HARVARD MEDICAL SCHOOL
BRIGHAM AND WOMEN'S HOSPITAL

CASES IN GLOBAL HEALTH DELIVERY

GHD-026
MAY 2012

Electronic Medical Records at the ISS Clinic in Mbarara, Uganda

In March 2010 Nneka Emenyonu participated in a stakeholders' meeting at the Immune Suppression Syndrome (ISS) Clinic, a public outpatient HIV/AIDS facility in Mbarara, Uganda. Emenyonu was the project director for a research collaboration between Mbarara University of Science and Technology (MUST) in Uganda and two American institutions, the University of California, San Francisco (UCSF) and Massachusetts General Hospital (MGH). Since 2004 she had been responsible for transforming the clinic's paper-based medical record system, including 1,000 patient's antiretroviral therapy (ART) records, into an electronic medical record (EMR) system.

By 2010 nearly 10,000 patients were receiving ART at ISS Clinic, and the EMR system had become more sophisticated and costly to operate. As the UCSF representative, Emenyonu's role was to support efforts to generate ample high-quality data. She had to determine how to develop and maintain a strong, positive relationship with the clinic stakeholders, local clinicians, and other staff, many of whom viewed the EMR system as somewhat tangential to ISS Clinic's clinical responsibilities, and to determine how to finance the EMR with grant funding dwindling.

Overview of the Republic of Uganda

As of 2011, the Republic of Uganda was a landlocked country on the Equator in East Africa. It shared its northern border with Sudan, its western border with the Democratic Republic of Congo, its eastern border with Kenya, and its southern border with Rwanda, Tanzania, and the largest lake in Africa, Lake Victoria (see **Exhibit 1** for map).

Uganda had two official languages, English and Swahili, and many other spoken languages.[1] There were multiple ethnic groups in Uganda; the largest were the Baganda, representing approximately 17% of the population. In 2008 the primary school education completion rate was 56%.[1] Adults age 25 and older reported an average of 4.7 years of education in 2010.[2] The agricultural and fishing industries were the largest employers in Uganda, providing roughly 80% of jobs.[1, 3] While international migration was limited,

Amy Madore, Julie Rosenberg, and Rebecca Weintraub prepared this case with assistance from Maria May, Jonathan Payne, and Joaquin Blaya for the purposes of classroom discussion rather than to illustrate either effective or ineffective health care delivery practice.

roughly 20% of the population had moved from one Ugandan district to another in 2005/2006 for employment and other income-related reasons (28%), civil insecurity (26%), and marriage and joining family (15%).[4]

Although fewer than 10% of Ugandans had access to electricity in 2011,[5] the use of information technology (IT) resources was increasing. Uganda was one of the first Sub-Saharan African countries to have Internet access and e-mail services (starting in 1994). In 1999 there were about 12,000 people using the Internet, and by 2007, about 125,000. Uganda founded its Ministry of Information and Communications Technology in 2006 to expand the IT sector and align it with the country's strategic growth and development plans.[6]

Basic Socioeconomic and Demographic Indicators[a]

INDICATOR		YEAR
UN Human Development Index ranking	143 (out of 169)	2010
Population	32.7 million	2010
Urban population (%)	13	2009
Drinking water coverage (%)	68	2006
Poverty rate (% living under USD 1.25 PPP[b] per day)	52	2010
Gini index	43	2010
GDP per capita in PPP (2008 USD)	1,251	2010
GDP per capita (constant 2009 USD)	490	2009
Adult literacy (% ; total/female/ male)	73/65/ 83	2010
Corruption Perceptions Index (CPI) score	2.5	2010

Health in Uganda

In 2009 the adult mortality rate was 449 per 1,000 people. The top causes of death for all ages were HIV/AIDS (25%), malaria (11%), lower respiratory infections (11%), diarrheal disease (8%), and perinatal conditions (4%) at the time of the last WHO report.[7] By 2009, malaria had surpassed HIV/AIDS to become the leading cause of morbidity and mortality.[8]

Health System

Upon independence, the Government of Uganda inherited a colonial health system centered on hospitals. During the political violence of the 1970s and 1980s, existing physical infrastructure decayed, and fragmented humanitarian aid was the primary source of health care. At the national level, Uganda's Ministry of Health (MOH) governed the public health system and was responsible for setting public and private health standards and mobilizing resources. It also advised health districts, coordinated health research, and monitored the performance of both public and private health care providers.[9]

[a] This data was compiled from the following sources: United Nations (UN), World Bank, World Health Organization's Global Health Observatory Data Repository, and Transparency International. CPI scale ranges from 1 to 10, with 0 signifying "highly corrupt" and 10 signifying "clean."
[b] Purchasing power parity.

Under the country's first strategic health plan during the mid-1990s, the MOH implemented a policy of decentralization. It gave greater regulatory and decision-making power to the provincial health authorities and established four levels of care: national referral hospitals, regional referral hospitals, general hospitals, and district and sub-district health centers. Nearly three-quarters of the population lived at least 5 kilometers from the nearest public or private health facility. Although the Government of Uganda abolished user fees in 2001, poor road infrastructure, health workforce shortages, medication and transportation costs, and drug stock-outs regularly constrained access to health services.[9, 10] Only slightly more than half (54%) of health care positions in the public sector were occupied. About 54% of health care providers worked in both the public and private sectors, and 22.5% worked only in the private sector.

The private sector—including nonprofit organizations, for-profit practices, and traditional healers—accounted for the majority of health care delivery in Uganda. Sixty percent of the population sought care from traditional healers (e.g., herbalists and spiritualists).[9, 10] Facility-based nonprofit institutions, primarily faith-based organizations, accounted for 41% of Uganda's hospitals.

Health System and Epidemiologic Indicators[c]

INDICATOR		YEAR
Average life expectancy at birth (total/female/male)	52/57/48	2009
Adult mortality rate (per 1,000)	449	2009
Maternal mortality ratio (per 100,000 live births)	430	2009
Under-five mortality rate (per 1,000 live births)	128	2009
Infant mortality rate (per 1,000 live births)	79	2009
Vaccination rates (% of DTP3 coverage among one-year-olds)	64	2009
Undernourished (%)	15	2006
Adult (15-49 years) HIV prevalence (%)	6.5	2009
HIV antiretroviral therapy coverage (%)	39	2009
Tuberculosis prevalence (per 100,000)	278	2009
DOTS coverage (%)	100	2006
Malaria cases (per 1,000)	40	2009
Government expenditure on health as a % of total government expenditure	11.6	2009
Government expenditure on health per capita (PPP international dollars, USD)	22, 8	2009
Total health expenditure per capita (PPP international dollars, USD)	115, 43	2009
Total number of physicians	3,361	2005
Physician density (per 10,000)	1	2005
Nursing and midwifery density (per 10,000)	13	2005
Number of hospital beds[d] (per 10,000)	4	2009

[c] This data was compiled from the following sources: WHO, UN Children's Fund (UNICEF), UN Development Program (UNDP).

[d] Hospital beds include inpatient and maternity but not cots and delivery beds (Source: WHO Global Health Observatory Data Repository).

In 2009 external donors contributed 40% of total health expenditure (USD 253 million) in Uganda. Out-of-pocket spending constituted 50% of health expenditures, and the Government of Uganda contributed the remainder.

In 1996 the MOH launched a national Health Management Information System (HMIS) to generate data that would inform operational decisions. Private and public health facilities were responsible for collecting data on standardized paper forms and sending them to the sub-district level, which relayed them to the district level. District-level administrators sent the forms to the central health data bank.[11] Underreporting was common, however, and only 68% of facilities submitted their reports to the MOH on time. Some health facilities started to use electronic databases such as Microsoft® Access to record and relay data; however, most did not have computer access, reliable electricity, and/or staff proficient in computer-based data entry. Despite efforts to prevent redundancies, the verticality of MOH programs, the participation of multiple Ugandan sectors (e.g., health and finance), and the involvement of international donors led to the rise of several monitoring and evaluation systems that increased the burden on the health workforce.[9]

HIV in Uganda

In 1998 the Government of Uganda introduced antiretrovirals (ARVs) through the Drug Access Initiative with support from the Joint United Nations Program on HIV/AIDS (UNAIDS), but access remained limited.[12] In 2004 funding from the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), allowed Uganda to offer free ARVs. By the end of 2009, 53% of HIV-infected people in need of ART were receiving it.[13] There were 398 active accredited "ART service outlets" in the public and private sectors across 96 of Uganda's 97 districts, including all public hospitals, in March 2010. More than half (62%) were providing pediatric services as well. About 88% submitted quarterly reports on the services they provided for the 218,359 active ART clients they saw between January and March 2010 to the MOH. Approximately one-third of patients received ART at specialized AIDS clinics; the rest of patients went to general hospitals (25.4%), referral hospitals (19.1%), advanced health centers (14.8%), basic health centers (4.2%), and private clinics (3.4%).[14]

In 2010 Uganda had a generalized HIV epidemic with an adult prevalence of 6.4%.[e] The most common modes of transmission were sexual (76% of new HIV infections) and mother-to-child (22% of new HIV infections). Women, urban residents, and people living in post-conflict northern Uganda were disproportionately affected by HIV/AIDS.[15]

Electronic Medical Records

Historically, health facilities recorded patients' medical histories, clinical, and demographic information on paper. In the 1960s and 1970s, there was a growing interest in the potential for information technology to drive innovation and improve the efficiency and quality of health care. Programmers in the US and other developed countries began to develop electronic medical records (EMRs). Proponents believed EMRs could enable faster, more reliable data storage and retrieval. EMR systems could display patient data, such as age or weight over time, with just a few clicks of the computer mouse and well-programmed queries. EMRs also regulated certain processes (e.g., legibility or level of detail recorded) and procedures that might

[e] These data were the results of the 2004/2005 Uganda HIV&AIDS Sero-Behavioral Survey (UHSBS); as of 2010, these figures represented the most recent national HIV/AIDS prevalence data available.

have been more difficult to regulate through a paper-based system. As the Internet developed and became more accessible, several EMR systems incorporated web-based features such as search tools or e-mail.

Despite mounting excitement in developed countries about the potential of EMRs, in 2009 fewer than 2% of US hospitals had a comprehensive EMR system (i.e., integrated with all clinical units), and 7.6% had a basic system (i.e., present in at least one clinical unit).[16] Adoption by smaller clinics and practices was even lower. Financial barriers and limited evidence that EMR systems were cost-effective were deterrents to EMR adoption. In fact, a poorly implemented EMR system might reduce efficiency and increase costs, facilitating unintended clinical errors[17] or leading to dissatisfaction and conflict among personnel,[18] for example.

EMRs in Developing Settings

As ART became more consistently available with the increase in international donor support in the early and mid-2000s, clinics' patient enrollment grew. By the end of 2009, the Global Fund and PEPFAR alone had financed ART for approximately 5 million people in more than 100 countries.[19, 20] With ART, a patient could live 40 additional years in the developed world[21, 22] or about 27 to 30 additional years in places such as Uganda.[23] As patients lived longer, compiling and monitoring patient information over time--including vitals, CD4 count, and viral load—using paper-based medical records became a greater challenge. Paper files overwhelmed administrative staff and clinicians, leading to patient registration delays and longer waiting times. It became harder to create progress reports for donors and other stakeholders, to gauge which patients were adherent, and to determine how many patients were lost to follow-up. Moreover, if anyone wanted to use clinic data for research, it was tedious and, in large-scale HIV treatment programs, nearly impossible to select participants systematically.[24]

In offering ART, clinics also had to track inventory and forecast needs to prevent stock-outs. This required knowing the volume of patients enrolling, how many previously enrolled patients were still on first-line treatment, and how many needed to transition to second-line therapies. Given the information management challenges that came with ART, some program managers decided to switch to electronic information management systems, especially those with funding to do so or a research agenda.

In 2001 the Moi University School of Medicine in Eldoret, Kenya, partnered with the Regenstrief Institute, Inc., and Indiana University in Indianapolis, US, to create the first outpatient EMR system in Sub-Saharan Africa (see **Exhibit 2** for examples of other EMR systems used in developing settings).[f] Using Microsoft® Access, they developed the Mosoriot Medical Record System (MMRS) for use at the newly launched Academic Model Providing Access to Healthcare (AMPATH) project, a primary care clinic in a rural community of western Kenya. As AMPATH expanded to offer HIV/AIDS prevention and treatment in western Kenya, it needed an EMR with greater capacity, functionality, and flexibility than the MMRS. The Regenstrief Institute and Indiana University considered purchasing a system or altering an existing system, but they found the open source[g] EMRs either fell short of serving "both clinical *and* research needs—i.e., to collect non-ambiguous, coded data—or were not easily adaptable to [their] setting."[26] They opted to design their own software, calling it AMPATH Medical Record Systems (AMRS). AMRS was modeled after the Regenstrief Institute's EMR system, which was being used to store more than 6 million patient records across 18 hospitals and 30 outpatient facilities in Indiana.[27] AMRS became one of the largest EMR implementations for outpatient care in Sub-Saharan Africa.[26]

[f] AMPATH was founded jointly by Moi University School of Medicine and Moi Teaching and Referral Hospital, together with a consortium of North American universities led by Indiana University.

[g] Software consists of a set of instructions (referred to as "source code") that guide the operations of a computer. Anyone can access open source code, whereas access to closed source code is restricted by the owner of the code.

OpenMRS

Partners in Health (PIH), a nongovernmental health care organization treating HIV/AIDS and TB since 1987, launched its EMR system to enable data collection and reporting in its Haiti- and Peru-based affiliated clinics in 2001. In 2004, PIH-EMR and AMRS creators met at an informatics conference and realized they were doing similar work; they shared a vision for developing an EMR system that could be customized for implementation in different contexts. Both had encountered challenges in adapting their EMR systems from HIV care to general care and from one country site to another. They decided to work together to build a stronger, more flexible, and more broadly accessible tool that other programs in resource–limited settings could use. Neither program had the resources to develop such a system singlehandedly.

At the same time, funders such as the World Health Organization (WHO) and the Rockefeller Foundation were receiving requests from programs in developing countries for financial support to develop or purchase customized EMR systems—particularly for HIV and TB, which were becoming increasingly complicated to treat as they became more chronic. Rather than give money to individual programs, funders believed they could expand their impact by seeding the development of one generic platform that many organizations could adopt. With funding from the Rockefeller Foundation, the WHO, and PEPFAR, the Regenstrief Institute and PIH joined forces with the South African Medical Research Council in 2004 to launch the Open Medical Record System, or OpenMRS®.

