS within the health ministry). It is dynamic and should be kept up to date as facilities are added or subtracted from the system. A master facilities list should have two components:

- The *signature domain* is a set of identifiers that permit the unique identification of a given health facility.
- The *service domain* identifies the available services and capacity of each health facility, information that is essential for health system planning and management, and resource allocation.

A master facilities list improves record keeping by improving transparency and reporting efficiency—it minimizes duplicate reporting. The list can facilitate effective sampling for health facility assessments and service availability mapping. Finally, it helps promote better analysis and synthesis of data to improve decision making and health system functioning.

*Geographic administrative areas* — Likewise, geographic areas should be identifiable by unique codes to avoid the incorrect attribution of health system results. Place names can have alternative spellings or even completely different names depending on the prevailing languages in the area. Identifying places with unique codes in electronic systems avoids the ambiguity of place names and helps correctly attribute results to the appropriate geographic area.

### A Single Master Set of Data Elements

A core dataset with attribute data and standard definitions is required to streamline data collection and eliminate redundancy. A data element should only be entered once into the system and should be available for multiple purposes — that is, it is reusable. Data elements that can be calculated automatically are preferred to those that need to be entered into the system by data entry staff.

In creating a master set of data elements, a thorough review of the utility of the data element should be conducted. Is it being used? Does it measure what it is supposed to measure? Can it be eliminated? The goal is to streamline data collection so that only data that are useful are being collected. This will save time and resources, and reduce the burden of data collection and entry at the periphery.

Shaw<sup>28</sup> advocates a top-down consultative process based on an information hierarchy (figure 1) because it establishes a framework within which information needs can be reviewed. Each level of the health system should add only the information required for management of the system at that level. Lower levels are able to add the information they need to the routine system, but only the information required by the higher levels is transmitted to them. This approach lends itself to standardization of what is being reported up, as well as reduces the amount of data required for reporting.

In RHIS, *stewardship of metadata*, or responsible planning and management of data about data, is needed to foster consistent use of data management resources and facilitate data mapping among computer systems. A data steward holds responsibility for maintaining a data element in a metadata registry. Data stewardship roles are common when organizations need to exchange data precisely and consistently among computer systems and to reuse data-related resources. A data steward ensures that each assigned data element:

- has a clear and unambiguous definition;
- does not conflict with other data elements in the metadata registry;
- is being used and is being used consistently in all interlinked computer systems; unused data elements are removed;
- has adequate documentation on appropriate usage and notes; and
- is documented with regard to its origin and sources of authority.

Assignment of data elements to an individual promotes trust in systems where users can contact a specific staff member with questions on specific data elements.

### Scalability

Scalability refers to the ability of health information system to grow — to add new users, new program areas, new levels of the health system, and new geographic areas of the country. Can a health information system which begins as a pilot project in a few districts accommodate the needs

<sup>&</sup>lt;sup>28</sup> Shaw V. Health information system reform in South Africa: developing an essential data set. *Bull WHO*. 2005. 83(8):632-636.

Standards for Integration of HIV/AIDS Information Systems into Routine Health Information System Integration

in data collection, reporting, analysis and dissemination for the entire country? Can it do so for all health programs?

Bondi describes scalability as "ability of a system, network, or process to handle a growing amount of work in a capable manner or its ability to be enlarged to accommodate that growth."<sup>29</sup> In computerized systems, a system whose performance improves after adding hardware, proportionally to the capacity added, is said to be a scalable system.

Properties of scalability include the following:

- Administrative scalability is the ability for an increasing number of organizations or users to share a single distributed system easily.
- *Functional scalability* is the ability to enhance the system by adding new functionality at minimal effort.
- Geographic scalability is the ability to maintain performance, usefulness, or usability regardless of expansion from concentration in a local area to a more distributed geographic pattern.
- *Load scalability* is the ability for a distributed system to expand and contract its resource pool easily to accommodate heavier or lighter loads or number of inputs. Alternatively, the ease with which a system or component can be modified, added, or removed, to accommodate changing load.
- Generation scalability is the ability of a system to scale up by using new generations of components. Thereby, heterogeneous scalability is the ability to use the components from different vendors.<sup>30</sup>

#### A Proposed Approach to Building Scalable Health Information Systems

Braa and colleagues argue that flexibility is required in health information system architecture such that different regions of the country, with different capacities for the use of information technology, can all access and use the health information system.<sup>31</sup> For example, areas with adequate Internet connectivity can access the system over

Bondi AB. Characteristics of scalability and their impact on performance. *Proceedings of the Second International Workshop on Software and Performance WOSP '00*. Held Ottawa, ON, Canada, 2000. El-Rewini H, Abd-El-Barr M. *Advanced Computer Architecture and Parallel Processing*. Hoboken, NJ: John Wiley & Son; 2005:66. Cited in Wikipedia, http://en.wikipedia.org/wiki/Scalability. Braa J, Hanseth O, Heywood A, Mohammed W, Shaw V. Developing health information systems in developing

<sup>31</sup> countries: the flexible standards strategy. MIS Quarterly. 2007. 31(2): 381-402.

the Internet, while other areas without such connectivity can still report results using the traditional paper-based information system.

