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HIVCore

HIVCore HIGHLIGHTS

JULY 2014

ROUTINE HEALTH CARE SERVICE STATISTICS: LOW-HANGING FRUIT FOR PROGRAM EVALUATION?

HIVCore researchers conduct studies using both primary data collection and secondary data analysis. Secondary analysis takes advantage of existing data to further research goals, from the evaluation of service delivery to answering new research questions. In the context of the health system, the process usually involves the review of "routinely" collected service statistics and patient medical records, allowing the study teams to examine details about the services provided and client health care-seeking behavior. Using these data, HIVCore researchers can further consult with the service providers to provide context as to why unexpected data patterns might have occurred.

HIVCore has conducted a number of studies using secondary data analysis, and our study teams have observed various challenges in the data extraction and analysis process which we would like to share in this newsletter issue. First, we highlight the data ownership and ethical considerations that need to be taken into account before conducting analysis on records that were originally collected for managing patient care, not for research. At all times the patient's privacy must be respected as established by the U.S. Department of Health and Human Services under 45CFR46 and the U.S. Agency for International Development under 22CFR225. This is especially true when dealing with already highly stigmatized and/or vulnerable popula-

Researchers can identify strengths and gaps in services by examining clinical data, test results, services provided (including when they were provided), and time intervals between clinical visits.

INSIDE

With multiple registries comes the concern of being unable to link the individual patient entries among the registries, as well as mother-baby pairs in order to track PMTCT outcomes.

tions, such as people living with HIV. Researchers must ask themselves, to whom do the data belong? How do you conduct research on records if it is not feasible to contact individual patients or the appropriate guardian? We explore this topic further in the article on page 3.

Second, data quality assurance is a major issue. When using routinely collected service statistics and patient medical records, study investigators are relying on access to complete and accurate patient files and registries. Health care personnel are often already overburdened by health care service delivery tasks, however, and may not always be able to give as much attention as needed to complete recording information for individual patient files. Some HIVCore study investigators have encountered incomplete patient charts and registries, inconsistencies across the often multiple registries, and an inability to link patient records between patient files, registries, and facilities. This is a common problem often encountered when analyzing data that were collected for purposes other than research. These challenges, though not insurmountable, make it difficult for researchers to draw conclusions about success and gaps in service delivery, uptake, and retention, and to provide recommendations to local, national, and global stakeholders. Recommendations emerging from HIVCore studies on how to address data quality assurance issues include establishing patient tracking systems, and simplifying and strengthening data collection, analysis, and reporting (page 6). HIVCore acknowledges the key role that secondary data can play in generating data for effective policy making and program guidance and thus the need to strengthen health care information systems.

Third, paper-based systems—whether for patient records or registry books—are very common in low-resource settings. As found in several HIVCore studies, the paper-based systems made data cleaning challenging—manually searching through and linking patient records across several registries—and time consuming. Electronic medical record (EMR) systems have the potential to help manage patient and clinic records as well as supplies. On page 9, HIVCore discusses the advantages and constraints of EMR systems, and resource requirements for implementing them. Although not immediately feasible in every country, it is worthwhile to consider investing in such a platform, as it has the potential to provide high quality data that can easily be analyzed to provide an evidence base for improving service delivery and program effectiveness.

HIVCore acknowledges the key role that secondary data can play in generating data for effective policy making and program guidance and thus the need to strengthen health care information systems.

Sincerely,

Samuel Kalibala, HIVCore Project Director

USING PATIENT MEDICAL RECORDS FOR RESEARCH: DATA OWNERSHIP AND ETHICAL IMPLICATIONS

Medical records are primarily kept for health care monitoring and not for research. For health care purposes it is important that personal identifiers are kept for every medical record in order to enable health care workers to provide follow-up care and treatment. However, research often does not focus on the individual, and therefore does not require patient identifiers. Conducting research can lead to a risk of personal clinical data being inadvertently disclosed, with potentially serious consequences for the individual. Therefore, a central ethical concern regarding the use of medical records for research or program monitoring and evaluation is protecting the patient's identity. Privacy is especially critical for people living with HIV (PLHIV), who can face social, economic, and legal discrimination because of their HIV status. Research using medical records must therefore follow firm ethical guidance based on existing recognized international ethical principles. Established in the *Belmont Report* and included subsequently in international guidelines, one fundamental principal of ethical conduct of research is respect for persons.[1] Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them or to sensitive, personal information about them.