All of the OpenMRS source code was publicly and freely available, and there were no product or licensing fees associated with downloading the software. In principle, any user could download OpenMRS and immediately begin to establish users, create forms, and run reports. Operating OpenMRS required minimal programming expertise (though adapting the system to specific clinical settings and incorporating special functions that did not come with the basic software package, such as text message (SMS) alerts or requiring double entry, did require medical and coding knowledge; see **Exhibit 3** for more OpenMRS features).[28]

Developers and implementers using OpenMRS in the field could communicate via OpenMRS group e-mail lists (i.e., listservs), discuss questions and challenges in real time via an online forum called Internet Relay Chat (IRC), and access practical resources on the OpenMRS Wiki.[h] Community members discussed and advised each other on development and deployment issues, submitted new feature requests to the OpenMRS development team, documented software problems (i.e., bugs), learned about upcoming informatics conferences and meetings, and could access user and developer guides. By facilitating collaborative development and problem-solving through a virtual network, the OpenMRS team hoped it would enable sites to save time and resources by becoming more self-reliant and optimizing OpenMRS utilization.[29] An annual OpenMRS conference began in South Africa in 2005 with funding from the Canadian International Development Research Centre (IDRC).

In 2010 PIH, the South African Medical Research Council, Regenstrief Institute, and the Millennium Villages Project provided core funding support for OpenMRS. In addition, the IDRC, Rockefeller Foundation, and WHO contributed substantial grant-based funding. Other donors included the US Centers for Disease Control and Prevention (CDC); the National Institutes of Health (NIH) Fogarty International Center, Google; and other for-profit, nonprofit, and academic partners. By 2011 OpenMRS was being used for clinical and/or research applications in more than 25 countries, a majority of which were African, supporting over 1 million patient records worldwide.

[h] A wiki is a type of type of website that allows users to contribute, revise, and remove content. The OpenMRS Wiki and mailing lists are public access and free to view and join: https://wiki.openmrs.org/display/docs/Home.

ISS Clinic at Mbarara Regional Hospital

History of ISS Clinic

In November 1998 American Dr. Larry Pepper, a physician working with the Baptist Mission in Uganda and teaching at Mbarara University Teaching Hospital—the teaching hospital for the Faculty of Medicine at Mbarara University of Science and Technology (MUST), founded the Immune Suppression Syndrome (ISS) Clinic to offer compassionate care to HIV-positive patients. The clinic was located in Mbarara, a small urban trading center in southwestern Uganda, in a small complex within Mbarara Hospital grounds.

In 2000 Dr. David Bangsberg, an American researcher at the University of California, San Francisco (UCSF), received an invitation to help MUST and Makerere University in Kampala develop a pilot study investigating treatment adherence and outcomes among AIDS patients living in severe poverty. Bangsberg was struck by what he saw: ARVs were available for purchase, but very few patients could afford to buy them. In response, Bangsberg established the Family Treatment Fund (FTF) in 2002 to provide ART for free to ISS Clinic patients who could not afford it and would likely die in the next 6–12 months without it.[i] Bangsberg's work with FTF led him to shift his research from vulnerable populations in the US to southern Uganda's generalized epidemic.

Following a grand rounds presentation at MUST in 2003, Bangsberg met a young physician named Dr. Bosco (Mwebesa) Bwana (see **Exhibit 4** for profile), a clinician at ISS Clinic. Bwana had created a Microsoft® Excel spreadsheet containing demographic and clinical information from the paper files of ISS Clinic's first 500 patients. He asked Bangsberg how the spreadsheet could be improved and adapted to generate required ART reports for the Ministry of Health and to support research programs.

When the ISS clinic became a Global Fund and PEPFAR beneficiary in 2004 and 2005, respectively, it became the outpatient ART center of Mbarara Regional Hospital and began offering free treatment. In only a few years the clinic saw its patient enrollment jump dramatically. As the project director explained:

> You have to understand that we went from having 1,000 patients receiving a little more than words of hope to 10,000 patients receiving comprehensive HIV care virtually overnight. The clinical staff went from Dr. Pepper, Dr. Bosco, and a counselor to a well-funded, multipartner effort in the same short span. It turned into a different entity once the PEPFAR funds were available; we had multiple partners, each contributing significant resources, and it became a little bit more difficult to manage, given the structural and political complexities.

ISS Clinic received PEPFAR funding as a sub-grantee through two Ugandan institutions: the Joint Clinical Research Centre (JCRC) and the Mulago–Mbarara Joint AIDS Program (MJAP) (see **Exhibit 5** for organogram of organizations involved). Global Fund finances went through the Ministry of Finance, Planning, and Economic Development to the MOH, which delivered the finances to the clinic. The FTF shifted its focus to resolving emergency ARV stock–outs and treating patients on the waitlist for PEPFAR–funded treatment. In the midst of these financial transitions, UCSF and MUST officially launched a research partnership in 2004, and Bangsberg returned to California to fundraise for the project.

Service Delivery at ISS Clinic

ISS Clinic consisted of a two-story building—housing the registration office, waiting area, and patient consulting rooms on the first floor, and the data management offices and patient records department on the second floor—and a building housing the clinic director's and administrative offices, ART counseling offices,

[i] See http://familytreatmentfund.org for more on the Family Treatment Fund.

a laboratory, a conference room, and two pharmacies (one for ARVs and one for medications to treat opportunistic infections) built in 2007. The clinic director was a MOH employee and medical doctor, responsible for coordinating ISS Clinic's institutional stakeholders and overseeing its staff, including its doctors, a pediatrician, clinical officers, nurses, adherence counselors, data entry clerks, a data manager, a receptionist, peer educators, pharmacists, and lab technologists. Staff turnover was high; in one year, three medical officers left ISS Clinic for other health facilities.

On any given day, there were four or five clinicians and one pediatrician in the clinic. Though some clinicians were full-time employees, not every clinician was in clinic every day of the week. In addition to the clinic director, the MOH paid the pediatrician and one clinical officer. MUST paid Bwana, while MJAP, which paid significantly higher salaries, paid the other clinicians. Faculty members from the Department of Internal Medicine at MUST served as clinic advisers, spending one day a week for a few months at a time consulting with the full-time clinicians and seeing patients. In addition, the MUST postgraduate medical students spent part of their internship year in ISS Clinic. Occasionally, visiting clinician researchers from UCSF spent time there as well. None of the local physicians were trained specifically in HIV/AIDS. Clinicians completed five years of medical training and one internship year before becoming licensed medical doctors. As one physician explained, "We don't encourage sub-specialization because there isn't enough manpower. Dr. Bosco Bwana and others are not specialists in HIV per se, but they have a lot of experience."

Because the medical team at ISS Clinic changed frequently, it was not uncommon for patients to see a different clinician at each visit. Clinicians relied on medical records to prescribe care for the approximately 200 adult patients and 40 pediatric patients seen at the clinic each day (see **Exhibit 6** for a description of patient flow).

Information Collection and Management

Paper Records

Prior to 2004, ISS Clinic used a paper-based registry book, patient encounter forms, questionnaires, and blank sheets of paper to document patient information and clinicians' notes. At a patient's first visit, the clinic receptionist or a nurse started a new paper file and an initial encounter form and created an identification number for the patient. If the patient had been to the clinic before, the receptionist or a nurse collected the patient's paper file from the records room and started a return visit encounter form, writing the patient's name and the date at the top before taking the patient's vitals and recording them in the designated areas. There were also two or three pages of prompts or "checkpoints" designed to guide the clinicians and ensure they did not miss any details; for example, there were questions about the patient's ART regimen, adherence, and comorbidities (e.g., TB). The majority of questions were followed by checkboxes. There were some blank spaces to detail the chief complaint and treatment plan (see **Exhibit 7a** and **7b** for patient encounter form).

The oldest encounter forms and notes were at the back of patients' charts, so to review any previous measurements (e.g., weight), treatment regimens, or test results, clinicians flipped through the file until they found it. Occasionally it was challenging to decipher other physicians' handwriting.

The ISS Clinic used the same clinical, paper-based records to compile reports for stakeholders. When a funder (e.g., the MOH) wanted to know how many patients the clinic was treating, the staff tallied patient records by hand. When a funder asked for information about specific outcomes, staff had to flip through the pages of each chart to review the patients' treatment regimens and outcomes over time.

With the establishment of the UCSF-MUST partnership in 2004, Pepper and Bwana wanted to develop a more efficient—ideally, electronic—patient registry. They hoped it would facilitate reporting. Bangsberg and UCSF colleague Dr. Jeffrey Martin began preparations to create an electronic database at ISS Clinic that would speed the process of aggregating and analyzing clinic data. They hoped it would also build research capacity at MUST and streamline patient care. Bangsberg and Martin had worked together for several years on HIV adherence research in San Francisco. They hoped that research in Uganda would help to improve interventions in resource-limited settings and prove to the international donor community that ART delivery was not only crucial but feasible in Sub-Saharan Africa.

Electronic Registry

Bangsberg and Martin secured a USD 1.7 million NIH grant to study treatment resistance, adherence, and survival at ISS Clinic for a year. Spending most of the year in California, Bangsberg hired Nneka Emenyonu to be the project director of the NIH-funded research collaboration between UCSF and MUST and to supervise the on–the–ground implementation of a new, computerized data collection and reporting system. Emenyonu had lived in West Africa until she was 19 years old and had both clinical research and public health experience (see **Exhibit 4** for profile). Emenyonu explained her role:

> We had a clear mission to build capacity in the clinic because we were planning on working in the clinic … They didn't specifically ask for us to help them develop an electronic medical record system. However, we needed it to realistically implement our research. There was no way we were going to recruit patients in a systematic fashion when the clinic didn't have an electronic method for keeping track of their patients.

Bangsberg asked Jay Jankowski, who had built datasets for his other research projects, to develop a Microsoft® Access database for ISS Clinic. Jankowski began building the database at UCSF with Bangsberg's guidance before flying to Uganda to visit ISS Clinic, install Access, and train Emenyonu's newly hired part-time data manager, Nicholas Musinguzi. Musinguzi had a bachelor's degree in statistics and computing from Makerere University and some knowledge of epidemiology and biostatistics. Jankowski worked with Bwana to determine what information he wanted to track while Emenyonu ensured that the electronic forms would also support potential research projects.

Emenyonu hired one full-time and one part-time data entry clerk with basic computer skills to enter the encounter form data into the electronic database and run reports. With limited research funding for human resources, Emenyonu initially used Bangsberg's UCSF discretionary funds to pay the salaries of the data manager (USD 500 per month) and clerks (USD 300 each month). She also hired file clerks (for less than USD 50 per month) to organize the patient file room and move paper files between the file room, registration desk, the data management office, and the patient consult rooms.

Emenyonu worked with the UCSF team and ISS clinicians, particularly Bwana, to adapt ISS Clinic's paper encounter forms so they would mimic the electronic forms of the Access database (see **Exhibits 8a** and **8b** for Access forms). Several of the clinicians felt overwhelmed by the new forms, which were longer and more prescriptive than the previous ones. It was not uncommon for physicians to leave areas of the patient encounter forms blank; many viewed the EMR system as a tool to support the UCSF research agenda.

When JCRC and MJAP began to finance ISS Clinic with PEPFAR funding in 2005, Bangsberg and Emenyonu were able to redirect some of their funding to buy additional computers and filing cabinets. They came to rely less on Bangsberg's discretionary UCSF research budget. Bangsberg and Emenyonu used a USD 72,000 grant from the Rockefeller Foundation to cover the cost of running and staffing the database. She also tried to include resources for database operational costs in UCSF's applications for smaller research grants.

By 2005 there were several thousand EMRs in the database. System performance slowed, and the limited number of user accounts Access could accommodate became problematic. Emenyonu and her UCSF colleagues worried that Access's storage capacity and functionality would not keep pace with the clinic's rising patient load.

A New System

Later that year, Bangsberg received a phone call from Dr. William Tierney, the Director of Research and Informatics at the AMPATH project in Eldoret, Kenya. Tierney believed that "health care was an information business"[30] and had called to encourage Bangsberg to apply to a new NIH–funded grant opportunity through the International Epidemiologic Databases to Evaluate AIDS (IeDEA). IeDEA aimed to establish regional consortia worldwide to which individual cohorts related to HIV disease would contribute their data. The East Africa Regional IeDEA Consortium included Uganda, Kenya, and Tanzania. This pooled data would be more representative than any single center's data and have enough patients to allow for the study of rarer clinical occurrences. Each grantee would receive five years of funding.

The WHO and the Rockefeller Foundation were providing AMPATH with financial support for OpenMRS, and they were interested in finding other sites to test the software. They selected three pilot implementation sites in concert with the Ugandan Ministry of Health: ISS Clinic at Mbarara Regional Referral Hospital; the HIV clinic at Masaka Regional Referral Hospital, supported jointly by Uganda CARES; and the HIV clinic at Mbale Regional Referral Hospital.

Having little technical background in electronic medical record systems, Bangsberg and Martin acknowledged, "It was not a highly informed decision to use OpenMRS. We wanted to be a research group, and there was some money there to use to begin with OpenMRS ... When you have a limited budget and find an opportunity, you pretty much take it." Martin also noted, "Microsoft® Access did not have a fixed package to be used for medical record systems, so anything that was done with it had to be built from scratch … People have been working on EMRs for a while, and the team in Eldoret had sizable experience with OpenMRS" (see **Exhibit 2** for more on other EMR systems).

Transition

In preparation for implementation, Nicholas Musinguzi became a full-time data manager. Bangsberg secured a USD 40,000 grant from the Antiretroviral Therapy in Lower Income Countries (ART-LINC) Collaboration[j] to hire an additional full-time data manager to oversee the UCSF-MUST field site, a small university building located 200 meters from the clinic facilities used for interviewing and other research–related activities. Bangsberg and Emenyonu also used the grant to hire more data entry clerks ("data entry specialists"), increasing the number from two to eight, file clerks ("records assistants"), a receptionist nurse, and a patient tracker (see **Exhibit 9** for the clinic's ART-LINC budget).