In addition, they propose that the use of gateways (points of inter-connection between disparate information systems which require linkages and translation for data sharing) and data standards are enough to ensure scalability of health information systems.

Gateways are required when information is not sharable between different information systems, or different levels of the same information system. For example, two computerized systems at the national level built on different platforms and having distinct indicators and definitions require a gateway to translate terms from one system to the other, and convert these to the appropriate format. A gateway is also required to transmit patient-level data (data on individuals) to aggregate data for reporting from health facility to the district level. This gateway can exist entirely on paper, but is increasingly being computerized with advances in electronic health records.

Three types of such gateways exist:

- 1. paper to paper
- 2. paper to computer
- 3. computer to computer

By reducing reliance on slowly evolving data transmission standards (syntactic interoperability, e.g. SDMX-HD) for ensuring interoperability between electronic systems, and concentrating on the data standards (semantic interoperability) and the gateways, an information system can grow more readily. Data transmission standards can be customized locally (i.e. within a country) and evolve as needed as the local standard. This tactic obviates the need to wait for standards development organizations to incorporate elements that are required locally. The flexibility of architecture allows areas of the country to evolve at different rates, so areas with better infrastructure can benefit and are not held back by less advanced areas.

#### **Buy-in of Key Stakeholders**

Much like the integration process, which requires a common vision and high-level buy-in of stakeholders, ensuring interoperability by selecting standards and ensuring their universal application requires buy-in of key stakeholders.

### Conformance to Local Norms for Privacy, Confidentiality

Every country has its own norms for ensuring patient privacy and confidentiality. The integrated and interoperable health information system should adhere to these local norms. In some countries these norms are codified by law or policies. If policies do not exist, the local RHIS governance board should articulate these policies according to local practice.

# Summary of Standards for Interoperability

• Use of agreed-upon electronic data exchange standards.

- Use of unique identifiers for individuals, health facilities and geographic administrative areas.
- Master set of data elements.
- Meta-data management.
- Scalability.
- Buy-in of important local stakeholders.
- Conformance to local norms for patient confidentiality and privacy.

# **MODELS OF HIV/AIDS INTEGRATION**

# General Models

### Data Warehouse

In the model below, each program has its own application and data. An interface tool is applied to extract data from these systems and load them into the district data repository.

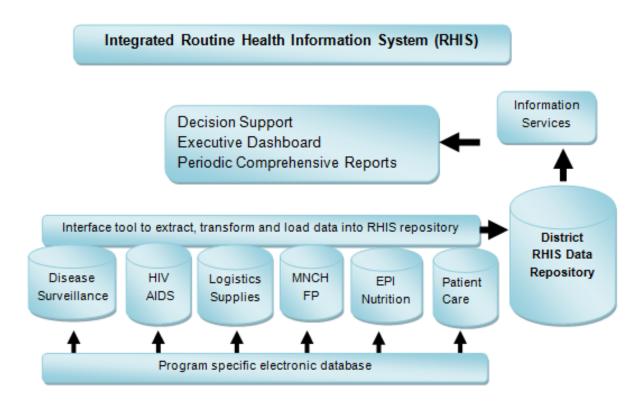
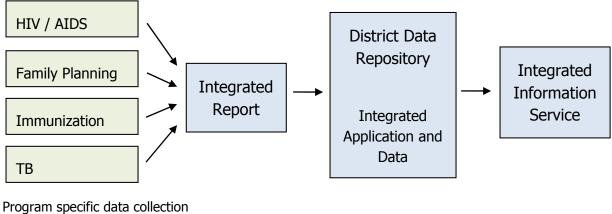


Figure 2. General integration model: data warehouse.

### Integration at the Point of Health Facility Reporting

Alternatively, the following framework can be applied if the vertical systems are paper-based. Each program collects a defined set of data, and analyzes and uses them in the paper-based system. The data are consolidated in an integrated report, which is then forwarded to a data center to capture in an electronic database that will provide integrated information services.

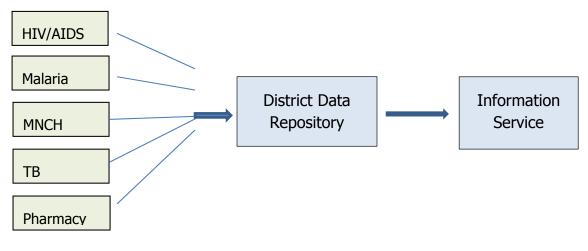


and monitoring tools

#### Figure 3. General integration model: integration at the point of health facility reporting.

#### Integration at the District

If the above integration is not viable in a given country context, the framework below might be useful. The vertical reports are sent to the data center for capture in a single system, which then outputs comprehensive information.



