Joining Up Health Data

A Case Study of The DREAMS Partnership in Kenya, Uganda, and Zimbabwe

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Global
Partnership
for Sustainable
Development Data

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List of Acronyms

CDC	U.S. Centers for Disease Control
DATIM	Data for Accountability, Transparency and Impact Monitoring
DHIS2	DREAMS District Health Information System
DREAMS	Determined, Resilient, Empowered, AIDS-free, Mentored and Safe
METS	Monitoring and Evaluation Technical Support
PEPFAR	U.S. President's Emergency Plan for AIDS Relief
SDG	Sustainable Development Goal
UDOTS	Uganda DREAMS Orphans and Vulnerable Children Tracking System
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United Stated Agency for International Development

Introduction

Despite great strides in the global response to the human immunodeficiency virus (HIV) epidemic, HIV among young women aged 15 to 24 years accounts for 74% of all new HIV infections among adolescents in sub-Saharan Africa in 2016.[1] According to estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the number of new HIV infections among adolescent girls and young women was 31,000 in Kenya, 29,000 in Uganda, and 22,000 in Zimbabwe.[2] Although new HIV infections among adolescent girls and young women have been declining in the last four years[3], HIV incidence rates are substantially higher among females than males of the same age because HIV is more commonly acquired from male sexual partners who are several years older. Adolescent girls and young women are also disproportionately affected by gender inequality and other risky health and social practices due to underlying social and cultural norms, increasing their risk of acquiring HIV. This urgent and complex issue requires a multi-sectoral approach to reduce the vulnerability of adolescent girls and young women.

DREAMS (Determined, Resilient, Empowered, AIDS-free, Mentored and Safe) is a partnership led by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR). The initiative is committed to helping adolescent girls and young women develop into determined, resilient, empowered, AIDS-free, mentored, and safe women. This is achieved through a core package of evidence-informed approaches implemented in 15 countries[4] that address the structural drivers which directly or indirectly increase girls' HIV risk beyond the health sector. The package includes interventions to strengthen families, reduce the risk of HIV acquisition from sexual partners, mobilize communities to change, and empower girls and young women.

Given the complexity and diversity in implementing these interventions, the "layering" in DREAMS provides multiple services from a variety of sectors to ensure that adolescent girls and young women are reached in a holistic manner. It is therefore crucial that data systems that collect various elements for each service be interoperable to facilitate seamless service delivery to DREAMS recipients. To accommodate this, organizations providing layered services need to agree to common principles, standards, and procedures that promote data integration and comparability. Such interoperable data systems would then be useful in optimizing data use to inform expansion and/or intensification of DREAMS interventions.

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1 https://www.state.gov/pepfar-dreams-partnership. More recent data is difficult to obtain given that the age bands used in DREAMS are different from more general HIV data reporting.
2 unaids.org/sites/default/files/media_asset/UNAIDS_HIV_prevention_among_adolescent_girls_and_young_women.pdf
3 https://www.state.gov/pepfar-dreams-partnership
4 Botswana, Cote d'Ivoire, Eswatini, Haiti, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe.

The Global Partnership for Sustainable Development Data is a global network working together to ensure that new opportunities from the data revolution are used to achieve the Sustainable Development Goals (SDGs). The Global Partnership convenes, connects, and catalyzes action to address the problems of poor data use, access, quality, and production. This includes highlighting the value of interoperable data to decision-making towards attaining the SDGs. The Global Partnership-facilitated Collaborative on SDG Data Interoperability developed the guide, Data interoperability: A practitioner's guide to joining up data in the development sector,[56] which helps organizations and institutions incorporate interoperability as they design and implement data systems.

The Global Partnership and PEPFAR identified the PEPFAR DREAMS partnership as an example that included significant experimentation across multiple countries towards interoperability for tracking delivery of layered services for adolescent girls and young women. By using the data interoperability guide as an analytical framework, this case study aims to distill good practices in developing and implementing interoperable data systems at the program level. The case study focused on analyzing DREAMS programs in three countries: Kenya, Uganda, and Zimbabwe. It also aimed to extract lessons learned and insights that could inform improvements across all DREAMS data systems to support similar efforts in other contexts and sectors.

Case study objectives

» Describe notable practices in developing and using interoperable data systems to track delivery of layered services for DREAMS beneficiaries. These include, but are not limited to:

  » Stakeholder engagement

  » Policy and regulatory framework

  » Infrastructural requirements

» Identify successes and lessons learned during the development of the system (system requirements, processes, and capabilities) and system use (technical features, organizational processes, policies, and regulations).

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5   data4sdgs.org/sites/default/files/services_files/Data%20Interop%20Brief_0.pdf
6   González Morales, L. and Orrell, T. 2018. Data interoperability: A practitioner's guide to joining up data in the development sector. Global Partnership for Sustainable Development Data.

Methodology

Design: A rapid qualitative assessment approach was used, maximizing time and resource efficiency.[7] This included a literature review, partner mapping, key informant interviews, focus group discussions, and direct observations.

Data collection: This was done between December 2019 and April 2020. Key informant interviews, focus group discussions, and direct observations were conducted in Kenya, Uganda, and Zimbabwe. These were thought to represent variations in contextual factors, such as health information system policies and guidelines, and organizational factors for local and international implementing partners, while still having a high level of implementation success in terms of layering of services. Each country visit lasted three days. In total, 5 individuals in Kenya, 20 in Uganda, and 14 in Zimbabwe were consulted in key informant interviews and focus group discussions. Due to the COVID-19 pandemic that restricted travel and limited gatherings, focus group discussions were not conducted in Kenya. In addition, the overlap in timing between data collection in Kenya and COVID-19 meant that stakeholders were focused on their pandemic response. Thus, responses to the study were generally lower than anticipated.

Figure 1 summarizes the details of activities involved in each step. The lists of interviewees and those who attended the focus group discussions can be found in Annexes A and B. Data collection tools were largely based on the data interoperability guide and MEASURE Evaluation's Health Information Systems Interoperability Maturity Toolkit.[8] The key informant interview guide was also used to guide group discussions with implementing partners during focus group discussions.

Site visit with a community-based organization implementing DREAMS in Mukono District, Uganda

Data analysis: Annotated notes from interview and group discussion responses were written out in full. Recorded interviews were also transcribed. Data was grouped around the themes outlined in the data interoperability guide and, where possible, a corresponding domain

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7   Ash, J. S. et al. 2008. A rapid assessment process for clinical informatics interventions. AMIA Annual Symposium Proceedings Archive. 20:26-30. PMID: 18999075.
8   measureevaluation.org/resources/tools/health-information-systems-interoperability-toolkit

and subdomain under the MEASURE's heath information system interoperability maturity model were included using Dedoose, a qualitative data analysis software.

The analysis focused on four key layers, as suggested by the data interoperability guide:[9]

» **Technology:** Representing the most basic level, this requires that data be published and made accessible through standardized interfaces on the web to address issues of health information system enterprise architecture and technical standards.

» **Data and format:** This addresses data structure in accordance with standard models and schemas, classifications, and vocabularies.

» **Human:** This addresses the need for a common understanding among data users and producers regarding the meaning of the terms used to describe its contents and its proper use.

