



DREAMS Innovation Challenge: Applying data to increase impact of HIV/AIDS Prevention for Adolescent Girls and Young Women in Uganda

A synthesis report and recommendations to design a decision-support tool responsive to user demand

November 2018

Determined Resilient Empowered AIDS-Free Mentored Safe



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Disclaimer

The opinions, findings, and conclusions stated herein are those of the author[s] and do not necessarily reflect those of the United States Department of State, JSI, AidData or ToroDev.

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Executive Summary

Working towards an AIDS-free Uganda

Uganda is home to an estimated 1.3 million people living with HIV, including 6.2 percent of adults aged 18-64.¹ Adolescent girls and young women are affected disproportionately by the HIV/AIDS epidemic: HIV prevalence among this group is four times higher than their male counterparts.² Without timely interventions and forward-thinking policy, adolescent girls and young women in Uganda are at risk of being left behind.

Ensuring a Uganda where these “girls develop into Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe women” is the goal of the DREAMS program, a multibillion-dollar partnership between a cross-cutting group of development partners, non-governmental organizations, and philanthropic foundations led by the U.S. Department of State. In 2016, the DREAMS partnership launched an Innovation Challenge (DREAMS-IC), managed by John Snow Inc. (JSI), to catalyze innovative solutions in six areas:

1. Strengthening capacity in communities;
2. Promoting education for girls;
3. Linking men to services;
4. Providing pre-exposure prophylaxis;
5. Ensuring a bridge to employment for affected populations; and
6. Applying data to increase impact.

As a component of DREAMS-IC, AidData, a research lab at William & Mary in the United States, collaborated with the Toro Development Network (ToroDev) in Uganda to address evidence gaps in Area 6: applying data to increase the impact of interventions for people living with HIV, particularly adolescent girls and young women.

Given insufficient data quality and reliability, policymakers in Uganda are often flying blind, using intuition rather than evidence in the fight against HIV/AIDS. Why does this happen? The project team sought to answer this question by assessing what data people use, what challenges they face in using it, and what improvements they would like to see to encourage more evidence-informed policy. We interviewed 73 people across 35 organizations and five user groups, undertook desk research and case study analysis, and held a workshop in Kampala to solicit feedback on three proposals for strengthening Uganda’s health management information systems.

What did we find? Assessing Uganda’s health data ecosystem

In the final project report, we identify three challenges to accessing and using data: (1) lack of access to the right data at the right time; (2) inconsistent data quality; and (3) limited capacity in facilities to deliver results. These insights emerge from consultations with data users in the government, civil society, private sector, and academia, as well as beneficiaries of prevention and treatment programs. Encouraging the use of evidence in policymaking will thus require modernizing and democratizing access to health data systems so that users can know who is doing what, where, and to what effect in response to the HIV/AIDS epidemic.

Outlining options to strengthen health systems in Uganda

To address these challenges, we propose three potential avenues for a decision support tool to equip policymakers and practitioners with the data they need to make informed decisions on where to allocate scarce resources. A decision support tool is a (computer-based) system that

provides information to improve planning and decision-making processes. In the health sector, this includes data on health services, outcomes, and populations of interest.

During a series of interviews and consultations conducted in Uganda, health policymakers and practitioners largely agreed on four priority features they would want to see in a future decision support tool: (1) an open-source, web-based platform; (2) interoperability between the decision support tool and other health management information systems in the Ministries of Health and Education; (3) Geographic Information Systems (GIS) and map-based services; and (4) feedback loops and information-sharing between organizations.

Based upon this input, we presented three potential solutions at an August 2018 validation workshop conducted with Ministry of Health officials in Kampala:

1. **Create an Open Data Center for Health (OpenDCH):** This option proposes a new decision support tool, OpenDCH, as a one stop shop for data and evidence on HIV/AIDS in Uganda. The tool would be publicly available, integrating information on HIV-affected populations and services from various data systems in the government, and featuring geospatial data and tools. By creating linkages between systems and featuring data publicly, OpenDCH would strengthen supply chain and patient management, while also mitigating data accessibility concerns among civil society and the private sector. Attendees acknowledged these strengths but were reticent to embrace another decision support tool, especially once the government introduced the Situation Room, a parallel tool with similar functionalities as OpenDCH.
2. **Strengthen the AIDS Commission’s E-mapping and Monitoring System:** This option proposes to upgrade an existing decision support tool, the E-mapping and Monitoring System, established by the Uganda AIDS Commission on HIV Prevention. Upgrades include: (1) digitizing data collection to streamline data entry and improve quality; (2) disaggregating indicators by sex and age; (3) integrating GIS tools to enable spatial analysis; (4) improving interoperability with other data systems; (5) enabling access for partners outside of the Commission; and (6) featuring visualizations and dashboards to facilitate use. Attendees preferred this option to the first, as it would strengthen existing indicators through improved data disaggregation while also addressing issues regarding interoperability with the rest of the data ecosystem. However, core users were satisfied by the E-mapping system and did not wish to invest scarce time and resources to improve it.
3. **Introduce a Community-based Health Management Information System (C-HMIS):** Our consultations emphasized the importance of community-based data to provide disaggregated and timely information on local health priorities. To that end, this option proposes to integrate a C-HMIS into the District Health Management Information System (DHIS2). Such an application would allow real-time data entry by community health workers and thus provide a more comprehensive view of community-level disease management. Despite concerns over costs and constraints to creating a new module within DHIS2, workshop attendees felt that this option would bridge the gap between community- and national-level data while also complementing existing health data systems. Thus, they felt most optimistic that this option would be a unique application of data to increase impact.

Participants in the August 2018 workshop emphasized the need for a multi-sectoral response that engaged relevant line ministries, leveraged the appropriate human and material resources, and accounted for issues related to sustainability, tool ownership, and capacity building among users. Our findings suggest that the third option above—the creation of a C-HMIS—best balances these priorities while also delivering a tool that meets users’ needs. Implementing this option, while addressing its potential pitfalls, is thus an important next step towards equipping policymakers with the tools they need to achieve an AIDS-free Uganda.

¹ Uganda Population-Based HIV Impact Assessment (UPHIA), 2016-2017.

² Ibid.

Glossary

AGYW:	Adolescent Girls and Young Women
ARV:	Antiretroviral
ART:	Antiretroviral Therapy
CSO:	Civil Society Organization
DHIS2:	District Health Management Information System
DREAMS-IC:	Determined Resilient Empowered, AIDS-free, Mentored, and Safe women—Innovation Challenge
DST:	Decision Support Tool
eMTCT:	Elimination of Mother to Child Transmission
HCII:	Level 2 Health Facility
HMIS:	Health Management Information System
HSDP:	Health Sector Development Plan
LMIS:	Logistics Management Information System
M&E:	Monitoring and Evaluation
MoH:	Ministry of Health
NGO:	Non-Governmental Organization
OpenDCH:	Open Data Center for Health
PEPFAR:	President's Emergency Plan for AIDS Relief
PHA Network:	People Living with HIV/AIDS Network
PIASCY:	AIDS Strategy for Communication to the Youth
ToroDev:	Toro Development Network
UAC:	Uganda AIDS Commission
VHT:	Village Health Team

CHAPTER ONE

Introduction

Uganda is home to an estimated 1.3 million people living with HIV, including 6.2 percent of adults aged 18-64.³ Young women and girls are disproportionately affected by the disease, as HIV prevalence is nearly four times higher among young women aged 18-24 compared with their male counterparts.⁴ Reducing the vulnerability of this at-risk population is critical to slowing the rate of new HIV infections in Uganda. However, despite advances in data collection and data visualization technologies, many decision-makers and key stakeholders in Uganda cannot readily access and analyze the data they need on HIV/AIDS incidence, prevalence, investments, and results.⁵ To combat this trend, systems are needed which leverage existing and novel data in formats conducive to evidence-informed decision-making.

This final project report synthesizes insights gleaned from interviews with 73 individuals from 35 Ugandan government, civil society, and development partner organizations regarding which information they currently use and what data they lack when attempting to deliver life-saving services and curb HIV prevalence for adolescent girls and young women (AGYW). Produced by AidData, a research lab at William & Mary in the U.S., with support from PEPFAR and in collaboration with the Toro Development Network (ToroDev), this final project report draws upon these interviews with diverse stakeholders to propose three options for Uganda's development community to build a future decision support tool (DST) that responds to user demand.

This work was made possible by a DREAMS Innovation Challenge grant, which aims to promote new thinking and approaches beyond conventional methods to fight HIV/AIDS.⁶ Led by PEPFAR, DREAMS is a collaborative partnership which aims to reduce HIV infection by 40 percent among adolescent girls and young women within the 10 highest-burden areas of sub-Saharan Africa with the support of the Bill and Melinda Gates Foundation, Girl Effect, Johnson & Johnson, Gilead Sciences, and ViiV Healthcare.⁷ The goal of the DREAMS initiative is to help "girls develop into Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe women."⁸

SECTION 1.1

Background

Given insufficient timely, comprehensive, and disaggregated information in an easy-to-use format,

policymakers in Uganda are all too often flying blind—relying on intuition rather than evidence to allocate HIV/AIDS prevention and treatment resources. Seeking to overcome this status quo, Uganda has a number of policies that aim to improve national health management information systems in order to realize the country's Vision 2040 of a "healthy and productive population that contributes to economic growth and national development."⁹

For example, the National Health Policy II aims to: (1) strengthen management of national health systems; (2) create a culture in which health research guides policy formulation and action; and (3) build a harmonized health management information system which generates data for evidence-informed planning and decision-making at all levels.¹⁰ In its second National Development Plan, Uganda associates improving health information and technology with its ability to enhance the competitiveness of its health sector globally and regionally. Finally, Uganda's National HIV and AIDS Priority Action Plan 2015–2018 explicitly identifies two objectives related to strengthening the production of comprehensive and timely HIV/AIDS information to support monitoring and evaluation, as well as to promote information sharing and utilization among producers and users of HIV/AIDS data and information at all levels.¹¹

In line with this enabling policy environment, the project team sought to uncover barriers to entry for policymakers and development partners in Uganda to access and use better data on HIV/AIDS. We interviewed 73 individuals to understand what data people presently use, the challenges they face in accessing and analyzing this information, and what they would like to see in the future. In addition to the key informant interviews, the project team conducted desk research to document what HIV/AIDS data is currently available in Uganda, in what form, and at what level of granularity. A validation workshop was also held in Kampala with 16 decision-makers in August 2018 to gather feedback on several proposed options for a decision support tool that would triangulate various HIV/AIDS data points and support planning and implementation of programs for Uganda's most at-risk populations, including adolescent girls and young women.

The remainder of this final project report synthesizes the main findings and recommendations emerging from key informant interviews, the validation workshop, and desk research on Uganda's HIV/AIDS data ecosystem. In Chapter 2, we provide a brief overview of the methodology for selecting who participated in the

interviews and consultations, as well as the types of questions posed. In Chapter 3, we assess the status quo of the supply of, and demand for, HIV/AIDS data with an emphasis on opportunities to close gaps. We conclude in Chapter 4 by outlining three options for

Uganda to move forward with a decision support tool that will make it easier for policymakers and implementers to access and use the HIV/AIDS information that meets their needs.

³ Uganda Population-Based HIV Impact Assessment (UPHIA), 2016-2017.

⁴ Ibid.

⁵ UNECA, 2015; UNAIDS, 2014; PEPFAR Zambia, 2015.

⁶ The DREAMS Innovation Challenge funded projects falling within six key focus areas: (1) strengthening capacity of communities to deliver services; (2) keeping girls in secondary school; (3) linking men to services; (4) supporting pre-exposure prophylaxis; (5) providing a bridge to employment; and (6) applying data to increase impact. This particular project falls within the sixth focus area on applying data to increase impact.

