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Viewpoint Paper ■

Viewpoint: A Pragmatic Approach to Constructing a Minimum Data Set for Care of Patients with HIV in Developing Countries

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A b s t r a c t   Providing quality health care requires access to continuous patient data that developing countries often lack. A panel of medical informatics specialists, clinical human immunodeficiency virus (HIV) specialists, and program managers suggests a minimum data set for supporting the management and monitoring of patients with HIV and their care programs in developing countries. The proposed minimum data set consists of data for registration and scheduling, monitoring and improving practice management, and describing clinical encounters and clinical care. Data should be numeric or coded using standard definitions and minimal free text. To enhance accuracy, efficiency, and availability, data should be recorded electronically by those generating them. Data elements must be sufficiently detailed to support clinical algorithms/guidelines and aggregation into broader categories for consumption by higher level users (e.g., national and international health care agencies). The proposed minimum data set will evolve over time as funding increases, care protocols change, and additional tests and treatments become available for HIV-infected patients in developing countries.

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In its landmark call for improving quality of care[1] and in an earlier monograph on patient-based medical records,[2] the Institute of Medicine found that electronic medical records (EMRs) were an "essential technology for health care." They

did not say that EMRs were only essential for *developed* countries. Indeed, the lack of information technology (the so-called digital divide[3,4] or technological apartheid[5]) has been cited as a limiting factor in the provision of health care in developing countries. There are few examples to date of EMRs that have been implemented in developing countries.[6–12]

"Timely and accurate health information forms the essential foundation for making policy on planning, implementing and evaluating all health programs" according to the World Health Organization (WHO) in the introduction to its "3 by 5 Program,"[13] in which the WHO advocated initiating antiretroviral therapy by the end of 2005 for three million persons living in developing countries with human immunodeficiency virus (HIV) infection. Indeed, WHO has drafted a comprehensive set of guidelines for monitoring care of patients with HIV infection who require the intensive collection and reporting of clinical data.[14]

Systems for providing, evaluating, and improving HIV care are desperately needed in developing countries that are bearing the brunt of the HIV pandemic. Unfortunately, despite the devastating prevalence and results of HIV infection, care systems are just now being deployed in developing countries such as those in sub-Saharan Africa where less than 10% of all HIV-infected persons are receiving treatment.[15] Similarly, there has been little experience creating and managing EMRs in such countries and thus few analyzable data from EMRs used in everyday HIV care. As a result, it is impossible to take an empiric approach to suggesting the optimal content or structure of EMRs to enhance HIV care delivery and the ongoing monitoring and evaluation of HIV services at health facility, regional, and national levels.

In response to this critical lack of EMRs for HIV care in developing countries, the WHO sponsored an international workshop in August 2004 in Nairobi, Kenya. At this workshop, a

group of medical informaticists and developing country HIV care providers, HIV clinic managers, and national HIV care program directors met to develop a minimum data set for HIV care in resource-deprived countries.[16]

Conceptual Framework: Who Will Use Human Immunodeficiency Virus Data?

This consensus development panel began by considering *who* would be using the EMR data and *how* those data would be used. The panel made three assumptions. First, HIV clinics in developing countries with restricted access to health care often provide *comprehensive* health care to HIV-infected persons, not just HIV specialty care. An EMR supporting HIV care in developing countries must therefore contain additional fields and data elements to support the provision of primary care. Because ongoing HIV management occurs in outpatient settings, data fields and elements required for hospital care of HIV were excluded from the proposed minimum HIV data set.

Second, the panel assumed that the HIV clinics would provide comprehensive prevention and treatment of HIV infection and its complications among HIV-infected patients and their families. Fields and data elements supporting prevention activities and linking family members would be required. Third, we assumed that the although the EMR data would be generated mainly during (and support care provided in) individual outpatient visits, these data would also be used to manage care in individual health care facilities and regional and national HIV care systems. We assumed that the data would be used by ministries of health, national AIDS control programs, and national and international funding agencies to assess the quantity and quality of HIV care delivered. Hence, the minimum data set must be useful to clinicians of all sorts, practice managers, program administrators, and policymakers as well as researchers and quality improvement officers.