» **Institutional and organizational:** This layer addresses factors that influence effective and ethical data collection, processing, analysis, and dissemination. These include leadership and governance, policies and legal frameworks, and data-sharing agreements.

Figure 1: Rapid qualitative assessment steps

Step	Key Activities
Literature Review	Review existing literature on DREAMS data systems. Review respective country eHealth policies and guidelines.
Partner Mapping	Identify DREAMS partners, services they offer, data systems they have in place, and data reporting structure and processes.
Development of Data Collection Tools	Based on the data interoperability guide, complemented by the Interoperability Maturity Toolkit.
Key Informant Interviews Focus Group Discussions	Ministry of Health officials, DREAMS implementing partners, monitoring and evaluation partner(s), community-based organizations, and AIDS Control Council officials.
Direct Observation	Site visits to observe data collection and system use during program implementation.

9   data4sdgs.org/sites/default/files/services_files/Data%20Interop%20Brief_0.pdf

Findings

Program and data system description

DREAMS implementation
Implementation of the DREAMS program in Kenya, Uganda, and Zimbabwe began in 2016 through local organizations that are recipients of PEPFAR funds and implementing HIV program activities. These implementing partners then sub-granted to community-based organizations that deliver services to vulnerable girls and, in some cases, their male partners. DREAMS services are divided into primary and secondary packages.

Figure 2: DREAMS primary and secondary service packages

Primary Package	Secondary Package*
» HIV testing services. » HIV prevention training through a set curriculum. » Gender norms curriculum. » Social assets building. » School-based HIV and violence prevention. » Combination of socio-economic approaches.	» Education support. » Gender-based violence response. » HIV pre-exposure prophylaxis. » Health services (other sexually transmitted infections) and contraceptive method mix. » Condom education, promotion, and provision. *Further details on each service can be found on the DREAMS website: usaid.gov/global-health/health-areas/hiv-and-aids/technical-areas/dreams

All adolescent girls and young women within the program should receive the primary package. Eligibility for the secondary package varies for different age groups (for example, ages 10–14, 15–19, and 20–24).

As shown in Figure 3, monitoring and evaluation partners are funded by implementing agencies. They support all implementing partners with routine data monitoring. This data is reported to Data for Accountability, Transparency and Impact Monitoring (DATIM)[10], PEPFAR's repository for all data on PEPFAR-funded programs.

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10   openhim.org/docs/implementations/datim/

Figure 3: DREAMS implementation organizational structure in the three countries

CDC: U.S. Centers for Disease Control
CBO: Community-based organization
DOD: Department of Defense

IP: Implementing partner
USAID: United States Agency for International Development
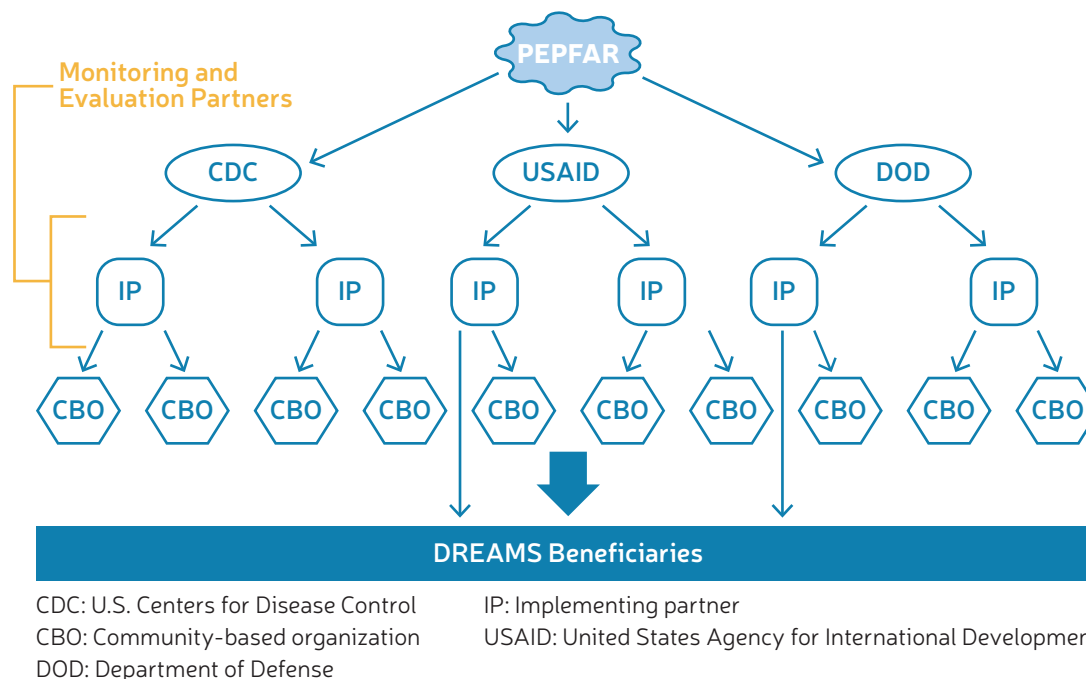
Different organizations offer some or all DREAMS services. For those that offer select services, girls are then referred to another organization for the remainder of the services package. Since DREAMS does not offer clinical services (HIV testing, pre-exposure prophylaxis, family planning, or sexually transmitted infection services), implementing partners refer girls to health facilities for relevant services. It is therefore important for the DREAMS program to track girls across services to ensure they receive appropriate layering, meaning all primary package services and additional secondary services they are eligible for. In addition, it is important to track them across organizations and geographical regions for performance monitoring.

Table 1: Geographical frequency distribution of DREAMS implementing partners

Country	N°/District* with DREAMS	Total N°/District	N°/Implementing Partners	FY 2019 adolescent girls and young women completing primary package
Zimbabwe	6	59	6	96,309 (25%)
Uganda	15	134	8	170,783 (44%)
Kenya*	7	47	10	120,193 (31%)

Note: Kenya has counties and not districts.

The DREAMS program has a common implementation approach across all three countries:

» **Screening and eligibility assessment:** Adolescent girls and young women are assessed for HIV risk and vulnerability to determine if they meet the criteria to become a DREAMS beneficiary.

» **Enrollment:** Once confirmed eligible, girls are enrolled in the DREAMS program. There are different entry points into the program, as long as they are offering one or all of the primary package services, i.e., schools, community health workers and peer networks, and orphans and vulnerable children platforms.

» **Service delivery:** Each service collects data elements during a client encounter. Some services, such as the gender norms curriculum, have multiple sessions. An adolescent girl or young woman must complete a minimum number of sessions to qualify as having received that service.

For each of the three steps, there are primary data collection forms. The data is then collated into aggregate registers. All DREAMS partners maintain this paper-based data collection system, alongside their respective DREAMS electronic data system for each country.

Referrals

As some services are not available within the community, DREAMS recipients are referred to health facilities for services such as pre-exposure prophylaxis. In these cases, girls receive a paper referral form which they are supposed to bring back to the DREAMS partner once they receive the service. Kenya and Zimbabwe use the national Ministry of Health referral form. In Uganda, they use a DREAMS-specific referral form.

