



ELECTRONIC CASE MANAGEMENT SYSTEM

KEY CONSIDERATIONS

ACKNOWLEDGMENTS

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This consideration document is intended as a tool for countries and implementing partners to use when developing an eCMS or updating/maintaining an existing system. It is not official guidance and is a product of USAID (not an inter-agency document).

ACRONYMS

AGYW Adolescent Girls and Young Women

AM Activity Manager

CBO Community-based organization

CDC U.S. Centers for Disease Control and Prevention

COP Country Operational Plan

DATIM Data for Accountability, Transparency and Impact
DREAMS Determined, Resilient, AIDS-free, Mentored, and Safe

DBS Dried blood spot

DHAPP Department of Defense HIV/AIDS Prevention Program

DHS Demographic and Health Survey

DoD Department of Defense
DSD Direct Service Delivery

DOTS Directly Observed Therapy, Short Course

DRA Drug regulatory Authority
EID Early Infant Diagnosis

eCMS Electronic Case Management System

ECT Epidemic Control Teams
ER Expenditure Reporting
FBO Faith-based organization

FDA Food and Drug Administration

FY Fiscal year

GF Global Fund to Fight AIDS, Tuberculosis, and Malaria

GBV Gender-based violence

GIS Geographic Information Systems

HO Headquarters

HCW Health Care Workers

HSS Health Systems Strengthening

HBC Home-based care

HHS Department of Health and Human Services
HMIS Health management information systems

HIV/AIDS Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome

HTS HIV Testing Services

HRH Human resources for health

HRSA Health Resource and Services Administration

ISME Implementation Subject Matter Expert

IM Implementing MechanismIP Implementing Partner

ICT Information and communications technology
IEC Information, Education and Communication

IT Information technology

ICPI Interagency Collaborative for Program Improvement

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INTRODUCTION

PEPFAR's focus on optimizing impact is a driving force behind global efforts to reach HIV epidemic control and to accelerate towards the UNAIDS 95-95-95 goals: 95 percent of people living with HIV know their HIV status, 95 percent of people who know their HIV status are accessing treatment, and 95 percent of people on treatment have suppressed viral loads. Annually, S/GAC releases the Monitoring Evaluation Reporting (MER) Indicator Reference Guide, which includes OVC indicators OVC_HIVSTAT and OVC_SERV. These indicators are reported semi-annually at the site level (community and facility) for all PEPFAR-funded countries supporting OVC services. The OVC_SERV indicator reports how many beneficiaries have been served by PEPFAR OVC programs, with disaggregates by program participation status (active/graduated), age, and sex. The OVC_HIVSTAT indicator reports the HIV status of orphans and vulnerable children (<18 years old) based on self-reporting and includes HIV positive, HIV negative, HIV test not required, or HIV status unknown.

PEPFAR OUs are collecting and reporting OVC indicators in various ways, including implementing robust electronic case management systems, electronic medical records, in-country based ministry systems, and other paper-based systems. Although not required, an electronic case management system is proven to be effective in storing key beneficiary information, tracking routine supporting service data, and tracks the progress towards completion of an individual's care plan. Moreover, the electronic case management system streamlines the reporting of OVC indicators into DATIM, provides greater visibility and accountability for partners, and allows service providers to monitor program performance and outcomes. The purpose of this document is to offer interagency country teams (i.e. SI, M&E, and program staff) a general systems consideration when designing, deploying, and maintaining electronic case management systems in support of OVC programming and reporting.

BACKGROUND

WHAT IS A CASE MANAGEMENT SYSTEM?

PEPFAR's Orphans and Vulnerable Children (OVC) programming delivers child-focused, family-centered interventions that seek to improve well-being and mitigate the impact of HIV and AIDS on children and families (households). An electronic case management system is intended to support end-users (e.g. case workers, case managers, and supervisors) to care for vulnerable children and families by facilitating the case worker's primary goal of assessing beneficiary needs and working with the beneficiary family to establish specific objectives, goals, and benchmarks. The system can also support end-users by facilitating case plan implementation through capturing and tracking the completion of services and progress toward objectives/goals achievement (e.g., child protection and well-being, including HIV prevention, treatment, and adherence). In addition, the system can automatically track the beneficiary information over time, allow for case workers to create customized plans for beneficiaries, and allow supervisors to have oversight on the case managers' performance and progress of the beneficiaries.

