

“Talkin’ About a Revolution”: How Electronic Health Records Can Facilitate the Scale-Up of HIV Care and Treatment and Catalyze Primary Care in Resource-Constrained Settings

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Abstract: Health care for patients with HIV infection in developing countries has increased substantially in response to major international funding. Scaling up treatment programs requires timely data on the type, quantity, and quality of care being provided. Increasingly, such programs are turning to electronic health records (EHRs) to provide these data. We describe how a medical school in the United States and another in Kenya collaborated to develop and implement an EHR in a large HIV/AIDS care program in western Kenya. These data were used to manage patients, providers, and the program itself as it grew to encompass 18 sites serving more than 90,000 patients. Lessons learned have been applicable beyond HIV/AIDS to include primary care, chronic disease management, and community-based health screening and disease prevention programs. EHRs will be key to providing the highest possible quality of care for the funds developing countries can commit to health care. Public, private, and academic partnerships can facilitate the development and implementation of EHRs in resource-constrained settings.

Key Words: Africa, medical informatics, monitoring and evaluation, observational research, HIV/AIDS, primary care, chronic disease, Kenya

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INTRODUCTION

Just a few short years ago, the political will, infrastructure, and funding levels for health care in sub-Saharan Africa seemed no match for the relentless devastation from HIV/AIDS. Now not only are HIV/AIDS programs in place, but some of them, including the partnership between the United States Agency for International Development (USAID) and the Academic Model Providing Access to Healthcare (AMPATH),¹ are openly speaking of bringing the pandemic to its knees over the next 5 years through widespread screening and effective treatment and prevention of HIV. Successful scale-up of HIV/AIDS programs in the world’s poorest countries sends a powerful message: In the public sector, systems of care can emerge that are capable of managing complex chronic diseases. The evolving success story of HIV care programs demands a rethinking of what is possible by applying the lessons learned to unmet needs of those in low-income countries who are living with and dying from other diseases. Two of the most important lessons AMPATH has learned are:

1. Health care is an information business. Managing patient care requires managing patients’ data at many levels.
2. An electronic health record (EHR) system is necessary to manage a chronic medical condition such as HIV in a large patient population.

In this article, we will briefly describe AMPATH, the development and applications of its EHR, and the evolution of that EHR to support primary care and other chronic conditions in Kenya.

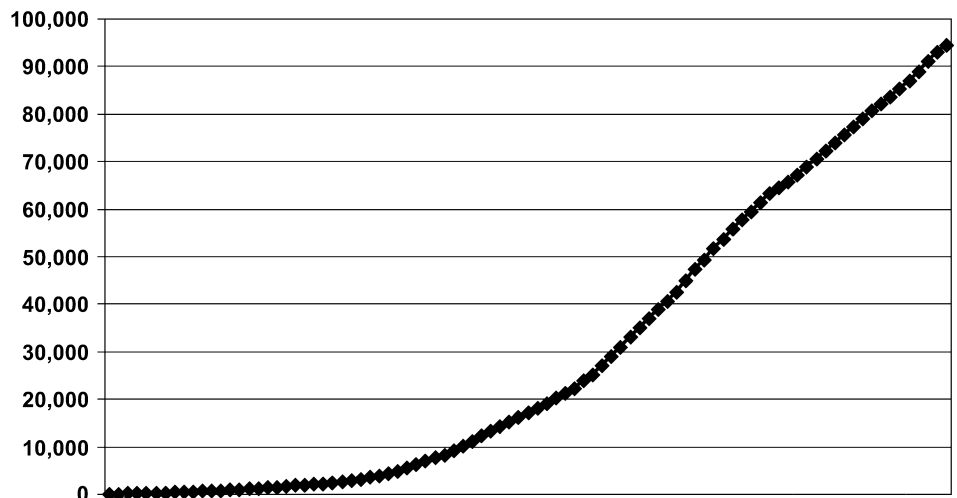
In 2001, Moi University School of Medicine and Moi Teaching and Referral Hospital in Eldoret, Kenya, together with a consortium of universities in North America led by Indiana University, established AMPATH to provide HIV care and treatment in Eldoret. At that time, AMPATH was an acronym for “Academic Model for the Prevention and Treatment of HIV/AIDS.” With additional funding in 2004 from USAID as part of United States President’s Emergency Plan for AIDS Relief, the USAID–AMPATH partnership was expanded and today provides HIV care and treatment to more than 90,000 HIV-infected individuals in 18 clinics across western Kenya.² In 2001, EHR developers from Indiana University, the Regenstrief Institute in Indianapolis, and Moi University established the first ambulatory EHR in sub-Saharan Africa to