⁷ DREAMS Website.

⁸ Ibid.

⁹ Health Sector Development Plan (HSDP) 2015/2016 – 2019/2020.

¹⁰ Ibid.

¹¹ National HIV and AIDS Priority Action Plan 2015/2016 – 2017/2018.

CHAPTER TWO

Approach

Because the project aims to support the creation of a decision support tool for decision-makers in Uganda's HIV/AIDS landscape, our study had to assess the data ecosystem and enabling environment for data use to ensure that our proposed tool did not duplicate efforts or muddle existing initiatives. The research team conducted this assessment through desk research and key informant interviews with stakeholders in the government of Uganda, civil society, academia, and the private sector. Following an initial scoping process that also leveraged ToroDev's local knowledge and network, we developed interview protocols for conducting consultations and identified key stakeholders and informants for interviews in Kampala and Oyam.

All interviews were analyzed by a member of the research team who identified common themes and looked for answers to the research questions asked. Interviews were analyzed individually, as well as by stakeholder group. Once all interviews in a stakeholder group were analyzed, a member of the research team drew parallels amongst the themes raised from the stakeholder group. Upon finalization of analysis for all stakeholder groups, the research team re-reviewed all interviews and pulled common themes across all stakeholder groups.

Following the conclusion of this research, we held a validation workshop in Kampala in August 2018 with key stakeholders identified by the Ministry of Health. The purpose of the meeting was to discuss insights from our research and receive feedback on our recommendations for a potential decision support tool. We held this workshop and consulted stakeholders at the central, district, and local levels to ensure that our research had identified the most significant data gaps and was aligned with existing needs and demands in the Ugandan data ecosystem. A subsequent validation meeting with additional representatives of the Ministry of Health was held in October 2018 and further feedback incorporated.

SECTION 2.1

Interviews

From January 2017 through April 2018, AidData and ToroDev interviewed 62 individuals representing 34 organizations and government agencies to learn about HIV/AIDS-related data needs in Uganda. We also interviewed 11 beneficiaries engaged with the People Living with HIV/AIDS Network (PHA Network) for a total of 73 individual interviews.¹² Interviewees represented

four stakeholder groups, including: (1) government (e.g., front line service providers, decision-makers at the national, subnational, and district level); (2) non-Governmental and Civil Society Organizations (NGOs/CSOs) that actively work on HIV/AIDS issues; (3) private sector companies and academia involved in delivering services or studying disease trends related to HIV/AIDS; and (4) beneficiaries of HIV/AIDS prevention or treatment programs. Tables 1 and 2 in Appendix 1 break down interviewees by organization and stakeholder group, respectively.

Over a quarter of interviewees were directly engaged in HIV prevention or treatment services as frontline providers in roles such as health facility in-charge, school nurse, or medical clinical officer. We also interviewed representatives from NGO/CSO programs in roles such as program director, program manager, project coordinator, and monitoring & evaluation (M&E) coordinator. Additionally, we gathered input from country leadership and chiefs of party, district planners, HIV focal persons, subject matter experts (specialists in HIV, M&E, and adolescent girls and young women), and technical experts on health systems strengthening programs. The diversity of stakeholders within organization, sector, and position allowed for a holistic view of the existing health data ecosystem and priorities of decision-makers for data sources and types. Lastly, 15% of interviewees were HIV+, currently engaged in HIV treatment services, and active with the People Living with HIV/AIDS Network in their community.

Interviews were semi-structured, in that interviewers used a set of suggested topics and questions as an initial guide, but treated the interviews as conversations. In conducting interviews with decision-makers, AidData and ToroDev covered three topics: what types of decisions they make (decisions); what types of data they use to make these decisions (current state of data); and what type of data and in what format would they like to have that is presently not easily available (future state of data). With beneficiaries of HIV services, interviewers focused on three different topics: how individuals access HIV treatment (access); how individuals identified treatment options (awareness); and what aspects of existing HIV/AIDS prevention and treatment services should be improved (needs).

SECTION 2.2

Data Scoping

In addition to the key informant interviews, we conducted an extensive desk review to pinpoint specific data sources that were publicly available for decision-makers focused on HIV/AIDS prevention and treatment. The purpose of this exercise was to gain a better understanding of current decision-making processes and identify existing data needs. Identification of data sources through both desk research and key informant interviews provided the research team with a comprehensive picture of the data ecosystem in Uganda.

Figure 2 outlines the primary and secondary data sources that we uncovered during our research. This table contains the results of research conducted in

Kampala in early 2016 during which an inventory of all known development datasets for Uganda was established. The inventory originally contained information on 1,150 datasets from 300 data sources. The research team then cross-referenced available data and gaps with findings from the key informant interviews and data validation workshop to determine what data currently exists to meet expressed need. The table below reflects data sources relevant specifically to the health sector. The extent to which interviewees reported using the data sources mentioned in Figure 2 varied by stakeholder type and role. Trust in a given data source was an important predictor of use.

A deeper understanding of publicly-available data sources and the data sources specifically mentioned as being utilized by decision-makers was a critical component to our analysis of current data gaps. This initial groundwork provided the context necessary to assess the types of decision support tools which may be useful in Uganda.

FIGURE 1

Four Ways in Which Interviewees Reported Accessing Data on HIV/AIDS

Databases/Big Data Sources	Summary Reports	Project Data Collection	Verbal Communication
HMIS (DHIS2) LMIS MTRAC Situation Room Partner-owned databases	District- and facility-level reports Partner organization program reports Ministry of Health website	Paper survey Electronic data entry	Partner meetings/workshops Community sensitization Village health teams (VHTs)

FIGURE 2

Strategic Health Data Systems in Uganda Based on AidData Literature Review

Data Source	Type of Information Collected in Data Source
Primary Data Sources	
Level of Disaggregation: National	
Uganda Heart Institute Patient Database Access System	Heart diseases and patient data
Clinical Trials Database	Clinical trials
Annual Pharmaceutical Sector Performance Report 2013-2014	Progress/funding of pharmaceutical indicators
Drug Registration Application	Drug registry
Exports Verification System	Drug exports
GAVI Statistics	GAVI supported projects; immunization coverage
Global Fund datasets/AidSpan (http://www.aidspan.org/country/260)	Global fund donors; MDGs; health systems; mortality and global health estimates
Level of Disaggregation: District	

U-reporter	Heart diseases and patient data; immunization
In-depth surveys	Various health indicators
Health Management Information System 2	Health datasets; hospital performance
Level of Disaggregation: Sub-country	
Health resources for Health Management Information Systems	Health resources per hospital
Integrated Management Information System	Uganda population and household census
Annual Health Sector Performance Report 2014-15	Hospital performance; DTL ranking
Level of Disaggregation: Statistical Region	
Uganda - AIDS Indicator Survey 2011	Household characteristics; knowledge of HIV/AIDS; attitudes related to HIV/AIDS; sexual behavior; HIV and Youth; HIV program coverage indicators
Uganda - Demographic and Health Survey 2011	Housing characteristics; marriage and sexual activity; fertility levels, trends, preferences; family planning; child health; nutrition; malaria; HIV knowledge, attitudes, behavior; mortality; women's empowerment
Uganda - Malaria Indicator Survey 2014-2015	Malaria prevention, knowledge, and management of fever
Uganda - Service Provision Assessment Survey 2007	Facility level infrastructure, resources, systems, services
Secondary Data Sources	
Level of Disaggregation: National	
AIDSinfo	HIV/AIDS
Demographic and Health Survey, Multiple Indicator Cluster Survey, etc.	Nutrition; health; HIV/AIDS; education; demographic; economic; women; child protection; early childhood development
Global Health Observatory data repository	MDGs; health systems; injuries and violence; HIV/AIDS
Human development data	Trends in human development; gender development index; poverty index; inequality index
Indicator Registry	HIV/AIDS indicators
IPUMS International	Fertility, mortality, disability
Knoema	Health
OECD data	Health
Uganda country page	HIV/AIDS estimates
Level of Disaggregation: District	
Higher Local Government Statistical Abstracts (2012-13)	Production and marketing; community-based services
Directorate of Water Development, Ministry of Water and Environment 2010	Access to piped water
District profiling and administrative records	Availability of health facility

Open Data for Africa (Open Data Uganda)	Health
Spotlight on Uganda	Health
Uganda National Household Survey, 2012-2013	Distance to drinking water; population that suffered illness/injury
Level of Disaggregation: Statistical Region	
UBOS - GDDS/SDDS, Economic and Financial Data for Uganda (Socio Demographic Data)	Health
World Bank data	World development indicators on health; health and nutrition population statistics

SECTION 2.3

Validation Workshop

Based upon the key informant interviews and data scoping exercise, the project team distilled several findings on the current use of HIV/AIDS data in Uganda and what improvements stakeholders wanted to see moving forward. From this foundation, we identified three options for a decision support tool that would closely align with the needs and priorities of decision-makers focused on HIV/AIDS prevention and treatment. To test and refine these recommendations, the project team met with key national-level stakeholders in August 2018 for a data validation workshop.¹³

The meeting had three objectives:

1. To discuss findings from earlier consultations conducted with 73 government, civil society, and private sector stakeholders on their data needs, including 11 beneficiaries of HIV/AIDS prevention and treatment programs;

2. To present recommendations and several options for a possible HIV/AIDS decision support tool and other data solutions to meet these needs; and
3. To solicit feedback from participants to inform the recommendations and design of future data solutions appropriate and relevant for Uganda.

Most stakeholders who attended the data validation workshop were from the Ministry of Health (8), with representation also from the Ministry of Education, the Ministry of Gender, Labour, and Social Development, the Uganda AIDS Commission, and JSI. Participants were excited about the diversity of representation at the meeting from various ministries as they felt it symbolized a multi-sector response. Stakeholders also provided useful feedback on data improvement initiatives that were taking place in Uganda and that had emerged after the project team had completed data scoping activities—more specifically the launch of the Situation Room, intended to act as a single source of health information for national level decision-makers.

¹² Interviews were conducted in-person in Oyam and Kampala at the interviewee's office or the most convenient and confidential place. With the interviewee's consent, interviews were recorded for note-taking purposes. Notes taken during the interview were cleaned and finalized within a 48-hour time frame after the interview. All interview records and notes are confidential and are only accessible by the primary and secondary investigators. The content contained in this document is the summary of the interviews and consultations. Interviews are referenced by number that correlate to the original interview notes for internal purposes only.

¹³ In addition to those that participated in the August 2018 workshop, there were several individuals that workshop participants agreed would have valuable feedback to inform the recommendations; however, these individuals were not available during the implementation timeframe. With guidance from focal contact points from the Ministry of Health and JSI, the decision was made that the feedback from just those individuals present at the data validation workshop would be sufficient.

CHAPTER THREE

Current Reality: The HIV/AIDS Data Ecosystem in Uganda

What information do policymakers and practitioners working on HIV/AIDS prevention and treatment in Uganda need to make effective decisions? To what extent do these decision-makers have access to the right data, in the right form, and at the right time? In this chapter, we summarize the key constraints in the current HIV/AIDS data landscape as identified by participants in the interviews and consultations.

SECTION 3.1

Key Challenges by Stakeholder Group

FINDING #1

Data is in a 'black box' at the district level. This creates perverse incentives and a 'race to the bottom' in reporting and data quality.

"Reporting is a major problem and the reporting tool for ART is not available here. We only report on the number of people receiving medication per month to the HIV focal person. I don't know how the data is used by the district...I do not use any external source of [data] for my work [as an in-charge]...we need involvement from district especially training and equipment."