Although there are established ethical principles of using patient medical records for research, in many countries there are no laws on how the analyses should be conducted. Discussion in the international community around protecting patient confidentiality while using patient data for program monitoring and evaluation has been sporadic. In 2006, UNAIDS and the President's Emergency Fund for AIDS Relief (PEPFAR) issued "interim" guidelines for protecting HIV information[2], and the 2009 UNAIDS follow-up workshop on individual patient identifiers touched on ethics concerns[3]. While they provide useful guidance, it is relevant to note that these guidelines have not been finalized. National and sub-national laws and practices vary widely, from adopting special protections for records of PLHIV to criminalizing HIV transmission, highlighting the urgent need for further discussion and standardization. In this article we discuss some of the guidance that HIVCore gives to its research teams to ensure ethical conduct of research using secondary data analysis.

A central ethical concern regarding the use of medical records for research or program monitoring and evaluation is protecting the patient's identity.

DATA OWNERSHIP AND ACCESS

Access to and ownership of patient medical records are separate legal and ethical issues. Ownership of patient medical records varies from country to country, but in principle the physical or electronic records them-

selves should be under the custodial responsibility of the health care provider or health care system. On the other hand, ownership of de-identified datasets created for research or program evaluation may not be clear.

When the researcher or analyst is not part of the program or health system from which the patient data originated, a good practice is to develop a signed data sharing agreement that describes what the data will be used for and what the researcher will do with the dataset after the research is completed. A good example of a data sharing agreement can be found on the USAID-funded Demographic and Health Survey (DHS) Program website. The DHS Program has earned worldwide recognition for collecting and disseminating nationally representative data, which is frequently used to conduct secondary analyses studies in public health research at a global level. It has well-established terms of access and use that lay out the requirements for requesting and permissible uses of the dataset, which every researcher must consent to before any data are given to them.[4] Establishing clear data ownership agreements helps ensure that de-identified health care service data are used in an ethical manner that respects client confidentiality and abides by key ethical principles.

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INFORMED CONSENT

Patients are given the opportunity to choose what shall or shall not happen to them or sensitive, personal information about them when adequate standards for informed consent are satisfied. Obtaining informed consent from individual patients for retrospective analysis of their medical records—e.g., looking at what services have already been provided—is beyond the scope of most program evaluation and research. As a first step, researchers should seek guidance on this issue from ethics committees (both national and international). One commonly used option is for researchers to obtain informed consent from the community to which the patients belong. This may be the facilities that provided care, the villages or towns where the facilities are located, the ethnic or self-identified group to which the patients belong, or even the health system writ large. Information provided in informed consent documents seeking community consent is comparable to that provided for individual consent. For example, the purpose of research or evaluation and risks and anticipated benefits to the community (as opposed to the individual) are described, as are the opportunity to ask questions and receive the results of the analyses.

On the other hand, research and evaluation that involves prospective analysis of patient medical records may require informed consent from individual patients, such as when a new mother returns to a health center for a postpartum clinical visit. This is especially true if the research protocol includes tracing patients from one facility to another and/or future contacts that are not part of the usual standard of care, such as follow-up interviews to gauge adherence to or satisfaction with care.

DE-IDENTIFICATION

As established by the U.S. Department of Health and Human Services under 45CFR46 and the U.S. Agency for International Development under 22CFR225 for using private, identifiable health information for research purposes,[5, 6] a best practice is to de-identify patients before analysis, regardless of the standard of informed consent employed. The intent is to minimize the likelihood that someone could deliberately discover a patient's identity either from the dataset itself or by combining the dataset with other, publicly-available records such as a telephone directory. This means removing patient identifiers as well as those of emergency contacts, relatives, employers, or household members of the patient that might be included in his/her record, including names, addresses, telephone numbers, and social security or national identity numbers.