WHAT ARE THE PROGRAM NEEDS?

Before countries implement an electronic case management system, it is critical to understand the community/country context, the users of the system to be designed, and the basic requirements for the system to address service delivery, program implementation, data collection, and reporting needs. To ensure an electronic case management system is designed to support your overall OVC program, countries should consider the following:

UNDERSTAND THE CURRENT COUNTRY CONTEXT

To design a case management system that adheres to the national requirements and end-users' needs, consider the structure and needs of each country, region, and community. As systems are being designed, it is critical to understand what current systems that exist in-country to ensure the electronic case management systems interacts with other systems. In addition to the systems that exist in-country, understanding the country's political context, stakeholder environment, ICT and interoperability governance, institutional structure, potential users environment and case management needs will help teams to select a technology tool that is relevant and sustainable for your context. As systems are being designed, countries must consider literacy levels and usage of digital platforms among case workers, managers, and supervisors. The system must address the design choices concerning consistency, robustness, interactivity, and usability for low-literacy users.

DEFINE WHAT YOUR SYSTEM NEEDS TO DO

To ensure that your electronic case management system operates properly, all stakeholders must work to define what the system needs to do. The electronic case management system you intend to build must have user requirements that can help to mitigate the risk of misunderstanding and ensure that the system is collecting the data it needs with confidentiality safeguards in place in order to provide quality services and monitor performance. In many cases, there are multiple stakeholder groups who have 2020 Electronic Case Management System Key Considerations 6

completely different backgrounds (i.e. program managers and developers or system architects). As a result, a lack of understanding between the future users (case workers, case managers, supervisors and program managers) and the people who design the software (developers and system leads) may cause delays, cost overruns, and even failures in IT projects. To avoid this, it is important to consider the proposed use, system specifications, operational functionality, infrastructure, human resources capacity, interoperability, and cost when designing a system.

PROPOSED USE

What current challenges or problems the system will need to address? What stakeholders are affected by these challenges? What is the impact of each of these challenges? What will be the benefits for end users on using the proposed system instead of the current procedures or systems? What are the information and reporting needs of the different user levels (community, district, national)? What will the process workflow look like with the case management system for the case workers, case managers, and supervisors? How many end-users will use the system? Who will be using the system, and how will they access this system?

SYSTEM SPECIFICATIONS

How can I document my requirements for the electronic case management system and communicate better with technical people (developers or system architects)? Will this system be used in the field by caseworkers at the point of service (real-time data capture/entry)? Or will the system support retroactive data entry? How will data be moved between the data entry system (phone or tablet if used in the field; office-based laptop or computer if retrospectively entered) and subnational or national systems? How will I ensure I have feedback from my end-users? How will case workers enter data to the case management system? What portions of the case management flow will the system cover? What patient health, education, financial, and/or legal records will be available during the beneficiary enrollment process? Does each piece of data need to be associated with a beneficiary and household? What type of reports will need to be generated from the system? What are the minimum data elements required for the success of my program? In what languages should the system be developed? What privacy and security standards and local regulations should the system comply, such as roles-based access, audit records, authentication, etc.?

OPERATIONAL FUNCTIONALITY

What functionality is the system expected to have? Is it intended to merely provide a digital repository of the paper forms, or is it intended to provide a field worker with full access to the beneficiary history? Is it intended to have workflows to improve care? Will it feature operational reports to allow managers to oversee case workers? Note that PEPFAR expects all systems to support the reporting of MER indicators, OVC_SERV and OVC_HIVSTAT. In addition, the system is expected to support the uptake of beneficiary data on PMTCT for mothers, HIV VL, and other subpopulations that fit the country context.

INFRASTRUCTURE

Will data entry be constrained by power or network outages? Is it safe for caseworkers to carry around tablets or mobile phones? If the data entry happens in the office, do the computers have the connectivity or specifications to run the browser or software? Note that office-based data entry is more likely to be constrained by power outages than field-based data entry, since the latter would be accomplished by a mobile device or other smartphone with low internet connectivity. However, a system predicated on point-of-care data entry (by field-based staff) would likely require an offline mode with periodic data transfer to subnational and national data stores. In addition, data may be collected on paper during point of care and transferred to a digital system by a Data Clerk at a separate location. If the system is going to be hosted in a central server define its location and define the backups policy. Note that some countries may have data privacy laws that regulate how client-level data should be processed and stored.

