

The AMPATH Medical Record System: Creating, Implementing, and Sustaining an Electronic Medical Record System to Support HIV/AIDS Care in Western Kenya

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Abstract

Providing high-quality HIV/AIDS care requires high-quality, accessible data on individual patients and visits. These data can also drive strategic decision-making by health systems, national programs, and funding agencies. One major obstacle to HIV/AIDS care in developing countries is lack of electronic medical record systems (EMRs) to collect, manage, and report clinical data. In 2001, we implemented a simple primary care EMR at a rural health centre in western Kenya. This EMR evolved into a comprehensive, scalable system serving 19 urban and rural health centres. To date, the AMPATH Medical Record System contains 10 million observations from 400,000 visit records on 45,000 patients. Critical components include paper encounter forms for adults and children, technicians entering/managing data, and modules for patient registration, scheduling, encounters, clinical observations, setting user privileges, and a concept dictionary. Key outputs include patient summaries, care reminders, and reports for program management, operating ancillary services (e.g., tracing patients who fail to return for appointments), strategic planning (e.g., hiring health care providers and staff), reports to national AIDS programs and funding agencies, and research.

Keywords:

Medical record systems, computerized; HIV; acquired immunodeficiency syndrome; developing countries; Africa south of the Sahara; Kenya.

Introduction

More than 38 million persons are currently living with human immunodeficiency virus (HIV) worldwide, 25 million (63%) in sub-Saharan Africa where only 1 million (<10%) of those eligible for antiretroviral drugs (ARVs) are receiving them [1]. To respond to the HIV crisis in Kenya, in 2001 Indiana University, Moi University, and

Moi Teaching and Referral Hospital created AMPATH – an Academic Model for the Prevention And Treatment of HIV/AIDS [2,3] to leverage the power of universities to establish systems of care, train multidisciplinary providers of HIV/AIDS care, and research innovative methods for enhancing the quality and outcomes of care. As shown in Figure 1, initial growth in AMPATH's care programs was slow until mid-2004 when major funding was obtained. By mid-2007, more than 45,000 patients have been enrolled, 1500-2000 new patients being enrolled per month.

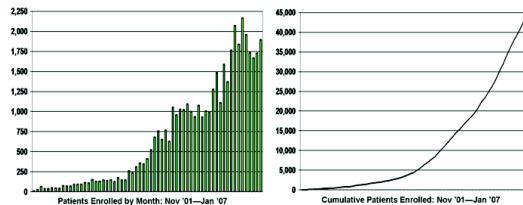


Figure 1 – Monthly and cumulative AMPATH enrollment

Hindering the ramping-up HIV/AIDS treatment programs is the lack of timely and accurate data on (1) the number of HIV-infected patients receiving care, (2) the number eligible for ARVs, (3) the number receiving ARVs, and (4) the positive and negative outcomes of treatment. Funding agencies often deny major program funding unless programs can document the number of patients treated and their outcomes. Paper-based record systems can only meet such information needs for small numbers of patients. The lack of EMRs has slowed the delivery of HIV care despite availability of funds for treatment from the U.S. [4], World Health Organisation [5], and philanthropic foundations [6]. This "Digital Divide" [7] has likely resulted in thousands of unnecessary deaths.

In this paper, we describe how a simple EMR implemented in a single Kenyan rural health centre in 2001 was transformed into a comprehensive, scalable EMR capable of

supporting large (even national) multifaceted HIV/AIDS care programs.

Methods

We describe the process used to initiate the Mosoriot Medical Record System (MMRS) and briefly listing its components, implementation, and use. We then describe how the MMRS was expanded in size and scope into the AMPATH Medical Record System (AMRS). We describe the data model and types of data stored and how the AMRS ultimately failed to support data input/management/output as enrolled patients exceeded 10,000, visits topped 100,000, and the needs of the clinical and funding programs demanded more data flexibility.

We then describe the evolution of the AMRS from its initial implementation as a set of linked spreadsheets into an object-oriented data management system. Finally, we describe how AMRS data serve clinicians, ancillary programs, strategic planning, and reporting to the Kenyan national AIDS control program and international funders.

Results

Initial implementation of the MMRS

In 1999, 3 of the authors (WMT, JKR, TJH) visited the six adult and pediatric clinics at the Mosoriot Rural Health Centre to design an EMR as part of the Indiana University-Moi University's NIH-funded medical informatics program. After several days studying local care, redundant data entry in logbooks, and handwritten reports for national reporting, they held discussions with local providers and managers to design the MMRS [8], modeled loosely after the Regenstrief Medical Record System [9]. The MMRS had a 1-page paper encounter form, designed by Kenyan clinicians and used to include a minimum dataset for each visit. After each visit, these data were entered into a computer by a checkout clerk. The MMRS had modules for patient registry, clinical data, reports, and a concept dictionary defining data elements.

