



Harnessing Data to Prevent HIV among Adolescent Girls and Young Women

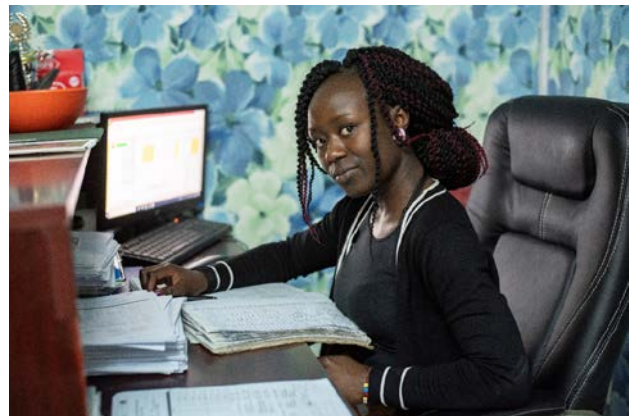
November 2019

Jamie Rosen, Amanda Johnson

Introduction & Background

Over the last decade, substantial advances have been made in data collection and visualization technologies used to inform HIV prevention, treatment, and care globally, and particularly in eastern and southern Africa. Despite these advances, parallel data collection and storage systems, and data quality, accessibility, and use challenges persist. Gender- and age-disaggregated data to pinpoint the most vulnerable populations, locate areas with high transmission levels, and identify inequities and bottlenecks in services as well as success points in care, are often lacking.

The DREAMS Innovation Challenge, with support from the Millennium Challenge Corporation, launched Data4DREAMS to seek investment opportunities to unlock datasets, fill gaps about adolescent girls and young women (AGYW), and improve data accessibility and use to inform policy and programs at the local and subnational levels. Selected innovations had to be responsive to local priorities in DREAMS districts and communities and accessible to key audiences from policy makers to community health workers and civil society, including women and girls. This technical brief describes the successes, challenges, and lessons from DREAMS Innovation Challenge grantees' work under Focus Area 6 (see box) to use data to increase efficacy of HIV prevention efforts for AGYW in four of the 10 DREAMS countries.



Staff at a Nairobi drop-in center run by Bar Hostess Empowerment Support Program tracks adolescent girls and young women who are new PrEP clients.

The DREAMS Innovation Challenge

The DREAMS Innovation Challenge was launched in 2016 to advance the U.S. President's Emergency Plan for AIDS Relief's commitment to reducing HIV infection among adolescent girls and young women in sub-Saharan Africa. Funded by the U.S. Department of State, Office of the Global AIDS Coordinator, and managed by JSI Research & Training Institute, Inc. (JSI), the Challenge spurred new partnerships and approaches in a multi-dimensional response to HIV prevention for AGYW ages 15 to 24 in 10 DREAMS countries: eSwatini, Kenya, Lesotho, Malawi, Mozambique, South Africa, Tanzania, Uganda, Zambia, and Zimbabwe. Forty-six global and local organizations implemented two-year projects in six focus areas: 1) strengthening the capacity of communities to deliver services; 2) keeping girls in secondary school; 3) linking men to services; 4) supporting pre-exposure prophylaxis (PrEP); 5) providing a bridge to employment; and 6) applying data to increase impact.

Focus Area Overview

Four DREAMS Innovation Challenge partners introduced Data4DREAMS solutions:

