

Accepted: July 22, 2011

# Improvement of Service Capabilities Following the Establishment of an Electronic Database to Evaluate AIDS in Central Africa

Jamie NEWMAN<sup>a</sup>, Pablo TORRES<sup>b</sup>, Innocent AZINYUE<sup>c</sup>, Jennifer HEMINGWAY-FODAY<sup>a</sup>, Joseph ATIBU<sup>d</sup>, Wilfred AKAM<sup>e</sup>, Ashu BALIMBA<sup>f</sup>, Lucien KALENGA<sup>g</sup>, Marcel MBAYA<sup>h</sup>, Henri MUKUMBI<sup>i</sup>, Théodore NIYONGABO<sup>j</sup>, Brigitte MFANGAM MOLU<sup>k</sup>, Godfrey WOELK<sup>a</sup>

<sup>a</sup>Statistics and Epidemiology, RTI International, Research Triangle Park, NC, USA <sup>b</sup>International Development Group, RTI International, Research Triangle Park, NC,

USA

<sup>c</sup>Vindata Solutions, Yaoundé, Cameroon <sup>d</sup>Ecole de Santé Publique, Kinshasa, DRC <sup>e</sup>Limbé Provincial Hospital, Limbé, Cameroon <sup>f</sup>Hôpital Militaire, Yaoundé, Cameroon <sup>g</sup>AMO-Congo, Lubumbashi, DRC <sup>h</sup>AMO-Congo, Matadi, DRC <sup>i</sup>AMO-Congo, Kinshasa, DRC <sup>j</sup>Centre Hospitalo-Universitaire de Kamenge, Bujumbura, Burundi <sup>k</sup>Hôpital Général de Yaoundé, Yaoundé, Cameroon

Abstract. Background: HIV care and treatment scale up has, in some instances, resulted in the development of electronic health records that have improved service delivery in resource-constrained settings. The International Epidemiological Databases to Evaluate HIV/AIDS (IeDEA) has enabled the establishment of a network of local site investigators and solid research infrastructure in participating regions through the creation of an international research consortium to address unique and evolving research questions in HIV/AIDS currently unanswerable by single cohorts.

Objectives: We provide an example of how establishing an electronic database to evaluate HIV/AIDS in the Central Africa region has improved service capabilities and patient care.

Methods: The IeDEA Central Africa region cohort includes adult data from 10 HIV treatment centers and pediatric data from four treatment centers in Burundi, Cameroon, and the Democratic Republic of Congo (DRC). Three research tools were developed while establishing the cohort: data collection forms, an electronic data management system and an accompanying reporting instrument.

Results: Data have been collected from 19,200 HIV-positive adults and from 470 HIV-positive children. Though unintended by research objectives, many participating health facilities independently decided to adopt the IeDEA Central Africa region research forms and accompanying electronic data management system (DMS) as their routine patient medical record system.



Accepted: July 22, 2011

Conclusions: The creation of clinical data forms, an electronic data management system and an accompanying reporting instrument have improved patient management, continuity of care and capability to fulfill reporting requirements. The establishment of the IeDEA Central Africa region database has enabled physicians and researchers in this region to establish adult and pediatric cohorts for the purpose of describing regional trends in HIV/AIDS, quickly identify populations at risk for dropping out of care and treatment, and has provided data needed to develop strategies for addressing gaps in behavioral implementation science.

Keywords. Electronic medical records, service capabilities, HIV research information systems

# Introduction

Two-thirds of the estimated 33 million people living with HIV/AIDS worldwide reside in Sub-Saharan Africa, making it the most affected region in the world [1]. International and local agencies have rallied around the need to scale up HIV care and treatment, which in some instances has resulted in the development of electronic health records that have improved service delivery in resource-constrained settings hardest hit by the epidemic [2]. According to the Institute of Medicine [3] the use of electronic medical records is essential for health care. Benefits include the potential to improve diagnostic and care decisions, adherence to clinical guidelines, and ability to identify patients that miss appointments. Rotich et al. [4] found that after establishing an electronic medical record system in Kenya, clinic visits were streamlined resulting in less waiting time for patients. In this paper, we provide an example of how establishing an electronic database to evaluate HIV/AIDS in the Central Africa region has improved service capabilities and patient care.