The Faculty for Computing and Information Technology at Makerere University received funding from the WHO to assign three of its employees to support OpenMRS implementation. ISS Clinic was the first site to initiate the implementation process in January 2007. The Makerere team traveled four hours to Mbarara to teach Musinguzi to install OpenMRS software, program the electronic forms, develop standard reports the data entry clerks could run, and update the electronic forms and build ad hoc reports in the event that the clinic wanted to capture and report on different indicators.

[j] The ART-LINC Collaboration was a network of HIV treatment programs and cohorts in developing countries financed by the NIH and France's National AIDS Research Agency.

Emenyonu allocated a USD 80,000 grant from the WHO to purchase computer and office equipment. Bangsberg also received continued funding for the NIH adherence, resistance, and survival study through June 2008 (see **Exhibit 10** for detailed WHO budget).

All of the clinic's computers were connected via a hardwired local area network (LAN), meaning that they could share and synchronize data without an Internet connection. Internet access was not essential to operating the OpenMRS database, although it was necessary to access the OpenMRS online community and e-mail the UCSF team. The only point of regular Internet access at ISS Clinic was in the director's office.

The first step to making OpenMRS operational was to design the electronic data input forms. Designing the electronic forms occurred in tandem with the revision of ISS Clinic's paper encounter forms. The UCSF team sent Musinguzi and Bwana to San Francisco and Eldoret to learn from the UCSF research team and AMPATH how to design the patient encounter forms and translate them into electronic versions in OpenMRS. "If one has a form that promotes nonreproducible completion by the clinicians, you are doomed from the get-go. Create systems that generate clear and unambiguous responses and then have a process in place that attempts to find inconsistency or 'missingness' shortly after the data is collected," Martin explained.

When Bwana and Musinguzi returned to Mbarara, Emenyonu solicited the other clinicians' feedback on the paper encounter forms. Emenyonu explained to the clinicians why OpenMRS was a useful clinical tool as well as an instrument for research. She highlighted a newly developed OpenMRS feature–-the patient summary module-–that enabled users to print one-page clinical summaries of patient information. It would include past lab results, recent CD4 counts, viral load, vital signs from the previous four visits, ARV history and regimen, other concomitant medications, and any side effects experienced. The module would also use Clinical Decision Support Systems (CDSS) functionality to display care-related suggestions and reminders (e.g., "Repeat CD4 count!") for clinicians. Plans were to integrate the patient summary module shortly after OpenMRS was implemented. Emenyonu made final revisions to the paper encounter forms and conducted group meetings with the clinicians to instruct them how to complete the forms (see **Exhibits 11a** and **11b**).

Despite their involvement in this process, after OpenMRS was implemented, clinicians were generally unaware of the transition from one electronic system to another. One clinician explained, "We never changed. The source for clinicians was still paper. The clinicians themselves still don't enter anything in the computer. The only thing we see from the EMR system is the patients' last results. The clinician does not have database access or enter anything into it." Some of the clinicians who were part of the UCSF-MUST research team, such as Bwana, used the database to conduct research, but the data management team generated the reports, not the clinicians.

JCRC- and MJAP-affiliated clinicians were frustrated that they had to use the UCSF team's encounter forms. The forms were more detailed and comprehensive than the standardized "blue" forms the MOH had developed and disseminated to public HIV clinics throughout the country. Collecting data that was not solicited by the MOH through its data collection tool went beyond their normal clinical duties, clinicians protested, and they therefore should be paid more to do so. Emenyonu hoped that she could convince them otherwise when they began to see and appreciate the clinical utility of OpenMRS.

Emenyonu and the UCSF team decided to merge everything in Access, including records of patient visits since 1998, into OpenMRS. Musinguzi's initial attempt to do this electronically was unsuccessful, however, so the two databases existed simultaneously for a while before being merged. Emenyonu explained, "It was more technically complicated than we envisioned. We were just learning as we went along."

Not all of the ISS Clinic databases transitioned to OpenMRS. The laboratory and pharmacies operated their own Access databases independently from UCSF. Pharmacy data and lab results were incorporated into the UCSF database manually; the lab technicians and pharmacists printed reports from their computers and sent them to the data management room, where data entry clerks added the data to patient records (see **Exhibit 12** for a screenshot of the OpenMRS data entry interface).

OpenMRS at ISS Clinic

After launching OpenMRS, Emenyonu met regularly with the clinic director and stakeholders from JCRC, MJAP, MUST, and Mbarara Hospital about OpenMRS and how it was working. ISS Clinic had access to a midlevel information technology professional at MUST who helped with computer and IT issues. For problems that required the purchase of new software or hardware, Emenyonu relied on Bangsberg's discretionary funds or small research grants that included minimal support for miscellaneous database needs. For example, when the clinic's antivirus software license expired and a virus infiltrated the computer system, Bangsberg's discretionary funding helped replace the server and buy new antivirus licenses for all of the clinic's computers. Once the IeDEA grant came through, it supported most of the database work and eventually provided all the database funding.

Because the OpenMRS software was only a few years old, bugs and errors occurred frequently. When Musinguzi encountered a bug that he could not fix on his own, he initially reached out to technologists at Makerere University. He soon discovered that they did not have enough time or knowledge of OpenMRS to help him. He turned to the global OpenMRS online community, where he received practical advice and solutions within 24 hours. "OpenMRS has been a lot harder than I thought it would be," Martin acknowledged. "Technically, it doesn't follow more conventional database structures, so not just anyone can work with it or understand it. That's been unfortunate." As Musinguzi interacted more with the OpenMRS community, he became increasingly familiar with how to solve common technical problems.

One challenge that Musinguzi struggled to resolve despite input from the OpenMRS community was incorporating the patient summary module into the database. With these technical complications and the manual merge of Access and OpenMRS data, patient summaries did not become operational for approximately 18 months. Emenyonu reflected:

> We had a situation where the clinicians really didn't see the clinical relevance of the data they were collecting, and they didn't see the clinical relevance of the system because its implementation took so long. I think that was a major mistake in implementing the system ... Clinicians participated in developing the forms, but we also should have made sure that the clinical components were up and running sooner than the research components.

In 2008 Bangsberg transitioned from UCSF to Massachusetts General Hospital (MGH) in Boston, bringing an additional group of stakeholders to the ISS Clinic. While at UCSF, Bangsberg had limited discretionary funds, at MGH he would have access to a larger community of donors. Martin remained in California and asked his research fellow, Dr. Elvin Geng, to help direct the UCSF component of the work.

Emenyonu struggled to convince JCRC, MJAP, the MOH, MUST, and Mbarara Hospital that the EMR system was essential to ISS Clinic's success. Emenyonu encouraged them to include database operational costs in their grant proposals, and she regularly invited MUST professors and students to use OpenMRS for their research.

By August 2008, the clinic had enrolled over 15,000 HIV-positive patients.[31]

Data Uses

The patient summary module became operational at the beginning of 2008 (see **Exhibit 13** for patient summary example). The receptionist was given a computer and a printer so that she could print a summary sheet when each patient registered. She placed the summary sheet on top of the patient's paper file after the file clerk retrieved from the records room.

Bwana, Emenyonu, Musinguzi, and others, led by an author from the Regenstrief Institute, published a study investigating the impact that patient summaries had on efficiency and "quality of care" at ISS Clinic. They found that clinical summaries shortened the amount of time it took clinicians to review patient data, enabling clinicians to spend more time with the patient, and shortened patient wait times by more than 30 minutes (see **Exhibits 14a** and **14b** for results of the time studies).[31] Patient summaries also decreased the incidence of data errors by prompting face-to-face interaction between the data management team and clinical staff. If clinicians had a question about a value on the patient summary sheet, they could inquire with the data management team or send a nurse to do so. Similarly, if the data management team had a question (e.g., if the CD4 count was out of range or the drug dosage was incorrect–-both of which OpenMRS automatically noted), they would walk downstairs to the patient consult rooms and inquire with the clinician. Clinicans were generally satisfied with the data summary sheets (see **Exhibits 15a** and **15b** for results of clinician satisfaction survey).[31] Clinicians could also ask the data management team for data not captured on the patient summary or to run a particular query/report.

OpenMRS enabled ISS Clinic to inform staffing, procurement, and other administrative decisions by analyzing trends in patient visits over the course of a week or month. When leaders realized that Wednesdays had the lowest patient volume, they decided to close ISS Clinic on Wednesdays so staff could meet and focus on administrative work. Eventually, the clinic started to use the appointment scheduling feature of OpenMRS, which gave clinicians a sense of how many and which patients were likely to attend clinic on any given day. "The volume of what goes on at that clinic is difficult to get a handle on without an EMR," Geng affirmed.

The data management team produced stakeholder reports using the EMR system with relative ease, including biannual reports to the IeDEA Consortium, quarterly reports for the MOH, monthly reports for clinic stakeholders, weekly internal reports, and ad hoc reports according to needs.

OpenMRS was "indispensable" to research at ISS Clinic, according to Bangsberg and his team. "There would be no research or operations research or internal reporting without an EMR," Geng noted. Bangsberg and other senior researchers spent a portion of their in-country visits training and advising junior Ugandan investigators. The primary and recurring research focus was patient loss to follow-up. Geng described its value:

> Patient retention and retention to care is a key aspect of care. People misinterpret clinic retention as patient retention, but you have to understand retention within the larger system of care. If you think about how care was rolled out—start at large hospitals and gradually care has been decentralized to smaller clinics—the whole point of decentralization is that patients who started at tertiary care centers end up receiving care at small delivery sites, but no one has accounting of that patient movement.

The UCSF team used the database as a launching point for the research. Martin explained: "It would have been impossible to do good research just by studying the people who don't disappear. The database was instrumental in identifying how many people are lost and who is lost. With the paper-based systems, you wouldn't know that—you couldn't quantify or know who is lost." The database allowed researchers to search for patients who failed to return to their appointments and generate a random list of them. The clinic hired an outreach director, bought him a motorcycle, and trained him to track as many of those patients as possible each week and bring them back to the clinic.

The UCSF/MGH team also turned to the database when a *New York Times* article[32] revealed that PEPFAR-recipient clinics in Uganda were turning away or wait-listing HIV-positive patients. They used OpenMRS to look for ART-eligible patients and patients starting ART between April 1, 2009, and May 14, 2010, and discovered that there had been a two-month gap in PEPFAR-funded treatment in May 2009 and that no new patients had been enrolled in PEPFAR treatment slots since October 2009. The MOH, with Global Fund support, and FTF were bridging this gap by enrolling new patients on treatment; by May 2010, FTF was sponsoring almost 90% of ART initiations (100 people per month) at ISS Clinic, "… and we didn't even know it. It was a good thing we checked," Bangsberg recalled.

Geng described the EMR system's role in identifying the ARV shortage: "When there were limited ARVs, we documented it at the clinic and evaluated how this affected how long it took people to start therapy, and we brought in additional private funding to make up the gaps so that people didn't wait for long periods to receive clinical care." Unlike many of the MOH clinics, ISS Clinic had a relatively steady supply of ARVs, insured in large part by the multiplicity of stakeholders. According to one researcher, ISS Clinic had not experienced a true stock-out in several years. The research team, including Bwana and the ISS Clinic director, published its study in an online open-access journal, *PLoS ONE*.[33]

If researchers wanted to investigate a variable not captured in the patient encounter forms (e.g., alcohol consumption, fertility desire), they used OpenMRS to screen and recruit study participants. They then created a separate questionnaire and database-–typically using Access-–to collect the information they needed. Most of the UCSF/MGH team's research required the creation of separate questionnaires and stand-alone electronic databases. For example, Bangsberg designed a study to assess the impact of transportation costs on adherence and retention. He used OpenMRS to identify eligible patients and created a paper-based questionnaire and an Access database to record patient information. The study showed that transportation costs were a reason patients cited for missing ARV doses and clinic appointments.[34] Bangsberg and the UCSF/MGH team then applied for funding to help ISS Clinic's poorest patients generate income (e.g., building chicken coops, purchasing chickens to raise, and selling eggs) and study the effect of income generation on adherence using a new dataset.

Blue Forms

At the beginning of 2010, the MOH notified ISS Clinic that it would no longer permit the clinic to use its own patient encounter forms. Instead, all public HIV/AIDS clinics in Uganda had to use the national "blue forms" (see **Exhibits 16a** and **16b** for examples of forms). The UCSF/MGH research team amended its encounter forms to include the information in the MOH blue form and requested permission to use the modified form in lieu of the blue forms, explaining the need to collect additional data for research, but the MOH declined.

The blue form was shorter. It removed blank text boxes for clinicians' notes, replacing several of them with pre-formulated responses and corresponding checkboxes. The blue form's ARV regimen section used small text boxes instead of a checklist of medications and dosages, thereby prompting clinicians to write out their own abbreviations or name of the prescribed medications and dosages. Most of the data entry clerks did not have clinical knowledge, limiting the accuracy of their interpretations. According to one UCSF faculty researcher, "You went from banker's accuracy to free-form."

Emenyonu saw the blue forms as a small but potentially terminal step back for the EMR system.

ISS Clinic in 2010

Bangsberg and Emenyonu helped establish a grants and contracts office at Mbarara University to streamline the process of spending NIH grants and other research funding in Uganda. The office began receiving 8% overhead for HIV grants and up to 15% for other grants, gaining administrative capacity.

Stakeholders continued to view OpenMRS as the American universities' financial and administrative responsibility, however. Emenyonu explained:

> There's still this concern on the part of the Ugandan clinicians that the data really belong to UCSF. The clinicians think, "Yes, it helps us in the clinic, but it's primarily Dr. Bangsberg's system ..." They're gradually beginning to accept it, but I think the underlying concerns about access, ownership, and perhaps even compensation sometimes, prohibit them from seeing the true value of an EMR system as a clinical tool. This concern is compounded by the fact that the US investigators are the first to publish papers using data from the ISS Clinic database. There has only been one publication from a Ugandan using data from the clinic database, and that person was not even a member of the clinic at the time; he was a member of our research team.

In 2010 there was a gap in IeDEA funds, and Emenyonu could not pay the data entry clerks' salaries for several months. She and the ISS Clinic director asked the MOH to help bridge the salary gap, but it declined. Emenyonu recalled a conversation with one of the hospital administrators: "'But this is your program, so you figure out how to fund it.' I said, 'But it's part of the clinic,' and they said, 'Well, we didn't ask for it; it's your problem, so figure it out.'"