support primary care in a rural health center that became one of the first AMPATH sites.³ That system was expanded into a more comprehensive EHR to support multidimensional HIV/AIDS care in AMPATH.⁴ The AMPATH Medical Record System (AMRS) then became the basis for OpenMRS, an open-source EHR that has now been implemented in more than a dozen countries in sub-Saharan African and a dozen more worldwide.^{5,6} OpenMRS provides both a free EHR that is useful in both HIV/AIDS and other settings and a global collaboration of developers. Local implementers of OpenMRS can seek advice and developmental assistance from the collaboration and are strongly encouraged to share their new tools and enhancements with the broader developer community.

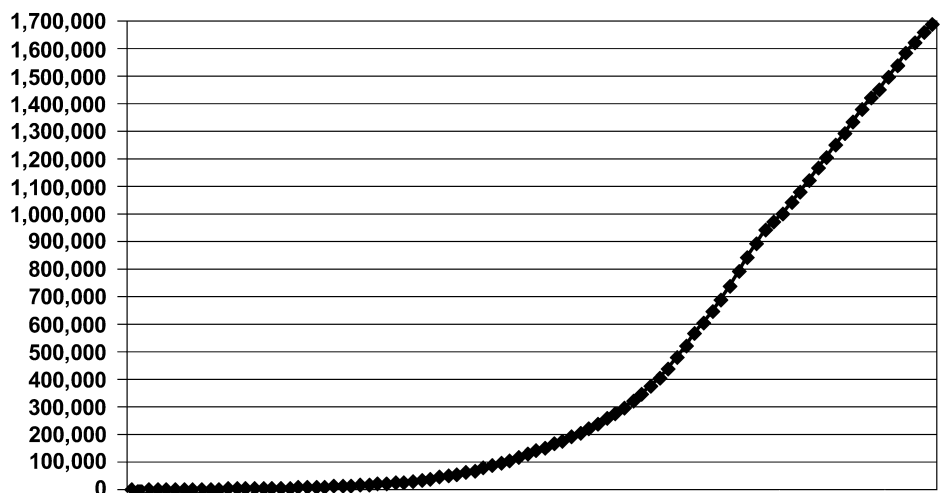
When AMPATH had a few hundred patients, the AMRS was useful for managing patients and clinics. But with more than 90,000 patients and 1.7 million visits—and those numbers are still growing—the AMRS has become essential (Fig. 1). It is essential because it provides AMPATH with care-level

data to monitor and improve the quality of care. It is essential because it helps program managers anticipate personnel needs and avoid medical errors, stockouts of key medicines, and wasted resources. It is essential because with access to treatment, HIV is a chronic and manageable condition—albeit one complicated by the presence of life-threatening comorbidities, such as tuberculosis, malaria, renal disease, and malnutrition. Quality care, particularly for chronic conditions, requires medical records that are continuous, highly detailed, captured over multiple visits to multiple venues, and describing multiple concurrent and previous diseases and conditions.