HCII, IN-CHARGE

Front-line service providers capture critical data points on individuals affected by HIV/AIDS in their communities; however, in their view, this information disappears into a black box once it is reported up to the district level. Patient information is typically documented on paper at the point of service delivery and is only digitized once it reaches the district level. However, most health facilities do not have direct access to the DHIS2 to input information electronically or use this data in their work.

It is important to acknowledge that this division of labor is by design. While reducing the data entry burden at the facility level is admirable, interviewees indicated that this might create unintended consequences. For example, front-line health workers highlighted their

discontent with the fact that strong feedback loops were not in place to ensure that facilities could use the digitized patient information that they themselves had provided to the district in hardcopy.

This information asymmetry may partly be a consequence of how (or where) resource allocation decisions are typically made. District-level officials make most routine decisions regarding the supply of drugs, staff, and other equipment allocated to facilities based upon patient numbers (e.g., the number enrolled/engaged in antiretroviral therapy, as well as the number of individuals testing positive). By contrast, health facility staff do not have direct planning authority over the type or amount of resources allocated to their facilities, which may explain why it has been a lower priority for district health officials to ensure that front-line staff in health clinics have access to the DHIS2.

Yet, this one-way information transfer from front-line providers to district health officials reduces the utility of available HIV/AIDS information in several respects. A number of front-line health workers raised concerns regarding the quality of patient information collected at the facility-level due to the higher risk of inaccuracy with manual reporting (e.g., missing fields, incorrectly completed fields) and there is no easy way for front-line staff to conduct quality assurance checks of the digitized information. Front-line staff may also have limited incentives to ensure the quality of the information they are reporting, as many questioned whether this data is even being used at the district or national level. In fact, there is also a risk of intentional inaccuracies, as several interviewees explained that data forgery is common as NGOs/CSOs compete for limited resources and must demonstrate the success of their programs, leading to inflated or skewed reporting. Meanwhile, interviewees from several implementing partners operating at particular facilities stated that they often do not report directly to the facility or share results (except to their funders), which further exacerbates the information gap.

In conversations with officials with the Ministry of Health, there is some indication that efforts have been made to increase the data collection capacity of front-line health workers in order to improve quality and increase compliance of implementing partners to reliably report on their results at the facility level. Nonetheless, the perspective of many front-line health workers interviewed was that there was still substantial room for further improvement.

Front-line service providers did mention their experience with several health data systems, such as the DHIS2, the Health Management Information System (HMIS), and Elimination of Mother to Child Transmission (eMTCT); however, the extent to which these information sources were used varied substantially. Interviewees identified several gaps, both human and material, that prevented them from leveraging HIV/AIDS data in their work, including: human resource constraints, lack of computers on site, and limited capacity of staff to conduct data entry.

FINDING #2

District- and subnational-level decision-makers are most concerned with the accuracy, timeliness, and usability of the HIV/AIDS information that is available to them.

“The quality of data is poor and the data is not updated into HMIS. In most cases this is because of staff shortages, often you find there is only one data entry person at the entire health center.”

SUBNATIONAL GOVERNMENT DECISION-MAKER

District- and subnational-level decision-makers typically have more ready access to electronic data points (e.g., the number of individuals tested, the number of patients on antiretroviral therapy) than their counterparts in front-line health clinics; however, this stakeholder group reported that this information is often in a form that is difficult to use and of questionable quality. Interviewees explained that, absent standardized methods to assess data quality, it is difficult to make resource allocation decisions in such a way that controls for potential errors. Meanwhile, while implementing partners have invested significant time and effort to improving data quality, several interviewees also reported that implementing partners do not value or prioritize submitting data on time, which compounds issues of data inaccuracy, as available information is often out-of-date in the various reporting systems.

District-level decision-makers are primarily concerned with implementing and achieving targets related to national plans and strategies for HIV/AIDS management. They identified a number of existing data sources which guide their decision-making including: partner data, the Health Management Information System, the Ministry of Health website, and the Logistics Management Information System (LMIS). Subnational-level decision-makers were concerned with how to ensure the adequate supply of drugs and testing kits, transportation services for beneficiaries to access clinics, etc. They also require data for planning and programming related to community mobilization and sensitization, testing, as well as adherence and empowerment around lab results for patient

management. An emphasis was placed on needing a better way to track and ensure appropriate drug supply.

FINDING #3

School educators identify limited public availability of health information as a major constraint to helping students reduce their risk of contracting HIV, getting tested, or accessing treatment.

Information on HIV/AIDS is not currently provided to students in a consistent way, as there is not a standardized health education curriculum and data quality is inconsistent. Blood drives conducted by Red Cross were frequently mentioned as the most common way in which HIV testing is conducted with students. However, students fear knowing their status and those who are aware of their HIV positive status fear unwanted disclosure to their classmates and teachers. Often, students who are found positive drop out of school.

In response to this state of affairs, Uganda’s Ministry of Health and Ministry of Education have invested significant resources to provide support networks and drafted a School Health Policy and Sexuality Education framework among other key initiatives. Additionally, significant investment was made through the presidential initiative on AIDS Strategy for Communication to the Youth (PIASCY) and health education integration of HIV awareness into the national curriculum, as well as extracurricular activities.

Finally, students and teachers are encouraged to participate in voluntary HIV counseling and testing. Schools refer those in need to dedicated service providers.

However, data quality regarding the whereabouts of these students and those at increased risk of dropping out is inadequate. Notably, participants in an October 2018 workshop with the Ministry of Health recommended that the government make a greater investment in data cleaning. The Ministry of Education, meanwhile, is investing in improving data quality for services provided to newly positive children. However, integration with other data systems remains limited.

School educators felt that developing and incorporating health education into schools is key to ensuring that students have access to information that is helpful and valuable. Providing teachers with a curriculum and access to necessary resources is essential to ensuring appropriate information on HIV prevention strategies is provided to students. Additionally, educators expressed the desire to develop stronger relationships between health facilities and schools. The hope is that such relationships could be used to ensure that the correct health information is shared directly to students and that students can ask questions directly of health professionals.

FINDING #4

Civil society actors have limited visibility on data collected by the government, and what data is publicly available is perceived to be of limited quality due to inaccuracies and reporting delays.

"In Uganda we have to invest in data, because you find in many organizations very few people take data seriously, and data is an area that needs a lot of advocacy. Information management practices are poor and we do not know the importance of data."

NGO, DIRECTOR OF SERVICES

Interviewees from non-governmental (or civil society) organizations involved in implementing HIV/AIDS prevention and treatment services need data to support a range of activities, including: resource allocation, budgeting, targeting, establishing early warning systems, and linking patients to services. Most interviewees use a combination of primary and secondary sources of data for decision-making; however, they expressed that the information they need is often not readily accessible from the district government or available in a format they can easily use.

While effective HIV/AIDS prevention and treatment efforts are cross-sectoral, information sharing between government agencies and organizations working in different sectors is relatively nascent. Implementing partners also express frustration that publicly available information systems do not speak to each other, and over-reliance on paper-based systems for data collection makes it difficult to reliably compare or integrate information across multiple sources.

Moreover, there was a perception voiced by many NGO/CSO interviewees that the data available from government and community-level actors was unreliable due to inaccuracies, missing fields, or the possibility of skewed reporting. This observation is consistent with findings in AidData's previous research in other countries and sectors, which indicates that ensuring the objective quality of data is insufficient, if there is not an equal effort to enhance the perceived trustworthiness of that data with end users (Custer and Sethi, 2017; Masaki et al., 2016; Sethi and Prakash, 2018).

FINDING #5

Barriers to access, concerns with quality, and competing risk factors are among the most significant concerns among beneficiaries. Addressing these bottlenecks through information will improve results.

"I usually walk about 6KM from home to the health center. I go to [this] health center because it is where I started my treatment from... However, services here are not good and they do not meet my needs. Sometimes the drugs are out of stock and [the health facility] is far from where I stay."

PATIENT ENGAGED IN PHA NETWORK

While beneficiaries may not be making decisions that affect others, per se, their views are important to understanding the data landscape for HIV/AIDS in two respects: (1) to what extent do these individuals feel that they have the information they need to make good choices about their treatment options; and (2) as individuals identify gaps in coverage, they could help pinpoint what data improvements are needed for government and non-governmental actors to be more responsive to beneficiary needs.

Figure 3 summarizes the main barriers to accessing HIV prevention, treatment, and care services. Interviewees varied in how they perceived their access to, and quality of, antiretroviral treatment services, as well as their overall satisfaction with the testing and treatment options available to them. Many beneficiaries were aware of HIV testing and treatment services in their communities. However, fear and stigma hindered their willingness to access testing services, particularly for men. At present, patients typically receive antiretroviral treatment services based upon the proximity to their home or at the facility where they initiated treatment. Common distances to health facilities ranged anywhere from 1 km up to 16 km and in rare cases 40 km. Most beneficiaries reported that the services available to them were of average quality, citing patient-provider relations as a leading factor why services were not considered optimal. In addition, facilities frequently run out of antiretrovirals, and HIV test kits and often do not have sufficient supplies to run lab tests considered crucial to patient management.

Interviewees identified several obstacles to receiving HIV treatment services, including: (1) inability to test everyone due to limited access to HIV services; (2) stigma and fear around knowing one's status; (3) distance to health facilities; (4) inadequate transportation to reach health facilities; (5) poor treatment of patients by health workers; and (6) patient congestion exacerbated by limited human resources for health. At the community level, interviewees pinpointed several additional challenges to reducing

new infection such as: alcohol abuse; risky behaviors; gender-based violence; poverty; and transactional sex.

Beneficiaries felt that more should be done to: (1) ensure a consistent and adequate supply of drugs and HIV testing kits; (2) staff health facilities with adequate numbers of well-trained staff; and (3) engage youth for community outreach and life skills activities. In this respect, the observations of beneficiaries mirror that of the other decision-makers we interviewed in that they imply the need for better data to support how staff resources, drugs, and other supplies are allocated at the health facility-level, as well as the need to increase the availability of health information to proactively engage with students and youth.

FIGURE 3

Main Barriers to Accessing HIV Prevention, Treatment, and Care, as Reported by Beneficiaries

Access

- Long distances to health facilities
- Poor transportation
- Fear and stigma
- Facility congestion
- Drug stockouts
- Lack of HIV test kits
- Insufficient supply of lab tests for patient management

Quality

- Poor patient-provider relations
- Human and material resource constraints
- Limited life skills and knowledge-based activities
- Limited engagement of youth

Competing Risk Factors

- Alcohol/drug abuse
- Risky behaviors
- Poverty
- Transactional sex
- Gender-based violence
- Multiple concurrent partners
- Lack of condom use
- Prostitution

SECTION 3.2

Cross-Cutting Themes Across All Stakeholder Groups

Ultimately, stakeholders across groups coalesced around three main challenges facing the current HIV/AIDS data ecosystem in Uganda: (1) increasing access to ensure all decision-makers have the data they need at the right time; (2) improving quality of the information that is available; and (3) strengthening both material and human capacity at the facility level to deliver results. Figure 4 provides additional detail on these three key challenges.

More effective collection, use, and interoperability of data on HIV/AIDS inputs and outcomes, particularly found within the Health Management Information System, will be critical to address existing access, quality, and capacity constraints. In Chapter 4, we turn from the discussion of the status quo to that of the desired future by outlining what interviewees and participants in a national-level validation workshop had to say about potential solutions to improve HIV/AIDS data for planning and decision-making. Based upon these inputs and our data scoping, we identify three possible options for how to proceed with a future decision support tool that addresses these key constraints.