Constructing a complete medical history often requires searching a variety of records such as intake registries, outpatient consultations, laboratory reports, pharmacy pick-ups, etc. In such cases, de-identification is conducted after the history is completed because without

patient identifiers it will not be possible to determine which records belong to which patient. Electronic medical records (EMRs) are especially suited for de-identification because the entire process of aggregation and de-identification can be automated (see page 9). Ideally, the process of aggregation and de-identification would be handled by someone who is already authorized to access those records such as the facility monitoring and evaluation officer. If record extraction and aggregation is performed by someone who does not normally have access to the records, then the procedures will require institutional review board (IRB) review and approval. Data extractors should be trained in research ethics and supervised to ensure adherence to patient privacy and confidentiality procedures.

Under U.S. regulations, appropriately de-identified patient records are not considered "identifiable private information" and are exempt from human subjects requirements for IRB review, as per 45CFR46.101(b)(4)[5] and 22CFR225.[6] Countries have different requirements regulating the use of medical records, and de-identified records that meet U.S. standards for exemption from IRB review may still require ethics review and approval in the host country. As a general practice, it is best to consult the institution where the data were obtained along with the researcher's host institution and review both human subjects determination policies when confirming whether or not a particular study will require IRB review.

KEY CONSIDERATIONS

When contemplating conducting a secondary data research study analysis, it is important to ensure that the fundamental principle of "respect for persons" is met. Consideration must be given to who owns the data and how to ethically obtain, process, and use them for research purposes, without compromising the patient's right to privacy. In the absence of a clearly established international code of conduct for protecting patient confidentiality while using patient data for program monitoring and evaluation, ethical guidelines in the researcher's country of residence and the host country should be consulted to determine if ethical review and approval are needed.

ADDITIONAL RESOURCES

The U.S. Office of Human Research Protections (OHRP) maintains and annually updates an International Compilation of Human Research Standards. The 2014 edition can be downloaded from their website: http://www.hhs.gov/ohrp/international/intlcompilation/2014intlcomp.pdf.pdf.

ENDNOTES

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[2]UNAIDS/PEPFAR. 2007. "Interim guidelines on protecting the confidentiality and security of HIV information," *Proceedings from a Workshop, 15–17 May 2006*. Geneva: UNAIDS. http://data.unaids.org/pub/Manual/2007/confidentiality_security_interim_guidelines_15may2007_en.pdf.

[3]UNAIDS. 2009. "Developing and using individual identifiers for the provision of health services including HIV," *Proceedings from a Workshop, 24–26 February 2009*. Geneva: UNAIDS. http://www.unaids.org/en/media/unaids/contentassets/documents/dataanalysis/20110520_Unique_Identifiers_Meeting_Report_Montreux.pdf.

[4]The Demographic Health Survey Program. "Access instructions." http://dhsprogram.com/data/Access-Instructions.cfm

[5]U.S. Department of Health and Human Services. 2009. Code of Federal Regulations, Title 45, Public Welfare, Department Of Health And Human Services, Part 46, Protection Of Human Subjects. http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.101%28b%29.

[6]U.S. Agency for International Development. 2003. Code of Federal Regulations, Title 22, Foreign Relations, Part 225, Protection Of Human Subjects. http://www.gpo.gov/fdsys/granule/CFR-2003-title22-vol1/CFR-2003-title22-vol1-part225