In late 2008, AMPATH made a conscious decision to expand its services beyond HIV into primary care and chronic disease management and redefined its acronym to mean “Academic Model Providing Access to Healthcare.” In many respects, health information technology and data management are leading this transformation. For example, with support from the US Centers for Disease Control, AMPATH is extending into primary care and reproductive



A Cumulative Patients Enrolled: Nov '01 – Jun '09



B Cumulative Patient Visits: Nov '01 – Jun '09

FIGURE 1. A, Cumulative patient enrollment in AMPATH. B, Cumulative patient visits to AMPATH HIV/AIDS clinics.

health clinics its model of standardized encounter forms and electronic registration of patients. The focus initially is on tuberculosis, antenatal and maternal care, child health, and adult primary care in a single urban site and a trio of rural sites. Here, AMPATH is partnering with clinicians, clinic managers, and record clerks to track patients, monitor their health information, and coordinate their care across multiple venues and specialties. Thus, each patient who presents at any clinic for care of any type is registered and given a universal identifying number on a laminated personal health card, which the patient keeps. This universal ID allows AMPATH to follow patients' care throughout the health care system. For example, a pregnant woman's medical records are linked from antenatal care, provider-initiated HIV testing and counseling activities, maternity, and delivery. If the woman is HIV positive, providers in antenatal and HIV clinics can cooperate to ensure complete and timely care to prevent vertical HIV transmission to her infant. The records of mothers and their children can be linked and followed over time, even among care sites.

Without EHRs, health care facilities rely on a multitude of paper registers that supply data to the Ministry of Health (MOH) via lists of patient visits, with no single identifier or platform to link information and care across multiple visits. As a result, clinicians must spend time recording data in registries, and clerks must manually collate statistics for requisite MOH reports while providing minimal if any data for individual patients' care. With an enterprise-wide EHR serving multiple care venue and specialties, AMPATH clinicians can now provide more comprehensive, patient-focused care.

AMPATH is also able to leverage the AMRS to support care in other ways—for example, by printing patient summary sheets that reduce clinician time spent scanning previous encounter forms. When fully developed, these summary sheets will also contain clinical decision supports, such as clinician reminders to order laboratory tests and start or stop treatment, such as TB prophylaxis. Because most AMPATH care is delivered by nonphysicians, reminders and other types of decision support can facilitate adherence with standard treatment and testing guidelines and hence increase the quality of care delivered.⁷

Not only does the AMRS enable clinicians to manage patients more effectively, it can also make their jobs easier. Clinicians can use simple check boxes and numeric fields to record a minimum set of data. In addition, the AMRS can routinely generate lists of patients who miss visits for follow-up by AMPATH's Outreach Team and can flag patients with special needs. For example, the AMRS allowed AMPATH to identify patients taking nelfinavir when it was recalled and to recognize trends in enrollment and patient visits, as during the 2007 postelection violence in Kenya, when threats to patient travel prompted the establishment of new satellite clinics.⁸ The AMRS also enables identification of patients eligible for novel care programs and research studies and supports monitoring and evaluation of care and its outcomes at the patient level across programs and facilities. Without an EHR, such assessments can happen only at facility level.

The foundation of the AMRS—and practically any EHR in low-income countries—is the paper encounter form. In

AMPATH, it is designed by the clinicians and clinic managers to serve their needs. It is the formal “medical record” and becomes the patient chart at the site of care. It ensures efficient collection of a minimum set of data⁹ required for care, reporting, and monitoring and evaluation. It also provides space for notes that contain information not captured in the minimum data. The AMRS is an electronic repository of these data and, once entered (manually in AMPATH, although other OpenMRS implementers have used scannable forms), these data are available for many other uses: oversight, quality improvement, and monitoring of clinicians' performance and productivity.

The key to success is to first serve the information requirements of clinicians, whose need for complete, accurate data is most acute. Because most other data users require a subset of clinicians' data, fulfilling clinicians' needs simultaneously satisfies the needs of others. And because clinicians serve their own needs first, the data recorded are more likely to be complete and accurate. Therefore, when AMPATH decided to expand its focus beyond HIV/AIDS to encompass primary care, reproductive health, diabetes, oncology, mental health, and cardiopulmonary disease, each effort began with a meeting of the physicians, clinical officers, and nurses in each specialty to develop encounter forms that would collect minimum data. AMRS developers then program AMRS input screens to capture these data, which can then serve patients, clinicians, clinic managers, AMPATH leaders, the MOH, agencies, and researchers.