Within the DREAMS network, if a girl is referred to a different organization for a DREAMS service, referral initiation, follow-up, and feedback are captured within the DREAMS system. DREAMS electronic data systems

DREAMS electronic data systems

Each of the three countries has a DREAMS data system that captures patient-level data:

» **Kenya:** Kenya DREAMS Database.

» **Uganda:** Uganda DREAMS Orphans and Vulnerable Children Tracking System (UDOTS).

» **Zimbabwe:** DREAMS District Health Information System (DHIS2).

Uganda and Zimbabwe use the DHIS2 Tracker, also known as DHIS2 Community Module.[11] This is an integrated module within the DHIS2 system, built to support case-level data and facilitate a smooth integration between individual-level data and aggregated data management.

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11 dhis2.org/individual-data-records

Kenya developed a custom web-based system using open-source technologies, including the Django framework and ODK for offline mobile data collection.[12]

In all three countries, monitoring and evaluation partners are responsible for system development, maintenance, and upgrades. They are also responsible for calculating and reporting the national AGYW_PREV indicator, which quantifies the number of adolescent girls and young women who have completed at least the primary package of DREAMS services within the past six months at Q2, or 12 months at Q4, to Data for Accountability, Transparency and Impact Monitoring (DATIM) semi-annually. This is the main DREAMS indicator collected from all countries. It is a composite indicator, requiring various data elements and a standard definition across partners for consistency and accuracy.

Uganda DREAMS and Orphans and Vulnerable Children tracking system

The Makerere University School of Public Health Monitoring and Evaluation Technical Support (METS) program's DHIS2 Tracker system was developed in 2016 and focused on the DREAMS program. METS added an orphans and vulnerable children component in 2019. The DREAMS system is available for all implementing partners, but the orphans and vulnerable children component is only available for those funded by the U.S. Centers for Disease Control.

The system captures data elements from paper forms, with standard definitions across partners.

Standardized Ministry of Health DREAMS registers in Uganda

Although the system is web-based, a mobile application with offline capability for data collection is available for point-of-service data entry. However, only a few implementing partners are currently using this application. This is likely because paper records are still expected to be maintained, and it is easier to keep paper records and key these into the system as a second layer of data entry.

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12   Using open-source technology to develop a web-based data management system for the DREAMS program in Kenya. Abstract submitted by the University of California San Francisco Global Programs for the Health Informatics in Africa (HELINA) 2019 conference.

The system uses a single web instance for access, with a similar login interface for all partners. However, each partner can only access forms relevant to the services they offer. For example, if a partner does not offer sexual violence prevention, their UDOTS program does not give them access to the sexual violence prevention module. However, all partners that offer sexual violence prevention use a similar form to report on this service, ensuring that all partners report the same data variables.

Individual clients are identified according to a user-generated unique identifier. Initially, this was an alpha-numeric identification that was specific to implementing partners and could also include special characters. However, this has since changed to a standardized set of 12 digits, which is generated by the lead implementing partner in a particular geographical area.

Zimbabwe DREAMS District Health Information System

The DHIS2 Tracker system for Zimbabwe was developed in 2016 by Population Services International, with international technical assistance for more complicated system design, development, and visualization work in the DHIS2 system architecture.

Figure 4: Screenshot of the DREAMS DHIS2 referral program showing outgoing referrals by service (last 6 months)
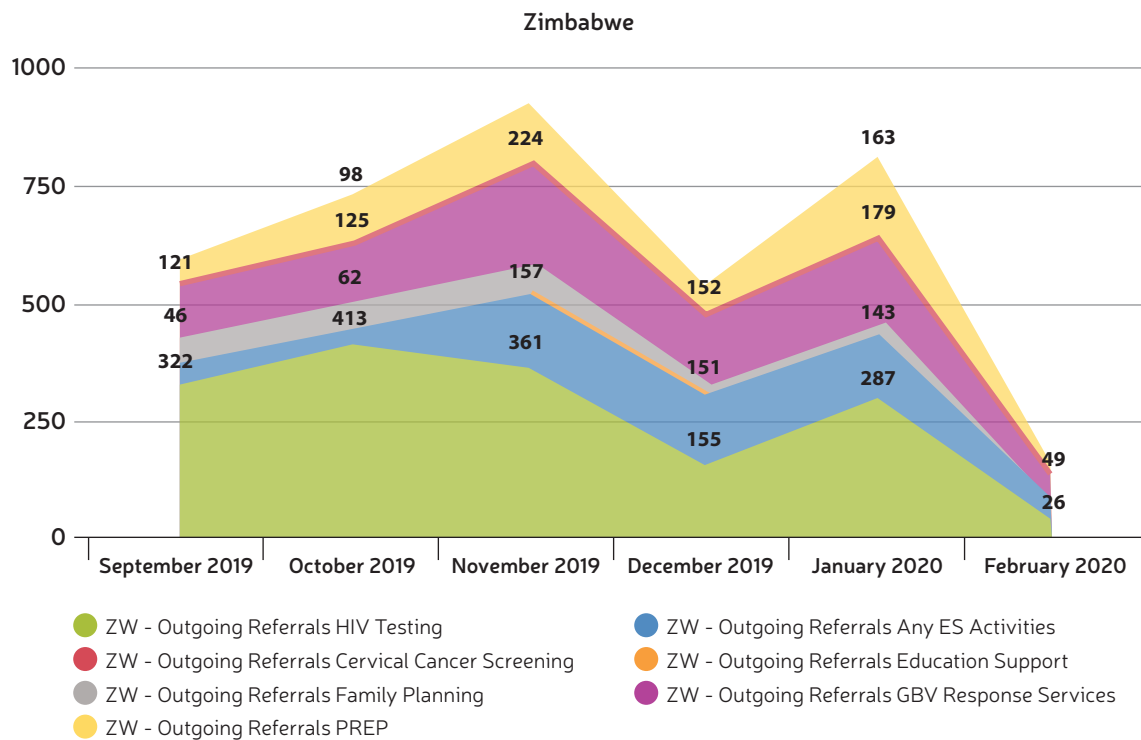
The system uses partner-specific web instances for access. The existing system comprises 16 DHIS2 trackers, or application interfaces, which allow for client registration and tracking of client level services. The 16 trackers are organized one per partner, per service. This means that each partner might access multiple trackers to capture the data for the distinct services they offer within the broader DREAMS service package. Each partner accesses their own partner- and service-specific tracker, customized to their data needs. However, they all have the same basic set of variables needed to generate the AGYW_PREV indicator. Therefore, one partner offering sexual violence prevention could have six variables, while another could collect nine variables for the same service.

The Zimbabwe DREAMS DHIS2 also has a referral tracker, modelled after the standard Ministry of Health and Child Care referral form. This form is used for referrals across all health services and health facility levels, such as from community to facility. All partners access the same referral tracker, which allows for the monitoring of client movement between partners.

Like Uganda, Zimbabwe also has a mobile version of the application (DHIS2 Tracker app), with offline data collection capability, but limited uptake among partners.

For client identification, Zimbabwe uses a separate unique identifier code application with a standard algorithm to develop a code generated from components of five pieces of demographic information. The unique identifier code can be created manually or with an app and can be modified to include the implementing partner's acronym. This identifier is then entered manually into the DHIS2 tracker.