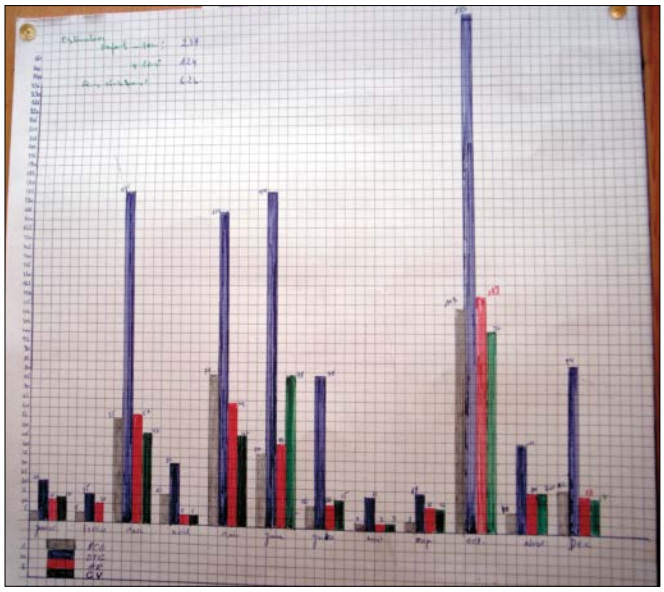
CHALLENGES OF USING ROUTINE HEALTH CARE DATA FOR EVALUATION

Routinely collected health care data—such as those found within patient registries at health care facilities—are widely available and comparatively easy to inexpensively access, and thus are an attractive source of information. Decision makers benefit from access to assessments of these service statistics and other routinely collected data so that they can understand what is working well and which programs and services require additional support. HIVCore studies support these goals by conducting analyses of existing service delivery data—information that can provide unique insights into both operational conditions and client health care-seeking behaviors. By examining clinical data, test results, services provided (including when they were provided), and time intervals between clinical visits, researchers can identify strengths and gaps in services.

However, the lack of data quality assurance—that is, ensuring the completeness and accuracy—of routine service records poses an ongoing challenge to successful secondary data analyses. Incomplete patient charts and registries, multiple registries, and the inability to link patient records between patient files, registries, and facilities, can impede researchers from assessing the data accurately. It is important to be aware of common sources of data inaccuracy, as well as strategies to overcome these challenges. We identify several below.

INCOMPLETE PATIENT CHARTS AND REGISTRIES

Unlike data collection for an intervention study, few, if any, clinical services routinely monitor accuracy and completeness of patient charts/registries. The normal service delivery-related demands on an already overburdened and limited health facility staff make it very difficult to focus on record keeping and very few health facilities have the money to hire a dedicated patient chart/registry data monitor.



Decision makers benefit from access to assessments of health care service statistics and other routinely collected data, so that they can understand what is working well and which programs and services require additional support.

Missing data often make it hard to ascertain the effectiveness of a program. As an example, we found this to be true in a recently completed HIVCore study in the Ivory Coast (Cote d'Ivoire), which evaluated antenatal clinics providing PMTCT and retention of HIV-positive pregnant and lactating women throughout the PMTCT cascade. Using all available data sources at the 30 study sites, 11 registry indicators were assessed to evaluate the PMTCT cascade. Of the 30 study sites, only six sites had no incomplete or missing data. Additionally, data collectors noted PMTCT registries, antiretroviral treatment (ART) registries, and patient charts that were incorrectly filled out at 10, 9, and 14 sites, respectively. When on-site registry indicators were compared against the same indicators in the national database, inconsistencies were found in every indicator

at every site. On average, more than half of all indicators compared had a discrepancy of larger than 5 percent between on-site data and the same data in the national database.[1]

Another HIVCore study sought to assess retention of HIV-positive pregnant women across the PMTCT cascade in four countries implementing the World Health Organization (WHO) Options A (Kenya and Swaziland), B (Rwanda), and B+ (Malawi). Mothers newly diagnosed with HIV and with known status during the study time period, October 2010 to March 2012, were included in the analysis. Researchers found this to be a challenge as many of the records were missing key data. For example, in Rwanda, of the 457 records of HIV-positive women analyzed, only 15 percent were recorded as having had the recommended four or more antenatal care (ANC) visits for their current pregnancy and there was no information on referral for ART initiation for over half of the women. Many of the reconstructed infant records were missing critical information, including place of delivery (18 percent), as well as mode of delivery, administration of infant polymerase chain reaction (PCR) test for HIV, dispensing of co-trimoxazole, and infant feeding practices (over 30 percent for each of these variables). Nearly two-thirds of infants had no information on HIV antibody testing at 18 months.[2]