- **AidData at the College of William and Mary(AidData/CWM)** partnered with Akros in Zambia and Toro Development Network in Uganda to implement “*Responding to Local Demand for HIV/AIDS Data and Accountability.*” The program improved a decision-support tool to give policymakers and development partners geospatial HIV prevalence, treatment, and prevention data.
- **Premise Data Corporation** worked with local partner Family Health Options Kenya on “*Empowering Patients as Data Contributors: Data Solutions for HIV Service Monitoring and Operations.*” They deployed a smartphone app-based program to improve HIV treatment adherence among recently diagnosed AGYW and solicit their feedback on services.
- **Ushahidi Inc.**, worked in Kenya, Uganda, and Tanzania to implement “*Use Feedback Data, Open Data, and Social Media to Enable Agile Response and Improve Decision Making.*” The project gave DREAMS partners a customizable mobile phone-based platform to deliver sexual and reproductive health and HIV information and collect feedback from beneficiaries.
- **Viamo** (formerly Voto Mobile) worked with Chama cha Uzazi na Malezi Bora Tanzania to pilot *Data for Health Service Delivery: Citizen Accountability and Responsiveness Dash*, known as ReportCARD. The platform crowdsourced data from AGYW using Random Digit Dialing to solicit feedback on quality of services, individual knowledge, behavior changes, and health outcomes.



A young mother uses Premise’s HIV treatment adherence smartphone application.

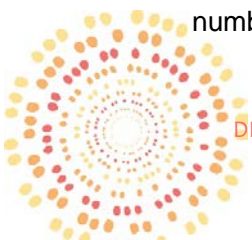
In two years, these Data4DREAMS partners engaged 356 institutions to improve data for HIV prevention approaches for AGYW, and reached 108,166 individuals with improved data platforms.

Selected Innovations & Results

Two case studies highlight how Data4DREAMS partners made critical adaptations to their innovations in order to respond to the needs of DREAMS partners and country counterparts, ultimately improving data platforms and use to guide decision-making.

CASE STUDY 1: Adapting tools to heighten the visibility of adolescent girls and young women

In Zambia, **AidData/CWM** and partner Akros originally aimed to develop a new decision support tool to equip stakeholders with information to allocate resources for HIV prevention and treatment services for AGYW. However, 47 key informant interviews across 22 organizations revealed that *existing* data and systems should be triangulated and strengthened to improve representation of AGYW, including data on prevalence of risk factors, locations and quality of facilities and projects, number of beneficiaries, funding allocation, and location of planned projects. In response,



AidData/CWM adapted their innovation by working with the National AIDS Council (NAC) to support their planned management information system (NACMIS) upgrade to improve quarterly reporting rates and data for decision making; align indicators with the 2017-2020 National AIDS Strategic Framework; and add data disaggregation by gender and age to support AGYW programming.

Challenges and Lessons: Delays in approvals meant interviews with Ministry of Health officials could not be conducted and the slow process of obtaining permission to access District Health Information System 2 (DHIS2) indicator data delayed development of visualizations. The experience underscored the importance of taking time for stakeholder engagement at all levels to introduce and advance innovations, and allowing for flexibility and receptivity to address stakeholder needs.

Achievements and Impact: Working closely with NAC and its technical partner BlueCode, the project added age disaggregation to indicators on out-of-school AGYW, sex workers, gender-based violence victims, post-exposure prophylaxis recipients, support groups, and orphans and vulnerable children. It also improved data visualizations by displaying DHIS2 treatment data and Demographic Health Survey (DHS) information together. Finally, the addition of district and provincial dashboards enabled NACMIS users to map stakeholders, HIV activities, and key populations.

Despite a significant shift in scope and unexpected implementation delays, CWM/AidData answered stakeholders' demand for four features in a decision support tool: open-source with interactive visualizations; geographic information system and location data; cross-comparisons with other data systems; and shared data dictionaries. The end result was an improved NACMIS that significantly strengthened the reporting and accuracy of prevention indicators and could be used at each level as a tool to drive decision-making around AGYW and other vulnerable populations. By the end of the project, NACMIS had registered 1,160 users, 908 reporting stakeholders, and 366 organizations. To ensure efforts were sustained, CWM/AidData trained 32 master trainers to cascade training to all 116 district AIDS coordination advisors and produced a full suite of support materials, including an end-user guide with online video tutorials, newsletters, a roles and responsibilities guide, training curricula and materials, a help-desk support process, a technical transition strategy plan process, and a frequently asked questions sheet.