The International Epidemiological Databases to Evaluate HIV/AIDS (IeDEA) is a global initiative funded by the National Institute of Allergy and Infectious Diseases (NIAID) to establish regional centers for the collection and harmonization of HIV-related data. Through IeDEA, a network of local site investigators and solid research infrastructure has been established in participating regions by creating an international research consortium to address unique and evolving research questions in HIV/AIDS currently unanswerable by single cohorts.

The IeDEA Central Africa region consortium, consisting of Burundi, Cameroon, and the Democratic Republic of Congo (DRC), was established by building on existing linkages between local physicians, treatment centers, and organizations in the region. Participation in IeDEA Central Africa has facilitated collaboration between physicians in the region that might not have occurred otherwise at this time due to limited resources, barriers of geographic distance and history of political unrest. The establishment of the IeDEA Central Africa region cohort has enabled us to describe HIV trends in the region, quickly identify populations at risk for dropping out of care and treatment, and has provided data needed to develop strategies for addressing gaps in behavioral implementation science.

Though unintended by research objectives, many health facilities participating in the IeDEA consortium independently decided to adopt the IeDEA Central Africa region research forms and accompanying electronic data management system (DMS) as their routine patient medical record system. This improved the quality, accuracy and completeness of patient data at these facilities. Data are collected and entered at



Accepted: July 22, 2011

participating health facilities into separate pediatric and adult databases and shared with the data coordinating center at RTI International in the United States. The IeDEA Central Africa region database has provided a unique opportunity to examine trends in HIV care and treatment that would otherwise not be possible at this time in this region at this scale.

The purpose of this paper is to describe the process of developing a cohort in the Central Africa region as well as the impact of establishing the cohort on improving service capabilities and patient care. First, we describe the situation at the onset of the project, followed by actions taken to encourage the success of the collaboration. We conclude by illustrating the effect these efforts have had on improving service delivery and patient care while describing how challenges and limitations were addressed.

## Situation at the Beginning of the Project

Prior to the IeDEA project, paper medical records at participating health facilities in the Central Africa region were difficult to read and analyze, with mostly open-ended text questions. The information collected at the clinic during initial and follow-up patient visits was minimal. In addition, patients were tracked manually using hardcopy registers which made it difficult and time consuming to report the number of consultations performed during a given time period, the number of active patients receiving antiretroviral therapy (ART), as well as outcomes such as death and loss-tofollow-up.

The establishment of the IeDEA Central Africa region cohort improved the state and organization of patient medical files. Prior to IeDEA, if a patient's medical file could not be located, the patient was sometimes given a new medical record number. This led to some patients having multiple records and made accurate reporting a challenge. Through participation in IeDEA, health facilities received much needed funding for medical record files and filing cabinets which greatly improved the state of patient records. Clinic staff embraced the need for well organized patient files once the tools to do so became available. As a result, locating a patient's medical file can now be done in a matter of seconds.

The establishment of the IeDEA Central Africa region cohort also improved patient management. At some of the participating health facilities, there was not a precise procedure in place specifying when patients should see a doctor. As a result, some patients were consulted by a physician each time they came to the clinic even when their clinical status had not changed and they simply needed to collect their medications. This resulted in heavy patient loads for physicians and long waiting times for patients. A structured system was designed so that patients on ART were obligated to see a physician on the third month after the prescription had been issued, unless a clinical event had manifested, in which case they would see a physician sooner.



Accepted: July 22, 2011

# Methods

Ethics

The IeDEA Central Africa region research project was reviewed by the Institutional Review Board (IRB) at the Kinshasa School of Public Health in DRC, the national ethics committees in Burundi and Cameroon as well as the data coordinating center IRB at RTI International.

#### Research tools

As described in detail below, three research tools were developed while establishing the IeDEA Central Africa region cohort: data collection forms, an electronic data management system and an accompanying reporting instrument.