While PMTCT data are some of the most widely available data, such issues do not only occur in the PMTCT context. Similar issues were found in another HIVCore study in Uganda, which sought to inform the knowledge base on ART task shifting and contribute to national policy and guidelines. An initial retrospective analysis of clinical and accounting data found that 11 percent of the files were missing key data to conduct an accurate analysis. However, with further searching through un-entered paper records, the data have been recovered and entered to increase the completeness of the records.[3]

BURDEN OF MULTIPLE REGISTRIES

The PMTCT-related studies conducted under HIVCore highlight the difficulties multiple registries introduce with regards to collecting, maintaining, and analyzing service statistics, especially when they are paper-based. The limited numbers of often over-worked health care workers need to document information in these various registries and files, sometimes duplicating the information in several places. This, combined with the large number of data fields required, can lead to missing data and misplaced or lost registries/patient files, resulting in data quality challenges.

For example, in order to conduct the four-country PMTCT retention study (described above), trained facility data entry clerks extracted data from over 10 different paper registries and patient charts. Mothers newly diagnosed with HIV and with known status during the study time period were identified from the ANC register using their ANC numbers. They were then linked with the pre-ART register to obtain their unique patient ID number (which differs from their ANC number) for retrieval of patient files and, together with ART, pharmacy, and lab registries, used to obtain details of the mothers' characteristics. The maternity, postnatal care (PNC) and HIV-exposed infant (HEI) registries were used to link the mother-baby pair. The facility data entry clerks obtained the infant characteristics from the child welfare clinic register, HEI register, HEI card, and PCR/dried blood spot files. Infants with positive PCR results also had their details obtained from pre-ART, ART, and patient files. Even with all of this effort, in many instances key variables were missing data, in some cases substantial amounts, making that particular variable less useful in the analysis and interpretation of findings difficult.[3] On a positive note, decision-makers in these countries have noted these gaps in data quality and are developing strategies to strengthen their health management information systems.

On average, the 30 study sites in the Cote d'Ivoire study recorded and stored data related to PMTCT in 11 different registries, reports, or other unofficial data sources. From these sources, the team found wide variability among the sampled clinics and major inconsistencies in the data from different sources, especially with respect to the proportion of women tested for HIV, which was recorded at much lower levels in *carnets* (mother-child vaccination booklets) than in registries. Therefore, the burden and confusing nature of so many registries was highlighted as a key finding of the study.[2] These findings were then shared with policymakers in Cote d'Ivoire who requested HIVCore to follow

through on recommendations by testing an intervention to address the stated issues. This "phase 2" study is currently being designed.

INABILITY TO LINK RECORDS

With multiple registries comes the concern of being unable to link the individual patient entries among the registries, as well as mother-baby pairs with regards to tracking PMTCT outcomes. If the information is not kept in an individual patient file, then health care workers have to search registries for information and test results pertaining to that patient. In some cases, there is a unique patient identification number. In other cases patients are only listed by name, making it difficult to link records given the number of patients who have the same (or similar) name.

Recommendations emerging from the HIVCore studies on how to address data quality assurance issues include establishing patient tracking systems and standard filing systems, and simplifying and strengthening data collection, analysis, and reporting.

There is also the issue of linking patients among the various health facilities at which they can seek services. The four-country PMTCT study highlighted the limitation in tracking each mother-baby pair and mothers from ANC to labor and delivery and into PNC, as the delivery often takes place in a different facility from where they receive ANC and PNC.[3]

WHAT CAN BE DONE

As a result of the aforementioned challenges, some adjustments were made on HIV Core studies. In some cases, additional time and effort from the data collection teams were needed to review more records than originally anticipated. Also, more time and effort were needed to try to link records when unique patient identifiers were not readily available, such as matching multiple pieces of personal information (name, age, address, etc). In one case, although the data were stored in an electronic medical record system, there were missing data, which required clinic staff to revisit the paper records and enter the missing data in the system.