Kenya DREAMS database
The system in Kenya was developed by the University of California San Francisco (UCSF) in October 2015. It applied the following technologies to its infrastructure design:

» Python/Django for the development framework.

» ODK for mobile data collection.

» Ubuntu for the operating system.

» MySQL for the database.

» JasperReports Server for reporting.[13]

Data was then migrated from Excel spreadsheets previously used by implementing partners for data collection. The current system is moving some features from JasperReports to Power BI.

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13   Using Open Source Technology to develop a web-based Data Management System for DREAMS program in Kenya." Abstract submitted by UCSF Global Programs for the HELINA 2019 conference.

Figure 5: Schema of Kenya DREAMS database structure
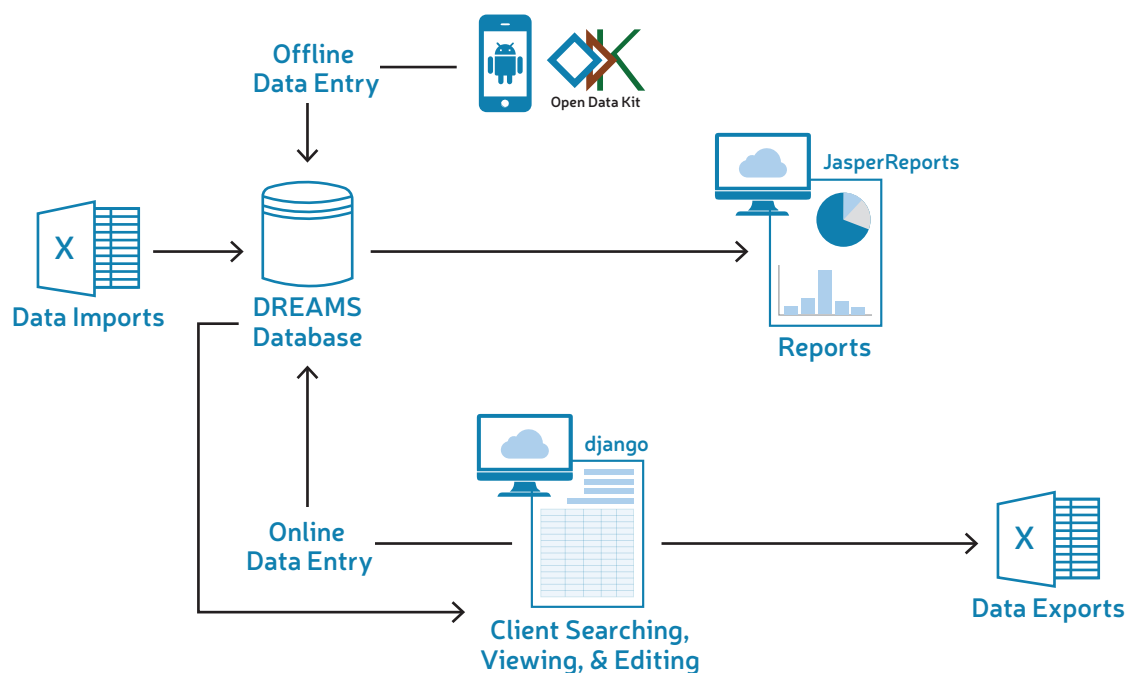
The system uses a single web instance for access, with a similar login interface for all partners, and an option to use ODK for offline data collection. All partners have access to the enrollment form and service uptake forms through a dropdown menu selection, depending on the services they offer.

The system allows for service referrals between different implementing partners.

There is a system-generated client unique identifier, consisting of the implementing partner code, ward (geographic administrative unit) code, and a serial number.

Interoperability within the context of the DREAMS program

Data "interoperability is the ability of different information systems, devices, and applications ('systems') to access, exchange, integrate and cooperatively use data in a coordinated manner, within and across organizational, regional and national boundaries, to provide timely and seamless portability of information and optimize the health of individuals and populations globally."[14] The health data interoperability ecosystem includes individuals, systems, and processes that share, exchange, and access various forms of health information among numerous stakeholders.

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14   Healthcare Information and Management Systems Society. (n.d.). HIMSS Interoperability Toolkit. himss.org/interoperability-toolkit

This case study's assessment of data interoperability within DREAMS was made in consideration of the following contextual factors:

» DREAMS data systems were primarily developed to address PEPFAR program requirements for performance monitoring. At the time of this case study, the data variables captured within the DREAMS program were not required for national health indicator reporting (monthly data reported to DHIS2) in any of the three countries.

» The primary objective of the DREAMS program is HIV prevention among adolescent girls and young women, with an emphasis on non-biomedical interventions. With that in mind, the need to exchange this information with clinical systems such as HIV electronic medical record systems in health facilities is limited, as the primary target.

However, DREAMS operates in an ecosystem with other stakeholders (especially government) who are interested in accessing and sharing DREAMS data to generate information that influences policy, planning, and resource allocation.

» Although some implementing partners had other organization-specific information systems, they were all required to use the DREAMS system in their country.

Given that DREAMS data systems are designed for DREAMS programmatic objectives, interoperability with non-DREAMs systems is limited. However, this does not indicate that data systems interoperability is impossible, but rather was not explored as it was not required. Where applicable, we refer to opportunities for DREAMS data integration with other systems[15] where program scopes align or overlap.

Common notable practices in the development and use of DREAMS data systems

Leadership and governance

Policy and regulatory framework
All countries have an eHealth policy document outlining their national digital health strategy.[16,17,18] Each policy document outlines the need for adoption of an eHealth enterprise architecture, supporting interoperability and standards.

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15 Data integration: The act of incorporating two or more datasets into the same system in a consistent way, which is one of the possible outcomes of data interoperability. Interoperability Guide, p.9.
16 Republic of Uganda. Uganda National eHealth Strategy 2017–2021. health.go.ug/sites/default/files/National%20e_Health%20Strategy_0.pdf
17 Government of Zimbabwe. Zimbabwe's E-Health Strategy 2012–2017. who.int/goe/policies/countries/ zwe_ehealth.pdf?ua=1 (a non-draft version now available in hard copy, provided to us by the Zimbabwe Ministry of Health and Child Care)
18 Republic of Kenya. Health Sector. Health Information System Policy. extranet.who.int/ countryplanningcycles/sites/default/files/country_docs/Kenya/health_information_system_policy.pdf

According to interviews, the three countries have adopted the OpenHIE[19] framework for their national health information system interoperability development. The countries are at various levels of ensuring compliance with data exchange standards. Kenya and Uganda are at varying stages of developing health information system interoperability guidelines. Kenya has a national information system certification framework document that facilitates interpretation, assessment, and compliance with the standards and guidelines for various digital health information systems.[20]

DREAMS system developers in the three countries were all aware of the existence of these documents, which they considered while selecting and developing the software platforms they used.

The policies state that ideal digital health systems should be affordable, easy to scale, and holistically meet the needs of users. As a global good,[21] DHIS2 lends itself well to this requirement.