ISS Clinic was 1 of 66 ARV delivery sites in western Uganda. Since 1998, the clinic had seen nearly 21,000 patients, of whom almost 10,000 had been enrolled on ART. At the end of 2010, there were approximately 8,500 active[k] adult patients and 1,000 active pediatric patients. Research from the clinic had contributed to more than 20 peer-reviewed articles (see **Exhibit 17a** for abbreviated list of articles and **17b** for select abstracts).

Three years after its debut at ISS Clinic, the OpenMRS database still lacked a long-term funding source. The IeDEA grant was drawing to a close, and while there would be an opportunity to apply for another five–year grant, the consortium was reducing its funding for the operational costs of running electronic databases. Emenyonu and the UCSF/MGH team would have to find additional funding, knowing they could only stretch the MGH donors' discretionary dollars so far. With her pending departure as project coordinator in the fall of 2010, Emenyonu worried that they had not secured the finances for the database and data collection:

> I'm not sure it has completely registered that if the clinic database is discontinued, then a large part of the clinic's organization and planning will likely cease to exist. Could the ISS Clinic do with a less complicated, less sophisticated system? Maybe. Maybe the MOH system would be sufficient, but it would mean going back to the drawing board, and that would really set the clinic back ... The clinic database has raised the visibility of the institution. It has raised the quality of patient care, and the flow of patients throughout the day has vastly improved. But I imagine it is hard for the average clinician who sees patients on a day–to–day basis to immediately see the value.

What more could she do to convince the clinicians and stakeholders of the EMR system's value? How would they continue to sustain OpenMRS, and what would be the impact of shutting down the EMR system?

[k] A patient was considered active if he or she had been seen at the clinic within the past six months.

Exhibit 1 *Map of Uganda*

Source: US Central Intelligence Agency, available at : https://www.cia.gov/library/publications/the-world-factbook/maps/maptemplate_ug.html.

Exhibit 2 *Examples of EMR Systems in Developing Settings*

System Name	Launch Year	Developers	Implementation Sites	Software	Implementation Process	Notable Features
Open Medical Record System (OpenMRS)	2004	Partners in Health and Regenstrief Institute	25+ countries; national implementation by Rwandan Ministry of Health	Open source	Free software download, trained implementation team required, free online support community	Flexible platform, global support community
IQ Care System	2004	Constella Futures Group, Catholic Relief Services, and Futures Group (AIDS Relief)	Kenya[l], Uganda, Nigeria, Tanzania[m]	Open source	Free software download, custom options available, train the trainer program available	Used to administer PMTCT, antiretroviral therapy
Smart Care	2005	Zambia Ministry of Health, US Centers for Disease Control	National implementation in Zambia, including CIDRZ[n]; Ethiopia, and South Africa	Not open source	Data unclear	Works with paper-based systems, durable design and limited Internet touch-screen option for easy learning
Care Ware	2000	US Department of Health and Human Services and PEPFAR; jPROG-developed the software	United States, Nigeria, Uganda, and Vietnam	Freeware	Free software download, free technical support, limited adaptability	Originally designed for HIV prevention and treatment
Baobab	2001	Baobab Health Trust	Malawi	Open source	Offers a suite of services, such as: open source software and low-cost hardware and operational support	Touch screen available for easy use, hardware designed for harsh environments, Malawi-based
OpenEMR	2005	Open Source Medical Software	United States, Puerto Rico, Australia, Sweden, Holland, Israel, India, Malaysia, Nepal, and Kenya	Open source	Free software download, options for customization, free online support, commercial support and licensing available	Multi language support, large online open source support community
OpenVistA	2002	US Veterans Health Administration	All VHA sites: 163 hospitals, over 800 clinics and 135 nursing homes; also used at sites in Mexico (over 100 hospitals), and 11 other countries around the world	Open source	Support license typically required for hospitals and larger clinics, commercial set-up available	Synchronization with multiple locations, management performance tools

[l] This is one example of an EMR system in Kenya; there are several others, including Care 2000, Aphia II Coast, EDMS, C-PAD (I-CAP).
[m] IQ Care is in operation at 81 hospital sites throughout these four countries.
[n] Largest medical record system in Africa in terms of patient volume.

System Name	Launch Year	Developers	Implementation Sites	Software	Implementation Process	Notable Features
Community Health Tracking System (CHITS)	2004	UP Manila-National Telehealth with support from the Canadian International Development Research Center	Philippines	Open source	Free software download, training and certification through the UP Manila National Telehealth Center	Rapid access to patient data, Internet connection not necessary
Hospital OS	2003	Thailand Research Fund, Thai National Health Foundation, Thai Medical Informatics Association, Software Industry Promotion Agency (Thailand)	75 hospitals throughout Thailand	Open source	Free software download, online support community, requires IT specialists to set up and run	Designed for rural Thai hospitals with limited IT budgets
Health Information Systems Program (HISP-SA)	2001	Government of South Africa, Norwegian Agency for Development Cooperation, USAID	South Africa, Kenya, Rwanda, Ghana, Lesotho, Zimbabwe, Mozambique, Sierra Leone, Uganda, Tanzania, and Latin America	Open source	Collaborative development for South Africa, implementation across African continent and Southeast Asia	South Africa–based; language options for Portuguese, Swahili, Spanish, Telugu, Russian, Mongolian, and Chinese
SIGA Saúde	2004	Centro de Estudos em Informática em Saúde [Center of Health Information Studies], Prefectura da ciadade de São Paulo [Prefecture of the City of São Paulo]	Brazil: Cities of São Paulo, Camaçari, and Campinhas; other sites in the State of São Paulo	Open source	Developed for the city of São Paulo, costs for software development and hardware	Utilized by every public health care facility in the City of São Paulo

Source: Compiled by case writers using publicly available sources.

Exhibit 3 *Basic OpenMRS Features*

Feature	Description
Central concept dictionary	Definitions of all data (both questions and answers) are defined in a centralized dictionary, allowing for robust, coded data
Security	User authentication
Privilege-based access	User roles and permission system
Patient repository	Creation and maintenance of patient data, including demographics, clinical observations, and encounter data, etc.
Multiple identifiers per patient	A single patient may have multiple medical record numbers
Data entry	With the FormEntry module, clients with InfoPath (included in Microsoft® Office 2003 and later) can design and enter data using flexible, electronic forms. With the HTML FormEntry module, forms can be created with customized HTML and run directly within the web application
Data export	Data can be exported into a spreadsheet format for use in other tools (Excel, Access, etc.)
Standards support	HL7 engine for data import
Modular architecture	An OpenMRS Module can extend and add any type of functionality to the existing API and web app
Patient workflows	An embedded patient workflow service allows a patient to be put into programs (studies, treatment programs, etc.) and tracked through various states
Cohort management	The cohort builder allows users to create groups of patients for data exports, reporting, etc.
Relationships	Relationships between any two people (patients, relatives, caretakers, etc.)
Patient merging	Merging duplicate patients
Localization/ internationalization	Multiple language support and the possibility to extend to other languages with full UTF-8 support
Support for complex data	Radiology images, sound files, etc. can be stored as "complex" observations
Reporting tools	Flexible reporting tools
Person attributes	The attributes of a person can be extended to meet local needs

Source: OpenMRS, http://openmrs.org/about/.

Exhibit 4 *Profile of Ugandan-Based Research Team Members*

Dr. Bosco (Mwebesa) Bwana, Clinician, ISS Clinic

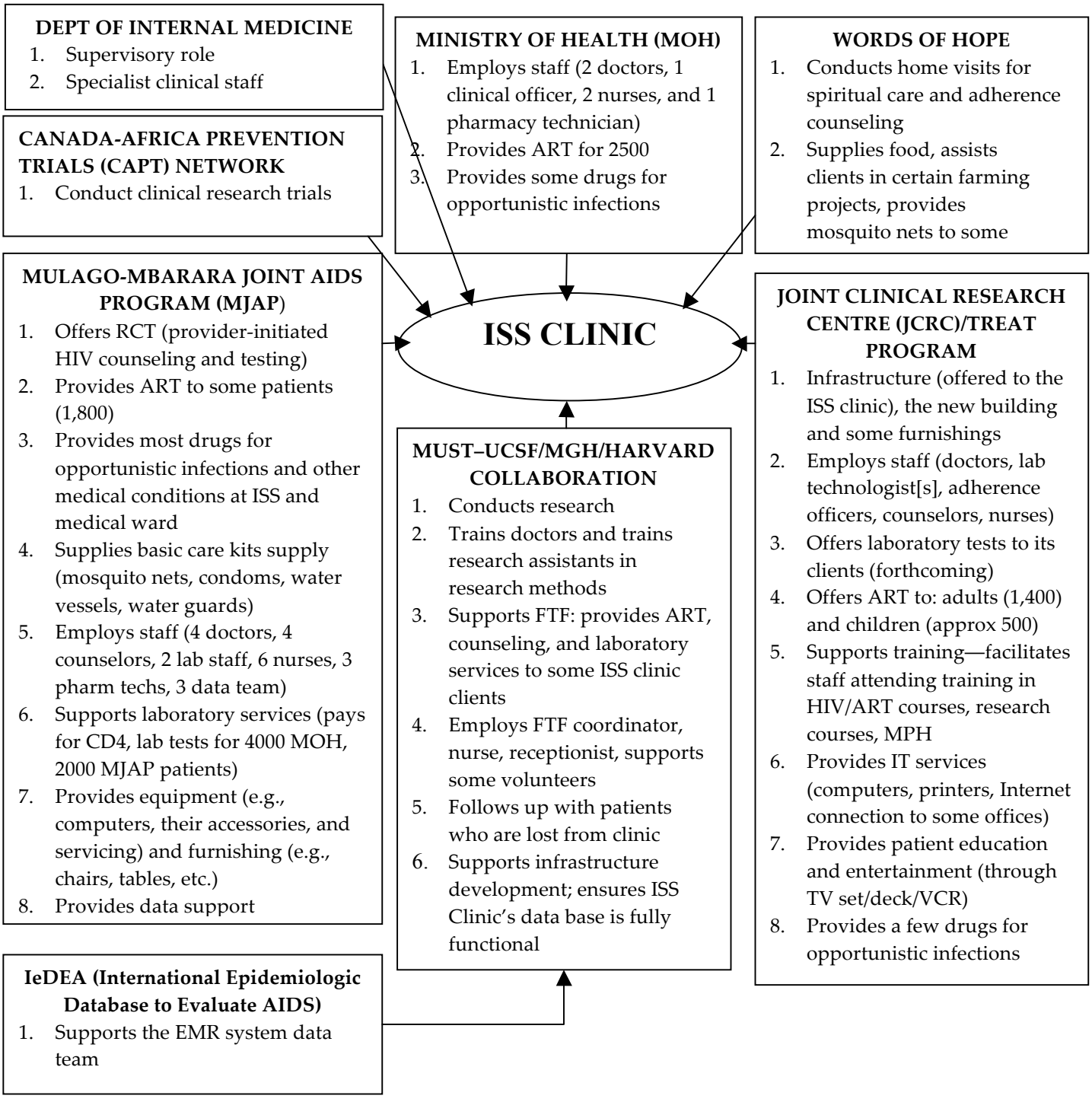
Bwana grew up in a small village near Mbarara. While still a teenager, his parents passed away from HIV. Bwana opted to pursue a career in medicine while caring for his six younger brothers and sisters. Bwana finished his five-year medical training and one-year internship at the ISS Clinic in 2002. He continued to volunteer at the ISS clinic until offered a medical officer position. Bwana was the first full-time clinician and persuaded the clinic to offer services Monday through Friday.

Nneka Emenyonu, Project Director, UCSF Epidemiology and Prevention Interventions Center

Nneka Emenyonu worked as the Project Director of the MUST-UCSF Research Collaboration in Mbarara, Uganda, though 2010. Emenyonu was born in Boulder, Colorado, and raised in Nigeria. She returned to the United States to attend Oberlin College in Ohio, where she completed a Bachelors of Arts in Biology. Emenyonu then attended the Johns Hopkins University Bloomberg School of Public Health in Maryland, where she received a Master of Public Health degree She coordinated breast cancer clinical trials at UCSF prior to joining the Epidemiology and Prevention Interventions Center. Emenyonu then instituted and built the MUST-UCSF Research Collaboration to expand capacity and learning so that African public health issues could be addressed primarily through African health professionals. She pursued a doctorate in public health, focusing on health policy and management, at the University of North Carolina Gillings School of Global Public Health.

Sources: Compiled by case writers and adapted from the UNC Executive DrPH in Public Health Leadership Class of 2010, available at: http://www.sph.unc.edu/images/stories/academic_programs/hpaa/documents/drph_bio10.pdf.

Exhibit 5 *ISS Clinic Collaborators and Their Roles, 2009*



Source: Adapted from ISS Clinic materials.