Table 1 shows the different users of EMRs whose needs must be considered when creating the content and format of the minimum data set. In general, clinicians (physicians, clinical officers [physicians' assistants], nurses, pharmacists, counselors, etc.) need to view explicit textual, categorical, and numeric data at the level of the individual patient visit (or a series of visits). Individual visit data items should be available for making clinical decisions for individual patients. As stored data increase, use of flow sheets and graphical displays can enhance clinical decision making.[17] However, those who manage HIV care programs, from individual practices up to international programs, more often need information summed from multiple patients and visits. For example, a clinician would need to know whether a patient were infected with *Pneumocystis carinii* to provide appropriate treatment,

Table 1 ■ Consumers of Data and Their Activities and Data Needs

Data Consumer	Activities Supported	Data Needs
Clinic management (clerks, etc.)	Registration, scheduling, billing	Unique patient identifiers Individual patient demographics Family identifiers Clinic/program identifiers Unique provider identifiers Financial data: payment program identifiers, charges, payments

Clinicians (physicians, physician extenders, nurses, pharmacists, therapists, counselors, etc.)	Diagnosis, treatment, prevention	Medical history: risk/exposure, symptoms, diagnoses
		Physical examination: vital signs, physical findings
		Diagnostic tests:
		    HIV-specific blood tests (CD4, viral load), general blood/ urine tests, imaging tests
		Diagnoses:
		    HIV status, class/severity of illness, HIV-associated conditions, prevalent unassociated conditions
		Treatment: drugs, procedures
		Counseling

Practice managers	Scheduling, inventory control, quality improvement	No. of visits, types Unique provider identifiers Provider characteristics Treatment: drugs, procedures Patient disposition Patient outcomes
District/regional/national program administrators	Program development, program monitoring, reporting to funders (e.g., ministry of health, government officials)	Patients receiving care: non–HIV-infected, HIV-infected, AIDS No. of visits: outpatient, inpatient (including length of stay) Treatment categories: antiretroviral drugs, antibiotics Patient outcomes Program costs Personnel involved
Funding agencies	Oversight, program productivity	Patients receiving care: non–HIV-infected, HIV-infected, AIDS No. of visits: outpatient, inpatient (including length of stay) Treatment categories: antiretroviral drugs, antibiotics Patient outcomes Program costs

HIV = human immunodeficiency virus; AIDS = acquired immunodeficiency syndrome.

whereas a national program administrator may only need to know whether the patient had an opportunistic infection to determine WHO severity classification.[14] However, even national programs may sometimes require more granular data, e.g., to allocate sufficient quantities of antibiotics for HIV-related infections. Therefore, the conceptual framework requires that the EMR's concept dictionary, which is the heart of every EMR,[18,19] must contain detailed terms for all data elements, with many synonyms and cross-references and the ability to group data elements into specific categories such as opportunistic infections, antiretroviral drugs, and antibiotics.

Why a *minimum* data set? Collecting, storing, and using data has nontrivial costs in terms of the time and money required for training providers and data managers, capturing data on paper forms or computer screens, and managing and reporting data. Our goal was to balance these costs against the benefits of gathering each data item to arrive at a minimum amount of data necessary for effective HIV patient management and program evaluation and improvement.

One consideration when considering a minimum data set is *who* will collect and enter the data. It is most accurate and efficient if the person generating a specific piece of information during the care process also records it on a paper encounter form from which data can later be entered into an EMR or, less frequently in developing countries, enters the data directly into the EMR. This means that clinicians should record clinical data such as vital signs, physical examination findings, and diagnoses; clerks should record registration data; laboratory technicians should record laboratory test results; and pharmacists should record data about drugs dispensed.