FIGURE 4

Challenges in Uganda's HIV/AIDS Data Ecosystem

Access

- Limited access to key data sources
- Limited to no data feedback loops for partners
- Primarily still paper based with limited electronic access
- Need for integration with other systems
- Desire for collaboration amongst partners

Quality

- Limited disaggregation
- Difficult to interpret/use
- Lack of trust
- Inconsistent reporting
- Timeliness of data

Resources

- Human resource constraints
- Material resource constraints
- Poor data literacy
- Frequent drug stockouts
- Financial resource allocation often not enough for programming

CHAPTER FOUR

Desired Future: Options for a DST

In determining options for a future decision support tool in Uganda, the project team accounted for: (1) existing data systems identified by desk research and interviewees; (2) current data challenges expressed by the stakeholder groups; (3) desired features of a data solution identified by interviewees; and (4) feedback from national-level stakeholders participating in a data validation workshop conducted in August 2018.

In this chapter, we first present the feedback from interviewees, then outline three options for the design of a decision support tool. We conclude by discussing the relative merits of the three options, based on insights from the workshop participants.

SECTION 4.1

User Feedback Regarding Desired Features in a Future Data System

Overall, stakeholders agreed on four features in a future decision support tool: (1) a web-based, open-source platform; (2) interoperability of key HMIS data with other complementary data sources; (3) GIS and mapping capability to support targeting of resources at the subnational level; and (4) the ability to facilitate information-sharing and data feedback loops amongst various government and non-governmental partners. We elaborate on each of these points below and discuss how these features may alleviate some key constraints identified in Chapter 3.

RECOMMENDATION #1

Democratize access to information through an open-source, web-based platform.

Paper-based collection methods and low accessibility of data on HIV/AIDS were two constraints that government and non-governmental stakeholders alike identified in their planning and decision-making. Introducing electronic data collection tools could be a game-changer in simultaneously reducing inaccuracies from manual reporting while also increasing the speed and timeliness by which data can be reported by health facilities. Additionally, the use of an open-source, web-based platform would potentially reduce barriers of entry for all stakeholders—front line service providers, policymakers at all levels, implementers in NGOs/CSOs, and beneficiaries—to make use of a shared data repository. However, stakeholders stressed that for a

web-based platform to be successful, streamlined national guidelines will be required to ensure alignment of quality assurance processes across all districts and regions. Existing systems (DHIS2) may have the functional capacity to address this task if use is optimized.

RECOMMENDATION #2

Facilitate interoperability between data systems and sources to address quality concerns.

The inability to easily integrate and compare Health Management Information System (HMIS) data with that from other relevant data systems was identified across all stakeholder groups as a key constraint and a missed opportunity for better supply chain management, and by extension, patient management. For example, all stakeholders emphasized the potential of closer integration of the HMIS and Logistics Management Information System (LMIS) to continually monitor the inventory of drugs and other supplies to more readily address (or mitigate) shortages.

RECOMMENDATION #3

Leverage GIS tools and methods to support sub-national targeting of resources based on need.

When it comes to allocating resources, monitoring inventory, and assessing trends, national-level information is not specific enough to support decision-making on HIV/AIDS prevention and treatment services at the community level. Stakeholders involved in planning and resourcing decisions emphasized maps as a desired feature of a future decision support tool, while those involved in supply chain and human resource management, as well as identification of HIV hotspots, cited geospatial tools, data, and methods as important. Mapping in combination with interoperable HMIS systems would provide decision-makers with layered data to look at geo-referenced information on resource inputs, risk factors, and disease prevalence among vulnerable populations simultaneously.

RECOMMENDATION #4

Facilitate feedback loops and information-sharing

Multiple stakeholders expressed the need for data feedback loops, including dashboards for individual organizations or agencies to monitor progress towards their own targets, as well as greater information sharing to facilitate coordination and visibility on what other actors are doing. Stakeholders highlighted that they are

currently burdened by data and reporting demands with limited to no benefits. Many interviewees stressed the importance of improving the flow of information by closing feedback loops with analyzed summary data. Returning data in a useful format to reporting stakeholders was noted as key to incentivize strong reporting. Stakeholders also felt that being provided with HIV/AIDS summary data handouts or participating in regular workshops with multi-sector representation could foster innovative ideas on how to encourage community members to go for testing, as well as improve strategies for HIV treatment. Implementing partners also expressed that this would offer the opportunity for more collaboration and unity between partners and sectors.

Other strategies to improve the usefulness of health data systems in Uganda included:

- Capacity building and training for data interpretation to inform decision-making; and
- Ensuring appropriate human resources to manage and disseminate information.

RECOMMENDATION #5

Invest in Internet network connection at priority health facilities.

Front-line service providers and staff at health facilities need a stable Internet connection to access and use e-health systems. Moreover, the lack of Internet access is a significant constraint to deploying a DST, especially for facilities in rural areas. The MoH can overcome this limitation by investing in IT infrastructure—such as routers, VSAT internet systems, and handheld devices—in health facilities or district offices where coverage is limited. Partnerships between the MoH, telecommunications companies, and development partners could ease the financial and logistical burden of purchasing and disseminating such infrastructure countrywide.

Even with significant additional investment, it will be some time before all Ugandans have access to Internet. With this in mind, traditional community outreach approaches should not be abandoned in favor of Internet dissemination. Rather, the two strategies should be pursued in tandem to maximize the reach of prevention and treatment services.

SECTION 4.2

Three Options for a DST

In proposing options for a decision support tool to support HIV/AIDS planning and decision-making in Uganda, the project team was guided by four criteria:

- Alignment with Ugandan health policies, programs, and vision;
- Responsiveness to what key stakeholders identified as desired features in a DST;
- Ability to address three key constraints (access, quality, capacity) in the current data landscape; and
- A clear rationale for how the data would be feasibly used for decision-making.

In this section, we provide a brief description of what three possible options for a future decision support tool would entail: (1) development of a new central database for all Health Management Information Systems (an Open Data Center for Health); (2) strengthening the Uganda AIDS Commission's (UAC) HIV prevention database (the HIV/AIDS E-mapping and Monitoring System); or (3) improving community-based data collection and analysis (e.g., Community-based Health Management Information System).

End users of the proposed systems will differ according to the option selected. However, in general, we would target key decision-makers in the HIV/AIDS space. The goal of all three proposed solutions is to improve information for decision-makers to better respond to adolescent girls and young women. However, there may be other beneficiaries of the system, as the decision support tool can also improve decisions and subsequent service delivery for broader target populations.

OPTION #1

Develop a central database, the Open Data Center for Health (OpenDCH)

In this option, Uganda would develop a new, publicly available central database as a one stop shop for HIV/AIDS information in the country. To be successful, the OpenDCH should be interoperable with the DHIS2 and other Ugandan HMIS, while integrating information from these sources into one tool to be responsive to stakeholder demand for a singular source of information.

There are several modules that could be incorporated into the OpenDCH to be responsive to user demand. These modules are depicted in Figure 5 and explained below.

Population Locator: This module would capture demographics data to help stakeholders track and target HIV/AIDS prevention and treatments services to at-risk populations (including adolescent girls and young women) based on risk factors or attributes of vulnerability.

Services Locator: This module would capture data on the location of HIV/AIDS prevention and treatment facilities (e.g. hospitals, health centers, health posts), education facilities (primary, secondary, tertiary schools, education centers) and laboratories, along with the types of services offered and available stocks of drugs, testing kits, and other commodities at each location. It is important to note that Uganda's LMIS currently tracks commodities. Integration of OpenDCH with LMIS data would be a crucial component to successful implementation of this option.

Data Analytics, Dashboards, and Advanced Spatial Analysis: This module would allow users to visualize data from the population and services locators allowing for descriptive analysis and interactive options for dashboards, charts, graphs, and maps. Menu options could be pre-configured depending on user type and decision-making role so that all individuals in particular roles are privy to the same information. This feature would allow for:

- Location patterns: hotspots analysis, clustering analysis
- Predictive patterns: catchment area analysis, investment/service gap analysis, "value-for-money" analysis

Data Extraction Tool and Report Generator: This module would extract and generate reports in customizable formats for users. Through pivot tables and variable selections, users could layer data types and customize their exports. Furthermore, the development of standardized reporting templates and presentations around key indicators and how to

interpret them would offer the opportunity for district meetings and technical working groups to utilize information from OpenDCH in a streamlined manner.

The OpenDCH option affords several benefits for decision-makers in Uganda. It would answer stakeholders' primary demand for better integration of Health Management Information System (HMIS) and Logistics Management Information System (LMIS) data, while also responding to the desire to reduce barriers to further information sharing and access to data from other partners. Creating linkages between HMIS/LMIS data would strengthen supply chain management and patient management by ensuring sufficient drug supplies reach facilities with the greatest need.

Inclusion of additional indicators from the Ministry of Education or the Demographic and Health Surveys within the OpenDCH would facilitate access to value-add information, such as education levels and health knowledge practices of at-risk populations. Meanwhile, the inclusion of population demographics would facilitate targeting and monitoring of services to support at-risk sub-populations, such as adolescent girls and young women. Additionally, including disaggregated facility-level indicators on services offered, numbers of beneficiaries, and current stockpiles would allow implementing partners to cross-compare. During the August 2018 validation workshop in Kampala, stakeholders felt that OpenDCH would add value, but were concerned about the merits of investing in another central health database considering the April 2018 introduction of the Situation Room. Intended for national-level decision-makers (rather than district- or local-level), inclusive of the President, the Situation Room aims to provide the most up-to-date health information relevant for decision-making. Stakeholders felt it would be imperative to explore ways in which these systems would complement each other to avoid any duplication of efforts. Figure 6 breaks down the critical path to implement the OpenDCH, if stakeholders identified this as the optimal path.

FIGURE 5

Proposed Design and Modules of OpenDCH

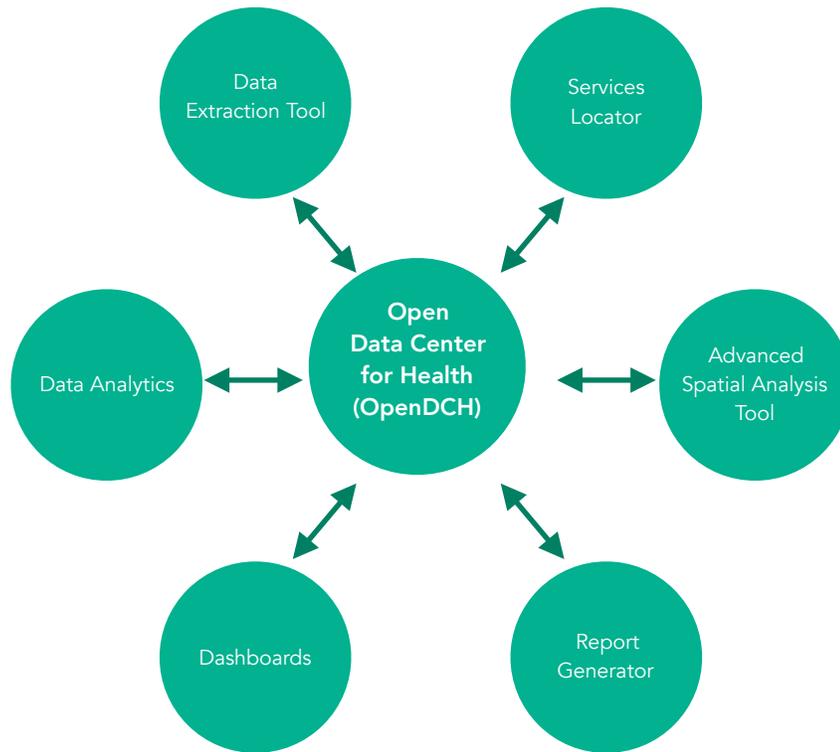
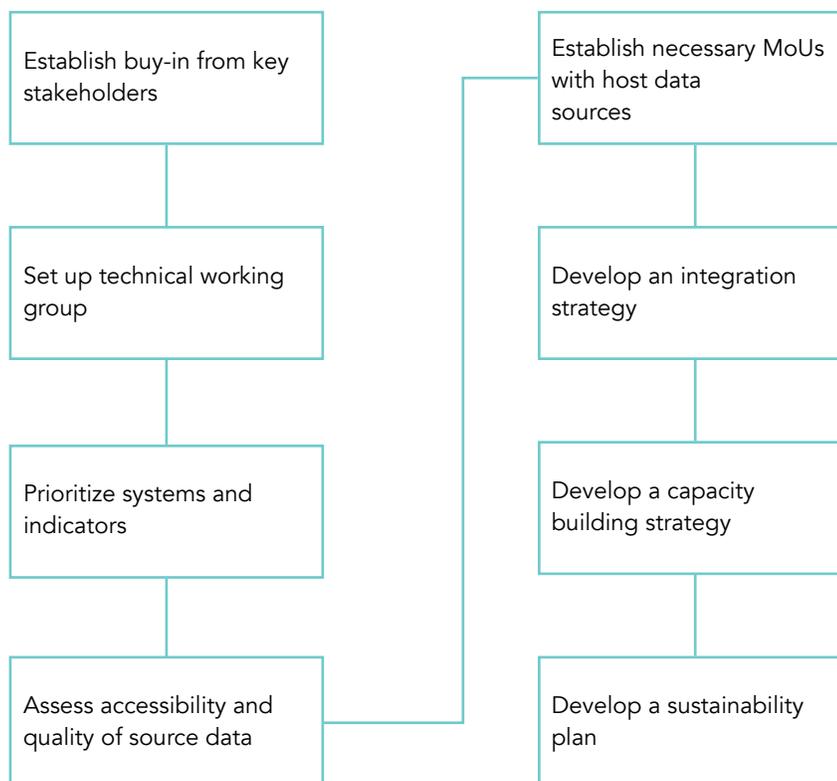