To minimize these challenges from the start, strengthened health management information systems are needed. Recommendations emerging from HIVCore studies on how to address data quality assurance issues include establishing patient tracking systems and simplifying and strengthening data collection, analysis, and reporting.

Establish patient tracking systems. Whether paper or electronic-based, establish a well-monitored systems approach. Ensure that there is adequate linkage of patient information, such as assigning a unique patient identifier that is consistently included in all files/registry entries/tests related to the patient. In Uganda, the HIVCore team is working with the AIDS Support Organization (TASO) on an adolescent ART study to generate evidence that will inform the design of effective, comprehensive services for young people who are living with HIV. Datasets derived from the various electronic registries are linked using a unique registration number, allowing the data managers to easily select and merge the required variables for analysis.

Simplify data sources, analysis, and reporting. Fewer indicators, fewer reports, and fewer registries would likely improve the usefulness of monitoring and evaluation.[4]

Routine chart review. Regularly reviewing charts would likely engage providers in frequent assessment and improvement of systems of care, helping identify problems and ways to address them. If possible, it is also ideal to have a staff member assigned to monitoring and evaluating clinic data.

ENDNOTES

[1]Gloyd, S. et al. 2014. "PMTCT cascade analysis in Côte d'Ivoire:Results from a national representative sample," *HIVCore Final Report*. Washington, DC: USAID | Project Search: HIVCore. www.hivcore.org/Pubs/CotedIvoire_PMTCTCascade_Phase1_Rprt.pdf

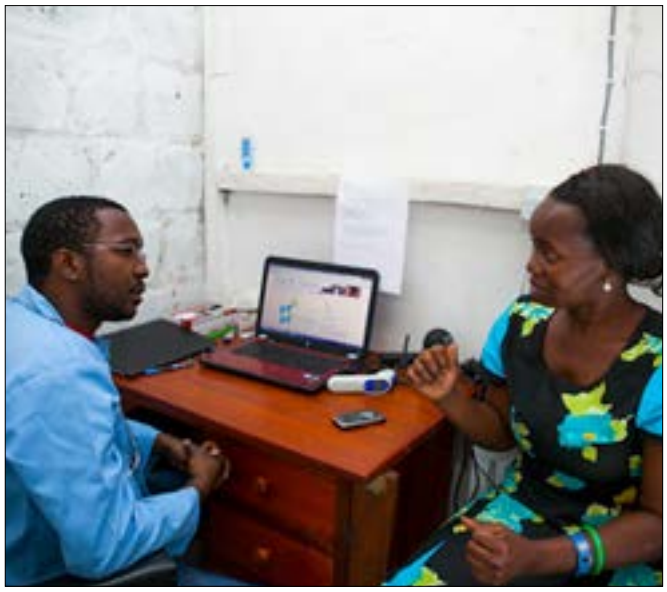
[2]HIVCore. 2013. "Secondary analysis of retention across the PMTCT cascade in selected countries implementing the various WHO guidelines: Kenya, Malawi, Rwanda, and Swaziland." www.hivcore.org/studies/MultiCntry_4CountryPMTCTRetention.html.

[3]HIVCore. 2013. "Review of various task-shifting community-based programs supporting antiretroviral treatment and retention in Uganda," www.hivcore.org/studies/Uganda_TaskShifting.html.

[4]Gimbel, S. et al. 2011. "An assessment of routine primary care health information system data quality in Sofala Province, Mozambique," *Population Health Metrics* 9: 12.

ELECTRONIC MEDICAL RECORDS IN LOW RESOURCE SETTINGS

Health care systems around the world, including those in low-resource settings, are gradually integrating electronic medical records (EMRs) into practice. Not only do EMRs hold a promise for improved patient and program management, they are also capable of providing clean, accurate, and timely datasets for secondary analyses in program evaluation and research. This article looks at how EMRs work, the considerations for using EMRs, and resource requirements for developing, implementing, and maintaining EMRs. An example of an EMR system is on page 12.