IeDEA Central Africa region data collection forms. Through an iterative process of workshops, meetings and email communications, the baseline and follow-up clinic visit forms and a common dataset were produced and finalized with the consensus of participating physicians from the Central Africa region. The questions on the forms were originally meant to satisfy research needs, however, questions were subsequently added to support routine patient care, such as temperature, heart rate, medication doses, and frequency with which medications should be taken. Data collection was standardized across all participating health facilities which made comparisons between clinics possible as well as consolidating information to describe regional trends. Many health facilities participating in the IeDEA consortium independently decided to adopt the IeDEA Central Africa region research forms and accompanying electronic DMS as their routine patient medical record system, improving their existing systems. Prior to participation in the IeDEA consortium, the information recorded in the patients' medical file was minimal and primarily consisted of difficult-to-read, open-ended text questions. For example, prior to adopting the IeDEA forms, patients' symptoms were often noted in open-ended format whereas the IeDEA forms prompted clinicians to systematically document symptoms in a check-allthat-apply list format that were organized by disease severity as per the World Health Organization (WHO) clinical staging system [5]. This improved format for noting symptoms assisted physicians with more accurately determining and documenting HIV disease progression at each clinic visit. The shift from paper medical records to an electronic medical record system with standardized case record forms improved the quality and completeness of information available to clinicians for each patient. By using the IeDEA data collection forms, clinicians were prompted to document aspects of routine patient care at each visit which provided a more complete history of the patient's clinical evolution than was previously available.

IeDEA Central Africa region data management system. Most participating health facilities lacked electronic systems for data collection and data management prior to establishing the IeDEA Central Africa region cohort. Those that did have electronic systems collected data in non-standardized formats, which made reviewing individual patient history as well as tallying statistics across clinics cumbersome. The IeDEA Central Africa region project developed an electronic DMS using Microsoft Access software for medical personnel to collect and manage patient data. Each participating health facility was provided with basic computer equipment and the project's DMS to electronically manage IeDEA Central Africa region research data. The DMS was developed as an identical representation of the paper forms used by the



Accepted: July 22, 2011

clinicians. This facilitated and sped up data entry by mirroring the DMS data entry screens to the paper forms. Edit checks improved the completeness and quality of patient data and were performed at the time of data entry and after data had been shared with the data coordinating center. Edits were designed to prompt for missing data as well as check for possible data entry errors such as out-of-range values, logical errors and inconsistencies between values.

Data management training and support was based on a three-tiered system. At the clinic level, data managers at each participating health facility were hired, trained and supported by a country-level information technology specialist. At the Central Africa regional level, a regional information technology specialist conducted yearly visits to all participating health facilities in the region and also provided remote support to these facilities. Lastly, an information technology specialist in the United States provided training and remote support to the health facilities and communicated frequently with country information technology specialists. This system allowed for the prompt identification of problems, support and in-person training when staff members were replaced or information systems improvements were introduced.

*IeDEA Central Africa region reporting instrument.* A reporting instrument was developed in conjunction with the DMS to serve three purposes. First, the instrument enabled clinical staff to query patients meeting a variety of medical criteria (such as CD4 count, WHO clinical stage, antiretroviral regimen, etc). Staff could also produce a list of patients scheduled to come to clinic on a given day or week, enabling clinicians to better anticipate patient volume. Second, the reporting instrument created a printable patient summary that included a table of critical clinical information over time as well as graphs charting the evolution of criteria such as CD4 count, weight, or body mass index (BMI) over time, for a quick visual overview of the patient's clinical evolution. Third, the instrument allowed clinic staff to generate aggregate reports for monthly clinic management and reporting to funding agencies, such as: breakdown of patients by gender, age, WHO clinical stage, number of scheduled vs. non-scheduled visits, number of patients on 1<sup>st</sup> line vs 2<sup>nd</sup> line therapy, or number of patients per antiretroviral regimen.

# Results

The IeDEA Central Africa region cohort has collected data from 19,200 HIV-positive adults at 10 HIV treatment centers since 2005 and from 470 HIV-positive children at four treatment centers since 2009 in Burundi, Cameroon, and DRC. Adult and pediatric site characteristics are presented in Tables 1 and 2, respectively.