The MMRS was programmed in MS-Access® as a set of spreadsheets for clinical observations, laboratory tests, and drugs, all linked by patients' unique ID# (with check digit) and visit date. Data were entered using checkboxes, dropdown menus, or partial name lookup of dictionary terms. The dictionary included term names, synonyms (to ease data entry), term classes (to aid reporting), and charges for drugs and tests. A report module printed standard reports required by the Ministry of Health and for local management activities.

Created and pilot tested in 2000, the MMRS was implemented in 2001 (Figure 2) [10]. Initial use was slow. Adding a second data entry computer (connected by a network cable), closing a clinic exit, and directing patients to the checkout window resulted in use of the MMRS for 100% of visits. Two months later, the logbooks were discontinued. Prior to 2001, creating monthly reports required a half-time clerk. With the MMRS, it took less than an hour. Mosoriot became the #1 health centre in Kenya. Managing drug inventory improved, and quantifying unpaid (charity) increased Ministry of Health funding.

The MMRS also allowed nurses to identify hidden problems: Monthly reports showed a village with few vaccinations (a nurse was sent to educate villagers and vaccinate children). A rabies cluster was identified (the rabid dog was found and shot). A cluster of sexually transmitted infections was noted (the index man was found and treated). A formal time-motion study showed a 10 minute (23%) reduction in patient visits and a tripling of providers' free time from 15% to 46% of the workday. Since 2001, Mosoriot has doubled its patient and visit load but needed no additional staff.

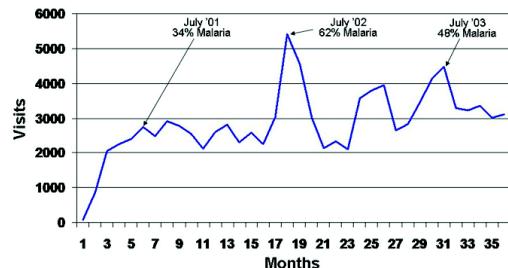


Figure 2 - Visits with data stored in the MMRS, by month

Expanding the MMRS into the AMPATH Medical Record System (AMRS)

In November of 2001, Moi University and Moi Hospital created AMPATH and opened its first 2 HIV clinics. Comprehensive HIV care requires more data and reports to the Ministry of Health and funding agencies. AMPATH directors designed 4 detailed encounter forms for initial and return visits for adult and pediatric patients. As at Mosoriot, data at the point of care were entered onto paper because there was inadequate electricity and funds for computers or hand-held devices. The AMRS' initial visit forms (5 pages long) captured demographics, family/social history, HIV risk, symptoms, prior hospitalizations and medications (ARVs, other antibiotics), alcohol use, physical exam, WHO stage, test results, problem lists and treatments (HIV- and non-HIV-related), and next visit [11]. The 2-page (1 sheet) return visit form collected a subset of the initial data: no symptoms, a limited exam, medication adherence, problems and treatments, and next visit. Importantly, the visit forms were designed by AMPATH clinicians and clinic managers to serve their needs, balancing the amount of data desired and the time it took to record them. Compromises and multiple iterations yielded a consensus minimum dataset [12].

As shown in Figure 3, most AMRS data were entered as checkboxes while the rest used menus and partial name lookup of dictionary terms. Text comments written on the encounter forms were transcribed into AMRS text fields. The data model behind the initial AMRS was the same as the MMRS: a series of MS-Access spreadsheets linked by patient ID# and visit date. The MMRS dictionary was expanded to include additional terms needed to count and describe enrolled AMPATH patients and report what care they received, and report their care and what outcomes occurred [11].

The screenshot shows a Windows application window titled "Misorot HIV Clinic - [frmHIVEncounter]". The interface includes a menu bar with File, Edit, Insert Records, Window, and Help. At the top, it displays the ID (1), Date of encounter (3/1/2002), Time (8:17 AM), and a Back to Main Menu button. Below this is a navigation bar with tabs: General Exam, Neurologic, Psychotic, Problems, Diagn, Tests, Next Visit, and Pbs. Under "General Exam", there are sub-tabs: Initial Visit, Chief Complaint, ROS, Vitals, HEENT, Chest, Heart, Abdomen, Extremities, and Musculoskel. A "Chief complaint" section contains a checkbox list: Feeling well and want to know HIV status, Feeling well and knows they are HIV positive, and Know they are positive and symptomatic. Below this are dropdown menus for "Releife illness" (days, weeks, months) and a list of symptoms: Pulmonary symptoms, GI symptoms, Weight loss, and Weakness. A "Chief Complaint Comment" field is present, along with a "See review of systems for details" link.