Program specific data collection, monitoring, and reporting tools

#### Figure 4. General integration model: integration at the district level.

# Specific Examples of Integration/Interoperability

### Ethiopia Electronic HMIS (eHMIS)

The Ethiopia electronic health management information system (eHMIS) is being implemented in Southern Nations Nationalities and Peoples Region (SNNPR) by the USAID-funded MEASURE Evaluation's HMIS Scale-up Project. Since 2010, this electronic application has provided a robust system serving the SNNP Regional Health Bureau. The eHMIS is a homegrown solution developed by Ethiopian IT experts taking advantage of international expertise. The development of the application took account of the Ethiopian health system's context and requirements, yet used the standard design and operational features seen in any internationally acclaimed IT application. The eHMIS has been developed with the ability to meet future changes or information needs as they evolve.

One aspect of the development of eHMIS was integrating data from different program areas, including HIV/AIDS (diagnostic and treatment services data). This was done through a consultative and consensus building process during the reform of HMIS in 2006 and 2007. All the health program unit managers, including the HIV/AIDS unit managers, worked together to rationalize their respective program indicators into HMIS. The data collection tools were also harmonized with those indicators. The reformed HMIS was piloted in four districts and then finalized and endorsed by the NAC on HMIS, which was formed to serve as the forum to coordinate the harmonization and standardization process and to approve the final design of HMIS and to coordinate the scale-up of the reformed HMIS. Thus, a standard list of HMIS indicators and data collection and reporting tools were prepared, endorsed by a joint steering committee with representatives from the health ministry and regional health bureaus.

However, the non-clinical multi-sectoral HIV& AIDS response activities are not captured through the HMIS. Therefore, there is a separate effort to introduce non-clinical services reporting, spearheaded by Federal HIV&AIDS Prevention & Control Office.

### Cote d'Ivoire Integrated Health Information System

The Cote d'Ivoire Ministry of Health's Department of Information, Planning, and Evaluation began a reform of the national HMIS (SIG Integré) in 2003. With technical assistance provided

by MEASURE Evaluation, the department began a process to rationalize and harmonize indicators, and to integrate parallel HIV/AIDS reporting systems.

Through engaging implementing partners and other stakeholders through meetings and workshops, a minimum data set and list of priority indicators with standard definitions were identified. Data collection tools were redesigned to incorporate the new content, which were pilot tested in the field. Training was conducted at the health facility and district levels on effective patient tracking and monitoring for ART, PMTCT, and voluntary counseling and testing using the new data collection and reporting tools.

Four years later, MEASURE Evaluation and the health ministry evaluated the HMIS using the PRISM framework and tools. The evaluation showed that implementation the system strengthening plan (2004-2008) achieved certain objectives such as integration of HIV data into the HMIS; availability of computers and software in most districts, made possible by coordination and collaboration with in-country implementing partners; and improvement of completeness and timeliness of data transmissions from health facilities to districts, and from districts to the national level. Though problems with data accuracy and the use of data for decision making persisted, the health ministry effectively integrated HIV/AIDS into the HMIS.

Subsequently, indicators and data collection tools were revised and updated again in 2006 and 2010 showing the flexibility of the HMIS to changes in HIV/AIDS programming. The ART patient tracking system was computerized with an MS Access-based data entry, reporting and analysis application, the SIGDEP. The HMIS software (SIGVISION) used at district level, region and national levels was revised by also incorporating the HIV/AIDS data elements.

At the organizational level, achievements in HMIS reform included the development of a health information policy document, two strategic plans (2005-2010, 2010-2014) for HMIS, a health data management procedures manual, and an organizational chart of the sub-directorate for health information.

#### Kenya PEPFAR Program Monitoring System

The Kenya PEPFAR Program Monitoring System (KePMS) is an MS Access-based data entry, reporting, analysis and decision support application that has been functional in Kenya since 2006, before the national district health information system 2 (DHIS 2) system was developed. KePMS collects site-level PEPFAR prevention, care, treatment and health system indicators. It is integrated with the national system in that USAID implementing partners conducting HIV/AIDS activities enter data directly from the national forms for ART, PMTCT and counseling and testing. KePMS also has integrated the site-level unique identifiers from the Kenyan health ministry's master facility list. Once the national DHIS 2 system is fully operational, these unique identifiers can be used to attribute data from the DHIS 2 system to implementing partners, as required for PEPFAR reporting.

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