Accepted: July 22, 2011

 Table 1. IeDEA Central Africa region adult site characteristics

Site Location (City, Country)	Availability of internet for support staff (% of time)	Availability of internet for clinical staff (% of time)	Patient population (urban/rural)	Type of clinic	Approximate number of HIV+ adults seen per day	Approximate number of HIV+ children seen per day	Number of beds	Number of exam/ consultation rooms	Year facility began providing HIV care to adults	Year facility began providing ART for adults
Limbé, Cameroon	100%	50%	Urban	Public or government	50	10	200	8	1998	2002
Yaoundé, Cameroon	100%	50%	Urban	Public or government	30	0	80	3	2003	2003
Yaoundé, Cameroon	100%	15%	Urban	Public or government	25	0	300	12	2000	2000
Kinshasa, DRC*	100%	100%	Urban	Private	70	7	4	5	1999	2005
Kinshasa, DRC*	0%	0%	Urban	Private	25	3	4	2	2007	2007
Kinshasa, DRC*	0%	0%	Urban	Private	15	1	3	2	2007	2007
Lubumbashi, DRC*	0%	0%	Urban	Private	40	5	2	4	2001	2005
Lubumbashi, DRC*	0%	0%	Urban	Private	20	3	4	2	2005	2006
Matadi, DRC*	0%	0%	Urban and rural	Private	30	4	7	2	2006	2006
Bujumbura, Burundi	80%	50%	Urban	Public or government	15	4	3	5	2006	2006

\*Denotes ambulatory care center open only during the day



Accepted: July 22, 2011

## Table 2. IeDEA Central Africa region pediatric site characteristics

Site location (City, Country)	Availability of internet for clinical staff	Patients served by the clinic	Population served (urban/rural)	Type of clinic	Approximate number of HIV exposed\ infected children seen at each half day clinic	Year facility began providing HIV care to children	Year facility begin providing ART for children
Yaoundé, Cameroon	At the center but outside the treatment area	Children only	Urban	University Hospital	5	2001	2002
Limbé, Cameroon	50%	Adults and children	In between rural and urban	Public or government	10	2002	2004
Matadi, DRC*	0%	Adults and children	Urban and rural	Private	5	2006	2007
Bujumbura, Burundi	80%	Children only	Urban	Public or government	3	2006	2006

\*Denotes ambulatory care center open only during the day



Journal of Health Informatics in Developing Countries

Submitted: April 15, 2011

Accepted: July 22, 2011



Accepted: July 22, 2011

## Impact of the research tools

The research tools discussed here have improved patient management, continuity of care and capability to fulfill reporting requirements in a variety of capacities. These improvements were made primarily through the systematic collection of data on each patient, creation of the IeDEA Central Africa region data management system, and use of the reporting instrument.

*Systematic collection of data on each patient.* Patients included in the IeDEA Central Africa region database were required to have hard-copy medical record files that were keyed on-site into the electronic database before being stored in locked filing cabinets.

Ameliorating the state and organization of hard copy patient medical files improved continuity of care in an environment where medical staff turnover is high and patients are transitory. Completing the IeDEA Central Africa region data collection forms systematized data collection. This ensured that important medical history and treatment plans had been documented throughout the patient's involvement in care and treatment. This enabled a new physician to pick up where a former physician had left off, providing the new physician with a wealth of information about the patient. When a patient was transferred to another site or opted to attend another treatment center (for example, one that was closer in proximity to the domicile), the patient's medical history followed, as it was clearly documented in the patient's folder.

Medical history information collected at baseline was not collected again at follow-up visits which reduced the time burden on staff and on patients. Eliminating the duplication of previously collected information helped to make clinic visits more efficient, reducing the waiting time for patients. This is notable because crowded clinics with long waiting times are barriers to accessing care in this setting. Furthermore, patient recall diminishes over time [6] so collecting family history at baseline and documenting illnesses and secondary effects as they occur during follow-up visits improves data quality.

IeDEA Central Africa region data management system. The utility of any electronic health record hinges upon the timely entry of information into the system. The creation of the IeDEA Central Africa region database has enabled clinicians and investigators to explore trends in HIV care and treatment in the region and has made it possible for the region to participate in queries concerning global trends with other IeDEA regions. At the clinic-level, the quality control of patient records has improved the integrity and completeness of the data while also encouraging clinicians to become more systematic about information collected on each patient at various time points in care. Furthermore, patient flow has been improved as the data management system has facilitated scheduling and planning for follow-up visits.