Exhibit 6 *Patient Flow at ISS Clinic*

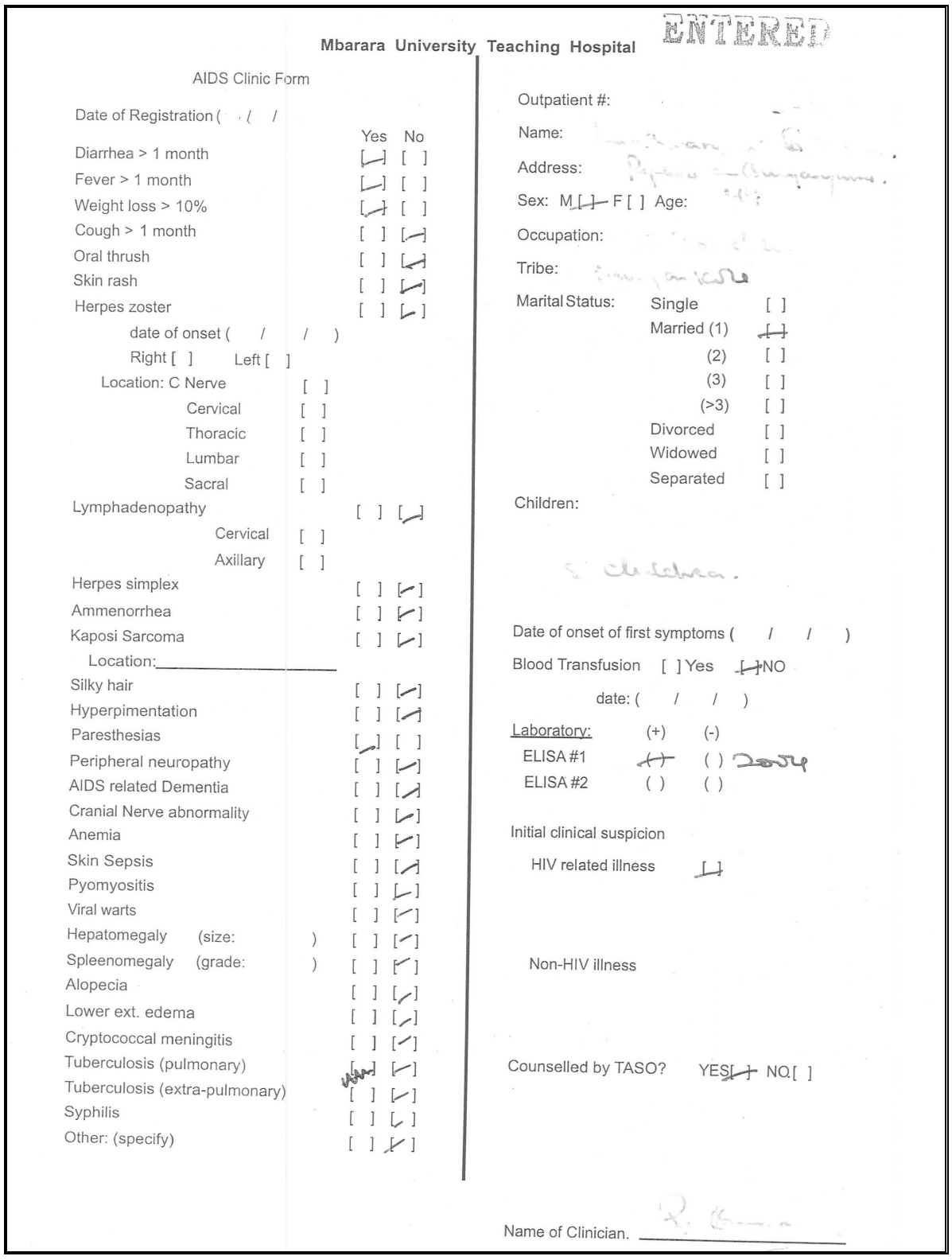
Patients typically arrived at ISS Clinic by way of referral from Mbarara Hospital, where both inpatients and outpatients received provider-initiated HIV testing on the hospital wards. The Mulago-Mbarara Joint AIDS Program (MJAP) provided this service by paying specific nurses to look for patients who had not already been tested. If a patient tested positive for HIV, the hospital referred him or her to ISS Clinic for additional counseling and treatment. Patients who enrolled at ISS Clinic but had not been sent by Mbarara Hospital typically came via referral from other facilities in the region or from another HIV clinic due to a move or other personal reasons.

When patients arrived at ISS Clinic, they registered with the receptionist in the registration office and then joined other patients in the waiting room. Peer educators and usually at least one nurse led discussions about health-related topics, such as nutrition, while patients waited to be called into the triage room. In the triage room, a team of three nurses measured patients' vitals (e.g., blood pressure, temperature, and weight), took blood samples, and recorded patient responses to questions regarding family planning, pregnancy, and the HIV status of their partner(s). Peer educators worked alongside the nurses to counsel or educate patients on health issues that had not been discussed in the waiting room. As they triaged patients, the nurses organized patients into groups based on the number of clinicians working that day. The triage process typically lasted for about one hour; once 20–30 patients had been triaged, the nurses moved them from the congested room and assigned groups of 8–10 patients to different consulting rooms where they sat on benches outside the office doors until the clinician or medical officer called each patient by name. The clinicians' offices were connected by doors so that clinicians could move between them.

Clinicians typically spent between 2 and 10 minutes with each patient. Patients who were relatively healthy and/or had been attending the clinic for several months and only needed a prescription refill might spend three or four minutes with the doctor, while a new or very sick patient might take up to 20–30 minutes. At the end of the visit, the clinician scheduled a follow-up appointment with the patient and advised him or her where to go next. If the clinician had prescribed ARVs and/or medication for an opportunistic infection, the patient took his or her prescription(s) to the ARV and/or OI pharmacy and picked up the medication. If the patient required further testing, the clinician would send him or her to the laboratory with a prescription for the necessary test(s). The clinician referred noncompliant patients to an adherence counselor. Before the patient left the clinician's office, he or she received a summary sheet showing the date of his or her next appointment and basic information about his or her health (e.g., CD4 count and weight).

Source: Compiled by case writers from informant interviews.

Exhibit 7a *ISS Clinic Patient Encounter Form, 1998–2005, page 1 of 2*



Mbarara University Teaching Hospital

ENTERED

AIDS Clinic Form

Date of Registration (/ /

Outpatient #:

Name:

Address:

Sex: M [ ] F [ ] Age:

Occupation:

Tribe:

Marital Status: Single [ ]
Married (1) [ ]
(2) [ ]
(3) [ ]
(>3) [ ]
Divorced [ ]
Widowed [ ]
Separated [ ]

Children:

	Yes	No
Diarrhea > 1 month	[ ]	[ ]
Fever > 1 month	[ ]	[ ]
Weight loss > 10%	[ ]	[ ]
Cough > 1 month	[ ]	[ ]
Oral thrush	[ ]	[ ]
Skin rash	[ ]	[ ]
Herpes zoster	[ ]	[ ]
date of onset (/ /)		
Right [ ] Left [ ]		
Location: C Nerve	[ ]	
Cervical	[ ]	
Thoracic	[ ]	
Lumbar	[ ]	
Sacral	[ ]	
Lymphadenopathy	[ ]	[ ]
Cervical	[ ]	
Axillary	[ ]	
Herpes simplex	[ ]	[ ]
Ammenorrhea	[ ]	[ ]
Kaposi Sarcoma	[ ]	[ ]
Location:		
Silky hair	[ ]	[ ]
Hyperpimentation	[ ]	[ ]
Paresthesias	[ ]	[ ]
Peripheral neuropathy	[ ]	[ ]
AIDS related Dementia	[ ]	[ ]
Cranial Nerve abnormality	[ ]	[ ]
Anemia	[ ]	[ ]
Skin Sepsis	[ ]	[ ]
Pyomyositis	[ ]	[ ]
Viral warts	[ ]	[ ]
Hepatomegaly (size:)	[ ]	[ ]
Spleenomegaly (grade:)	[ ]	[ ]
Alopecia	[ ]	[ ]
Lower ext. edema	[ ]	[ ]
Cryptococcal meningitis	[ ]	[ ]
Tuberculosis (pulmonary)	[ ]	[ ]
Tuberculosis (extra-pulmonary)	[ ]	[ ]
Syphilis	[ ]	[ ]
Other: (specify)	[ ]	[ ]

Date of onset of first symptoms (/ /)

Blood Transfusion [ ] Yes [ ] NO

date: (/ /)

Laboratory:	(+)	(-)
ELISA #1	(+)	( ) 2054
ELISA #2	( )	( )

Initial clinical suspicion

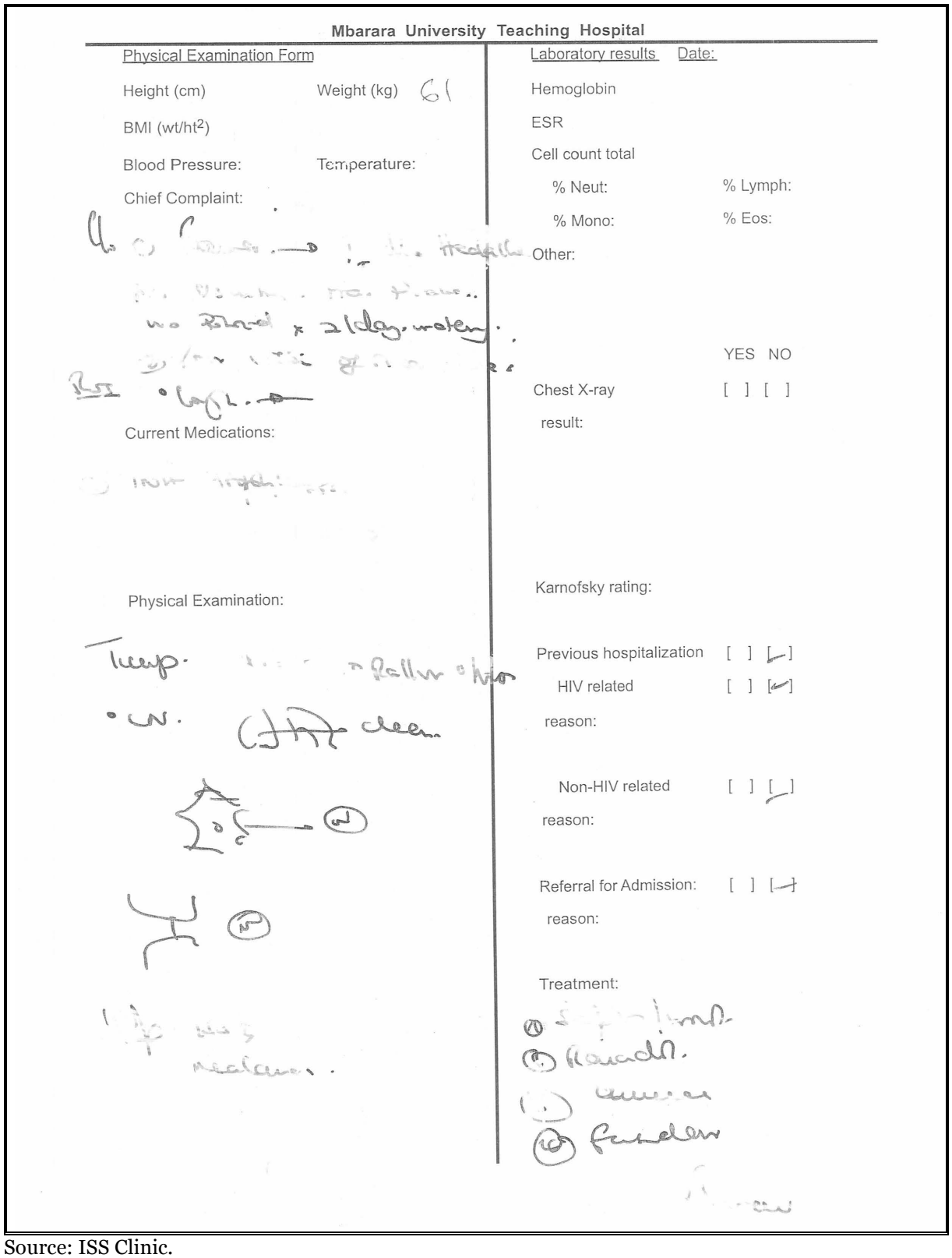
HIV related illness [ ]

Non-HIV illness

Counselled by TASO? YES [ ] NO [ ]

Name of Clinician. _____

Exhibit 7b *ISS Clinic Patient Encounter Form, 1998–2005, page 2 of 2*



Mbarara University Teaching Hospital

Physical Examination Form

Height (cm) Weight (kg) 61

BMI (wt/ht^2)

Blood Pressure: Temperature:

Chief Complaint:

Current Medications:

Physical Examination:

Laboratory results Date:

Hemoglobin

ESR

Cell count total

% Neut: % Lymph:

% Mono: % Eos:

Other:

YES NO

Chest X-ray [ ] [ ]

result:

Karnofsky rating:

Previous hospitalization [ ] [ ]

HIV related [ ] [ ]

reason:

Non-HIV related [ ] [ ]

reason:

Referral for Admission: [ ] [ ]

reason:

Treatment:

Source: ISS Clinic.

Exhibit 8a *Patient Encounter Forms for Access, 2005–2006, page 1 of 2*

ENTERED

Form 08, 2004

Mbarara University Teaching Hospital
ISS Clinic Intake Form

Patient Number: [illegible]
Registration Date: [illegible]
PATIENT DEMOGRAPHICS

Patient First Name: [illegible]
Patient Last Name: [illegible]
Form Completed By: [illegible]

Date of Birth [illegible]
Gender Male ☐ Female ☒
Tribe [illegible]
Marital Status: Single ☐
Married (1) ☒
Married (2) ☐
Married (3) ☐
Married (<3) ☐
Divorced ☐
Widowed ☐ Date

ISS Status of Spouse: Unknown
TASO Registered? Yes ☐ No ☒

Village [illegible]
Parish [illegible]
Subcounty: [illegible]
District:
Telephone:
Occupation: [illegible]
Transportation Cost: [illegible]
Total Children: [illegible] Living Children [illegible]
ISS Stratus of Children:
Non-children Dependents:
Next of Kin: [illegible] Relation:

MEDICAL HISTORY

Date of First NYY Test: [illegible]
Initial Clinical Suspicion: HIV Illness: ☒
Non-HIV Illness ☐

NYY Test 2: NYY Test 3:
Blood Transfusion: Y/N: Date:

Current Symptoms	Yes/No		Yes/No
Diarrhoea > 1 month	No	Anal Sores	Yes
Fever> 1 month	No	Anal Swelling	[illegible]
Weight Loss >10%	No	Genital Sores	one off
Cough >1 month	No	Genital Swelling	No
Skin Rash	No	Genital Itching	No
Paresthesias	No	Oral Sores	No
Ammenorrhoea	No	Odynophagia	No
		Dysphagia	No

Current Signs	Yes/No		Yes/No
Oral Thrush	No	Hepatomegaly	
Silky Hair	No	Splenomegaly	[illegible]
Hyperpigmentation	No	Alopecia	
Lymphadenopath	No	Lower Extremity Oedema	
Cranial Nerve Abnormality	No		

Past Diagnoses	Yes/No Year		Yes/No Year
Herpes Zoster	No	Anaemia	No
Herpes Simplex	No	Viral Warts	No
Peripheral Neuropathy	No	Cryptococcal Meningitis	No
AIDS Related Dementia	No	Pulmonary TB	No
Kaposi Sarcoma	No	Extra -pulmonary TB	No
Skill Sepsis	No	Syphillis	No
Pyomyositis	No	Others	No
PCP			

Exhibit 8b *Patient Encounter Forms for Access, 2005–2006, page 2 of 2*

Physical Examination — Form 08, 2004

Height (cm): Weight (Kg) Blood Pressure Temperature Heart Rate:

Karnofsky Rating:

Chief Complaint:	Current Medications:
abd. discomfort. … symptoms.	None.