Another critical aspect of the development of the minimum data set to support HIV care is generating data that are useful to the various consumers of these data with minimal secondary manipulation. That is, clinicians should see medical terminology they understand while national program administrators may need data using a standard international coding scheme and summaries of categories of data rather than individual observations. Although free text may be useful to clinicians caring for patients during individual visits, coded data are required to summarize data among multiple visits, providers, clinics, care programs, and countries. Free text, although readable by clinicians providing care to individual patients, is time-consuming to record and retrieve and impossible to summarize for managerial purposes. Hence, the concept dictionary should contain mainly numeric and coded categorical data, the latter with multiple representations for each observation, intervention, or concept. The dictionary can include text names or descriptions for display to clinicians. Where available, coded data should employ appropriate widely accepted coding systems such as ICD-9 (International Classification of Disease version 9) or ICD-10 for diagnoses and procedures, CPT-4 (Current Procedural Terminology version 4) or ICD-10-PCS (Procedure Coding System) for procedures, or LOINC (Logical Observation Identifiers, Names, and Codes) for laboratory tests and results.

Finally, an EMR should be capable of producing a data stream that can be read by other EMRs and other data management systems. This provides interoperability that supports continuous care of patients who move between health care systems and merging data from multiple sites of care for regional, national, and international monitoring and

policymaking. Hence, reporting functions built into EMRs should contain programs for importing and exporting data that both accept and transmit data in a standard format such as HL7.[20]

The Minimum Data Set

The proposed minimum EMR data set to support HIV care in developing countries is shown in Table 2. In developing this list, we took a parsimonious approach, limiting the list to the fewest number of critical data elements required by a broad spectrum of future users of these data. The approach was to envision a local practice and the EMR system it would need to provide in managing HIV care. *A critical assumption was that the data needed by higher level users (clinic managers and local, regional, national, and international regulator) would be a subset of the granular data required by the local clinicians to deliver care to their patients and their families.*

Therefore, the most basic unit of observation is the individual outpatient visit. Each visit must be identified by the patient's unique identifier, the visit date, the clinic site, and the identifiers of all providers seen. Hence, the first entries in Table 2 are data elements for registration, scheduling, and managing practice logistics.

Registration, Scheduling, and Practice Management Data

Key to managing patient data in all EMRs in developed and developing countries is establishing unique patient identifiers. This number or alphanumeric term should contain a check digit (to prevent data entry errors) and be based on the minimal fields necessary to uniquely identify a patient. This may not be easy, especially in countries without a national identification number. For example, it took Hannan et al.[21] half a day to arrive at the minimum set of criteria to uniquely identify rural Kenyans. The final criteria included the patient's first (Christian), middle (Kenyan), and last (family) names, date of birth, and mother's first name. Difficulties arose because many Kenyans do not know their date of birth, and the order in which they present their names is not consistent. Difficulties also arise because patients in developing countries are mobile, often seeking employment or health care at multiple geographically widely separated sites. EMRs must therefore have the capability of recording multiple record numbers per patient for collating data for individual patients across sites of care. A data model accommodating multiple identifiers per patient has been proposed.[22]

Similarly, to ascribe care to individual providers, a unique provider identifier (with check digit) should be included as well. Because many of the treatment and prevention activities for comprehensive HIV care involve family interventions, there should also be an identifier for the patient's family (defined as appropriate for each site). In Kenya, because of the patterns of care seeking, the mother's identifier is used as the family indicator.