FIGURE 6

Key Steps Prior to OpenDCH



OPTION #2

Strengthen the Uganda AIDS Commission's (UAC) HIV/AIDS E-mapping and Monitoring System

In this second option, stakeholders would focus their efforts on upgrading an existing system—the UAC's HIV/AIDS E-mapping and Monitoring System—to allow prevention and treatment data to more readily speak to one another. Responsible for overall coordination, monitoring, and evaluation of HIV/AIDS-related activities, the UAC established an online database with the objective to improve coordination in the allocation and alignment of resources, as well as facilitate a more efficient and effective response to the epidemic.¹⁴

The UAC platform includes an E-mapping and Monitoring System to capture who is doing what and where in Uganda in terms of HIV/AIDS prevention. Figures 7 and 8 show examples of the data visualization capabilities of the current system.¹⁵ Currently, the behavioral data questionnaire (Figure 10) captures information on the number of individuals reached with prevention interventions, disaggregated by sex and group categorization (i.e., general population versus sex worker). Option 2 would build upon the current foundation of the existing platform while also introducing features to respond to user demand:

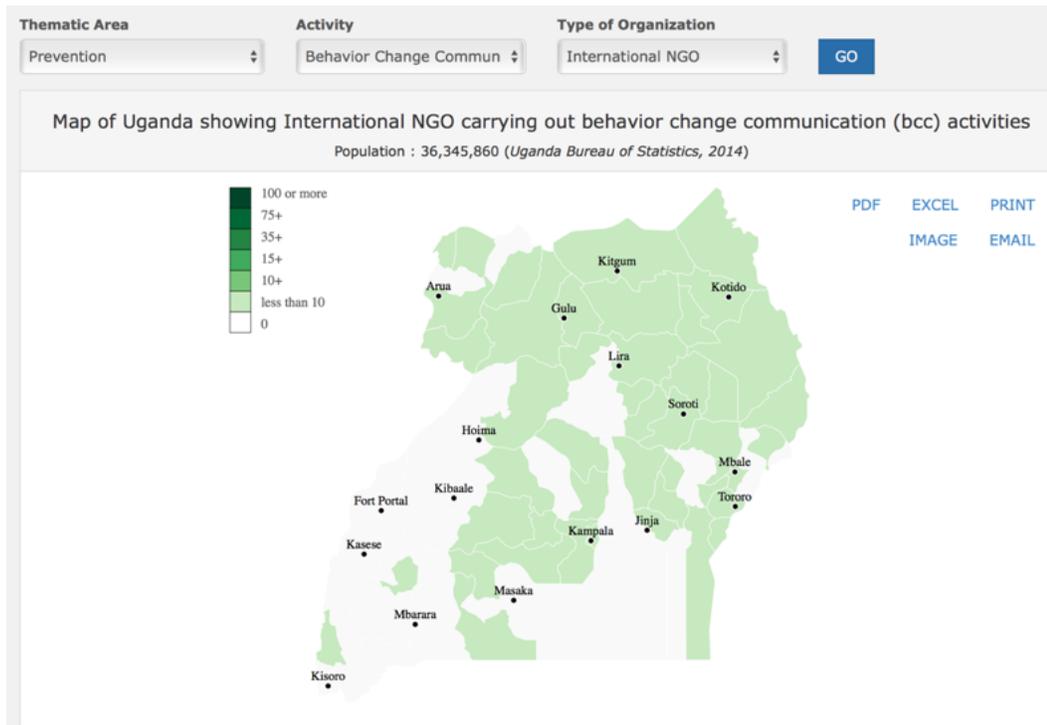
- Improve data quality by streamlining data entry processes via digitizing data collection;
- Disaggregate indicators not only by gender, but also age to improve understanding of prevention efforts for adolescent girls and young women ages 10-24;¹⁶
- Integrate with GIS to visualize where partners are operating in relation to HIV/AIDS prevalence in order to better coordinate intervention efforts and address gaps in programming (particularly for more vulnerable populations such as adolescent girls and young women);

- Improve integration and interoperability with other databases (e.g., Ministry of Health, partners, HMIS, LMIS, Ministry of Education) via the use of an open-source system;
- Expand use of data to implementing partners outside of the UAC;
- Enhanced data visualizations and data dashboards for improved decision-making;
- Provide quarterly feedback through a summary report/newsletter to reporting stakeholders on successes and challenges in order to close the data feedback loop; and
- Develop streamlined information sharing templates and presentations that would facilitate data interpretation and streamline technical working group meetings to focus on key indicators.

Stakeholders participating in the August 2018 workshop in Kampala felt that upgrading the E-mapping System would strengthen current indicators and facilitate greater disaggregation of HIV/AIDS data in order to better understand gaps for key populations and adolescent girls and young women. In addition, this approach would address key constraints in the current HIV/AIDS data landscape regarding interoperability, mapping for targeting resources, and increasing access via a web-based platform. However, participants also felt that the current system was deemed satisfactory by its core users and that project stakeholders had limited desire to improve this pathway. Instead, participants suggested that focusing on an area with more gaps, such as community-based data collection, would be of greater value to the HIV/AIDS planning and decision-making community. Figure 9 presents a critical path to implement the upgraded E-mapping System, if stakeholders identified this as the optimal choice for a future decision support tool.

FIGURE 7

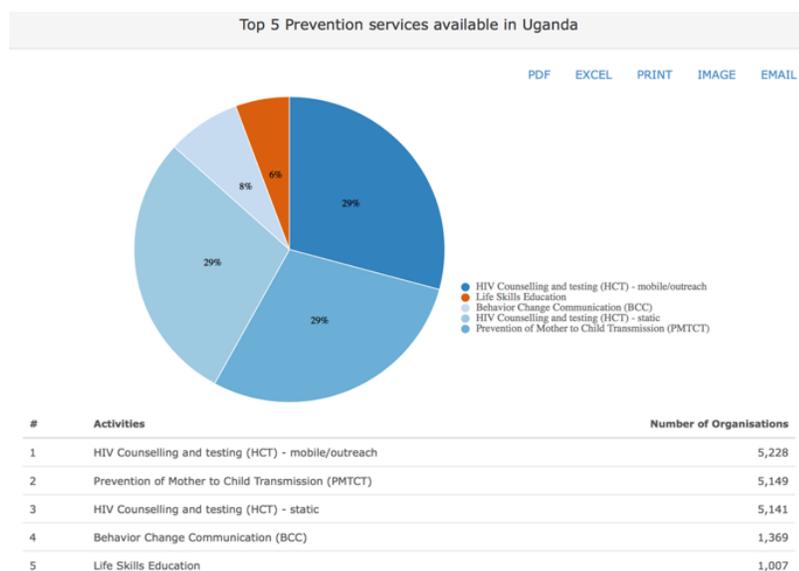
Example of Current Capability of Data Visualization on HIV/AIDS E-mapping and Monitoring System



Source: UAC, 2018.

FIGURE 8

Example of Current Capability of Data Visualization on HIV/AIDS E-mapping and Monitoring System



Source: UAC, 2018.

FIGURE 9

Key Steps to Ensure E-mapping Platform Success

Preparation	Technical Build	System Integration	Launch Readiness
<ul style="list-style-type: none"> Establish buy-in from UAC and key stakeholders Set up technical working group Assess accessibility and quality of source data Establish necessary MoUs with host data sources Develop a sustainability plan 	<ul style="list-style-type: none"> Conduct user requirement workshop Revise and update e-mapping indicators Finalize indicators and build data elements into system Workshop to identify desired data visualizations Back data entry into system 	<ul style="list-style-type: none"> Develop an integration strategy Acquire permissions for access to other data systems Set up API bridges for integration with desired data sources 	<ul style="list-style-type: none"> Develop capacity building strategy End user testing workshop to pilot system Ongoing capacity building and stakeholder engagement

FIGURE 10

Quarterly Questionnaire from UAC on Behavioral Indicators

PILOT SURVEY in COMBINATION HIV PREVENTION in MAYUGE DISTRICT Form MB

Module 2: Behavioural Data Questionnaire

Targeted respondent: **Manager, Civil Society Organisation (CSO) of line department (LD), or most senior staff in charge of the CSO or LD**

Enumerator	CSO	eID
Subcounty	Contact Person	
Municipality	Cell Phone	
Time and Date	Email	

Introduction: My name isand I come from the Uganda AIDS Commission. We are collecting data on services you have delivered in the past 3 months (JAN-MAR 2014) in the MUYAGE DISTRICT. The UAC will use this information to help understand the total service coverage in this district, to inform all stakeholders and to use this information to help direct the future response to the AIDS epidemic. The UAC asks that you would endeavour by all means to furnish us with as much data as possible.

BEHAVIORAL INTERVENTIONS (1) <small>(Include a range of sexual behavior change communication (SBCC) programs that use various communication channels (e.g., mass media, community-level, and interpersonal) to disseminate behavioral messages designed to encourage people to reduce behaviors that increase risk of HIV and increase protective behaviors)</small>	B1: Number of individuals reached with individual and/or small group level preventive interventions run by your organization, that are primarily focused on partner reduction messages		B2: Number of couples that have been exposed to sexual behaviour change communication (SBCC) package through interpersonal communication channels or methods, run by your organization		B3: Number of key populations that have been exposed to an SBCC package through individual and/or small group level preventive interventions, run by your organization		B4: Number of target populations reached with individual and/or small group level interventions run by your organization, that are primarily focused on abstinence, being faithful & condom use (ABC), based on minimum standards required		B5: Number of Most At-risk People Groups (MARPs) reached with individual and/or small group level behavioural interventions run by your organization, that are based on evidence and/or minimum standards required		B6: Exposure to HIV messages: percentage of target population reached by your broadcasting: number of people estimated to have been reached, by channel (radio or TV) divided by the estimated size of the target population Radio: ____ TV: ____		B7: Number of individuals from target audience who participated in a community-wide event (e.g. Community drama; choral events; AIDS day; other advertised events with platforms, speakers, entertainment etc – to draw crowds to hear HIV messaging) supported by your organization	
	Male	Female	Couples		Key populations	Target Populations	Male	Female	Male	Female	Male	Female	Male	Female
1. General Population 15+ years														
2. Youth														
3. MARPS	Sex Workers													
	Fisherfolk													
	Truck Drivers													
	MSM													
Other:														
4. Community/Opinion Leaders														
5. PLHIV														
6. Couples														
TOTALS MALE / FEMALE														
GRAND TOTAL														

Source: UAC. (2018). Uganda HIV/AIDS E-mapping and Monitoring System.