END USER CAPACITY & USABILITY

Particularly if proposing a field-based, point of care electronic case management system, your solution should consider the digital literacy level of your end-users. A system that is very intuitive to professionals used to working with word processing programs or other technology may be less intuitive to a case manager with no meaningful exposure to computer programs. Where possible, before choosing technology, a program may elect to have potential users review candidate programs through a hands-on demonstration (if not building custom technology). If you plan to build a custom solution, potential users should be involved in the requirements gathering process and should be involved in approving user interface (UI) or user experience design (UX) to ensure usability. Consider if there is enough availability of developers specialized in the technology that you selected to ensure that maintenance is going to be feasible. Training programs should consider user capacity in their design and implementation and thus may need to be significantly changed across or even within country programs. HR capacity consideration should also include providing ongoing support on the case management system.

INTEROPERABILITY

Since OVC programming collaborates with various ministries, teams should consider systems that are interoperable with other data systems (i.e. Ministry of Gender, Social Welfare, DREAMS databases, etc.). Will this system need to interact with other systems, either now or in the future? For example, the electronic case management system may interact with the electronic medical record if case management includes treatment support (such as adherence support, transportation to appointments, viral load status etc.). The electronic case management systems may interact with the civil registration records, for example, if those records are used to verify identity. Even if not part of the immediate release, interoperability should be considered during the decision-making process, and if likely to be part of the roadmap, interoperability with other systems should be included in the requirements. When defining interoperability, take into consideration any enterprise architecture that might already exist in the country. Data sharing agreements should be established between institutions to regulate data exchange.

Cost

Cost is a primary concern for host country governments, donors, and implementing partners. When budgeting for an electronic case management system, be sure to include the full cost of ownership: the cost of building or altering the technology (if applicable), licensing the technology (if applicable), the software and hardware necessary to run the software, the devices (plus a buffer for loss/breakage), as well as development and training associated with any reporting needs. If an additional cadre of staff need to be hired and trained to support the system implementation and/or monitor its use and provide help-desk support to final users, these costs should be considered and addressed upfront as well. Lastly, the cost of network connectivity per device or Wi-Fi dongles should be accounted for as applicable if the system is expected to work online.

OPEN SOURCE VS. CUSTOM VS. LICENSED/PROPRIETARY TECHNOLOGY

As you are building an electronic case management system, consider using more than one platform for a successful electronic case management system, including mobile applications, databases, and data visualization tools. Having a system with multiple components can provide your end users with their specific needs (i.e. data collection, analysis, and storage). Where possible, teams are advised to use the Global Goods Guidebook when choosing systems. The reasons for this are four-fold:

- I. The technology already exists, which allows for improved vetting and for faster deployment. Potential users can thoroughly explore the technology prior to implementation. If the technology suits the program or country's needs, it can be implemented immediately (note: this benefit also applies to licensed/proprietary technology).
- 2. There is no licensing fee. Generally, features of open source technology are free and open to the public (note: custom technology also generally has no licensing fee).
- 3. If any other implementer of the open-source technology improves the application or software, those improvements are available to all. This is a reciprocal relationship—depending on the licenses associated with the open source technology, all improvements have to be committed to the open-source community—meaning that if your program makes any improvements, those will also be available to the open source community.
- 4. The open-source community can provide support and assistance in understanding the tool, its implementation, and its functionality.

Despite the advantages of open source technology, the following caveats must be noted:

Open-source technology is not free. While there are no licensing fees, total cost of ownership will include implementation, data storage, connectivity, training, and use; many of these costs require development, incurring cost. In addition, the open source technology may not cover all the use cases necessary for your program, so additional development may be necessary. Open-source functionality should be assessed as rigorously as any technology that involves licensing, and cost analyses should include the full cost of ownership, including incremental development, not just licensure.

Finding software development talent is not easier for open source technology than it is for other technology. Software development talent does not typically focus on applications such as OpenMRS, DHIS2, or OpenELIS. Software developers learn the underlying technologies, such as Java, HTML, SQLServer, and others, which are then used to create these tools.