> *"We selected DHIS2 because of its scalable, extensible, and open-source architecture. DHIS2 is the same open-source software used by PEPFAR for DATIM, and by ministries of health around the world, for performance management. This made a DHIS2-based system theoretically easier to plug into other DHIS2 systems like DATIM and Zimbabwe's national health management information system."*
> – Monitoring and evaluation partner, Zimbabwe

Governance structure
There is a governing body for health information systems within the ministry of health in each country. These departments host a government-led eHealth technical working group, which includes other relevant government ministries and non-government stakeholders. In Uganda and Zimbabwe, DREAMS monitoring and evaluation partners sit within the technical working group. This close collaboration with ministry of health information system departments ensures that the ministries of health are aware of the DREAMS data systems, their functional capability, and the data available.

Data standards
The three DREAMS data systems reported results using international data exchange standards. For the DHIS2 Tracker systems, this is designed to use aggregate data exchange for data exchange.[22] This supports interoperability, as data is structured according to standard classifications, permitting meaningful interpretation across systems.

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19 ohie.org
20 Kenya Health Information Systems Certification Framework. A non-public document was shared by the Ministry of Health for the purposes of this study. The Ministry expects to make a version public in 2021.
21 PATH. Digital Square Global Goods Guidebook. 2019. Seattle. static1.squarespace.com/static/59bc3457ccc5c5890fe7cacd/t/5ced6f3c7817f7e261ddbc0a/1559064401781/Global-Goods-Guidebook_V1.pdf
22 wiki.ihe.net/index.php/Aggregate_Data_Exchange_-_HIV

Data ethics

DREAMS data systems adhere to ethical principles of data management. Such responsible data practices include varying levels of access to DREAMS data; variable data rights depend on the user's role and the use of unique identifier codes with minimal collection of personal identifiers within the system. This applies not only to digital systems, but also to paper records. This governance ensures that data is collected and maintained in an ethical manner, as outlined in the Health Information System Interoperability Maturity model.[23]

Good practice: *DREAMS participation in governance promotes interoperability*

Uganda has a separate sub-group on interoperability within the eHealth technical working group, which the DREAMS monitoring and evaluation partner sits in. They therefore share their insights and experiences with development and deployment of the UDOTS systems with the Ministry of Health's Information and Communications Technology department as they seek to develop their interoperability guidelines, frameworks, and even their use cases.

Business continuity

Formal data back-up processes and procedures for DREAMS data include weekly manual back-ups at the implementing partner level and automated cloud server back-up at the monitoring and evaluation partner level.

Institutional layer (government ownership)

Based on the UN's SDG 3, good health and well-being is a human right, whose main custodian is the government. Government buy-in and involvement in any digital health system used in the public domain is therefore imperative if governments are expected to provide strategic leadership and an environment that promotes interoperability.

Stakeholder engagement during system development

For all three countries, DREAMS monitoring and evaluation partners were instrumental in leading the process of mapping, streamlining, and harmonizing the integration of partners' existing data capture forms and processes. In Uganda, the Monitoring and Evaluation Technical Support (METS) program convened the process and facilitated the Uganda AIDS Control Program to lead this process. This resulted in government-owned final forms, registers, and reporting processes that were widely accepted by implementing partners. This consultative process also gave district and community-level government public health

Good practice: *Meaningful stakeholder engagement leads to more opportunities to showcase DREAMS systems*

The Uganda AIDS Commission oversees the implementation and coordination of other HIV prevention interventions among adolescent girls and young women funded by The Global Fund and other partners. Due to government participation and involvement during the development of the UDOTS system, and continued engagement with DREAMS data utilization, the Uganda AIDS Commission has engaged METS to provide technical advice as they agree on a set of indicators and consider using the district health information Tracker system for these programs.

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23   Health Information Systems Interoperability Maturity Toolkit. measureevaluation.org/resources/tools/
     health-information-systems-interoperability-toolkit/health-information-systems-interoperability-toolkit

officers a well-grounded understanding of the data elements collected by the DREAMS program, which allowed them to participate meaningfully in data review meetings.

In Zimbabwe, Population Services International Zimbabwe worked with each partner organization to thoroughly assess and map the partner's existing data capture into DHIS2 technical system requirements. This led to the harmonization of definitions. For example, some implementing partners were capturing age, while others were capturing date of birth. Even though each partner still has the autonomy to capture more variables as needed for their organizational use, they have a standard definition and syntax for common variables.

In Kenya, the University of California San Francisco convened the implementing partners to discuss standardization of data elements and definitions. They also facilitated the legacy data import process from the Excel-based systems, which were being used by implementing partners at the time, to the Kenya DREAMS database. The Kenya Ministry of Health officials interviewed did not report being involved in this process.

Good practice: *Government ownership of DREAMS systems fosters adoption of interoperable systems in the public sector*

In Zimbabwe, the DREAMS district health information system was developed in close consultation with the Ministry of Health and Child Care and the National AIDS Council. Involving these agencies in the early days increased ownership and appreciation of the complementarity of the DREAMS DHIS system to the national aggregate district health information system.

Following this close relationship, the National AIDS Council received resources from The Global Fund to implement an HIV prevention program among adolescent girls and young women in 30 districts (DREAMS Lite). Population Services International Zimbabwe provides them with technical assistance as they adapt the DREAMS district health information system and adopt it to suit their program needs.

"Why would we go for another system? DREAMS works. It can track girls from one district to another. Layering of the services is clear because of the unique identifier code and we can deploy it on tablets to be used as a point of care system."
– NAC Zimbabwe

Stakeholder engagement for data use
One of the greatest successes of DREAMS data systems is availing data for use by the respective government agencies as and when needed.

"I may have forgotten my login credentials. But if I need any data, I just call Population Services International and I will get it. How I wish it were the same for HIV data."
– Ministry of Health and Child Care, Zimbabwe

DREAMS data access processes and procedures could be better standardized and communicated to all stakeholders, so everyone is clear on the data request procedure. However, non-state actors agreed that the data belonged to the respective governments and ministries of health.

"Yes, the data belongs to PEPFAR, but it also belongs to the government. As long as a Ministry of Health official follows the right protocol to request the data, we will avail it to them."
– Implementing partner, Uganda

Organizational and human layer

Systems are developed, used, and maintained by people who, in turn, must have the right skills. Policies need to be in place to guide how various people interact with the system to ensure their use fosters interoperability.

Human resources

In all three countries, monitoring and evaluation partners have multiple health information system officers to support system development and maintenance. They also have a help desk to address any system issues raised by implementing partners from the field.

> *"For us, we use the system daily. One of the reasons this has been possible is because when we call Monitoring and Evaluation Technical Support (METS) with an issue, they address it either immediately, or if it's something that will require more time, they will ask us to wait, and will always alert us when they fix it."*
> — Implementing partner, Uganda

Implementing partners also have monitoring and evaluation officers tasked with inputting data into the DREAMS data system and data verification. In some organizations, they lead data demand and information use at an organizational level.

Community-based organizations that use laypersons for data entry, including peer adolescent girls and young women, ensure that at minimum, these people have basic information and communications technology skills.

Capacity building

In all three countries, monitoring and evaluation partners are responsible for initial training and on-boarding of any new implementing partner joining the DREAMS program. They train them mainly on use based on user roles. In Uganda and Zimbabwe, training often involves district health and community development officers to foster government ownership and ensure standardized understanding of the data system across all relevant stakeholders. In Kenya, the monitoring and evaluation partner convenes and facilitates relevant training with implementing partners and provides help desk support.