Data elements required for registering and scheduling activities must help manage appointments but also produce summary reports likely to be required by local, regional, national, and international program managers. For example, the U.S. Presidential Emergency Plan for AIDS Relief (PEPFAR)[23] requires quarterly reports of patient enrollment, visits, and treatment by site, gender, age, and WHO class (John Wasonga, Director of PEPFAR, USAID-Kenya, personal communication,

Table 2 ■ The Minimum Data for an Electronic Medical Record Supporting Human Immunodeficiency Virus Care

Data Category	Data Element	Data Type	Who Records It
Registration, scheduling, and practice management	Unique patient identifier	Alphanumeric with check digit	Registration clerk
	Patient name	Text	Registration clerk
	Patient address	Text	Registration clerk
	Visit date	Date	Registration clerk
	Site of care (clinic, home, etc.)	Coded	Registration clerk
	Demographics (birth date, sex, race/tribe)	Coded	Registration clerk
	Family identifier	Numeric	Registration clerk
	Unique provider identifiers	Alphanumeric with check digit	Physician/extender,* nurse, clerk
	Payment program identifiers	Coded	Financial officer, clerk
	Charges, payments	Numeric, financial	Financial officer, clerk
Clinical	History		
	Symptoms	Coded	Physician/extender, nurse
	Prior diagnoses	Coded	Physician/extender, nurse
	Prior treatment (drugs, procedures)	Coded	Physician/extender, nurse
	Physical examination		
	Vital signs (weight, height, pulse, etc.)	Numeric	Physician/extender, nurse
	Physical findings	Coded	Physician/extender, nurse
	Diagnostic tests		
	Test orders		
	Ordering provider	Alphanumeric with check digit	Physician/extender, nurse, clerk
	Test ordered	Coded	Physician/extender, nurse, clerk
	Clinical laboratory test results	Coded, numeric	Physician/extender, nurse, clerk
	Imaging test results	Coded	Physician/extender, nurse, clerk
	Treatment		
	Drugs		
	Antiretroviral drugs	Coded	Physician/extender, nurse, pharmacist
	Other antibiotics, other drugs	Coded	Physician/extender, nurse, pharmacist
	Drugs dispensed	Coded	Pharmacist
	Procedures	Coded	Physician/extender, nurse
	Physical therapy	Coded, free text	Physician/extender, nurse, therapist
	Counseling/family planning	Coded, free text	Physician/extender, nurse, counselor
	Visit diagnoses	Coded	Physician/extender, nurse
	Medication adherence	Coded, numeric	Physician/extender, nurse, pharmacist
	Disposition: clinic referral, hospitalization	Date, coded	Physician/extender, nurse, clerk
	Death (date, cause)	Date, coded	Physician/extender, nurse, clerk

*Physician/extender refers to either a physician or a physician's assistant (called a "clinical officer" in many developing countries), nurse practitioner, or physician trainee (medical student or resident), etc.

February 2, 2006). Therefore, the minimum data set must also include the sites of care, demographic information (sex, date of birth, race/tribe), and identifiers for the various programs providing funding for HIV care (e.g., ministry of health, external funding agencies, state-funded or commercial health insurance, patient self-pay). Most of these registration data do not change and will only need entering once. Addresses can also be included (to the degree possible in developing countries that often lack formal street names and numbers) to assist patient tracking, but addresses often change and have to be updated. Alternatively, an EMR could allow recording of multiple addresses rather than just updating a single address record.[22] Similarly, charges, billing, and payment information will often need re-entering at subsequent visits as payment schemes change. The minimum data recommended for registering patients, scheduling visits, and managing practices are shown in Table 2.

Clinical Data
The clinical data elements included in the minimum data set should reflect the activities likely to be undertaken in most

clinical venues providing reasonably comprehensive care to HIV-infected patients. As both clinical programs and clinical record systems are now being developed and evolving rapidly, statements about the minimum data set must be based on clinical acumen for judgments of current and future data needs. Activities that need to be described include preventing HIV infection, screening patients, caring for patients with HIV both before and after developing frank acquired immunodeficiency syndrome (AIDS), treating common non-HIV-related conditions (e.g., malaria, injuries), and caring for AIDS-related conditions.