Lastly, open source technology is not "owned" by the open source community. This is a double-edged sword; your program or country can do anything with the technology, but there is no recourse if the technology fails or if local adaptations made to the software cause future compatibility issues with the original software package (this is called "code branching"). In these cases, your in-country talent must be able to comprehensively troubleshoot the technology because while open source communities are generally very supportive, they do not own your implementation of the software and have no fiduciary responsibility to maintain it if customizations have been put in place.

How do Electronic Case Management Systems fit into the Broader Country Context?

Electronic case management systems generally do not exist in a vacuum, particularly when serving orphans and vulnerable children. The system may not be primarily funded by PEPFAR and may include information across child welfare needs—nutrition, anti-violence programs, legal action, etc. This will influence the design and implementation of the system, and several parameters such as data standards, data ownership, privacy, confidentiality, and security.

DATA STANDARDS

In a country with multiple electronic case management systems, data will need to be consolidated or pooled in order to de-duplicate beneficiaries and report on program progress at the subnational and national level. To ensure that data can be easily pooled, PEPFAR and other stakeholders must ensure that data is collected into a similar data structure. For example, as the system receives information about a beneficiary, the date of birth should be recorded in the same structure; sex should be recorded consistently (e.g. 0 = female, I = male or F = female, M = male, etc.). If the variables have identical names and definitions, the data will be very easy to pool, and calculating indicator results will be streamlined and simplified. Moreover, the system requirements should include unique ids for an individual and household in order to link them very easily. Additional examples of data standardization are available on the minimum requirements section of this document.

DATA QUALITY

When an electronic case management system is functioning effectively, the data collected is expected to be of high quality. However, if the system is not functioning properly or as intended to, the quality of data will likely be poor. For example, if the system collects the status of HIV positive beneficiaries and their link to treatment, but the system does not validate whether the beneficiary is on treatment, then the data reported up the system may not reflect the reality, which could lead to missing data. In addition to systems issues, data quality could also be affected by insufficient training, low literacy rates, lack of data verification at the household level, and overburdening of case workers, data clerks, and case managers.

DATA OWNERSHIP

In many countries, the country government maintains ownership of data derived from publicly supported programs. This may include community health information systems that support data collection, management, and analysis of health services provided to communities outside of facilities. Many stakeholders may have legitimate need to use the data, including to avoid costly and inefficient parallel systems. For example, implementing partners need to be able to oversee staff (which requires identifiable, individual-level data) and to monitor their program (which requires aggregate data at a minimum but will benefit from individual level, unidentifiable data). Funders will likely require reported aggregate data. The system should be set up in a way to minimize the effort needed to provide stakeholders with the data they need for decision making, monitoring and reporting.

PRIVACY, CONFIDENTIALITY, AND SECURITY

Many of the benefits of a community health information system can be realized only if case workers and beneficiaries have trust that individuals' sensitive information will be kept confidential and secure. Central to achieving this level of trust is a health care provider organization's compliance with the national security and data privacy regulations. These regulations should cover data storage, transport, and use. Be sure that the system follows international best practices for responsible handling of data for and about children.

INFORMATION SYSTEMS GOVERNANCE

Information Systems (IS) governance defines the ways and methods to implement, manage, utilize, and monitor within partner organization and stakeholders. Governance can support stakeholders from different sectors (i.e. both private and across government agencies, and coalitions) when sharing data or need to interoperate. To streamline the process, consider determining the mechanisms used to endorse institutional decisions related to information systems and identify the stakeholders who are responsible and accountable for the results of these decisions.

Universal Identity Documents (UIDs)

Although universal IDs are certainly a consideration when choosing or developing an electronic case management system, we did not give strong guidance in this area for a couple of reasons:

- I) Because OVC programs are typically managed at the household level, rather than the individual beneficiary level, that could complicate the use of universal IDs, especially where interoperability with other systems are concerned. Most applicable systems for interoperability track individuals, so the systems would not be able to exchange information about individual beneficiaries.
- 2) Interoperability between systems is also complicated by the nature of consent (particularly where personal health information and HIV status are concerned); interoperability could render consent and disclosure meaningless.
- 3) Universal IDs are difficult to implement and rarely a panacea. They can give a program false confidence about the prevalence of duplicates and do not guarantee the availability of historical data for a beneficiary. A country may be equally well-served with a robust de-duplication methodology and ensuring that the systems are sufficiently connected to allow users to access past information about a beneficiary to improve program quality and reporting.