For sub-grantee organizations, training is done by the primary implementing partner. However, they can reach out to the monitoring and evaluation partner as and when needed to assist with this second tier training.

Partner coordination

An interesting indirect effect of DREAMS data system use has been fostering cooperation among implementing partners. In Uganda, they organized themselves outside of PEPFAR supervision and agreed that to ensure consistency, minimize duplication, and confirm the correct attribution of numbers to the respective organization, only the lead partner would

generate unique identification numbers and share these with other implementing partners during their monthly data review meetings.

In Zimbabwe, implementing partners have a point-of-contact partner in every district who leads the unique identification de-duplication process during their monthly data review meetings. They have a written standard operating procedure for this. This integrating partner also convenes an inter-partner referral meeting to follow up on inter-partner referrals for the week.

Data quality review meetings
In all three countries, a schedule for data entry, consolidation, cleaning, and review is in place and enforced by the monitoring and evaluation partner. Although various implementing partners have different workflows and data flows, and follow different processes for service delivery and data management, they all reported that the process has improved over time as implementing partners have continued to engage with the DREAMS data system.

The monitoring and evaluation partner coordinates implementing partners for routine quarterly data review meetings that reference data from DREAMS data systems, regardless of any other data system used by implementing partners.

Technology layer

Technical standards
Each country cited technical standards in light of future interoperability as one of the factors they considered while developing or adopting their DREAMS data system. These include Health Level Seven (HL7) Fast Healthcare Interoperability Resources, Aggregate Data eXchange (ADX), and vocabulary standards such as the International Classification of Diseases.

The underlying design for DHIS2 accommodates commonly used standards and profiles from standards development organizations, including the International Organization for Standardization (ISO), Integrating the Healthcare Enterprise (IHE International), and Health Level Seven.

> *"For us, going with DHIS2 was a no-brainer. It's free, everyone already knows it, so it won't feel like we are introducing something new. The district health information system already offers a lot of development support and we also have the local expertise to manage it locally. That is why even for orphans and vulnerable children, we are going the DHIS2 way."*
> — Monitoring and evaluation partner, Uganda

Another critical factor in selecting a system was its ability to support analysis of layering. That is, the system needed to distinguish programs, or specific interventions, from services and events within a program, such as sessions within a training curriculum. Finally, the

system needed to provide layering, such as tracking an individual girl across programs and services, to ensure she received the complete DREAMS package.

DHIS2 provides the element of hierarchical relationality. That is, it tracks services and relationships between services and across organizational units over time. This enables DHIS2 to support the various constructs of the DREAMS service delivery structure. Having both data capture and visualization capabilities also gives it an edge over other systems.

> *"DHIS2's suite of out-of-the-box tools, including data entry and analytics, gave it an edge over other management information system solutions that often contain components of these tools but not all. This necessitates linking and maintaining multiple software packages to implement a comprehensive solution."*
> – Monitoring and evaluation partner, Zimbabwe

Online and offline capability

For the three countries, online and offline capability was a key consideration in deploying their respective DREAMS systems. Implementing partners lauded the efforts of monitoring and evaluation partner(s) to roll out offline versions of the system, which happened more recently in Zimbabwe and Uganda. In Kenya, ODK mobile was a preferred choice largely for this reason. A system's ability to be available for use at all times is critical in minimizing missed data capture opportunities, thereby facilitating interoperability.

Data layer

For data from interoperable systems to provide information that can be used effectively across systems and organizations, it must first meet the needs of the primary user.

Donor reporting requirements

All DREAMS data systems capture the minimum data elements required to calculate the AGYW_PREV indicator, which quantifies

Good practice: *Use of third generation DHIS2 analytics beyond DREAMS for data integration*

With help from the district health information system consultant, Population Services International Zimbabwe is using DREAMS to push the boundaries of analytics available through the district health information system. With the unique identifier code, not only can a user link a girl to the program and services or events, but the user can also track the layers of services she received. Through DREAMS layering, DHIS2 developers are further refining the system's hierarchical relationality.

In theory, DHIS2 can adapt this for the national district health information system to track when a pregnant woman received ante-natal care services at a maternal health clinic, when her child received vaccines at a well baby clinic, and when she received family planning services at a family planning clinic; for example, services that are currently reported as stand-alone programs. In these situations, DREAMS DHIS2 development will contribute significantly to data integration.

the number of adolescent women and young girls who have completed at least the primary package of DREAMS services/interventions within the past six months at Q2 or 12 months at Q4. This is the DREAM indicator that is reportable to DATIM. It is a percentage indicator, with composite elements for the numerator and denominator. Patient-level DREAMS systems are

designed to capture single data elements consistently. This means that, for the most part, a change in the composite definition of the AGYW_PREV indicator does not affect client-facing data elements.

However, as Uganda and Zimbabwe use the DREAMS system for analytics with customized built-in reports, reports and dashboards must be updated to reflect changes in various elements of the indicator, such as age-group eligibility for certain services. Kenya did not report this as a challenge.

Data from DREAMS systems is also used for PEPFAR's annual country operational planning.

Data use

A major success with the DREAMS data system has been data demand and information use from the system by implementing partners. Notably, there has been data demand and consumption by government officials, including district level health and community health officers in Uganda and Zimbabwe.

All implementing partners reported using the DREAMS data system to monitor their performance, using reports and dashboards at various levels within their organizations.
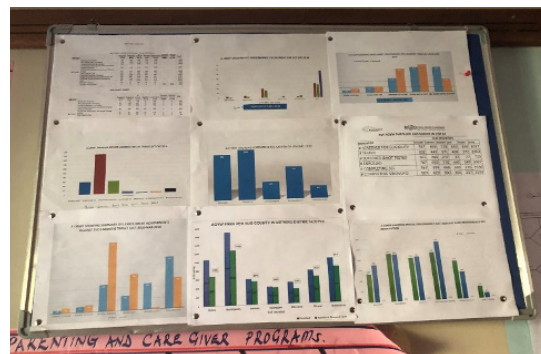
Organizations use the information from DREAMS systems for performance monitoring and to track their progress.

> *"We share the report with the community-based organization in that region, and ask them, 'How are you doing?' and 'What can you do to improve?'."*
> — Monitoring and evaluation officer, implementing partner, Uganda

> *"There's no more excuse that, 'That is not our data.' The data is in the system."*
> — Monitoring and evaluation officer, implementing partner, Uganda

The DREAMS partners appreciate the importance of layering and referrals.

> *"With UDOTS, I can see whether a girl I referred to another partner for a service actually went. It's good because then I'm confident we have helped that girl in the best way possible."*
> — Community officer, community-based organization, Uganda

Lessons learned with opportunities for improvement

Establish a robust unique identification system

The DREAMS program is a unique ecosystem in that:

» It is implemented in the community as a program with wide reach and acceptability.

» It requires referral to clinic services (hence future interoperability needs with hospital-wide health information systems).

» While each country has a system in place for unique identification, the following challenges emerged with every system:

  » **Duplication:** Having the same girl appearing with multiple identification numbers within the DREAMS database.

  » **Lack of verification:** Since the algorithm for generating the unique identification is known, it is possible to circumvent the existing unique identification.