OPTION #3

Create a Community-based Health Management Information System (C-HMIS)

In this third option, stakeholders would strengthen the reliability and quality of one category of data—community-based health information—through training community health workers to collect and enter data directly (in real time) into the DHIS2 via an application that could be easily operated with a cell phone or tablet. If a community health worker did not have a cell phone or network reception, information could be stored on the electronic data collection device and synced later.

The Community-based Health Management Information System (C-HMIS) would have multiple modules with separate forms that function within DHIS2. Some examples include:

- Disease management and patient tracking:
 - Including referrals, illness, number of patients tested in the community, etc.
 - Focusing on gaps identified by stakeholders and key populations such as adolescent girls and young women (AGYW) and men.
- Patient referrals: Community health workers could open a referral for patients testing positive, while health care providers at the referral site would know which patients to expect and then close out completed referrals.
- Managing drug stocks, HIV test kits, and other materials:
 - Drugs delivered in the community and availability of drugs at the facility;
 - Managing the HIV test kits utilized and how many are in stock; and
 - Capturing the number and proportion of days over a period that stock outs of key HIV materials took place (condoms, clean needles, necessary items for labs, etc.).

C-HMIS offers several potential benefits to decision-makers focused on HIV/AIDS prevention and treatment. Community health workers can automate the process of data collection to reduce inaccuracies from manual reporting. C-HMIS would integrate critical data from the Ministry of Health's District Health Information System (DHIS2). Allowing community health workers to push information directly to the DHIS2 would increase the timeliness of this data and facilitate its integration with other information from the facility, district, and national level. C-HMIS offers stakeholders the opportunity to track disaggregated information on

adolescent girls and young women at the community level (e.g., number referred, number with completed referrals) and provides a comprehensive view of community-level disease management (from patient management to inventory tracking). C-HMIS also offers the opportunity to identify gaps in real time around which populations are being missed with testing, referrals, or seeking treatment.

Participants in the August 2018 validation workshop viewed C-HMIS as the most favorable option. They felt it was an innovative way to ensure community-level data effectively feeds into the national-level data ecosystem, as well as complement existing systems (e.g., the Situation Room, UAC E-mapping System). Concerns around how to implement C-HMIS successfully were related to capacity building, the sustainability of human and material resources, as well as fostering a culture of data demand and use within community-based HIV programs. Figure 11 depicts the steps to implementing C-HMIS and Figure 12 visualizes necessary linkages for community-level data to be utilized by key policymakers to reduce HIV incidence. Figure 13 shows the ideal structural relationship of all Health Management Information System (HMIS) stakeholders. In the diagram, information flows from the community upstream, ultimately feeding into a central HMIS where different data sources interact.

All three proposed decision support tool options take into consideration what diverse stakeholders in Uganda identify as the challenges in the status quo, key features desired in a future system, as well as service delivery challenges and solutions expressed by beneficiaries to HIV services. Each option strives to ensure that indicators for adolescent girls and young women are streamlined across data systems to facilitate integration of key health information and capture the complete picture of prevention and treatment needs. Furthermore, each option aims to streamline reporting templates and feedback loops to ensure that all stakeholders and stakeholder groups have access to the information that they need to directly impact decisions in their respective roles.

During the August 2018 validation meeting,¹⁷ stakeholders felt that it would be critical to keep in mind the following in selecting which of the three options to pursue:

- The need for multi-sectoral response and engagement of all relevant line ministries so that programs are not operating in silos but in collaboration;
- The required human and material resources to be successful; and
- Aspects of sustainability, ownership, and ongoing capacity building.

For all three of the proposed models, stakeholders had questions around how to appropriately assess feasibility of implementation and ensure long-term sustainability.

Pursuing the development of any one of the above proposed decision support tools would provide the opportunity to meet stakeholder data demands for HIV/AIDS information while also addressing cross-

cutting themes identified across all respondent groups: increasing access, improving quality, and strengthening capacity. Providing accurate, timely, and digestible information into the hands of key stakeholders offers a long-term solution to improve targeting of resources and, as a result, increase the probability that funding and activities are reaching populations who need them the most.

FIGURE 11

Steps Required to Ensure C-HMIS Success

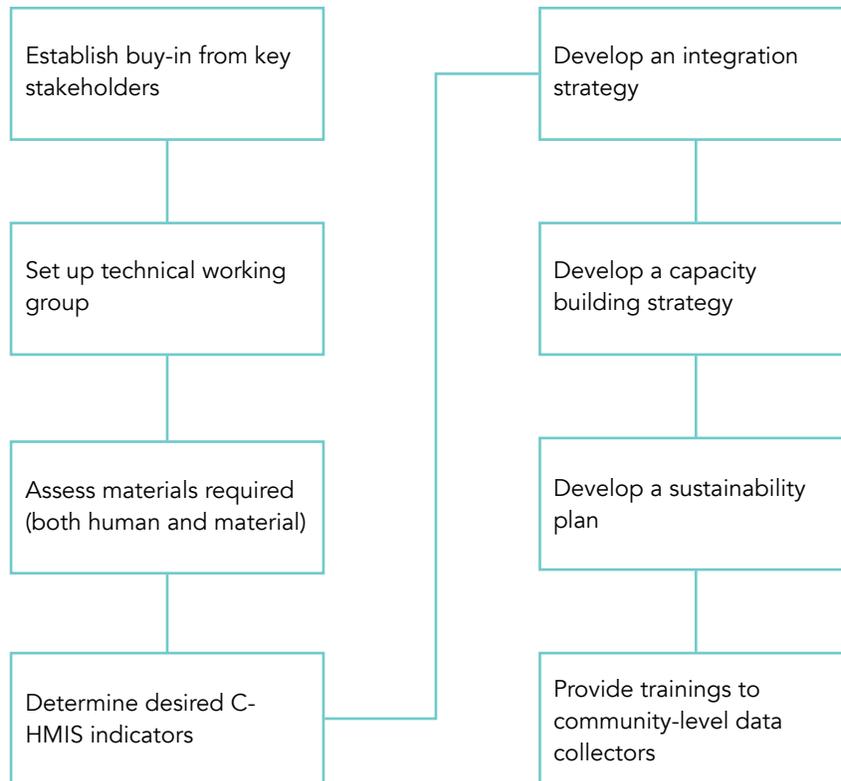


FIGURE 12

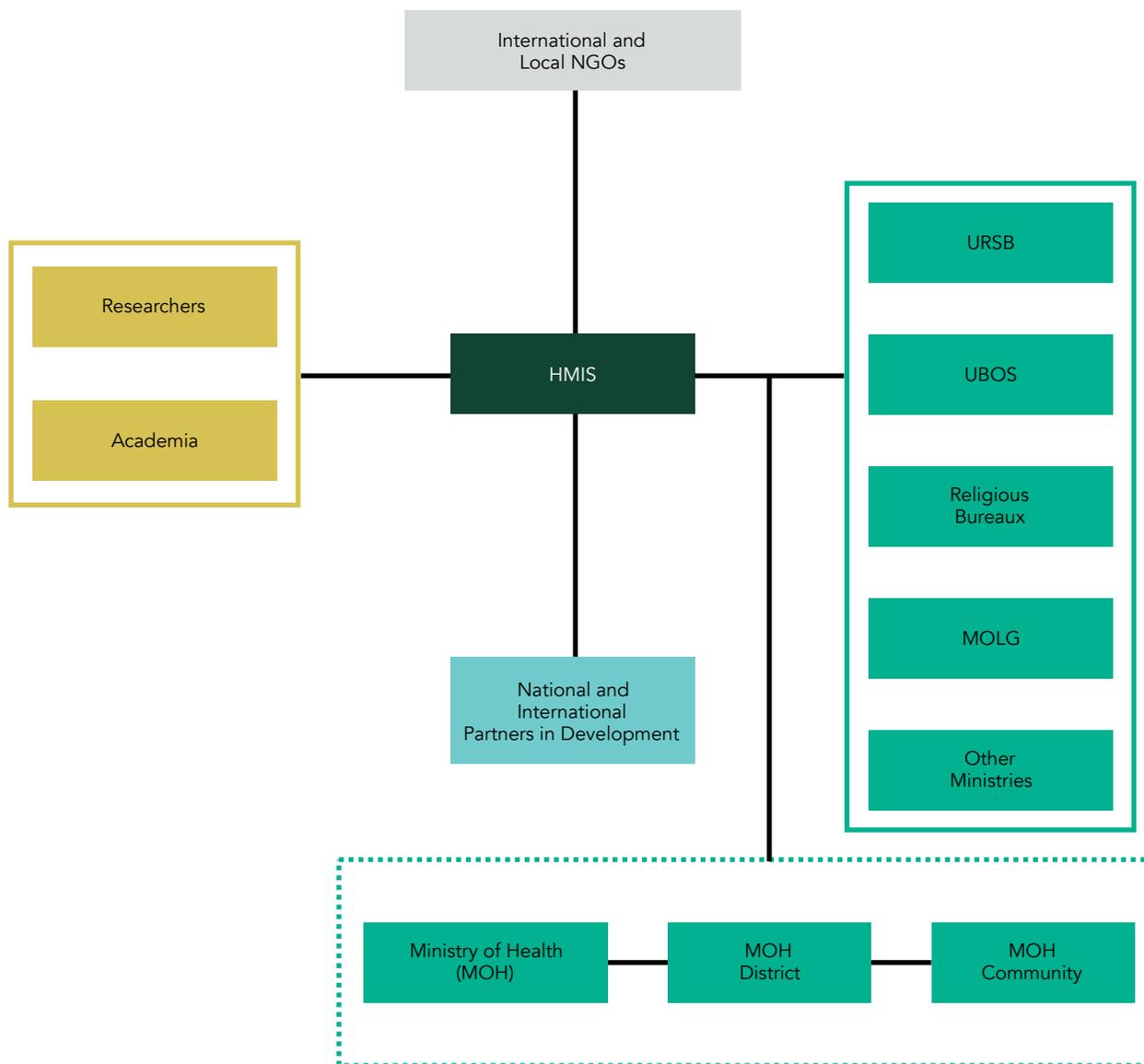
Data Use Conceptual Framework



Source: Adapted from the MEASURE Evaluation Data Use Conceptual Framework in MEASURE Evaluation (2012).

FIGURE 13

Structural Relationship of HMIS Stakeholders in the Health Sector Strategic & Investment Plan



¹⁴ Additionally, the UAC aims to ensure effective harmonization of national policies and guidelines within partner activities in the HIV/AIDS response. While the UAC is able to map out and see the types of services provided and where partners are located, stakeholders did not mention this as a system that is currently being utilized for decision-making.

¹⁵ The UAC and other stakeholders developed 19 key indicators to track the contribution of civil society actors to behavior change at the sub-county level.

¹⁶ In making this adjustment, age segmentations (10-14; 15-19; 20-24) in the UAC upgrade should align with other data systems.

¹⁷ Due to schedule conflicts, not all key individuals from the Ministry of Health, the UN, PEPFAR, and a few other line ministries were able to attend the August 2018 validation workshop. In order to give these individuals the opportunity to provide inputs, AidData shared the draft synthesis report and a PowerPoint presentation for detailed feedback during an open window period.