EMRs hold out a promise for improved patient and program management as well as providing clean, accurate and timely datasets for secondary analyses in program evaluation and research.

WHAT IS AN EMR SYSTEM

EMR systems replace physical paper-based patient charts with an electronic database, although facilities might continue to use paper forms at point of service to collect patient information, prescribe medications, and order and record the results of laboratory tests. At some point in time, staff can enter the paper forms into the database following standardized menus. The EMR systems could also be paperless and staff could enter the information directly into the system. Each patient's record includes his/her unique identification number. This allows any authorized user to pull up any patient's entire history quickly and easily from any computer connected to the network. These systems can also quickly and easily generate routine reports.

ADVANTAGES AND CONSTRAINTS

As with any technology, there are both benefits of and constraints to adopting an EMR system. Compared to wholly paper-based systems, EMRs make it easier to consolidate multiple patient records in a single place. This is especially valuable for chronic-care programs which employ services across diverse sites (e.g., outpatient clinic, laboratory, pharmacy, etc.) and must closely monitor patient adherence to care over many years. Consolidated records reduce costs and time, support clinicians and improve coordination of care and patient outcomes, and reduce the administrative burden of reporting. On the other hand, EMRs require significant upfront investments in software, hardware, and physical infrastructure; impose a learning curve for new users and may face difficulty gaining user buy-in, especially among older, less technologically savvy staff; and require enhanced security to protect confidential patient health information. System architects and project managers should carefully study their specific context to understand what will work well for that point in time and often must make tradeoffs between desired features of the new system and external constraints. Table 1 summarizes some benefits and costs associated with EMRs.

TABLE 1 BENEFITS AND COSTS OF EMRS

Benefits	Costs
Cost savings • Less paper, storage space needed • Automates reporting • Integrates business rules to reduce errors • Processes information with latest billing codes	**Upfront costs** • EMR software and system development • Hardware and infrastructure • Roll-out and training costs
Clinician support • Patient history, test results, imaging in one place and easily accessible • Embeds best practices • Decision support for diagnosis and treatment • Check-up reminders; identify overdue patients • Monitor how patients compare to other cohorts, how one facility compares with others • Share data with other providers • Analyze records across the facility to identify gaps in services and treatment plans with the best patient outcomes • Monitor health care work load	**Learning curve** • Needed technical skills may not be readily available • Possible conflicts with productivity and patient care during start-up • Resistance from health care workers, especially if system increases their workload **Computer issues and security** • Privacy concerns • Computer crashes, viruses and user error • Data loss from hardware failure

RESOURCE REQUIREMENTS

Regardless of the health care setting, all EMRs require the same basic resources. However, the costs associated with those resources will vary from setting to setting. For example, computers need reliable electricity. If facilities already have good electrical connections, the extra electricity consumed by the EMR system will be minimal. However, if the electrical service is unreliable, purchase of generators and/or batteries may be needed to ensure adequate functioning. Similarly, there may be economies of scale: the greater the number of facilities using the system, the lower the per-facility costs for system development. Round-the-clock staffing of data entry clerks may reduce the number of computers needed, although this might not be an issue as hardware prices continue to decline. Open-source or public domain software packages are freely available but still require an experienced designer to customize the application.

The greatest costs are incurred during the design and implementation stages. Once the EMR system is up and running, a budget will be needed for maintenance, upgrades and replacement, supervision, refresher training, and training new staff, etc. Careful selection and implementation are critical to secure the benefits and reduce the limitations of EMRs. While EMRs can be a valuable data source for secondary analyses for program evaluation and research, by themselves they do not solve the problems of missing, incomplete, and incorrect data.