IeDEA Central Africa region reporting instrument. The reporting instrument has enabled physicians to produce reports by key variables such as gender, age, and antiretroviral regimens that have been useful for clinic management and for fulfilling reporting requirements for funding agencies. Prior to the reporting instrument, many physicians were spending large amounts of time tallying these reports manually, which took away from time that they spent providing patient care. Figure 1 provides an example of a patient distribution report that physicians can produce from data keyed at their clinic showing patient breakdown by gender and by age group. The reporting instrument has assisted clinic staff with lost-to-follow-up tracking by producing a listing of patients that have not returned to clinic for their scheduled appointments.



60 yrs and above

25 11 14 0 Accepted: July 22, 2011

This versatile tool has also been useful for producing enrolment graphs for presentations and other advocacy activities.



Figure 1. Patient distribution report by gender and by age group.

Graphs of weight and immunological progression over time for individual patients have been helpful for monitoring disease progression though they have not been used to the extent anticipated due to limited resources for printing. Figure 2 provides an example of graphs that physicians can produce from data keyed at their clinic showing an individual patient's weight, CD4 count, body mass index (BMI), and Hemoglobin over time.



```
Accepted: July 22, 2011
```



Figure 2. Graphs produced by the reporting instrument of an individual patient's weight, CD4 count, body mass index (BMI), and hemoglobin (Hgb) over time.

#### Discussion

#### Limitations

Frequent electricity outages were a challenge in establishing the IeDEA Central Africa region cohort. The establishment of the cohort hinged upon reliable electricity for keying data and a stable internet connection for sharing data and for email communication. In clinics where frequent electricity cuts disrupted data entry, fuel generators were used on a limited basis for data entry to resolve the accumulating data backlog.

Another challenge to setting up the IeDEA Central Africa region cohort was altering work habits of physicians and other clinic staff. Physicians were accustomed to using paper patient folders throughout their careers. However, they responded favorably to the need for data entry staff to key data collected on hard-copy patient forms into the electronic DMS. Clinic staff buy-in was initially achieved by involving physicians in the development of the data collection forms and responding to their requests for improving the forms after data collection had begun. Clinic staff buy-in was maintained, in part, by installing the reporting instrument at each clinic so that clinic staff could produce aggregate patient reports which have been useful for clinic management and for responding to funding agency reporting requirements. Physicians recognized that the individual patient summaries, such as weight over time, were valuable instruments for quickly obtaining an overview of the patient's medical history. However, the daily use of these patient summaries was limited by the availability of printers, printing paper and toner.

Unintended by research objectives, many health facilities participating in the IeDEA consortium independently decided to adopt the IeDEA Central Africa region DMS as their routine electronic medical records system. As such, the IeDEA Central



Accepted: July 22, 2011

Africa region forms, DMS, and reporting instrument were improved and extended to provide data outputs necessary to meet routine clinical information needs and funding agency requirements. We learned that conducting a formal evaluation prior to and following the DMS release would have been helpful in describing potential changes in process and outcomes measures of clinic and patient management. Given the finite duration of the IeDEA Central Africa region research project, our DMS will need to be transferred to locally-supported health information systems in order to ensure the sustainability of electronic medical records at participating health facilities.

## Conclusions

Despite the aforementioned challenges, the establishment of the IeDEA Central Africa region database has enabled physicians and researchers in this region to establish adult and pediatric cohorts for the purpose of describing regional trends in HIV/AIDS. Health facility administrators and clinicians embraced the introduction of the IeDEA Central Africa region research data collection forms and electronic DMS. This high level of support was due, in large part, to the iterative process of workshops and meetings as well as teleconferences and email communications necessary for physicians and researchers from the region to come to consensus for developing the forms, data management system, and reporting instrument. Our experience echoes the experience of Rotich et al. [4] who found that involving clinicians and staff in the development and evolution of an electronic medical record system in a rural Kenyan health center was crucial to its initial acceptance and continued use.