CHAPTER FIVE

Conclusion

Lowering barriers to entry for policymakers and implementing partners to access information critical for providing timely HIV/AIDS services that meet population needs is crucial to both prevent new infections and meet UNAIDS goal of ending AIDS by 2030. Development of a decision support tool that allows key stakeholders to capture a holistic and realistic view of the HIV/AIDS epidemic in Uganda to support planning, implementation, monitoring, and evaluation requires action. Although Uganda's data ecosystem is saturated with programs, initiatives, and tools to enable data use for planning and decision-making, data sources operate in silos and do not provide stakeholders with necessary and timely information. Through careful analysis of the Ugandan data ecosystem through data scoping, key informant interviews, and a data validation workshop, the project team feels strongly that investing in fulfilling stakeholder demand for a decision support tool that is open-source, interoperable with other systems, has GIS functionalities, and offers both online and offline functionalities and feedback loops will position Ugandan decision-makers well in the fight against HIV/AIDS and help ensure that "girls develop into Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe women."

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Appendix 1: Interviews

TABLE 1:

Organizations Represented in the Interviews and Consultations

Organization	Individuals Interviewed
Abdala Nyolo Secondary School	1
Abela HCII	1
Aber HCII	2
Acaba Secondary School	1
Acaba Technical School	1
Agulurude HCIII	1
Amwa HCII	1
Ariba HCII	2
Atapara Secondary School	1
CARITAS	1
Evarest Girls School	1
Kamdini HCII	3
Loro Core PTC	1
Loro HCII	1
Loro Secondary School	1
Loro Vocational School	1
Mercy Corps	5
Minakulu HCII	2
Minakulu Training Institute	2
PHA Network	20
Plan International	3
World Vision – Oyam	2
Uganda Health Marketing Group (UHMG)	1
AIDS Information Center	1
STRICT LED Program	1
HEPS Uganda	1
Uganda AIDS Commission	1
RHU	2
UNAIDS	1
AMICAAL	1
DREAMS-IC	1
Oyam District Headquarters	4
Oyam District Health Office	2
Oyam District Local Government	3
Total	73

TABLE 2:

Stakeholder Groups Represented in the Interviews and Consultations

Stakeholder Group	% of Total Interviewees
Government	42.5%
Front line service provider (27.4%)	
Local government decision makers (8.2%)	
District government decision makers (5.5%)	
National government decision makers (1.4%)	
NGO/ CSO	38.4%
Private sector/ Academia	4.1%
Beneficiaries	15%
Total	100.0%

Appendix 2: General Consent Form

Project Title: HIV/AIDS Prevention and Treatment Decision Support Tool for Uganda

Consent to Participate in Research

IRB # 02-XXAA

Identification of Investigators & Purpose of Study

You are being asked to participate in a study conducted by researchers from AidData, a research institution at the College of William and Mary in the United States, and ToroDev, an Ugandan non-governmental organization. The purpose of this study is to understand how decisions are made regarding the financing, targeting and evaluation of HIV/AIDS treatment and prevention programs in Uganda, and where vulnerable target populations are located.

Research Procedures

Should you decide to participate in this research study, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. This study consists of an interview that will be administered to individual participants in Oyam. You will be asked to provide answers to a series of questions about the allocation of HIV/AIDS prevention and treatment resources in Oyam. Upon agreement from the participant, the research team will audio record the interview to ensure that we are capturing his or her answers as accurately as possible. The audio recording is optional and will only be accessible to the primary and secondary investigators.

Time Required

Participation in this study will require between 45 and 60 minutes of your time.

Risks

The investigator does not perceive more than minimal risks from your involvement in this study (that is, no risks beyond the risks associated with everyday life).

Benefits

There are no personal benefits of participating. The societal benefits of participating are that we may be able to identify improvements to the decision-making process involving the allocation of HIV prevention and treatment resources. The final study will be shared publicly and with all participants.

Confidentiality

All interviews will be confidential. No personal identifiers such as name or telephone number of the interviewee will be registered. Only the occupation (category of the interviewee) will be recorded. Primary and secondary investigators will be the only ones to have access to the interview data, and participants will be identified by a list of numbers or codes. When the results of this research are published or discussed in meetings or events, no information will be included that would reveal the interviewee's identity. Upon completion of the study, all information that matches up individual respondents with their answers (including notes and audio files) will be destroyed.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact:

Jacob Sims

Samantha Custer

AidData

AidData

The College of William & Mary

The College of William & Mary

jsims@aiddata.org

scuster@aiddata.wm.edu

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form. I certify that I am at least 18 years of age.

- I give consent to be (audio) taped during my interview. _____ (initials)
 I do not give consent to be (audio) taped during my interview. _____ (initials)

Name of Participant (Printed)

Signature of Participant

Date

Signature of Researcher

Date

Appendix 3: Interview Guidelines

General Guidelines

Please follow these guidelines when conducting the qualitative interviews. If you have any questions or concerns about specific protocols, please send an email to either Jake Sims jsims@aiddata.wm.edu or Stephen Mugabe smugabe@torodev.kabissa.org. Copies of the interview templates can be found [here](#).

1. All interviews with female beneficiaries should be conducted by females. We want the beneficiaries to feel as comfortable as possible during the interview, and we believe that having a woman conduct the interview will improve the beneficiary's experience.
2. Move methodically through the guide and listen carefully to everything the interviewees have to say. Rushing or interrupting the person will decrease response quality.
3. Avoid asking leading questions that will influence what the interviewee will say. If the interviewee does not respond immediately, please rephrase the question. If the interviewee has nothing to say after rephrasing the question, please move on to the next question.
4. Avoid making comments that will make the interviewee uncomfortable. Please keep your own opinions and thoughts to yourself. Voicing your views on what the interviewee said may unintentionally come across as disrespectful.
5. Maintain a humble attitude throughout the interview. Please remember that the interviewee has taken time out of her/his schedule to speak with us.
6. A maximum of 2 people should be involved in each interview. One person should be the lead interviewer and the other should be lead note-taker and supporting interviewer, interjecting with relevant questions where appropriate. Involving more than 2 people can create distraction or intimidation and prevent the lead interviewer from asking all of the priority questions in the interview guide.
7. Before the interview begins, please place your phone on silent and ensure that people will not be coming in and out of the interview space.
8. At the end of the day, please upload the most relevant comments from each interview to this file.
9. Every three days of interviews, please upload the audio files to this folder in the following format: Name_Group_Day. An example would be: Jake_beneficiary_2.1.

Appendix 4: Beneficiaries and Beneficiary Groups Interview Protocol

Introduction

Thank you very much for taking the time to talk with us.

My name is [say your name], and we work with AidData, an organization in the United States that studies international development programs. We are currently conducting a study to help government officers and development partners make better decisions in the distribution and reporting of HIV/AIDS resources. As a part of this study, we are interviewing HIV positive young women, teachers, clinic coordinators and directors, and non-governmental organizations.

After we finish the interviews, we will create a report that summarizes the results. We would like to share the report with you once complete.

This conversation will be confidential. This means that what you say will never be associated with your name.

The conversation will not last more than 45 minutes. Is that ok with you?

To make sure that you are aware of the minor risks associated with this study, we would like you to read the following document [give Informed Consent Statement to the person you are interviewing]. If you agree, please sign it at the bottom.

Finally we would like to record the conversation to help us take notes. Is this okay?

Interviewee details

Please fill out this section at the beginning of the interview

Lead interviewer name:

Site of interview:

Date of interview:

Name of interviewee:

Age of interviewee (approximately):

Gender of interviewee:

Organization of interviewee:

Title of interviewee:

Module 1 - Access:

We are now going to ask you about how you (or people in your community group) access HIV treatment facilities.

1. Where is the facility that you use?
2. Is this the closest facility?
3. If not, what is the closest?
4. How far do people with HIV typically travel to reach this facility?
5. Why do you choose this facility?
6. What services are provided to you at this facility?
7. How well do these services meet your needs?
8. Do you go to another facility besides the one you mentioned already?

Notes:

Module 2 - Awareness:

We will now ask you a few questions about how you (or people in your community group) found out about their status and treatment options.

1. How do you (or people in your community group) find out about testing and treatment facilities in this district/sub-district?
2. In general, are people aware of the location of testing and treatment facilities in the district?
3. Why would someone not get tested once they learn about the risks and treatment facilities?
4. How do community-based organizations and NGOs know which communities need more education or information of HIV/AIDS?
5. How do community-based organizations and NGOs know what information to convey?

Notes:

Module 3 - Needs:

To finish, we are going to ask you a couple of questions about what things you (and/or your community group) need to prevent new HIV infections and treat existing infections better.

1. Why are HIV/AIDS infections so common in this sub-district?
2. What are the biggest obstacles to reducing new infections?
3. What are the biggest obstacles for people who want to get treatment?
4. What factors do you think would reduce HIV/AIDS infections in your sub-district?

Notes:

Conclusion

Thank you very much for taking the time to speak with us. We appreciate it.

1. Do you have any final comments for us?

[priority question]

Thank you. Please get in contact with us if you have additional comments or questions about our project.

Appendix 5: Central/District Decision Makers Interview Protocol

Introduction

Thank you very much for taking the time to talk with us.

My name is [say your name], from AidData, an organization in the United States that studies international development programs. We are currently conducting a study to help government officers and development partners make better decisions in the distribution and reporting of HIV/AIDS resources. As a part of this study, we are interviewing government stakeholders, HIV positive young women, clinic coordinators and directors, and non-governmental organizations.

After we finish the interviews, we will create a report that summarizes the results. We would like to share the report with you once complete.

This conversation will be confidential. This means that what you say will never be associated with your name.

The conversation will not last more than 45 minutes. Is that ok with you?

To make sure that you are aware of the minor risks associated with this study, we would like you to read the following document [give Informed Consent Statement to the person you are interviewing]. If you agree, please sign it at the bottom.

Finally we would like to record the conversation to help us take notes. Is this okay?

Interviewee details

Please fill out this section at the beginning of the interview

Lead interviewer name:

Site of interview:

Date of interview:

Name of interviewee:

Gender of interviewee:

Organization of interviewee:

Title of interviewee:

Module 1: Decision-Making Process:

We would like to ask you some questions about the decisions that you and your [insert organization/department/agency] make in targeting HIV/AIDS resources or evaluating HIV/AIDS projects.

1. Could you briefly summarize your role in your organization?
2. Do you personally make decisions or take actions that support HIV/AIDS prevention, testing, and treatment in Uganda ?
 - 2.a. What is your own role in this decision process?
[Ask if response to question 2 is yes]
 - 2.b. Can you take a moment to think through all the types of decisions you are engaged in?

Write down all responses, then go through them one by one and try to slot them into the following types of decisions:

Types of decisions

- Drug supply and distribution
- Treatment initiation
- Defaulter follow up
- Beneficiary Retention

- Program Performance monitoring (benchmarks etc)
- Increase Uptake of Services
- Staffing or Workload Management
- Supportive Supervision to Volunteers or Program Staff
- Prevention and Education Materials
- Targeting of Programs by Location
- Targeting of Programs by Beneficiary Group
- Resource Prioritization/Allocation (give funds)
- Resource Mobilization (seek funds)
- Resource Coordination (monitor or distribute funds)
- Data quality assurance
- Service Integration
- Program/Intervention Design
- Program Effectiveness Research
- Advocacy
- Community Outreach

2.b. Are there specific individuals/organizations outside of your organization that support this decision-making process?

[Ask if response to question 2 is yes]

2.c. What is their contribution?

[Ask if response to question 2.b is yes]

Notes:

Module 2: Status Quo –

Data and Information: Keeping in mind the types of decisions you just described, we would like to ask you several questions about how different types of data or information are used to assist you with this decision-making process.