Assessing patients at initial and subsequent visits is necessary for making treatment and monitoring decisions and prescribing appropriate follow-up care. Although clinics differ in what comprises an adequate assessment, the participants in the August 2004 Nairobi consensus panel thought that the minimum data set should accurately reflect the locally accepted comprehensive assessment. This should consist of relevant elements of the medical history and physical

examination, diagnostic test results, and treatments (drugs, procedures, physical therapy, and counseling). In addition, diagnoses for that visit must be recorded separately to identify the dates of first occurrence of each condition, complication, adverse event, and outcome of HIV care. Including data elements to document medication adherence is of critical importance to HIV care because even minor lapses in adherence can result in the development of HIV resistant to antiretroviral drugs.[24] Finally, to assess outcomes and avoid double counting patients, there need to be fields recording patient disposition (referral to another clinic or hospital) and date and cause of death. Table 2 lists the types of clinical data (coded and numeric) and who should record each item.

Data Elements Stored: An Example

Table 3 shows examples of detailed data elements from an existing EMR system[12] created to support an HIV care program in western Kenya[25,26] that has been used in care management and assessing the outcomes of care.[27] (This system's software and encounter forms are available for inspection and comment and free download at http://amrs.iukenya.org). Decisions about which data elements to include depended on the available resources (i.e., available tests and drugs), while the level of detail and the coding scheme used depended on the subsequent uses of the data by providers caring for individual patients, program managers making decisions about personnel and equipment allocations, and funding agencies needing documentation of the number of patients receiving care, whether that care meets international standards, and patient outcomes. In some cases, standard coding schemes were used (e.g., ICD-10 for diagnoses). In other cases, such as drugs, codes were created in the local dictionary because existing coding schemes (e.g., National Drug Code) were too complex for local use. Data categories (e.g.,

Table 3 ■ Examples of Data Elements for a Minimum Data Set for Human Immunodeficiency Virus Care

Data class	Data Element	Format and Units	Range of Values
Demographics	Birth date	DD/MM/YYYY	<01/01/1900 to today's date
	Birthplace:		
	village/city	Text	Variable
	province	Text	From list
	country	Text	From list
	Sex	Coded	Male, female
	Tribe	Text	From list
History	HIV-related diagnoses	Coded: ICD-10	B20–B24, F02.4, R75, Z21
	Comorbid diagnoses	Coded: ICD-10	From ICD-10 codebook
	Medications	Coded: NDC, other system	From available drug list
	Treatment adherence	Numeric: ordinal scale	Likert scale (excellent to poor)
		Semiquantitative	Ranges: % of prescribed doses taken
		Numeric: ordinal scale	Depends on scale (e.g., Morisky)*
		Numeric: pill count	% of prescribed doses taken
	Alcohol use	Coded	Use: yes, no; abuse: yes, no
		Numeric: drinks/day	0 to >10
		Numeric: scale score	Depends on scale (e.g., AUDIT)†
	WHO class	Numeric: ordinal scale	1, 2, 3, or 4.
Physical examination	Blood pressure, systolic	Numeric: mm Hg	30 to >300
	Blood pressure, diastolic	Numeric: mm Hg	30 to >300
	Heart rate	Numeric: beats/minute	0 to >200
	Weight	Numeric: Kg	0.5 to >300
	Temperature	Numeric: °C	30–44
	Various physical findings	Coded: LOINC, other system	From a local data dictionary‡
Laboratory: HIV specific	HIV antibody	Coded	Positive, Negative
	CD4 cell count	Numeric: cells/mm^3	0 to >1,000
	CD8 cell count	Numeric: cells/mm^3	0 to >1,000
	HIV viral load	Numeric: Copies/mm^3	0 to >1,000,000
Laboratory: HIV monitoring	Alanine aminotransferase	Numeric: IU/L	0 to >1,000
	Albumin, serum	Numeric: g/L	0–10
	Hemoglobin, blood	Numeric: g/L	0–25
	Leukocytes, blood	Numeric: cells/mm^3	0 to >100,000
	Platelets, blood	Numeric: count/mm^3	0 to >1,000,000
	Lymphocytes	Numeric: count/mm^3	0 to >10,000
	Creatinine	Numeric: mg/dL	0.1 to >25
Imaging	Chest x-ray findings	Coded: LOINC, other system	From a local data dictionary
	EKG findings	Coded: LOINC, other system	From a local data dictionary