The research tools discussed here have improved patient management, continuity of care and ability to respond to reporting requirements. These improvements were made primarily through the systematic collection of data on each patient, creation of the IeDEA Central Africa database, and use of the reporting instrument. We found that timely data entry and a high degree of data quality were essential for these research tools to be useful to clinicians providing patient care. Routine data audits were helpful for ensuring data quality and identifying areas for refresher training for clinicians and staff.

Systematic collection of data on each patient eliminated the duplication of previously collected information. This helped to make clinic visits more efficient, while ameliorating hard copy patient medical files and improving continuity of care. The reporting instrument has been used extensively for producing enrollment graphs, querying patients meeting specific clinical criteria, and for fulfilling reporting requirements. However, it has not been heavily used to produce individual patient summaries that may be insightful for informing patient care, for example, charting an individual patient's immunologic progression over time. Making timely use of collected data to inform clinical decision making is a challenge in resource-constrained settings. However, Edmonds et al. [7] incorporated a simple, user-friendly Microsoft Excel tool for monitoring HIV disease progression indicators over time into an existing framework used by clinicians to record laboratory and clinical data at a pediatric hospital as well as a primary health care clinic in Kinshasa, DRC. Experience such as this demonstrates that it is feasible for physicians to make timely use of the data they collect for research purposes to monitor disease progression, identify treatment failure, and inform clinical decision making.



Accepted: July 22, 2011

We have demonstrated that the creation and maintenance of a regional database to evaluate HIV/AIDS is feasible through partnering with international agencies while building on existing linkages between local physicians, treatment centers, and organizations in the region. The establishment of the IeDEA Central Africa region cohort has enabled researchers and clinicians to describe HIV trends in the region, quickly identify populations at risk for dropping out of care and treatment, and has provided data needed to develop strategies for addressing gaps in behavioral implementation science. Future research consortia implementing electronic databases in settings where there were previously no electronic medical records may find it beneficial to conduct formal evaluations prior to and following the database release so that process and outcomes measures can be well-documented at various points in time.

# **Conflict of interest statement**

The authors do not have any conflicts of interest to disclose concerning financial and personal relationships with other people or organizations that could inappropriately influence (bias) their work such as employment, consultancies, stock ownership, honoraria, paid expert testimony, or patent applications/registrations. The authors do not have any additional conflicts of interest to disclose concerning relations other than of financial and personal nature that could be a potential conflict of interest.

#### References

- WHO. Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector Progress Report, 2009. [electronic version]. Retrieved May 3, 2010 from http://www.who.int/hiv/pub/tuapr\_2009\_en.pdf.
- [2] P. Braitstein, R.M. Einterz, J.E. Siddle, S. Kimaiyo, & W. Tierney, "Talkin' about a revolution": How electronic health records can facilitate the scale-up of HIV care and treatment and catalyze primary care in resource-constrained settings, *J Acquir Immune Defic Syndr* 52 (2009), S54-S57.
- [3] Institute of Medicine. The computer-based patient record: An essential technology for health care, Revised edition. National Academy Press, Washington, DC, 1997.
- [4] J.K. Rotich, T.J. Hannan, F.E. Smith, J. Bii, W.W. Odero, N. Vu, B.W. Mamlin, J.J. Mamlin, R.M. Einterz, & W.M. Tierney, Installing and implementing a computer-based patient record system in sub-Saharan Africa: the Mosoriot Medical Record System, J Am Med Infor Assoc 10 (2003), 295-303.
- [5] WHO. Antiretroviral therapy for HIV infection in adults and adolescents: Recommendations for a public health approach: HIV/AIDS Programme, 2006. [electronic version]. Retrieved May 3, 2010 from http://www.who.int/hiv/pub/guidelines/artadultguidelines.pdf.
- [6] G. Cohen and R. Java, Memory for medical history: Accuracy of recall, Appl Cogn Psychol 9 (1995), 273-288.
- [7] A. Edmonds, F. Kitenge, & F. Behets, A simple spreadsheet application for routine immunological and virological monitoring of HIV in resource-limited settings. Poster presented at HIV/AIDS Implementers' Meeting, Windhoek, Namibia, 2009.