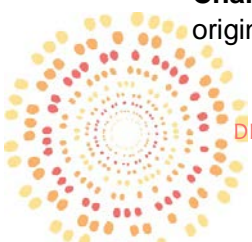
[The NACMIS upgrade] is a critical tool for engaging policy makers and reflecting on the type of HIV and AIDS services being implemented in their wards. [It] helps identify gaps in programming and service delivery. It also reduces duplication of services, thereby contributing to equity of services."

-- William Sikazwe, grants and de-centralised response coordinator

CASE STUDY 2: Promoting girl-centered HIV programming by prioritizing beneficiary feedback

Ushahidi aimed to improve DREAMS partners' ability to collect and use beneficiary feedback from their HIV prevention programs to improve decision-making. The three key objectives were to expand interaction between DREAMS partners and the AGYW they sought to reach; build partner capacity to collect data; and facilitate use of its platform for cross-organizational data sharing.

Challenges and Lessons: Ushahidi was not able to gather data from social media platforms as originally planned, because AGYW primarily used WhatsApp, which does not have an open



application program interface that could be integrated with Ushahidi's platform. Other challenges included lack of access to smart phones among younger girls, which required Ushahidi to procure tablets, and the need to invest more in training partner staff to the use of the platform and the data it generated. Further, the diversity of partner projects meant beneficiary feedback could not be generalized or aggregated across projects as planned.

While providing training and technical support to the organizations using the platform was more time-consuming than anticipated, it ultimately led to significant improvements to the platform. Based on partner feedback, Ushahidi added three new features: direct sending of targeted short messages from within the platform; the ability to download data in comma-separated value format; and a new "data mode" to view messages received. To address sustainability issues, Ushahidi bore hosting costs for partners for six months after the project ended, then subsidized hosting costs by 50% for another six months to encourage continued use of the platform. Ushahidi is working with partners on funding proposals to support the platform deployments that have demonstrated impact.

Achievements and Impact: Ushahidi reached 15 organizations and 105,451 individuals, recording 374,812 interactions through online and offline tools. Eighty percent of partners reported making at least one programming decision based on feedback gathered through the Ushahidi platform. For example, HOPE Worldwide Kenya dispelled myths and misconceptions related to PrEP uptake, resulting in an 80% increase in the number of new PrEP users during the messaging campaign period. The Nyanza Initiative for Girls Education and Empowerment partnered with health facilities to send mobile clinics to specific geographies based on client feedback. Partners also reported collecting data more efficiently and at lower cost than through traditional methods. For example, Wizarts Foundation in Uganda was able to survey beneficiaries in remote and geographically disparate communities, confirming that its "SuperWoman" girl-produced radio spots were being aired and reaching the target audience, while using the two-way SMS feature to solicit their feedback and ideas for future shows.

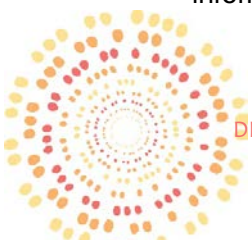


A participant discusses Ushahidi's two-way toll-free feedback system at the dissemination forum in Nairobi, Kenya.

Lessons & Recommendations

Enable two-way communication and real-time beneficiary feedback data.

Many monitoring and evaluation tools require an employee to conduct in-person surveys, which is resource- and time-intensive and logistically difficult. Two-way communication is essential for girl-centered programming to adapt quickly. In addition to gathering beneficiary feedback on services or programming that they received, data4DREAMS innovations allowed organizations and governments to communicate directly with users, answering young women's questions with information and messages that enabled them to reduce their risk for HIV infection.



Assess technology and internet availability, access, and literacy among targeted stakeholders during design phase.

Several data4DREAMS partners found that while national statistics pointed to high mobile phone use throughout the DREAMS countries, adolescent girls were less likely to have access than other demographic groups. Implementers must understand local circumstances including gender norms, select appropriate technologies, and incorporate training for use of digital technology (and subsequent upgrades) into budgets, workplans, and staffing plans. Incorporate interactive voice response systems in local languages to accommodate all literacy levels.