Program implementers in low-income countries sometimes see clinicians' recording of patient data and the management of those data as secondary to providing good care, or even a distraction. AMPATH has shown that good data collection and management are critical and integral to providing high-quality care, because everything that a clinician or clinical manager does revolves around patient information: collecting, recording, retrieving, transmitting, managing, and processing data to provide the right care to the right patient at the right time. And the investment in EHRs can pay off: Despite having arguably the most comprehensive health information system in sub-Saharan African, AMPATH's total cost of care is low: less than US \$100 per year (plus antiretroviral drugs that USAID provides at no charge). Consequently, increasing numbers of national health programs and international funding agencies are willing to pay for electronic data collection (including investments in training, developing and printing forms, EHR programming, and data entry), data management (data cleaning, queries, quality checks, extraction), and monitoring and evaluation (analysis, synthesis, linkages between programs). Because these functions support efficient and effective management of large-scale health care programs, some agencies and programs are now requiring electronic data collection.

The need for timely data for large populations of HIV/AIDS patients is shared by other programs in developing countries. In 2006, Forster et al¹⁰ reviewed 18 EHRs serving such HIV/AIDS programs and found the majority to be using software developed for personal or small business purposes. This, along with inadequate training for local support staff and difficulties in maintaining clinical data quality in nonclinical

information systems, has limited the usefulness of these systems for supporting increasingly complex clinical enterprises.

There are a multitude of unanswered questions about both HIV and non-HIV health issues (eg, child health, diabetes, tuberculosis, malaria) and their treatment and prevention in resource-limited settings. These questions remain largely unanswered, despite the enormous sums of money spent over the years on diagnosis and treatment, because so little data are available from everyday care. Although the optimal way to answer many of these questions in principle is via randomized clinical trials and other controlled experiments, the time and the funds to conduct such studies are lacking. We urgently need answers about the effectiveness of ongoing care, novel care models, and interventions that improve the health of individuals and communities to inform the continuing scale-up of HIV care and treatment. At the same time, the HIV model of care can and should be expanded into acute and chronic disease management, primary care, and community health as envisioned, for example, by Kenya's Essential Package for Health.¹¹ The Kenyan MOH and AMPATH have collaborated in this regard by sharing information about the conditions that AMPATH clinicians treat and the outcomes of those conditions. They have also collaborated on conceptualizing how EHRs can be implemented more broadly in Kenya, supported by the MOH both financially and through training in EHR implementation, data management, and data analysis.

Literally millions of lives are at stake. Investment in EHR systems and the resources needed to support data capture and management will be recouped by scaling up efficient, effective clinical services, enhancing operational management, and allowing expansion of successful programs such as HIV/AIDS laterally into preventing and treating other conditions, building on local evidence about what works and what does not. Observational research has its limitations, to be sure. Yet it has the potential to provide evidence and insight in close to real time and can answer questions not easily answerable with clinical trials. The investment in EHRs and good data collection has enabled mounds of excellent research in resource-rich settings.^{12–15} Somewhat less but nonetheless important observational research has occurred in resource-constrained settings as well.^{16–20} AMPATH has demonstrated that implementing EHRs in such a setting is practical, scalable, and affordable. In truth, health care systems the size of AMPATH (or larger) cannot effectively be managed without EHR data. The AMRS has reinforced AMPATH's data-focused approach to care, which has allowed it to expand into preventing and treating conditions beyond HIV/AIDS. The AMRS has allowed AMPATH to provide evidence-based practice grounded in relevant, practice-based evidence. The investment in good data yields dividends in efficient, effective, high-quality care.

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