Figure 3 - Initial AMRS data entry screen

Failure of the initial AMRS

Initially, the MS-Access AMRS worked adequately, recording data and providing clinical summaries for providers and reports for AMPATH program managers and funding agencies. However, once the number of patients exceeded 10,000 and visits topped 100,000, the system bogged down. Most symptoms and exam findings were negative, yet an empty field was stored in the AMRS database. The limit of 256 fields per table caused major problems. Variables appearing on multiple forms had to be redefined each time they were used. Patients could only have one AMPATH number, which caused problems when patients visited more than one AMPATH clinic. It was impossible to extract sets of data, such as all patients on ARVs: each drug had to be extracted separately. Thus the MS-Access AMRS became huge, unwieldy, and limiting.

Transforming the AMRS into a Scalable EMR

To deal with these limitations, Regenstrief developers evolved the AMRS data model into one more tightly aligned with the Regenstrief Medical Record System [9]. Written in MySQL, the new, enhanced AMRS [13] has the following components:

Encounter forms

These continue to be defined by the data needs of AMPATH clinicians and managers, led by 3 of the authors (WMN, SK, JJM). They have evolved with changing data and reporting needs. By using checkboxes, menus, and numeric data, the AMRS return visit form takes 1-2 minutes to complete. (Page 1 of the 2-page form is shown in Figure 4, left.)

Patient registry

This defines "who" is providing care. Patients are registered and assigned AMRS numbers. They can have multiple names (e.g., get married, have aliases) and multiple AMPATH numbers: each clinic assigns a local number with a check-digit for ease of filing charts. This database also contains demographics and a history of funding sources. Patients can be linked in families for social, economic, and nutrition interventions.

User registry

This defines "by whom," persons who record, enter, and manage and report AMRS data. Each system user is regis-

tered, given a number (with check digit), and provided access and data management privileges needed for his/her required tasks.

Concept dictionary

This is the database of concepts that controls all data entry and extraction. It consists of both terms (e.g., chest xray, diagnosis) and findings (e.g., infiltrate, pneumonia). It defines the format of a term (e.g., coded text, numeric) and the allowable codes or numeric ranges. Terms can be sets (e.g., ARVs) or elements of sets (e.g., AZT) to facilitate data extraction. Term classes include tests, drugs, diagnoses, vital signs, etc.

Encounter site database

This stores "where" care is provided. Each site has a code, and by using the patient identifier, date, and encounter site, an episode of care can be recreated. These codes allow reports to be generated separately for each AMPATH clinic.

Observation database

This stores "what happens" and is the AMRS' heart. Each observation on the encounter forms (other than patient registry data, user ID#, and encounter site) is entered into this database and has 3 components: term ID#, date entered, and result (defined by the dictionary term linked to the data entry screen). Unlike MS-Access, there are no empty fields.

Data lookup

With this program, clinicians and managers look up data on individual patients for making patient and practice decisions.

Data entry

The encounter form is the official medical chart. Once entered into the AMRS, these data serve multiple clinical and managerial needs. Efficient data entry screen mirror the encounter forms which also allows them to be used for direct data entry at the point of care. Figure 4 below shows page 1 of the adult return visit form (filled in) and its AMRS data entry screen.

The figure shows two side-by-side windows. The left window is a scanned copy of a paper "AMRHS Adult Return Visit Short Form" from page 1, dated 3/5/02, with various fields filled in with handwritten text. The right window is a screenshot of the "AMRHS Adult Return Visit Short Form" in an electronic form, showing the same fields but with typed data and dropdown menus. Both forms include sections for patient information, clinical history, medications, and laboratory results.

Figure 4 - Paper and electronic AMRS encounter forms

Arden query and reporting system

Using the if/then/else logic of the Arden Syntax [14], this query system provides standard and custom reports such as patient summary flowsheets and reminder reports. Knowledge of clinical medicine, the AMRS database and concept dictionary, and hierarchical data (observations within visits, visits within patients, patients within providers, and providers within clinics) is necessary to generate useful reports [15].

Patient summary and reminder reports

After receiving data for a visit, the AMRS prints out a report that contains diagnoses (with date recorded), WHO HIV stage, drug therapy, drug adherence, serial weight and test results, and reminders (e.g., "Order 6-month CD4 count") [11]. This summary/reminder report is placed in the patient's chart for viewing by clinicians during and between visits.

Non-clinical databases

AMPATH includes programs to prevent HIV infection, provide social and nutritional support, follow-up missed appointments, etc. To enhance efficiency, data security, and avoiding redundant data collection, the AMRS stores data for all ancillary programs and link with clinical data as needed.