DOES THE SYSTEM MEET THE REPORTING NEEDS?

Similar to other MER indicators, OVC_SERV data are reported semi-annually disaggregated by age, program participation, and sex at the community and facility levels. OVC_HIVSTAT data are reported semi-annually at the community and facility levels, and are disaggregated by self-reported HIV status type (positive, negative, test not required based on risk assessment, or no status). In addition, the system should collect other disaggregates required for the OVC program (VL, PMTCT, CLHIV) The system must adhere to DATIM's MER reporting requirements for consistent and accurate reporting.

MINIMUM REQUIREMENTS FOR PEPFAR REPORTING NEEDS FOR OVC SERV AND OVC HIVSTAT.

Field Content	Format	Notes and Example(s)
Beneficiary ID	Alphanumeric	The electronic case management system can automatically generate unique IDs by the system. Alternatively, the system can generate unique IDs based on a combination of name, date of birth (DOB) and location. Notes: IDs will facilitate de-duplication of beneficiaries (note that they will not solve de-duplication of beneficiaries) to count unique individuals in DATIM for reporting.
Household ID	Alphanumeric	The electronic case management system can automatically generate unique household IDs by the system. Alternatively, the system can generate unique IDs based on a combination of location, town name and partner name.
Beneficiary Names	Text	Beneficiary's name must include the first and last names.
Beneficiary Date of Birth (DOB)	Date	The system should use a consistent date format (DD/MM/YYYY or MM/DD/YYYY). The system should NOT allow users to enter dates in any format (i.e. free entry field). If a DOB is not available, then the year must be estimated by using the closet birth date of the OVC If the month and date cannot be estimated, use January I st with the actual year the beneficiary was born.
Sex	Boolean	Enable the system to select the sex of the OVC (i.e. male / female).

Beneficiary Types	Characters / Picklist	 Allow the system to categorize the beneficiaries into the following categories. The system can require this criteria in a dropdown format. Active children aged 0-17 Active OVCs 18-20 receiving educational and vocational subsidies or trainings Active caregiver aged 18+ Graduated child aged 0-17 Graduated caregiver aged 18+ Active DREAMS beneficiary aged 10-17 Children aged 9-14 receiving only primary prevention of HIV and sexual violence intervention
Location	Characters / Picklist	The system should have one-to-one mapping to each beneficiary and household.
Service Provider	Characters / Picklist	Implementing Partner or Sub-partner name
HIV Status	Characters / Picklist	The electronic case management system should have, at a minimum, the following options to select for DATIM reporting. Reported HIV positive to implementing partner Reported HIV negative to implementing partner Test not required based on risk assessment No HIV status reported to implementing partner (status unknown) If option one is selected, the system must require the user to select between the following: Currently receiving ART Not currently receiving ART or ART status unknown
Caregiver HIV Status	Characters / Picklist	The electronic case management system is expected to record the status of the caregiver (i.e. HIV positive/negative). If HIV Positive is selected, the system must require the user to select either HIV positive currently receiving ART or HIV positive not on ART, and status not reported.
OVC Service Received	Alphanumeric/ Picklist	For the system to be successful, all implementing partners must agree on the packages of eligible services and their names. List the packages of eligible services for active OVC beneficiaries (children and caregivers) in a data dictionary for easy reference.