Physical Examination

Fair young lady; A°, apyrexic

… IN°, O, J°,

(Ch) clear P/A Big spleen

… overlying skin.

-Non tender.

Diagnosis: *(please write specific dx and reason for staging)*	Treatment:
I - ?/U UTI	[illegible]

Previous Hospitalisations:	Referral for Admission:
	R/v 2/12.

Provider [illegible]
(Please PRINT Name)

Source: ISS Clinic.

Exhibit 9 *ART-LINC Budget, October 1, 2007–April 30, 2008*

SUB CATEGORY	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Total
	$	$	$	$	$	$	$	$	$
IT Manager	250	468	468	715	715	715	715	715	4,761
Data Entry Specialist		400	400	603	603	603	603	603	3,815
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Data Entry Specialist	250	338	338	495	495	495	495	495	3,401
Patient Tracker		204	204	204	267	267	267	267	1,680
Recepitionist Nusre							344	344	688
Records Assistant				63	63	63	63	63	315
Records Assistant			63	63	63				189
Records Assistant					63	63	63	63	252
Total - Salaries	**1,750**	**3,100**	**3,163**	**4,618**	**4,744**	**4,681**	**5,025**	**5,025**	**32,106**
Health Insurance for 20 pple	-	690	-	-	-	-	-	1,789	**2,479**
Total - Benefits	**-**	**690**	**-**	**-**	**-**	**-**	**-**	**1,789**	**2,479**
TOTAL PERSONNEL	**1,750**	**3,790**	**3,163**	**4,618**	**4,744**	**4,681**	**5,025**	**6,814**	**34,585**
Communication								136	136
Travel		213							213
Study Supplies	527	729		530				206	1,992
8% Indirects	3,024								3,024
TOTAL OPERATIONS	**3,551**	**942**	**-**	**530**	**-**	**-**	**-**	**342**	**5,365**
GRAND TOTAL	**5,301**	**4,732**	**3,163**	**5,148**	**4,744**	**4,681**	**5,025**	**7,156**	**39,950**

Source: ISS Clinic.

Exhibit 10 *WHO Budget*

BUDGET ITEM	ITEM QUANTITY	TOTAL COST
Server	1	6,813.00
Uninterruptable power supply (UPS)	1	2,375.00
Generator	1	19,800.00
Photocopier	1	9,255.00
Printer	1	2,260.00
Desktop computer	5	6,100.00
Local area network (LAN)	1	9,346.00
Laptop	1	1,502.00
Internet bandwidth	12	9,600.00
Antivirus software	1	2,500.00
Intercom system	1	4,000.00
PC blower (fan to cool computers)	1	300.00
Flash drives	10	500.00
Toner for printer	12	2,175.00
Ink cartridges for photocopier	12	1,840.00
Chairs	5	212.00
Desks	1	270.00
Photocopying paper and stamps	50	890.00
Volt-ampere (VA) power voltage regulator	1	200.00
Extension cables	2	62.00
TOTAL		**80,000.00**

Source: ISS Clinic.

Exhibit 11a *Initial Adult Patient Encounter Form, Developed May 2008 (page 1 of 4)*

Version: May 08, 2008 **ISS CLINIC ADULT INITIAL ENCOUNTER FORM** **Date of visit:** / /

Patient ID:		**ART Number:**	
Surname:		**Other names:**	
Patient Category:	☐ New ☐ Transfer in		
Treat category:	☐ N/A ☐ Orphan caretaker ☐ Health worker ☐ Poor woman ☐ Pregnant ☐ Widow ☐ Spouse of poor woman ☐ JCRC transfer ☐ Other:		
Sex:	☐ Male ☐ Female	**Date of birth** (dd/mm/yy): / /	or **Age:**
Patient address:	District:	Sub County/Division:	
	Parish/Ward:	Village/LC1:	
	Phone number:	Landlord Name:	
Treatment Supporter:	Surname: Other name: Phone no.:		
	Relation to patient: ☐ Spouse ☐ Other family member ☐ Friend ☐ Other:		
Education:	☐ none **Primary:** O entered O completed **Secondary:** O entered O completed **Tertiary:** O entered O completed		
Occupation:	☐ Unemployed ☐ Student ☐ Civil servant ☐ Business ☐ Armed forces ☐ Farmer ☐ Other:		
Tribe:	☐ Kiga ☐ Nkole ☐ Hima ☐ Ganda ☐ Toro ☐ Konjo ☐ Other:		
Religion:	☐ Catholic ☐ Protestant ☐ Moslem ☐ Other:		
Monthly income:	☐ <100,000 ☐ 100,000 - 250,000 ☐ 250,001 - 500,000 ☐ >500,000		
Do you have piped/tap water inside your home?	☐ Yes ☐ No		
Care entry point:	☐ RTC (#_____) O Outpatient O Inpatient O TB Ward ☐ PMTCT ☐ AIC ☐ TASO ☐ CBO ☐ Private ☐ Self Referral ☐ Other:		
Time needed to reach clinic today:	☐ less than 30 minutes ☐ 30-60 minutes ☐ 1-2 hrs ☐ 2-3 hours ☐ 3-4 hours ☐ 4-5 hours ☐ 5-6 hours ☐ > 6 hours		
For men: Are you circumcised?	☐ Yes ☐ No ***If yes, at what age?***	***If no, would you consider?*** ☐ Yes ☐ No	
Date of first positive HIV test:	(mm/yyyy) /		
Where was the test done?	☐ AIC ☐ Government facility ☐ Private facility ☐ Other		
Is it okay for a member of this clinic to confidentially look for you in case you do not return for care in future? ☐ Yes ☐ No			

Family Status

Current marital status:	☐ Single ☐ Separated ☐ Divorced ☐ Widowed ☐ Married **For men if married: How many wives do you have?**:		
HIV status of spouse(s):	☐ N/A ☐ At least one Positive ☐ All Negative ☐Unknown		
Discordance	Any sexually partners in last 4 weeks known to be HIV negative? ☐ Yes ☐ No		
Have you disclosed your status to anyone?	☐ No ☐Yes, *if yes* ***whom*** *(mark all the apply):* ☐ Spouse ☐ Other sexual partner ☐ Friend ☐ Brother/Sister ☐ Parent ☐ Other:		
No. of biological children still living:	**No. HIV-positive biological children < 18 years still living**:		
Other than patient, how many people in household including children at school?	**No. HIV-positive:**	**No. HIV status is unknown:**	
	No. HIV-positive and in care:	**No. under 5 years:**	

	Names	Age	Relationship	Clinic where cared for
House-hold members in HIV care:				

Are you/your partner using any form of family planning (mark all that apply)? ☐ N/A (not sexually active) ☐ none
☐ Oral contraceptive pill ☐ Condoms ☐ Natural family planning / rhythm ☐ Sterilization/hysterectomy
☐ Diaphragm/cervical cap ☐ IUD ☐ Injectible hormones (e.g. Depo-provera, Norplant) ☐ Other:

Alcohol Use Questions (AUDIT-3)

How often did you have a drink containing alcohol in the last year?
☐ Never ☐ Monthly or less ☐ 2 to 4 times a month
☐ 2 to 3 times a week ☐ 4 to 5 times a week ☐ 6 or more times a week

How many drinks containing alcohol did you have on a typical day when you were drinking in the past year?
☐ 0 drinks ☐ 1 to 2 drinks ☐ 3 to 4 drinks
☐ 5 to 6 drinks ☐ 7 to 9 drinks ☐ 10 or more drinks

How often did you have six or more drinks on one occasion in the past year?
☐ Never ☐ Less than monthly ☐ Monthly ☐ Weekly ☐ Daily or almost daily

Counselor's name: **Counselor's signature:**

Exhibit 11b *Initial Adult Patient Encounter Form, Developed May 2008 (page 4 of 4)*

WHO STAGE 4

Pre	Cur		Pre	Cur	
☐	☐	Wasting Syndrome	☐	☐	Atypical leishmaniasis
☐	☐	Extrapulmonary TB (includes treatment phase)	☐	☐	Lymphoma (includes treatment phase)
☐	☐	Oral or genital ulcers (HSV) > 1 month duration	☐	☐	Recent septicemia
☐	☐	CMV retinitis or CMV in other organ system	☐	☐	Recurrent bacterial pneumonia
☐	☐	PCP pneumonia	☐	☐	HIV encephalopathy
☐	☐	Esophageal candidiasis	☐	☐	Progressive multifocal leukoencephalopathy
☐	☐	Kaposi's sarcoma (includes treatment phase)	☐	☐	Disseminated non-tuberculous mycobacteria
☐	☐	CNS toxoplasmosis	☐	☐	Cryptosporidiosis or isosporiasis
☐	☐	Cryptococcal meningitis/disseminated (inc treatment phase)	☐	☐	Disseminated mycosis
☐	☐	Invasive cervical cancer	☐	☐	Symptomatic HIV-nephropathy, cardiomyopathy

Other Diagnoses for Current Problem List	1.	2.
	3.	4.
	5.	6.

PLAN

ARV Plan:	**Reason** (tick all applicable)
☐ **Continue current**	
☐ **No ARV's**	☐ no indication Indicated, but: ☐ defer until TB treatment ☐ patient refusal ☐ on hold for toxicity wash-out ☐ adherence concerns ☐ stockout ☐ no available active drugs ☐ supporter pending ☐ counseling ongoing
☐ **Start initial regimen** ☐ **Re-start** ☐ **Book** →	☐ Clinical ☐ CD4(_____) ☐TLC(_____) ☐ pMTCT ☐ PEP ☐ Other:
☐ **Switch** ☐ **Stop** →	**Failure:** ☐ clinical failure ☐ immunologic failure ☐ virologic failure **Toxicity:** ☐ anemia/neutropenia ☐ nausea/vomiting ☐ diarrhea ☐ liver toxicity ☐ peripheral neuropathy ☐ sleep disturbance ☐ lipodystrophy ☐ rash ☐ dizziness **Misc:** ☐ poor adherence ☐ pregnancy ☐ stockout ☐ new TB tx ☐ finished pMTCT ☐ Other, specify:

ARV Regimen:	☐ AZT (zidovudine)	☐ CBV (AZT/3TC)	☐ NVP (nevirapine)	☐ Atripla (EFV/TDF/FTC)
	☐ 3TC (lamivudine)	☐ ABC (abacavir)	☐ EFV (efavirenz)	☐ Other:
	☐ D4T 30 (stavudine)	☐ Tenofovir (TDF)	☐ Kaletra (lopinivir/ritonivir or Aluvia)	
	☐ DDI (didanosine)	☐ Truvada (TDF/FTC)	☐ Triomune 30 (D4T/AZT/NVP)	

Provider: ☐ MOH ☐ MJAP ☐ TREAT ☐ FTF ☐ TASO ☐ Other:

Counseling Plan

☐ None ☐ First Pre ART ☐ Second Pre ART ☐ Adherence/ongoing ☐ Psychosocial ☐ Other

OI Plan:		
	PCP	☐ none ☐ septrin proph ☐ dapsone proph ☐ septrin tx ☐ other: ☐ stop (Why?:O improvement O toxicity)
	TB	☐ none ☐ SRHZE ☐ RHZE ☐ EH ☐ RHE ☐ RH ☐ INH ☐ other: ☐ stop
	CCM	☐ none ☐ diflucan prop ☐ diflucan tx ☐ other: ☐ stop (Why?:O improvement O toxicity)

Other Medications:	1.	2.
	3.	4.
	5.	6.

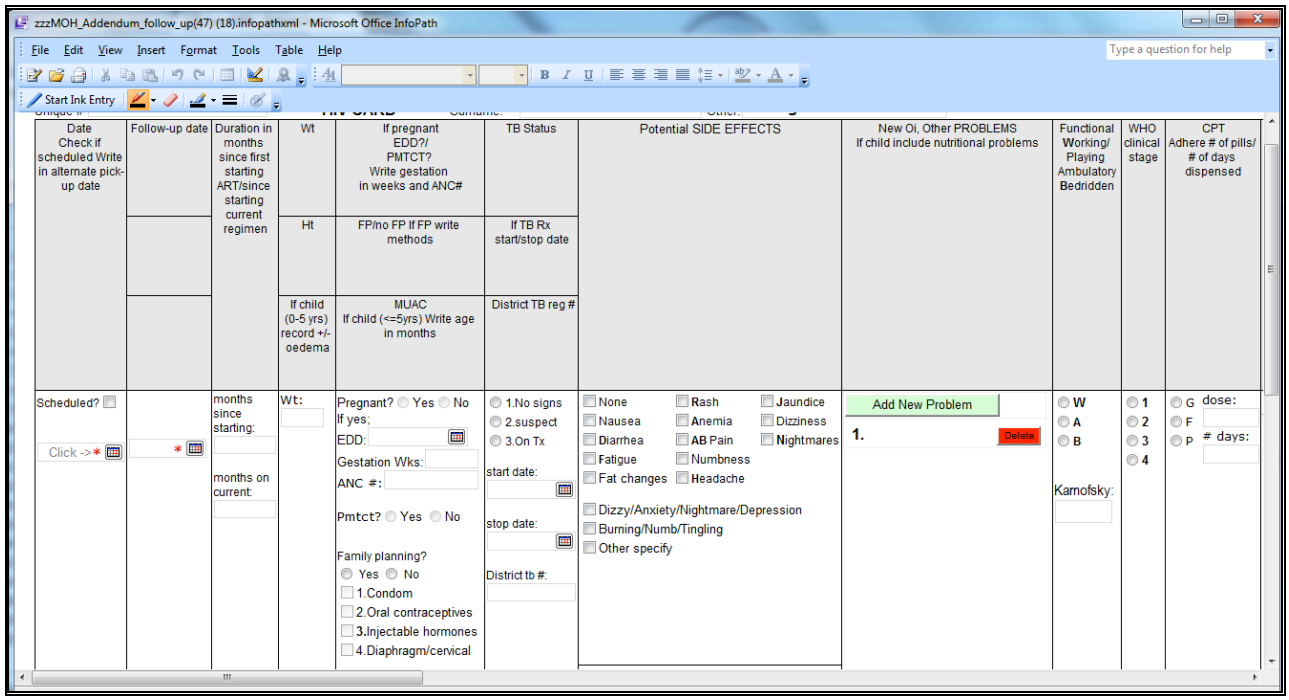
Tests ordered: ☐ CD4 ☐ Viral load ☐ creatinine ☐ ALT/AST/ALP ☐ CXR ☐ sputum AFB ☐ CBC ☐ urine HCG ☐ urinalysis ☐ RPR/VDRL ☐ stool ☐ lipid profile ☐ Others:

Transferred out: ☐ no ☐ yes: transferred to:
Referred: ☐ no ☐ yes: referred to:
Admission: ☐ none ☐ medical ward ☐ TB ☐ OBS/GYN ☐ psychiatry ☐ emergency ☐ surgical

Next scheduled appointment date: / / **Provider name:**

Source: ISS Clinic.