1. Which sources of information do you use to make the decisions about HIV/AIDS resources?
2. What does this information help you accomplish? What specific parts of your job duties does this information support?
 - a. Refer back to the groups of actions/decisions and link each action/decision to a data source
3. Where is this information located? Is this information in a single location or do you have to go to many different sources to obtain?
4. For the data sources you use, how would you assess the quality of this information?

5.a. Aspects of Quality for potential further drill down:

[use these questions if response to question 5 is not detailed]

- a. Accessibility – How easy is the data to access?
 - b. Granularity – Is the information broken down by geographic area or people group?
 - c. Credibility – Do you trust the data?
 - d. Timeliness – How frequently is the data updated?
 - e. Coverage – Whose projects are covered by this source of information or data?
6. Do you face any obstacles in obtaining or analyzing this information?

Notes:

Module 3 - Needs:

Now that we've learned about the information that you currently use, we want to ask a few questions about what type of information and in what format might be useful for making decisions in the future.

What additional sources of information would be useful in helping you approach these decisions more effectively?

[Ask questions 2-4 if, in response to question 1, the interviewee indicates additional sources of information]

1. How would this additional source of information help you make better decisions?
2. Which characteristics would make this information more effective?
 - a. Are you aware of any specific challenges with HMIS? In your opinion, how could these systems be improved?
3. Finally, are there other tools or information that we have not yet discussed that currently exist and are useful in your decisions about HIV/AIDS?

Notes:

Conclusion

Thank you very much for taking the time to speak with us. We appreciate it.

9. Do you have any final comments for us?

[priority question]

Thank you. Please get in contact with us if you have additional comments or questions about our project.

Appendix 6: Clinic Coordinators Interview Protocol

Introduction

Thank you very much for taking the time to talk with us.

My name is [say your name], and we work with AidData, an organization in the United States that studies international development programs. We are currently conducting a study to help government officers and development partners make better decisions in the distribution and reporting of HIV/AIDS resources. As a part of this study, we are interviewing HIV positive young women, teachers, clinic coordinators and directors, and non-governmental organizations.

After we finish the interviews, we will create a report that summarizes the results. We would like to share the report with you once complete.

This conversation will be confidential. This means that what you say will never be associated with your name.

The conversation will not last more than 45 minutes. Is that ok with you?

To make sure that you are aware of the minor risks associated with this study, we would like you to read the following document [give Informed Consent Statement to the person you are interviewing]. If you agree, please sign it at the bottom.

Finally we would like to record the conversation to help us take notes. Is this okay?

Interviewee details

Please fill out this section at the beginning of the interview

Lead interviewer name:

Site of interview:

Date of interview:

Name of interviewee:

Gender of interviewee:

Organization of interviewee:

Title of interviewee:

Module 1 -

Decision-Making: Let's start with a discussion about how you (or your clinic) are involved in HIV prevention and treatment efforts?

1. What is your specific role at the clinic (or in the sub-district)?
2. How does this role involve HIV treatment and prevention?
3. How do you plan to ensure sufficient staffing and testing/treatment supplies at your clinic (or the clinics in your sub-district)?
4. [Skip for politicians] Who are your patients?
 - a. How many do you serve?
 - b. From how far away do they come?
 - c. Why do they come to your facility instead of other facilities in the area?
 - d. What are their needs regarding HIV/AIDS? Ex. education, medicine, etc.
5. How do you plan for staffing and testing/treatment supply stock at your clinic (or in your district)?
 - a. What is your specific role in this process?
 - b. Do you draw on any sources of information in this planning process?

Notes:

Module 2 - Current State:

Now we want to ask you a few questions about the resources you provide as a clinic and the types of information are collected and provided to assist with the treatment/prevention services you offer.

1. [Skip for politicians] What are the primary resources that you deliver to patients?
2. What information do you currently collect regarding HIV patients or services provided?

[If any are noted, ask questions a and b]

- a. What do you do with these pieces of information? What functions do they help you accomplish?
 - b. Where are they kept?
3. Are any of these records reported to the district or another decision-making group?

[If yes, ask questions a-e]

- a. Which ones are reported?

- b. What specific fields are reported?
 - c. In what format is this information reported?
 - d. To whom is it reported?
 - e. Do you know what happens with this data? How it is used?
4. Is there information that you access from external sources to do your job, regarding HIV?

[If yes, ask question a]

- a. How helpful is this information? How easy to access? How specific? How trustworthy? How frequently is it updated?
5. Is there information you need to access to do your job, but cannot access?

[If yes, ask question a]

- a. What keeps you from getting this information?

Notes:

Module 3 -

Desired State: Our last set of questions involve your needs as a clinic (or district representative).

- 1. What are the key resources you need to better serve your patients [or constituents] living with HIV?
- 2. What is keeping you from obtaining those resources?
- 3. Is there any information that would help you carry out your work more effectively that you don't currently possess?

[If yes, ask questions a-c]

- a. If so, what information?
- b. What would that information help you accomplish?
- c. What is keeping you from obtaining this information?

Notes:

Conclusion

Thank you very much for taking the time to speak with us. We appreciate it.

- 9. Do you have any final comments for us?

[priority question]

Thank you. Please get in contact with us if you have additional comments or questions about our project.

Appendix 7: Development Partners Interview Protocol

Introduction

Thank you very much for taking the time to talk with us.

My name is [say your name], and we work with AidData, a research lab at The College of William & Mary in the US that studies development programs, particularly concerning the targeting and evaluation of aid projects. We are currently undertaking a project to build a web-based tool which will improve upon decision makers' ability to effectively target the provision of HIV/AIDS treatment and prevention related resources. We are conducting consultations with potential users of such a tool as well as beneficiaries of HIV/AIDS assistance to determine how decisions are currently being made and how our tool could add the most value.

After we finish the interviews, we will create a report that summarizes the results. We would like to share the report with you once complete.

This conversation will be confidential. This means that what you say will never be associated with your name.

The conversation will not last more than 45 minutes. Is that ok with you?

To make sure that you are aware of the minor risks associated with this study, we would like you to read the following document [give Informed Consent Statement to the person you are interviewing]. If you agree, please sign it at the bottom.

Finally we would like to record the conversation to help us take notes. Is this okay?

Interviewee details

Please fill out this section at the beginning of the interview

Lead interviewer name:

Site of interview:

Date of interview:

Name of interviewee:

Gender of interviewee:

Organization of interviewee:

Title of interviewee:

Module 1: Decision-Making Process:

We would like to ask you some questions about the decisions that you and your [insert organization/department/agency] make in targeting HIV/AIDS resources or evaluating HIV/AIDS projects.

1. What is your role in your organization?
2. Do you make or support decisions in the distribution of HIV/AIDS prevention and treatment resources?

2.a. What is your own role in this process?

[Ask if response to question 2 is yes]

2.b. Are there specific individuals/organizations outside of your organization that support your decision-making process?

[Ask if response to question 2 is yes]

2.c. What is their contribution?

[Ask if response to question 2.b is yes]

Notes:

Module 2: Status Quo –

Data and Information: Keeping in mind the types of decisions you just described, we would like to ask you several questions about how different types of data or information are used to assist you with this decision-making process.

1. Which sources of information do you use to make the decisions about HIV/AIDS resources?
2. What does this information help you accomplish? What part of your decision making process does this information contribute to?
3. Where is this information located? Is this information in a single location or do you have to go to many different sources to obtain?

4. Why do you use these sources of information or data?

5. How would you assess the quality of this information?

5.a. Aspects of Quality for potential further drill down:

[use these questions if response to question 5 is not detailed]

- a. Accessibility – How easy is the data to access?
- b. Granularity – Is the information broken down by geographic area or people group?
- c. Credibility – Do you trust the data?
- d. Timeliness – How frequently is the data updated?
- e. Coverage – Whose projects are covered by this source of information or data?

6. Do you face any obstacles in obtaining or using this information?

Notes:

Module 3 - Needs:

Now that we've learned about the information that you currently use, we want to ask a few questions about what type of information and in what format might be useful for making decisions in the future.

What additional sources of information would be useful in helping you make these decisions more effectively?

[Ask questions 2-4 if, in response to question 1, the interviewee indicates additional sources of information]

1. How would this additional source of information help you make better decisions?

- a. What specific questions do you want to be able to answer that you are not currently able to address?

[use this question if response to question 2 is not detailed]

2. Which characteristics would make this information more effective?

- a. [If mapping functionality mentioned]: what type of map would be most helpful (streetmap, satellite image, etc.)
- b. What is the bandwidth environment like?
 - i. Will export functionality be necessary?
 - ii. Will offline functionality be necessary?
- c. [use these questions if response to question 3 is not detailed]

3. Finally, are there other tools or information that we have not yet discussed that currently exist and are useful in your decisions about HIV/AIDS?

Notes:

Conclusion

Thank you very much for taking the time to speak with us. We appreciate it.

9. Do you have any final comments for us?

[priority question]

Thank you. Please get in contact with us if you have additional comments or questions about our project.

Appendix 8: Educators/Teachers Interview Protocol

Introduction

Thank you very much for taking the time to talk with us.

My name is [say your name], and we work with AidData, an organization in the United States that studies international development programs. We are currently conducting a study to help government officers and development partners make better decisions in the distribution and reporting of HIV/AIDS resources. As a part of this study, we are interviewing HIV positive young women, teachers, clinic coordinators and directors, and non-governmental organizations.

After we finish the interviews, we will create a report that summarizes the results. We would like to share the report with you once complete.

This conversation will be confidential. This means that what you say will never be associated with your name.

The conversation will not last more than 45 minutes. Is that ok with you?

To make sure that you are aware of the minor risks associated with this study, we would like you to read the following document [give Informed Consent Statement to the person you are interviewing]. If you agree, please sign it at the bottom.

Finally we would like to record the conversation to help us take notes. Is this okay?

Interviewee details

Please fill out this section at the beginning of the interview

Lead interviewer name:

Site of interview:

Date of interview:

Name of interviewee:

Gender of interviewee:

Organization of interviewee:

Title of interviewee:

Module 1: Activities about HIV/AIDS:

We are now going to ask you a couple of questions about your involvement with HIV/AIDS activities.

1. What is your role at the school?

[change school for organization if the educator does not work at a school]

[priority question]

2. What are your responsibilities related to HIV/AIDS?

[priority question]

3. Does the school [or organization] offer HIV/AIDS services to the students?

[priority question]

- 3.a. If so, which prevention and treatment services does the school [or organization] offer?

[only ask if response to question 3 is "yes"]

[priority question]

Notes:

Module 2: Information use and needs:

We are now going to ask you a few questions about the information you use and would like to have.

4. Which type of information do you communicate to the students?

[priority question]

5. From where do you get this information?

[priority question]

6. How well does this information meet your needs?

[priority question]

7. What information would you like to have access to?

[priority question]

Notes:

Module 3: Collaboration with other organizations:

Before we finish, we want to ask you a few questions about collaboration with other organizations.

8. Do you have any interactions with development organizations or clinics?

[secondary priority question]

- 8.a What can be improved from your interactions?

[only ask if response to question 8 is "yes"]

[secondary priority question]

Notes:

Conclusion

Thank you very much for taking the time to speak with us. We appreciate it.

9. Do you have any final comments for us?

[priority question]

Thank you. Please get in contact with us if you have additional comments or questions about our project.

About AidData

AidData is a research lab at William & Mary's Global Research Institute. We equip policymakers and practitioners with better evidence to improve how sustainable development investments are targeted, monitored, and evaluated. We use rigorous methods, cutting-edge tools and granular data to answer the question: who is doing what, where, for whom, and to what effect?

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