ADDITIONAL RESOURCES

WHO Global Observatory for eHealth
www.who.int/goe

mHealth Alliance's Health UnBound
www.healthunbound.org

ISfTeH's Med-e-Tel Knowledge Repository
www.med-e-tel.lu

European Commission eHealth portal
ec.europa.eu/health/ehealth/portal/index_en.htm

HIVCORE STUDIES

HIVCore is initiating a range of operations research studies and program evaluations. The below studies are in various stages of development. For more information, please visit www.hivcore.org.

Country	Study Synopsis
Care and Support	
Ethiopia	Determine whether a psychosocial intervention for marginalized young people improves their responsiveness to HIV programs.
Ghana, Uganda, Zambia	Describe and identify factors affecting access to and use of HIV services for persons with disabilities as well as determine the gaps and opportunities within these services.
Global	Develop a pathway that leads to various care and support service delivery models for specific populations based on needs and vulnerabilities.
Haiti	Conduct retrospective review with program staff and participants of a community-managed savings and internal lending community intervention for households affected by HIV.
Kenya	Evaluate a computerized alert and reminder system for medical providers to improve tuberculosis case finding and therapy for adults living with HIV.
Mozambique	Identify facilitators and barriers to linking HIV-positive patients to care, and evaluate interventions to address these barriers.
South Africa	Aims to ensure that all PLHIV on ART have enhanced access to TB screening and testing so that those found to have active TB are put on treatment and those without active TB are put on prophylaxis.
Gender	
Kenya	Evaluate the effects of addressing intimate partner violence within individual and couples HIV testing and counseling.
PMTCT/Pediatrics	
Cote d'Ivoire	Identify reasons for delays and loss to follow-up at each step of the PMTCT cascade and potential interventions to improve program effectiveness and design and implement an intervention study.
Kenya, Malawi, Rwanda, Swaziland	Assess retention across the PMTCT cascade in countries implementing WHO Options A, B, and B+.
Tanzania	Determine whether SMS reminders and notifications to mothers increase the proportion of HIV-exposed infants tested for HIV.
Zambia	Evaluate the effectiveness of the PMTCT program in reducing newborn infection rates and improving child survival.
To be determined	Test the effectiveness of community health workers in increasing follow-up of PMTCT-enrolled mothers and HIV-exposed infants in their homes and encouraging them to attend PMTCT services and bring their infants for follow up.
To be determined	Explore the operationalization of pediatric ARV resistance monitoring using early warning indicators and test approaches to address identified gaps.
Treatment	
Kenya	Determine whether a cell-phone based counseling intervention can increase early initiation of and adherence to HAART among HIV-positive pregnant women.
Kenya and Tanzania	Conduct secondary analyses of patient-level data to identify factors that contribute to the continuation of HIV treatment.
Uganda	Compare different models of task shifting for delivering ART at the community level in terms of efficiency, patient satisfaction, knowledge, retention, and cost.
Uganda	Document ART retention and adherence among adolescents living with HIV.

BOX 1 EXAMPLE EMR SYSTEM: IQCARE

In Kenya, HIVCore will be conducting a secondary analysis of the PEPFAR-funded AIDSRelief patient-level data on operational factors and client behaviors that contribute to the uptake and effectiveness of HIV treatment services. This data will come from an EMR system, IQCare, initially built by Futures Group for the AIDSRelief Project. Today, IQCare is operational in over 250 facilities in four countries, providing day-to-day patient management, clinician decision-support and reporting; and program and supply chain management.

In some facilities, paper forms are still used at point of service and then the information is entered later into the database. The IQCare system also includes touch forms to capture demographics, clinical findings, and adverse events as well as clinical alerts. This point-of-service model allows health care workers to enter patient information directly into IQCare without any paper forms and receive immediate decision support for improved patient care.

A version of IQCare is now available for mobile tablets, which are roughly one-fifth the price of a desktop computer. IQCare is open source and freely available under the Creative Commons license.

More information on IQCare can be found at http://www.iqstrategy.net/products/iqcare/.

HIVCore HIGHLIGHTS

HIVCore Highlights is a semi-annual newsletter produced by the HIVCore project.

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HIVCore

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