Given its current implementation and the data systems in place, DREAMS is in a unique position to demonstrate the viability of creating and implementing a unique identifier –preferably with verification, such as biometrics – for unique identification within the DREAMS data systems. This is a prerequisite for successful interoperability.

Limit the use of parallel (paper-based and digital) data systems
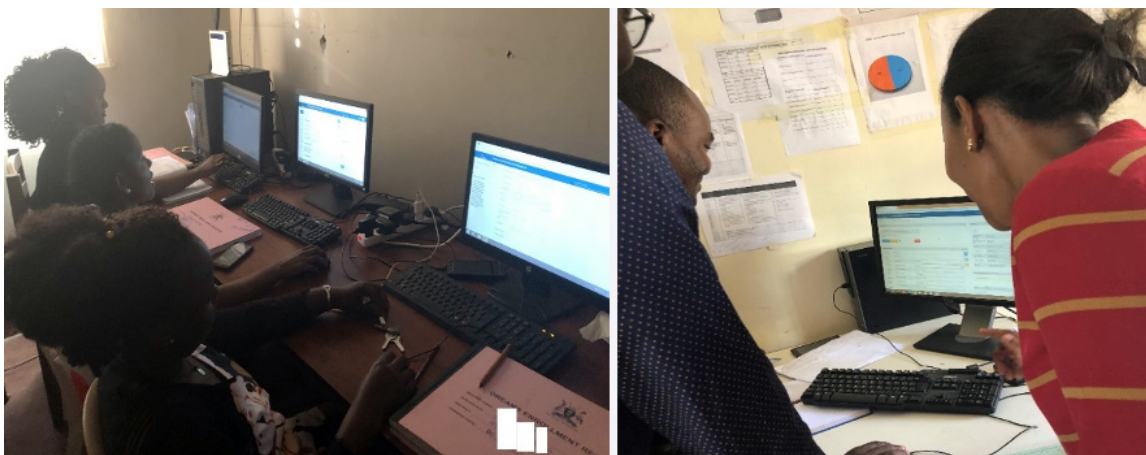
Transcription of information from registers into the DREAMS data system.

Despite the success of the DREAMS data systems, the fact that users have to use paper entry forms and registers in parallel to using the electronic system creates redundancies and duplication of efforts.

"I wish we could just key the data straight into the system. It would reduce the amount of time and manpower we use to transfer the data from paper to the system. We could then use the resources to reach more girls."
— Monitoring and evaluation officer, community-based organization, Uganda
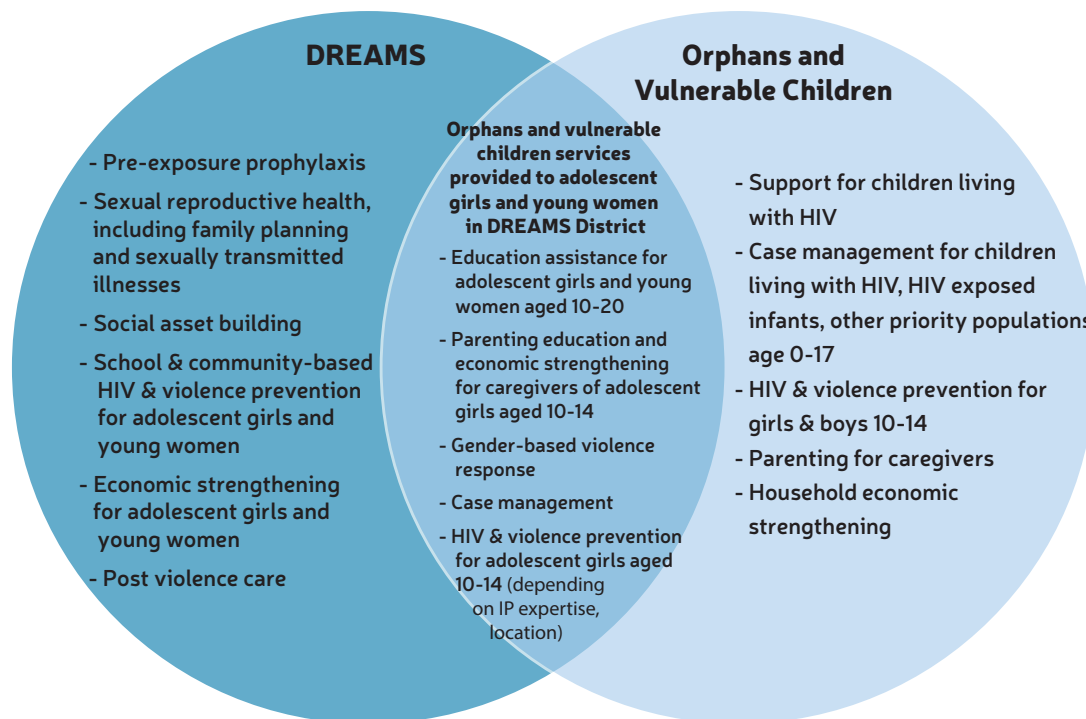
Given its closed nature, the DREAMS program and data systems are in a unique position to inform other systems and programs on how to go paperless.

All DREAMS data systems have both online and offline capability. It is therefore possible to systematically implement and evaluate use of point-of-care data collection systems (mobile phones and tablets) for DREAMS data systems, and use lessons learned to inform the bigger PEPFAR HIV program and ministry of health systems in the respective countries.

Standardize training curriculum for sustainability and government ownership

While the process of requesting training on DREAMS system use (data entry and analytics) was clear among current DREAMS partners, the content covered during training was largely ad hoc. Training schedules and content were needs-driven — for example, how to use the

Figure 6: DREAMS and orphans and vulnerable children platforms converge to deliver a comprehensive package of services for vulnerable adolescent girls

DREAMS

- Pre-exposure prophylaxis
- Sexual reproductive health, including family planning and sexually transmitted illnesses
- Social asset building
- School & community-based HIV & violence prevention for adolescent girls and young women
- Economic strengthening for adolescent girls and young women
- Post violence care

Orphans and vulnerable children services provided to adolescent girls and young women in DREAMS District
- Education assistance for adolescent girls and young women aged 10-20
- Parenting education and economic strengthening for caregivers of adolescent girls aged 10-14
- Gender-based violence response
- Case management
- HIV & violence prevention for adolescent girls aged 10-14 (depending on IP expertise, location)

Orphans and Vulnerable Children

- Support for children living with HIV
- Case management for children living with HIV, HIV exposed infants, other priority populations age 0-17
- HIV & violence prevention for girls & boys 10-14
- Parenting for caregivers
- Household economic strengthening

Source: Natalie Kruse-Levy, USAID Zimbabwe

system – versus skills-based and did not seem to vary in relation to the people being trained. There is an opportunity to develop a standardized, formal training curriculum for DREAMS data systems, with involvement from ministry of health eHealth governing bodies. Such institutionalization would enhance system ownership by the government and act as a case for advocating for the integration of a digital health curriculum when training health professionals at all levels.