Exhibit 12 *Screenshot of an Electronic Form in OpenMRS, ISS Clinic*



Source: ISS Clinic.

Exhibit 13 *Sample Patient Summary Sheet*

Mbarara University Of Science & Technology
Department Of Internal Medicine
P.O Box 1410 Mbarara Uganda
Tel. 256-485-21623 Fax. 256-485-20782

Mbarara Regional Referral Hospital
P.O Box 40 Mbarara Uganda
Tel. 256-485-20007

John, Doe **Clinic Id: XXXX-XX-XXXX**

Female, 36yrs Art number: KK-YYYY

Address: Rwakirore, Kikokwa, Birere, Isingiro

Last seen on: *18 Jun 2008 by: Jane, Jones*

Who stage: **Toxicities:** **Current art regimen:**
Tb status: **Other drugs:** AZT/3TC/NVP
Other diagnoses: **Previous Regimen(s):**
Allergies: **Duration(months):** 49/49

First line Substitution(s)	
Date	*Reason*

Second line Substitution(s)	
Date	*Reason*

VITALS				
	Weight	**Temperature**	**Blood Pressure**	**Karnofsky score**
Enrollment *27 Feb 2007*	46	37.7	100/60	90
Art start *24 Apr 2007*	58	36.5	110/80	90
12 Mar 2008	62	36.1	100/80	80
30 Apr 2008	55	36.4	88/53	90
18 Jun 2008	62	36.2	80/60	80

LABORATORY RESULTS		
CD4	**Haemoglobin**	**Viral load**
147 *27 Feb 2007* 87 *23 Jan 2008*	8.2 *27 Mar 2007* 10 *23 Jan 2008*	

OPPORTUNISTIC INFECTION MEDICATIONS		
Drug	**Start date**	**Stop date**
Cpt/Dapsone	27 Feb 2007	
Fluconazole		
Tb rx		

Alert! Please Repeat Cd4!

Printed on: May 23, 2011 9:10 AM

Source: ISS Clinic.

Exhibit 14a *Results of Mbarara Time-Motion Study: Providers*

Measure	Before Summaries	After Summaries	Before–After Difference
Number of physicians	3	3	0
Number of clinic hours/day	6.5	6.4	−0.1
Number of patients/day	41	44	3
Direct patient care (%)*	25.7	34.6	8.9
Indirect patient care (%)	35.6	33.2	−2.4
Administration (%)	6.0	8.8	2.8
Personal (%)	14.5	13.3	−1.2
Miscellaneous (%)	16.7	6.6	−10.1
Waiting (%)	1.4	3.4	2.0

*Time is measured in percent of a provider's workday. No between group differences were statistically significant (p-value <0.05)

Exhibit 14b *Results of Mbarara Time-Motion Study: Patients*[*]

Measure	Before Summaries n = 88	After Summaries n = 94	Before-After Difference
Time in registration	1.2	1.0	−0.2
Time with clinicians	7.7	6.4	−0.7
Time with other staff	42.3	61.3	+19.0
Time with pharmacy	1.7	11.6	+9.9
Miscellaneous activities	22.9	17.9	−5.0
Waiting	121.9	88.0	−33.9
Waiting for registration	0.3	0.0	−0.3
Waiting for clinicians	45.1	44.5	−0.6
Waiting for other staff	52.4	28.9	− 23.5
Waiting for pharmacy	24.1	14.6	−9.5
Total visit time	197.7	186.2	−11.5

[*]Time is measured in minutes per patient visit observed. Statistically significant differences (p-value <0.05) are indicated by shading.

Source: Were M, Shen C, Bwana M, et al. Creation and evaluation of EMR-based paper clinical summaries to support HIV-care in Uganda, Africa. *International Journal of Medical Informatics*. 2010;79:90-96.

Exhibit 15a *Provider Satisfaction with Clinical Summaries*

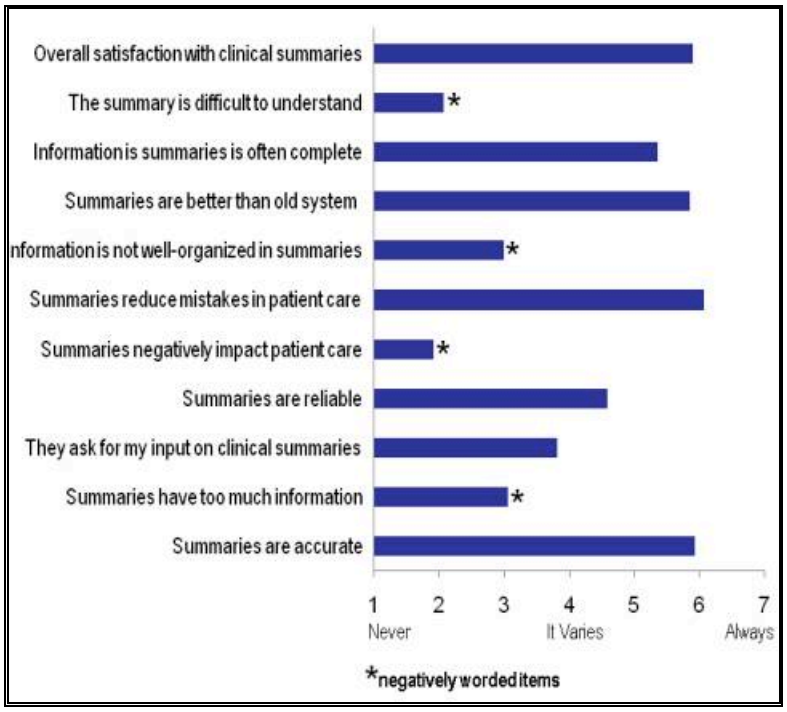
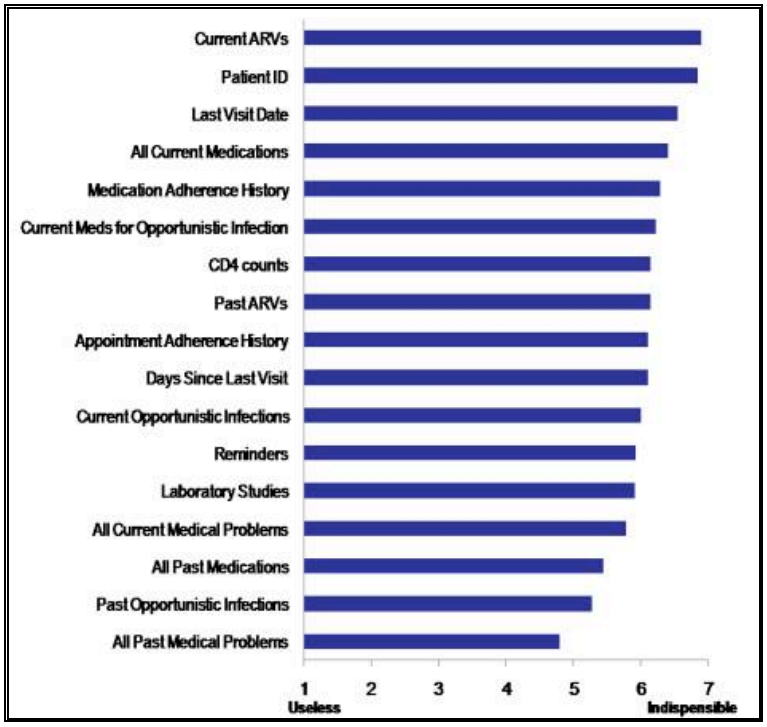
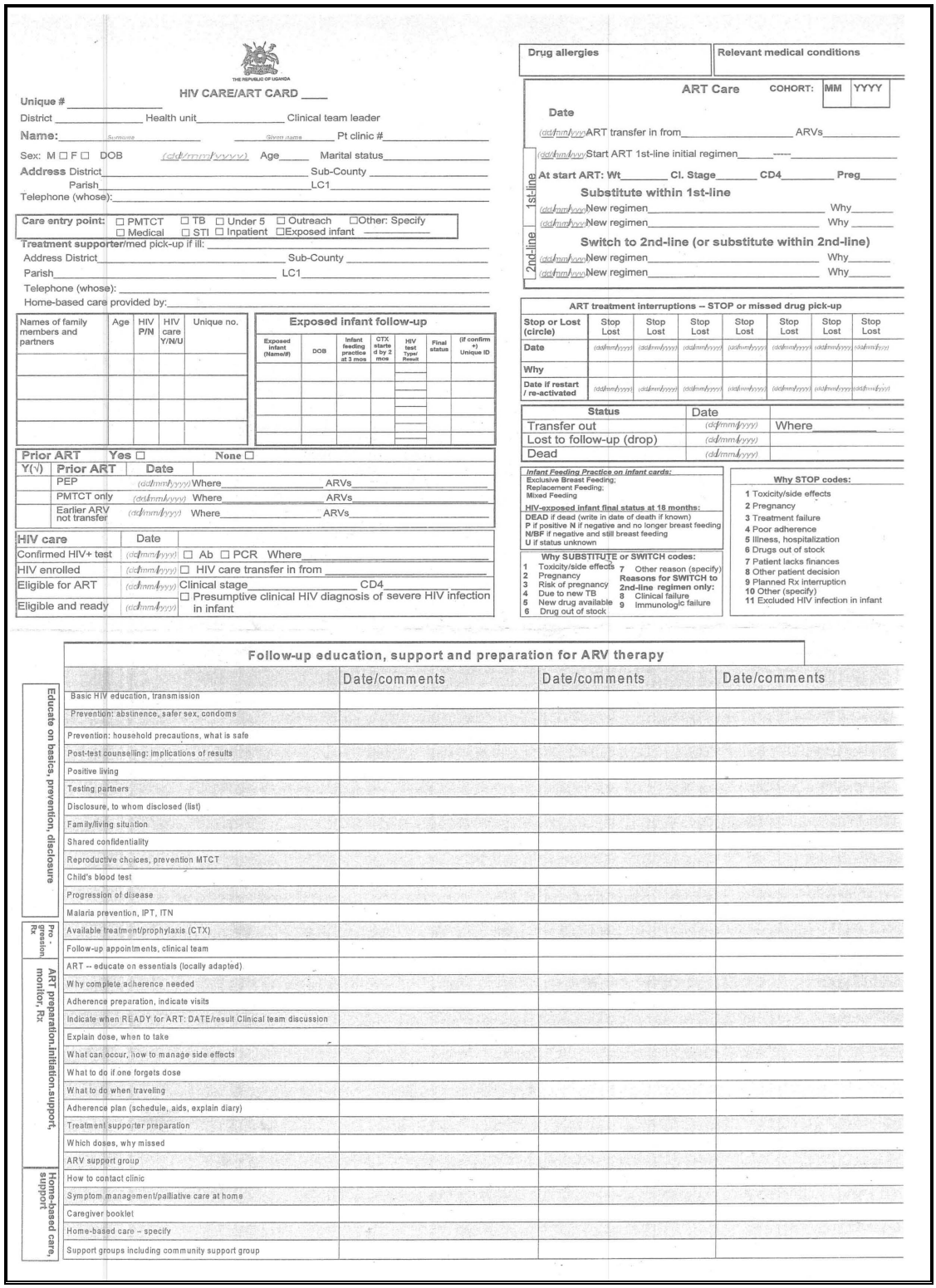


Exhibit 15b *Desirability of Elements in Clinical Summaries Among Practitioners*



Source: Were M, Shen C, Bwana M, et al. Creation and evaluation of EMR-based paper clinical summaries to support HIV-care in Uganda, Africa. *International Journal of Medical Informatics*. 2010;79:90–96.

Exhibit 16a *Ministry of Health's HIV ART Form, August 2009, page 1 of 2*



HIV CARE/ART CARD ____

Unique # _____

District _____ Health unit_____ Clinical team leader

Name:_____ Surname _____ Given name _____ Pt clinic #_____

Sex: M ☐ F ☐ DOB (dd/mm/yyyy) Age_____ Marital status_____

Address District_____ Sub-County _____

Parish_____ LC1_____

Telephone (whose):_____

Care entry point: ☐ PMTCT ☐ TB ☐ Under 5 ☐ Outreach ☐Other: Specify ☐ Medical ☐ STI ☐ Inpatient ☐Exposed infant _____

Treatment supporter/med pick-up if ill: _____

Address District_____ Sub-County _____

Parish_____ LC1_____

Telephone (whose): _____

Home-based care provided by:_____

Names of family members and partners	Age	HIV P/N	HIV care Y/N/U	Unique no.