Plan for continuous training and technical support.

Partners learned that one-time orientations or training sessions were not enough to make users comfortable with the technology. Grantees and partners often underestimated the staff capacity and time needed to gather and analyze feedback from data platforms for decision-making, especially if it was not clear from inception who would complete data structuring and analysis tasks. Further, because AGYW are a highly mobile demographic, projects experienced frequent turnover among users. For these reasons, initial and refresher trainings must be available on an ongoing basis. Premise used push notifications to update training and user engagement, while CWM/AidData trained master trainers who cascaded training to lower levels.

Collect standardized, disaggregated data.

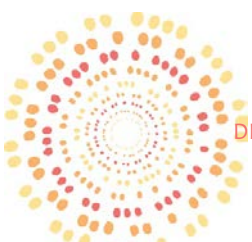
While it has become standard practice to disaggregate data by age and sex, data4DREAMS partners found that national data in many dashboards was not disaggregated at the level of the target population, specifically AGYW ages 10-14, 15-18, and 19-24. Without this level of detail, a wealth of data that could be used to provide evidence-driven, girl-centered programming, is lost. Further, organizations may track different indicators, making it difficult to compare data across programs and limiting cross-program learning. DREAMS Innovation Challenge grantees advocated for the collection of standard indicators, where possible, and for disaggregated data to allow analysis focused on AGYW that cuts across projects.

Involve government structures at all stages of project design and delivery.



National stakeholder meeting hosted by Viamo.

The design process for a decision support tool or open-data platform must involve the intended user and rapid iterations to build political will, ensure the tool serves its purpose, and cultivate ownership. It further ensures that data platforms fill gaps instead of duplicate efforts, and that data are useful and actionable at all levels. For example, at the individual level, Premise alerted health workers about its patients' self-reported HIV treatment adherence. Working with organizations, Ushahidi availed them with beneficiary feedback data to improve programming, while at the sector-level, CWM provided MOH and NAC decision-makers with action-oriented dashboards.



Integrate multiple data sources using open and accessible platforms.

Combining two or more data sources into one dashboard can produce insights that may not otherwise be possible. The innovations sought to present integrated data dashboards online so that all registered stakeholders could access information, and in some cases customize the dashboards depending on type of user, from national level planners to implementing partners to district health officers.

Conclusion

Data4DREAMS innovations aimed to fill gaps in existing datasets and dashboards to help HIV-prevention program decision-makers and implementers respond to the needs of vulnerable AGYW. These projects enabled organizations to gather data from many beneficiaries simultaneously via online and mobile platforms, enabling affordable, repeated follow-up at multiple time-points.

Resources

[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: Based on a series of interviews and consultations conducted in Uganda by AidData at CWM and partners, this report details the findings and priority features that health policymakers and practitioners largely agreed they would want to see in a future decision-support tool.

Acknowledgments

The authors extend thanks to College of William and Mary AidData, Premise Data Corporation, Ushahidi, and Viamo for providing reports on their DREAMS Innovation Challenge projects that fed into this technical brief. We are also grateful to Emilie Efronson of AidData at College of William and Mary for sharing her insights with us.

Recommended Citation

Rosen, Jamie and Amanda Johnson. 2019. Harnessing Data to Prevent HIV among Adolescent Girls and Young Women: Insights and Lessons from the DREAMS Innovation Challenge. DREAMS Innovation Challenge Technical Brief Series. JSI Research & Training Institute, Inc. (JSI): Boston, MA.

This publication was funded through a grant from the United States Department of State as part of the DREAMS Innovation Challenge, managed by JSI Research & Training Institute, Inc. (JSI). The opinions, findings, and conclusions stated herein are those of the author[s] and do not necessarily reflect those of the U.S. Department of State or JSI.