HIV = human immunodeficiency virus; AUDIT = Alcohol Use Disorders Identification Test; WHO = World Health Organization; EKG = electrocardiography; LOINC = Logical Observation Identifiers, Names, and Codes.
*See reference 32.
†See reference 33.
‡See reference 12 and 22.

tests, drugs) were included in the data dictionary to limit the available items in menus in the data entry programs, while sets of data fields (e.g., antibiotics) were included in selected dictionary terms to help summarize data for reporting purposes. The data set supporting this EMR has continuously evolved to meet the changing requirements of care delivery and management, international monitoring and evaluation criteria,[14] and reporting requirements of the government of Kenya and HIV funding agencies.

Discussion

Although the suggested minimum data set for HIV care is based mainly on the authors' experience in managing HIV and non-HIV clinics in developed and developing countries, it is just a first iteration. As HIV clinics in developing countries increase the number of patients treated and the types of care offered (e.g., new treatments and tests) and as monitoring and evaluation guidelines evolve, new data needs will emerge. One driver of this evolution will be standards for monitoring and evaluating HIV care that have been developed by WHO[14] and PEPFAR. These standards require specific data elements that must be summarized within individual patients and among multiple patients cared for in multiple sites of care. These summarized data will be used locally to manage individual patients and care programs among the care venues of a single institution or program and nationally and internationally to document the care being delivered and its outcomes. To date, accurate reporting and monitoring in developing countries have been practically impossible due to there being no widely available means for storing and retrieving the required data.

WHO's HIV monitoring standards were kept in mind during the Nairobi meeting in 2004 when the minimum data set was initially discussed and subsequently in developing the proposed minimum data set for HIV care. Conversely, those developing the WHO monitoring and evaluation standards have kept the limitations of available data and data systems in mind (Christopher Bailey, Knowledge Management Advisor, WHO, Geneva, personal communication, March 14, 2006). Clearly, these standards and the EMRs providing data for their implementation will continue to evolve in tandem. As providers, care managers, and funders begin routinely receiving clinical data for their patients, they will likely want more detailed data to drive a data-based approach to caring for patients and managing systems. At the local level, as evidence-based guidelines for HIV care in developing countries become widely available and EMRs proliferate in these settings, data-based continuous quality improvement will become possible.[28] We therefore offer this initial minimum data set for outpatient HIV care in developing countries as an early statement on what must be an ongoing dialogue involving computer scientists, medical informaticists, clinicians, practice managers, epidemiologists, economists, policymakers, and funders of HIV care.

Supporting EMRs in developing countries is challenging but not impossible. Most of the existing EMRs in developing countries use paper encounter forms at the point of care rather than an electronic interface.[29] Hence, clinician training should focus on the meaning and importance of the individual data items on the encounter forms, while entering data into a computer database is the purview of

trained data entry technicians. Where possible, use of check boxes on the forms reduces the amount of interpretation of clinical information required by nonclinically trained data technicians. As in all EMRs in developing and developed countries, there must be ongoing efforts to enhance completing the requisite data fields and maintaining the validity of the resulting data. All these activities—recording, entering, and validating data—require formal training and monitoring activities that should be standard procedures of HIV care programs.