Data management

Kenya has limited electricity and Internet access in urban and rural settings. Completed encounter forms are carried by courier to AMPATH's data center where clerks enter data into the AMRS. Data accuracy is enhanced by a financial incentive program. The forms and summary/reminder reports are then returned to the clinics. The AMRS currently contains 10 million data items for 45,000 patients and 400,000 visits to 19 AMPATH clinics. The encounter form is the only medical record, and data are entered into AMRS for virtually all visits. Moving forms between clinics and the data entry centre takes time (~2 days) and petrol. AMPATH will soon move to on-site data entry and printing. Data will be sent to the central database by flash drive or (where available) wireless Internet.

Costs and sustainability

Costs of computers, data entry, and data management are sustained by the agencies that fund HIV/AIDS care. Although originally resistant, these agencies now realize that complete, believable, timely data are essential providing high-quality care and monitoring and evaluating this care and its outcomes.

More constraining is the expertise needed to implement, maintain, and evolve EMRs. For AMPATH, the U.S. and Kenyan partner universities provide sufficient expertise to make this arrangement sustainable. It would be most appropriate for Kenyans to be wholly responsible for managing EMRs supporting care in Kenya. However, the requirements and costs of most medical informatics training programs are currently beyond the reach of most Kenyans. Hence, academic partnerships such as Indiana/Moi can help sustain EMRs in developing countries while training Africans to manage their EMRs.

Uses of AMRS data

Clinicians use the forms and patient summaries and computer reminders [16] for every day patient care. Clinic managers use monthly reports to assess productivity and anticipate personnel needs. For AMPATH, data managers report AMRS data to governmental and funding agencies. Ancillary programs use AMRS data as well: Outreach workers assess no-shows in their homes and facilitate visits. Med nurses assess reasons for non-adherence and counsel patients. Social workers assess financial needs and send patients to AMPATH's economic development program. Nutritionists refer underfed patients to AMPATH's nutrition program, with sufficient foodstuffs from the World Food Program and local farms to feed 30,000 persons/week. Prevention workers help pregnant mothers and newborns to lower HIV risk, caring for those who become infected. Researchers and quality improvement officers assess and improve processes and outcomes of care [17,18].

Expansion beyond Kenya: The OpenMRS Consortium

AMRS developers are committed to improving HIV/AIDS care in developing countries beyond Kenya. In 2004, they teamed up with Partners in Health [19] to expand the AMRS data model into OpenMRS, a free open-source EMR and an international collaboration of implementers [20]. OpenMRS has been implemented in Kenya, Rwanda, South Africa, Tanzania, Uganda, and Lesotho and is being installed in other developing countries. As a result, the Regenstrief Institute is WHO's first Medical Informatics Collaboration Centre. OpenMRS aims to enhance the productivity and accountability of HIV care programs. Key is independence and sustainability of local EMRs. Since early 2006, OpenMRS meetings have been held in Kenya and South Africa, attracting developers from more than two dozen countries. Information about OpenMRS, training, and downloads of programs and encounter forms can be found at www.openmrs.org. Widespread use of OpenMRS, which uses standard messaging formats and data coding, will enhance interoperability between HIV/AIDS providers, enhancing their ability to manage and improve care within and between provider systems.

Discussion

The AMRS has evolved from a simple MS-Access EMR serving a single rural health center in Kenya into a comprehensive, scalable, sustainable, multinational EMR capable of supporting multicomponent HIV/AIDS care. It has succeeded because it meets the needs of clinicians, who need the most data. Others (practice managers, Ministries of Health, funding agencies) need a small subset of clinicians' data. AMRS is the sole medical record; thus clinicians will complete the encounter forms, as they are meeting their own information needs.

The AMRS has succeeded where national HIV/AIDS registry systems have failed, largely because registries—which require completed visit forms to be sent to the Ministry of Health—do not provide any useful information to the clinicians or their practices. Clinicians thus have no incentive to complete these registry forms, and they often do not. Yet to date, many Ministry of Health officials in developing countries are not convinced that the expense of EMRs will

be offset by increased efficiency of care, as was shown with the MMRS [10].

Lack of training in medical informatics for EMR developers and managers will continue to limit the expansion, independence, and sustainability of EMRs in developing countries. Unfortunately, most medical informatics training programs in the U.S. cannot provide stipends to trainees who are not U.S. citizens or permanent residents. This problem needs urgent attention: capacity building will depend on funding from either non-governmental sources in the U.S. (e.g. philanthropic foundations) or governmental sources outside of the U.S.

The AMRS currently uses paper at the point of care. Personal computers, tablets, and other hand-held devices might yield efficient and effective data collection efficiently and accurately. Better Internet accessibility will further enhance connectivity. This should facilitate data collection and management, although even in developed countries, EMRs often use paper forms at points of care [9].

By creating, implementing, and evolving effective data collection and management systems, EMR developers contribute to care by magnifying the abilities of clinicians and managers to care for patients – especially those with HIV/AIDS – who so desperately need it. In no other way can these developers contribute so meaningfully to the battle against HIV/AIDS and other medical miseries that afflict the developing world.

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