Exposed infant follow-up

Exposed infant (Name/#)	DOB	Infant feeding practice at 3 mos	CTX started by 2 mos	HIV test Type/ Result	Final status	(If confirm +) Unique ID

Prior ART Yes ☐ None ☐

Y(√)	Prior ART	Date	
	PEP	(dd/mm/yyyy)	Where_____ ARVs_____
	PMTCT only	(dd/mm/yyyy)	Where_____ ARVs_____
	Earlier ARV not transfer	(dd/mm/yyyy)	Where_____ ARVs_____

HIV care	Date	
Confirmed HIV+ test	(dd/mm/yyyy)	☐ Ab ☐ PCR Where_____
HIV enrolled	(dd/mm/yyyy)	☐ HIV care transfer in from _____
Eligible for ART	(dd/mm/yyyy)	Clinical stage_____ CD4_____
Eligible and ready	(dd/mm/yyyy)	☐ Presumptive clinical HIV diagnosis of severe HIV infection in infant

Drug allergies | **Relevant medical conditions**

ART Care COHORT: MM YYYY

Date

(dd/mm/yyyy) ART transfer in from_____ ARVs_____

(dd/mm/yyyy) Start ART 1st-line initial regimen_____-----_____

1st-line

At start ART: Wt_____ **Cl. Stage**_____ **CD4**_____ **Preg**_____

Substitute within 1st-line

(dd/mm/yyyy) New regimen_____ Why_____

(dd/mm/yyyy) New regimen_____ Why _____

2nd-line

Switch to 2nd-line (or substitute within 2nd-line)

(dd/mm/yyyy) New regimen_____ Why_____

(dd/mm/yyyy) New regimen_____ Why_____

ART treatment interruptions -- STOP or missed drug pick-up

Stop or Lost (circle)	Stop Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost
Date	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)
Why							
Date if restart / re-activated	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)	(dd/mm/yyyy)

Status	Date	
Transfer out	(dd/mm/yyyy)	Where_____
Lost to follow-up (drop)	(dd/mm/yyyy)	
Dead	(dd/mm/yyyy)	

Infant Feeding Practice on infant cards:
Exclusive Breast Feeding;
Replacement Feeding;
Mixed Feeding

HIV-exposed infant final status at 18 months:
DEAD if dead (write in date of death if known)
P if positive **N** if negative and no longer breast feeding
N/BF if negative and still breast feeding
U if status unknown

Why SUBSTITUTE or SWITCH codes:
1 Toxicity/side effects
2 Pregnancy
3 Risk of pregnancy
4 Due to new TB
5 New drug available
6 Drug out of stock
7 Other reason (specify)
Reasons for SWITCH to 2nd-line regimen only:
8 Clinical failure
9 Immunologic failure

Why STOP codes:
1 Toxicity/side effects
2 Pregnancy
3 Treatment failure
4 Poor adherence
5 Illness, hospitalization
6 Drugs out of stock
7 Patient lacks finances
8 Other patient decision
9 Planned Rx interruption
10 Other (specify)
11 Excluded HIV infection in infant

Follow-up education, support and preparation for ARV therapy

		Date/comments	Date/comments	Date/comments
Educate on basics, prevention, disclosure	Basic HIV education, transmission			
	Prevention: abstinence, safer sex, condoms			
	Prevention: household precautions, what is safe			
	Post-test counselling: implications of results			
	Positive living			
	Testing partners			
	Disclosure, to whom disclosed (list)			
	Family/living situation			
	Shared confidentiality			
	Reproductive choices, prevention MTCT			
	Child's blood test			
	Progression of disease			
	Malaria prevention, IPT, ITN			
Pre-progression Rx	Available treatment/prophylaxis (CTX)			
	Follow-up appointments, clinical team			
ART preparation, initiation, support, monitor, Rx	ART -- educate on essentials (locally adapted)			
	Why complete adherence needed			
	Adherence preparation, indicate visits			
	Indicate when READY for ART: DATE/result Clinical team discussion			
	Explain dose, when to take			
	What can occur, how to manage side effects			
	What to do if one forgets dose			
	What to do when travelling			
	Adherence plan (schedule, aids, explain diary)			
	Treatment supporter preparation			
	Which doses, why missed			
	ARV support group			
Home-based care, support	How to contact clinic			
	Symptom management/palliative care at home			
	Caregiver booklet			
	Home-based care – specify			
	Support groups including community support group			

Exhibit 16b *Ministry of Health's HIV ART Form, August 2009, page 2 of 2*

Unique # ☐☐☐☐☐☐☐ **HIV CARE/ART CARD** Name____________________

Date Check if scheduled. Write in alternate pick-up if ill	Follow-up date	Duration in months since first starting ART/ since starting current regimen	Wt Ht If child (0-5yrs) record +/- oedema	If Pregnant EDD? PMTCT? Write gestation in weeks and ANC # FP /no FP If FP write method(s) MUAC If child Write age in months if ≤5 yrs	TB status If TB Rx, start /stop date (mm/yyyy) and District TB reg #	Potential SIDE EFFECTS	New OI, Other PROBLEMS If child, include nutritional problems	Functional Work/ Playing Amb Bed	WHO clinical stage	CPT Adhere Dose/# of days Dispensed	Other meds dispensed (including nutritional supplements/ RUTF)	ARV drugs (incl. prophylaxis) Adhere/ Why	Regimen/ Dose/ # of days dispensed	Investigations CD4 If < 5, record CD4% +/- severe	Hgb, RPR, CXR, TB sputums, Infant Ab/PCR, other	Refer or consult or link/provide (including nutritional support and infantfeeding) If hospitalized, # of days	Name of attending clinician
☐			Wt Ht Oedema		TB Status mm/yy Reg No.							ADH Why	REGIMEN DOSE No. of Days				
☐			Wt Ht Oedema		TB Status mm/yy Reg No.							ADH Why	REGIMEN DOSE No. of Days				
☐			Wt Ht Oedema		TB Status mm/yy Reg No.							ADH Why	REGIMEN DOSE No. of Days				
☐			Wt Ht Oedema		TB Status mm/yy Reg No.							ADH Why	REGIMEN DOSE No. of Days				
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☐			Wt Ht Oedema		TB Status mm/yy Reg No.							ADH Why	REGIMEN DOSE No. of Days				

Pregnancy/family planning status if woman is of childbearing age:
P = Pregnant
If pregnant, give estimated due date (EDD), write PMTCT if referred to PMTCT and record gestational age in weeks and ANC #
FP= Not pregnant and on family planning
If using FP, note methods (note: more than 1 method may be recorded)
No FP = Not pregnant and not using FP

Codes for TB status (check on each visit):
1 No signs = no signs or symptoms of TB
2 Suspect = TB refer or sputums sent (Record sputum sent & results in lab column; record referral in Refer col)
3 TB Rx = currently on TB treatment. Record
i) month/year started and stopped and
ii)district TB reg #
(Record INH in INH col and TB treatment regimen in Other meds col)

Nutritional support and infant feeding:
Therapeutic Feeding
Infant Feeding Counselling (if <2 yrs)
Nutrition Counselling only (if > 2yrs)
Food Support

problems:
Nausea | Rash | Headache
Diarrhoea | Anaemia | Jaundice
Fatigue | ABdominal pain | FAT changes
BN burning/numb/tingling
CNS: dizzy, anxiety, nightmare, depression
Other (specify)

Codes for Family Planning
1 Condoms
2 Oral Contraceptive pills
3 Injectable / Implantable hormones e.g (depoprovera)
4 Diaphram / Cervical Cap
5 Intra uterine device (IUD)
6 Vasectomy/ tubal ligation/ hysterectomy

Codes for new OI or other problems:
Zoster
Pneumonia
DEmentia/Enceph
Thrush—oral/vaginal
COUGH*
FEVER*
DB difficult breathing
Weight loss*
UD urethral discharge
PID pelvic inflammatory disease
Ulcers—mouth or other ___
GUD genital ulcer disease
IRIS Immune reconstitution inflammatory syndrome
Symptoms with * are suggestive of TB

Ok - **Green**
Moderate Acute Malnutrition - **Yellow**
Severe Acute Malnutrition - **Red**
Severe Acute Malnutrition with Oedema

Poor Weight Gain/ Poor Appetite

Codes for CTX/ART adherence:
% Adhere = no. of pills taken: x 100 / Total no. of pills expected to have been taken
(Add all the drugs in the regimen)

		Missed doses per month	
Adherence	%	1x daily dosing	2x daily dosing
G(good)	≥ 95%	<2 doses	≤ 3 doses
F(fair)	85-94%	2-4 doses	4-8 doses
P(poor)	< 85%	≥ 5 doses	≥ 9 doses

Codes for why poor/ fair adherence:
1 Toxicity/side effects
2 Share with others
3 Forgot
4 Felt better
5 Too ill
6 Stigma, disclosure or privacy issues
7 Drug stock out
8 Patient lost/ran out of pills
9 Delivery/travel problems
10 Inability to pay
11 Alcohol
12 Depression
13 Pill burden
14 Lack of food
15 Other (specify)

Source: ISS Clinic.

Exhibit 17 *Peer-Reviewed Articles from ISS Clinic, 2006–2010*

1. Andia I, Kaida A, Maier M, Guzman D, Emenyonu N, Pepper L, et al. Highly active antiretroviral therapy and increased use of contraceptives among HIV-positive women during expanding access to antiretroviral therapy in Mbarara, Uganda. *Am J Public Health*. 2009 Feb;99(2):340–347.
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17. Tuller DM, Bangsberg DR, Senkungu J, Ware NC, Emenyonu N, Weiser SD. Transportation costs impede sustained adherence and access to HAART in a clinic population in southwestern Uganda: a qualitative study. *AIDS Behav*. 2010 Aug;14(4):778–784.
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Exhibit 17b *Abstracts of Select Articles Emerging from ISS Clinic*

Antiretroviral Initiation Among HIV-Infected ART-Eligible Patients in Uganda (2010)

Background: The impact of flat-line funding in the global scale up of antiretroviral therapy (ART) for HIV-infected patients in Africa has not yet been well described.

Methods: We evaluated ART-eligible patients and patients starting ART at a prototypical scale up ART clinic in Mbarara, Uganda between April 1, 2009, and May 14, 2010, where four stakeholders sponsor treatment—two PEPFAR implementing organizations, the Ugandan Ministry of Health-Global Fund (MOH-GF) and a private foundation named the Family Treatment Fund (FTF). We assessed temporal trends in the number of eligible patients, the number starting ART and tabulated the distribution of the stakeholders supporting ART initiation by month and quartile of time during this interval. We used survival analyses to assess changes in the rate of ART initiation over calendar time.

Findings: A total of 1,309 patients who were eligible for ART made visits over the 14 month period of the study and of these 819 started ART. The median number of ART-eligible patients each month was 88 (IQR: 74 to 115). By quartile of calendar time, PEPFAR and MOH sponsored 290, 192, 180, and 49 ART initiations, whereas the FTF started 1, 2, 1 and 104 patients, respectively. By May 2010 (the last calendar month of observation) FTF sponsored 88% of all ART initiations. Becoming eligible for ART in the 3rd (HR = 0.58, 95% 0.45–0.74) and 4th quartiles (HR = 0.49, 95% CI: 0.36–0.65) was associated with delay in ART initiation compared to the first quartile in multivariable analyses.

Interpretation: During a period of flat-line funding from multinational donors for ART programs, reductions in the number of ART initiations by public programs (i.e., PEPFAR and MOH-GF) and delays in ART initiation became apparent at the a large prototypical scale-up ART clinic in Uganda.

Tracking a Sample of Patients Lost to Follow-up Has a Major Impact on Understanding Determinants of Survival in HIV-Infected Patients on Antiretroviral Therapy in Africa (2010)

Objective: To date, data regarding the determinants of mortality in HIV-infected patients starting antiretroviral therapy (ART) in Africa have been primarily derived from routine clinical care settings practicing the public health approach. Losses to follow-up, however, are high in these settings and may lead to bias in understanding the determinants of mortality.

Methods: We evaluated HIV-infected adults initiating ART between January 1, 2004 and September 30th, 2007 in an ART clinic in southwestern Uganda. Clinical and demographic characteristics were obtained through routine clinical care. In evaluating determinants of mortality, a 'naïve' analysis used only deaths known through routine processes. A 'sample-corrected' approach incorporated, through probability weights, outcomes from a representative sample of patients lost to follow-up whose vital status was ascertained through tracking in the community.

Results: In 3,628 patients followed for up to 3.75 years after ART initiation, the "naïve" approach identified male sex and lower pre-ART CD4 count as independent determinants of mortality. The "sample-corrected" approach found lower pre-ART CD4 count, older age, lower weight and calendar year of ART initiation, but not male sex, to be independent determinants of mortality.

Conclusions: Analyses to identify determinants of mortality in HIV-infected patients on ART in Africa that do not account for losses to follow-up can identify spurious associations and miss actual relationships—both with the potential to mislead public health efforts. A sampling-based approach to account for losses to

follow-up represents a feasible and potentially scalable method to strengthen the evidence available for implementation of ART delivery in Africa.

Understanding Reasons for and Outcomes of Patients Lost to Follow-Up in Antiretroviral Therapy Programs in Africa Through a Sampling-Based Approach (2010)

Objectives: Losses to follow-up after initiation of antiretroviral therapy (ART) are common in Africa and are a considerable obstacle to understanding the effectiveness of nascent treatment programs. We sought to characterize, through a sampling-based approach, reasons for and outcomes of patients who become lost to follow-up.

Design: Cohort study.

Methods: We searched for and interviewed a representative sample of lost patients or close informants in the community to determine reasons for and outcomes among lost patients.

Results: Three thousand six hundred twenty-eight HIV-infected adults initiated ART between January 1, 2004 and September 30, 2007 in Mbarara, Uganda. Eight hundred twenty-nine became lost to follow-up (cumulative incidence at 1, 2, and 3 years of 16%, 30%, and 39%). We sought a representative sample of 128 lost patients in the community and ascertained vital status in 111 (87%). Top reasons for loss included lack of transportation or money and work/child care responsibilities. Among the 111 lost patients who had their vital status ascertained through tracking, 32 deaths occurred (cumulative 1-year incidence 36%); mortality was highest shortly after the last clinic visit. Lower pre-ART CD4+ T-cell count, older age, low blood pressure, and a central nervous system syndrome at the last clinic visit predicted deaths. Of patients directly interviewed, 83% were in care at another clinic and 71% were still using ART.

Conclusions: Sociostructural factors are the primary reasons for loss to follow-up. Outcomes among the lost are heterogeneous: both deaths and transfers to other clinics were common. Tracking a sample of lost patients is an efficient means for programs to understand site specific reasons for and outcomes among patients lost to follow-up.

Source: Abstracts reproduced from bold sources cited in Exhibit 17a.

Appendix *Abbreviations*

AMPATH	Academic Model Providing Access to Healthcare
AMRS	AMPATH Medical Record Systems
ART	antiretrovital therapy
ARV	antiretroviral
DOTS	directly observed treatment, short-course
EMR	electronic medical record
FTF	Family Treatment Fund
IDRC	Canadian International Development Research Centre
IeDEA	International Epidemiologic Databases to Evaluate AIDS
ISS	Immune Suppression Syndrome
IT	information technology
JCRC	Joint Clinical Research Centre
MGH	Massachusetts General Hospital
MJAP	Mulago–Mbarara Joint AIDS Program
MOH	Ministry of Health
MUST	Mbarara University of Science and Technology
OpenMRS	Open Medical Record System
PEPFAR	President's Emergency Plan for AIDS Relief [US]
UCSF	University of California, San Francisco

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