Given existing financial, communication, and transportation constraints in developing countries, how feasible is it to implement EMRs there? There have been a number of encouraging successes to date. For example, the primary care EMR implemented in Kenya's Mosoriot Rural Health Center[8] has been in continuous use since 2001 and currently contains more than 200,000 visit records for 70,000 individual patients. The AMPATH Medical Record System that supports 12 HIV clinics in Kenya[12] contains more than 200,000 visit records for more than 25,000 enrolled patients and provides quarterly reports to PEPFAR and supports monitoring and evaluation of HIV care.[27] The AMPATH EMR is now being implemented in six demonstration Ministry of Health HIV clinics in Tanzania and Uganda. Partners in Health has successfully implemented EMRs in tuberculosis clinics in Peru[7] in 2001 (8,100 patients) and the Philippines in 2004 (3,300 patients) and HIV clinics in Haiti[11] in 2003 (7,000 patients) and Rwanda in 2005 (2,100 patients). An EMR that supports HIV clinics in Mbarara, Uganda, has more than 10,000 patients enrolled and is used for reporting to funding agencies, and for quality improvement and research (David Bangsberg, personal communication, January 31, 2006). One of the authors (MS) has deployed an EMR in Zambia deployed over an urban-wide area network and rural smart-card system that uses touch screens to enter data and currently includes records for more than 35,000 patients receiving care in 20 clinics. The EMR implemented in Lilongwe Central Hospital in Malawi[9] captures data at the sites of care via touch screens and bar codes rather than paper encounter forms and currently contains visit records for more than 300,000 visits, including 72,000 visits by 11,000 HIV-infected patients. The hardware for these EMRs systems is usually modest, consisting of microcomputers and, in an increasing number of sites, Internet connectivity via very small aperture terminals.[30] Although even this simple infrastructure may seem out of reach for programs in developing countries, PEPFAR has been willing to pay for the costs for both personnel and hardware for data management as essential components of HIV treatment programs.

In addition to the EMR software and requisite computer hardware, there are personnel requirements for maintaining these EMRs. Key personnel include clinicians who understand information technology and data needs of clinical care and practice management, dedicated information technologists capable of maintaining the hardware and software, and a data management team to enter, manage, and report the data. A working relationship with an established medical informatics program or private sector company with experience in developing and implementing EMRs is also key. Most important are leaders, both locally within the HIV care programs and nationally and internationally, who are capable of recognizing the importance of timely information to HIV care and

providing vision for the development, support, and evolution of electronic information management for HIV care.

The data and databases listed in Table 2 may seem overly complex to those contemplating establishing an EMR for HIV care. Yet a simpler data model quickly breaks down when meeting the needs of HIV care systems that involve multiple sites of care, providers, treatments, tests, and the data requirements of national and international regulators and funding agencies. Linking data on visits, illness severity, tests, and treatments across sites of care and within both providers and families requires a balance between simplicity and complexity: a simple EMR will not meet data needs, and an overly complex EMR could be too difficult to implement and sustain. An international collaboration of EMR developers in developing countries (OpenMRS) has been established and is evolving a common data model specifically aimed at balancing the needs of complex clinical data versus the ease of system implementation, management, and sustainability.[22] This same collaboration is encouraging use of standard coding systems such as ICD-10 and LOINC. The data model and these coding systems have been incorporated into the successful systems described above that have proven feasible and sustainable. Linking data items across the different subsystems in an EMR requires a robust concept dictionary, the heart of any sustainable EMR capable of supporting more than the simplest care.[19] The OpenMRS collaboration has proposed a concept dictionary capable of meeting the needs of the more sophisticated EMRs required to provide adequate data for HIV care and monitoring.[22]

Information is care, whether in developed or developing countries. The worldwide HIV epidemic has created a need for clinical data that EMR developers are beginning to meet. Our minimum data set is a first step toward developing EMRs that support both (a) local care and care management and monitoring and (b) initiatives to share data between EMRs to aid understanding of the care and outcomes of patients infected with HIV, such as the recently launched National Institutes of Health International Epidemiologic Databases to Evaluate AIDS.[31] EMRs and the data that they provide will become a powerful weapon in the global war against AIDS.

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