Date of Service	Date	When designing the system, consider having separate fields for service packages for better analytics in the future. Record when the service was provided for each beneficiary by date and time. Note, with each service provided, the associated package should be listed with associated completed date.
Graduation Benchmarks	Alphanumeric	The system may record the dates of each individual benchmark as its met or may have a flag (such as a tick box) for each benchmark and a date associated only with graduation List the eight global OVC graduation benchmarks in a data dictionary
Graduation Date	Date	Date format should be the same in all systems
Transferred Status	Characters/Picklist	 The system should track whether the status of the beneficiary. Transferred out to a non-PEPFAR supported partner Transferred to a PEPFAR supported partner Exited without graduation
Transfer Date	Date	Date format should be the same in all systems
Sub-populations	Characters/Picklist	The electronic case management must support the beneficiaries of OVC subpopulations listed below, and other country specific sub-populations. • HIV+ Children • Children living in households with a biological parent or caregiver who is living with HIV • Children of KP • HEI • Children Experiencing Violence • Child Orphaned due to HIV • Child with Disability

Some electronic case management systems may also include a flag or drop down for OVC program status: active, LTFU, graduated, transferred, etc. In lieu of a flag (and to preserve data integrity), the same information can also be derived based on the most recent visit date (to identify active and LTFU),

service date (date the services were provided), graduation and transferred date (to identify those beneficiaries). Age disaggregates can be derived based on beneficiary DOB.

In addition to the minimum requirements listed above, the electronic case management system should adhere to the following criteria to ensure the system is supporting the needs of the beneficiary.

Child beneficiary ("OVC") aged 0-17 (children aged 18 to 20 still completing secondary education or an approved economic intervention):

- Develop a system that triggers / notifies case workers when the child's case plan needs to be updated prior to reaching the 12-month period
- Consider allowing the case workers to implement triggers based on the needs of the child (child's safety, schooling, stability, and health status)
- Allow the system to require documentation of the necessary forms for the child's case management plan (Intake assessment, enrollment, subsequent assessments including HIV risk assessment, case plan monitoring)
- Allow the system to flag if the child has not received at least one intervention from the project in advance of the reporting quarter
- Enable the system to track the HIV positive children and ensure that the VL is tracked in the system

Caregiver beneficiary (primarily aged 18+) of an OVC:

- Allow the system to flag if the caregiver has not received at least one intervention from the project in advance of the reporting quarter
- Allow the system to track HIV positive caregivers and ensure that the VL is tracked in the system

Active DREAMS beneficiary aged 10-17:

• Enable the system to detect girls aged 10-17 and ask if they are an active DREAMS beneficiary. If there are girls that are **only** enrolled in the DREAMS program, they are not required to be monitored towards the OVC graduation benchmarks. Therefore, consider building a system that is interoperable with the DREAMS system (if possible).

Children aged 9-14 receiving **only** a primary prevention of HIV & sexual violence intervention:

- Enable the system to detect children 9-14 and ask if they **only** receive a primary prevention of HIV & sexual violence intervention.
- Allow the system to track children that are receiving primary prevention services through a community entry point.
- Consider allowing the system to track the approved prevention of sexual violence and HIV
 interventions (e.g. Families Matter Program, Sinovuyo Teen, Coaching Boys into Men, IMpower,
 and Stepping Stones). In addition, the system should be flexible to allow users to adopt other
 country specific curricula as needed.

TECHNICAL SUPPORT AND NEXT STEPS

Need help in planning and implementing OVC Integrated Electronic Case Management system investments in COP20? Please reach out to Joshua Volle and copy Seghen Haile and Julianna Kohler, USAID HQ's systems point of contact. We're happy to discuss the current status of your portfolio and plan out next steps for support. We can help define system requirements, identify promising existing technologies, and evaluate technology vendors, among other assistance.

POINTS OF CONTACT

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Resources

- CMIS framework Palladium developed for D4I: https://www.measureevaluation.org/resources/publications/ms-20-186
- Digital Square's Global Goods Guidebook (to promote reusing systems): https://digitalsquare.org/resourcesrepository/global-goods-guidebook?rq=global%20goods%20guidebook
- Principles for Digital Development: https://digitalprinciples.org
- MEASURE Evaluation's Health Information System Strengthening Model: https://www.measureevaluation.org/his-strengthening-resource-center/his-strengthening-model
- Model of a Community-Based Information System Essential Components and Functions: https://www.measureevaluation.org/resources/publications/tr-18-243
- Responsible Data for Children: www.RD4C.org
- United States Agency for International Development (USAID): Considerations for using data responsibly at USAID (https://www.usaid.gov/responsibledata)
- World Health Organization, PATH: Planning an Information Systems Project (https://path.azureedge.net/media/documents/TS opt ict toolkit.pdf)