> *"The monitoring and evaluation partner is also the national HIV program monitoring and evaluation partner. Funded by PEPFAR, we partnered with the Ministry of Health, Centers for Disease Control, and other stakeholders in developing e-learning content for the HIV monitoring and evaluation program. This could be leveraged to include the Kenya DREAMS database system e-learning content, ensuring that should new implementing partners come on board, they have access to the learning content. It would also foster more ownership of the DREAMS data within the Ministry of Health, since the HIV program (National AIDS and STI Control Program, National AIDS Control Council) would be involved in content creation for the learning material."*
> – Monitoring and evaluation partner, Kenya

Leverage programmatic convergence to promote system interoperability

As a strategic priority in its 2020 Country Operational Plan Guidance, PEPFAR indicated the need to promote synergy between the DREAMS and Orphans and Vulnerable Children programs. This lends itself as an opportunity to showcase interoperability. As PEPFAR continues to support system implementation across both programs, emphasis should be placed on interoperability as new systems are on-boarded alongside DREAMS data systems.

This overlap in scope also highlights an opportunity for interoperability with existing national systems in the social protection ministries. For example, the Ministry of Gender Labour and Social Development in Uganda runs a national program and maintains a data system for orphans and vulnerable children with support from various donors. In Kenya, the Ministry of Education is rolling out a biometrics-based student identification system. In both instances, DREAMS data systems should endeavor to be interoperable with these national and sub-national systems.

Data exchange with existing national HIV prevention programs

The National AIDS Control Council maintains an HIV dashboard specific to Kenya, which contains HIV prevention indicators for adolescent girls and young women. However, the Kenya DREAMS database does not contribute to this dashboard. This remains an opportunity where DREAMS data systems could demonstrate interoperability and data exchange.

Conclusion

The findings from this study indicate that DREAMS data systems in Kenya, Uganda, and Zimbabwe can track the layering of DREAMS services among adolescent girls and young women. These can be used to assess the impact of the DREAMS program in reducing HIV incidence among adolescent girls and young women. While design and implementation of the DREAMS data systems considered key elements from the four layers outlined in the data interoperability guide, there still are opportunities where DREAMS data systems could be improved to promote interoperability with other systems supporting adolescents and young women to ensure they remain healthy, as is their human right.

Lessons on interoperability that can be extrapolated to inform other program-level work include the need for fostering government ownership and stakeholder consensus during data system development, and continued engagement through system implementation and data use. This is critical to ensuring buy-in and creating value for the government to invest in the process. In turn, this will ensure interoperability and sustainability.

Another key lesson is the need to use standard syntax and definitions and, if possible, adopt those that already exist as indicators in developing a new program, such as capturing date of birth instead of age. Adhering to commonly used technology standards and profiles, such as Health Level Seven (HL7), will ensure that these issues are considered. It will also foster interoperability with other systems in the health sector.

In conclusion, the data interoperability guide and MEASURE's Health Information Systems Interoperability Maturity Toolkit are practical frameworks that can be used in the health sector to inform interoperability in health system design, implementation, and evaluation.

Annexes

Annex A: DREAMS implementing partners and funding agencies in Kenya, Uganda, and Zimbabwe

Country	Implementing Partner	Funding Agency	Monitoring and Evaluation Partner
Zimbabwe	AfricAid	USAID	Population Services International (PSI)
	Catholic Relief Services (CRS)	USAID	
	Centre for Sexual Health and HIV AIDS Research Zimbabwe (CeSHHAR)	USAID	
	Family AIDS Caring Trust (FACT)	USAID	
	FHI 360	USAID	
	Population Services International	USAID	
Uganda	Catholic Relief Services	USAID	Makerere School of Public Health – Monitoring and Evaluation Technical Support Program (METS)
	John Snow Inc. (RHITES–N, Lango)	USAID	
	Makerere University School of Public Health, Rakai Health Sciences Program	U.S. Centers for Disease Control (CDC)	
	Makerere University Walter Reed Project	Department of Defense	
	Mildmay Uganda	CDC	
	Uganda LARA – RTI International	USAID	
	University Research Co., LLC (RHITES–N, Acholi)	USAID	
	World Education (Better Outcomes for Children and Youth)	USAID	
Kenya	Afya Pwani	USAID	University of California San Francisco Global Programs – Kenya
	Bomu Hospital	CDC	
	Coptic Hospital	CDC	
	Henry M. Jackson Foundation	Department of Defense	
	HOPE Worldwide Kenya	CDC	
	HSDA/Nyanza (Afya Ziwani)	USAID	
	HSDA/Central-Eastern (Afya Kamilisha)	USAID	
	IMA World Health (Afya Jijini)	USAID	
	Impact Research & Development Organization	CDC	
	LVCT-Health (DARAJA)	CDC	
	LVCT-Health (STEPS)	CDC	

Annex B: List of interviewees and focus group discussion participants

Zimbabwe Focus Group Discussion with Implementing Partners		
1	Senior monitoring and evaluation officer	AfricAid
2	Monitoring and evaluation officer	AfricAid
3	Strategic information specialist	FACT
4	Monitoring and evaluation officer	FACT
5	Strategic information and evaluation manager	FHI
6	Program coordinator, DREAMS and key population	Ministry of Health and Child Care

Zimbabwe Key Informant Interviews		
1	Program Coordinator, DREAMS and key population	Ministry of Health and Child Care
2	Deputy Director, ICT services	Ministry of Health and Child Care
3	Senior monitoring and evaluation officer	National AIDS Council (NAC)
4	Monitoring and evaluation officer	NAC
5	Senior systems architect, DHIS2	Population Services International (PSI)
6	Senior information systems manager	PSI
7	Digital health solutions teaching assistant	PSI
8	Senior health advisor	USAID

Uganda Key Informant Interviews		
1	Health information systems analyst	Monitoring and Evaluation Technical Support (METS)
2	Health systems strengthening teaching assistant	METS
3	Senior health information systems advisor	METS
4	Data officer	ISORE (community-based organization under the Makerere University Walter Reed Project
5	DREAMS focal person	ISORE
6	Data entrant	ISORE
7	Social worker	ISORE
8	Monitoring and evluation officer	MOD (community-based organization under Mildmay)
9	Monitoring and evaluation officer	SOCY (project under Catholic Relief Services)

Uganda Focus Group Discussion with Implementing Partners		
1	Monitoring and evaluation advisor	RHITES-N, Acholi
2	Monitoring, evaluation, and learning director	Better Outcomes for Children and Youth (BOCY) project
3	Senior program coordinator	RTI-LARA
4	Gender and youth program coordinator	Makerere University Walter Reed Project
5	Monitoring and evaluation officer	Mildmay
6	Senior monitoring and evaluation officer	Mildmay
7	Monitoring and evaluation officer	RTI-LARA
8	Monitoring and evaluation officer	Rakai Health Sciences Program
9	Senior program officer, DREAMS	SOCY (project under Catholic Relief Services)
10	Monitoring and evaluation officer	RHITES-N, Lango
11	Senior program officer	Makerere University Walter Reed Project

Kenya Key Informant Interviews		
1	Monitoring and evaluation director	National AIDS Control Council
2	Focal person - Strategic information, HIV prevention	National AIDS and STI Control Programme
3	Monitoring and evaluation director	University of California San Francisco (UCSF-Kenya)
4	Monitoring and evaluation director	UCSF-Kenya
5	Health information system analyst	UCSF-Kenya