Support Clubs for Children and Youth in Haiti Living with HIV:
Technical Brief on a Case Study

This document is part of a series that describes how routine data were used in research and evaluations of health programs and projects. Data for Impact (D4I) has compiled these examples from its own work and the work of others found through a literature review—and consultation with the original authors—to compare ways routine data can be appropriate for evaluations and to shed light on its benefits and shortcomings for evaluation.

A companion guidance document compiling these lessons is available at the [D4I website](). This suite of materials may be useful for others contemplating using available and routine data in their own work.

This report details how routine data were used to evaluate a program to retain children and youth in HIV treatment and care. Read the full report at http://www.projsoar.org/resources/haiti-ylhiv-kidsclub/.

Program Description

Although access to antiretroviral therapy (ART) among children and youth living with HIV has increased dramatically in recent years (UNICEF 2018), adherence to medication and viral load suppression have remained challenges (Teasdale, et al., 2018; Davies, et al., 2011; Iacob, et al., 2017; Glass, et al., 2015; Teasdale, et al., 2013). Psychosocial and adherence support groups have shown promise for improving the health and well-being of younger populations, but few have been studied (Murray, et al., 2017; PEPFAR Solutions Platform, 2018; World Health Organization [WHO], 2016).

In Haiti, an estimated 3,000 children and youth are receiving ART (UNICEF 2018). Caris Foundation, with funding from the United States President's Emergency Plan for AIDS Relief (PEPFAR) through the United States Agency for International Development (USAID), provides hospital-linked psychosocial support groups known as Kids Clubs for young people ages nine and older. The clubs were part of the USAID project *Bien Et ak Santé Timoun* (BEST) that ran from 2014–2018, and are continuing under USAID's Project Impact Youth. They are intended to help ensure that HIV-positive children and youth stay in contact with health services and adhere to their medications. They also serve as a conduit for delivery of other services, including health messages and health products.

In 2019, USAID's Project SOAR conducted a study of the Kids Club program implemented under the BEST project. Findings of the study were intended to contribute to the broader evidence base on support groups for young people living with HIV, fill knowledge gaps on how to operationalize and improve this approach, and guide decisions on scale-up and resource allocation in Haiti and globally.

Study Design

A retrospective case study was designed to address the following topics and questions:

- **Program implementation: How does the Kids Club program operate?** What is its history? What are its interventions? How are they implemented? To date, what have been the success factors and challenges in implementation? How can the program be strengthened?

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- **Program outcomes: What effect has the Kids Club program had on participants?** Who participates, how often, and for how long? What effect has club participation had on participants' lives and the lives of their families? Is club participation associated with better treatment outcomes, including ART adherence, retention in care, and viral load suppression? What do participants and their parents or caregivers value about the clubs?

- **Program costs: What is the cost of the program?** What are the resource requirements and costs of operation? What are the cost drivers? What are the unit costs?

The study utilized mixed-methods data from primary and secondary sources.[1] These included document reviews, routine project monitoring data, in-depth interviews, direct observation, focus group discussions, and clinical records data.

Justification for the Use of Routine Data

Routine, quantitative, secondary data were included in the case study to supplement, validate, and triangulate findings obtained from the primary qualitative data. The combination of data sources allowed a rich analysis that enabled us to examine the program from multiple perspectives. Two sources of routine data were included. Routine project monitoring data provided information on characteristics of Kids Club program participants, their participation in the program, program rollout and trends, and per capita costs. Clinical records data maintained by the Haiti *Ministère de la Santé Publique et de la Population* (MSPP) allowed us to examine HIV clinical outcomes of program participants (i.e., ART adherence and viral load suppression) and explore associations between those outcomes, reported psychosocial outcomes, and program exposure.

Data Collection and Data Management

Data Collection

Caris Foundation maintained an individual-level project monitoring database on all clients supported by the BEST

project—including socio-demographic and household information, and select clinical information extracted from facility records through paper copy. The project maintained a separate database on Kids Club scheduling and individual-level club participation. In collaboration with the study team, the Caris Foundation monitoring and evaluation (M&E) director identified data potentially available for the study, extracted data from these two databases on all children enrolled in the Kids Club program from 2014 through 2018, merged the databases, and created indicators to study team specifications. A Microsoft Excel file was created that contained 1,330 records (one for each enrolled child). Variables included sex of the child, date of birth, club name and location, type of club defined by age (9–12 year-olds, 13–17 year-olds, and 18+ years), date of first club meeting, date of most recent club meeting, number of club meetings attended, and attendance status in 2018. The file also included the unique client IDs used at the health facilities.

The study team obtained clinical record data from the MSPP *iSanté* national electronic medical record central server database, managed by *Unité de Gestion des Projets* (UGP). The clinical forms were first obtained from the Care and Treatment Unit at the National AIDS Program/MSPP and were used to identify the data fields of interest. Since access to the central database was restricted to UGP, we contracted with the UGP data manager to extract the files for us. He extracted the data based on the listing of client IDs for the 1,330 children ever enrolled in the Kids Club program and data specifications provided by the study team. Data were extracted from six clinic forms: client registration, initial visit, follow-up visit, medication, adherence, and laboratory. All but the first two forms are completed on multiple occasions and track client visits at the facilities. Data were obtained from all forms that captured multiple visits for the three-year period, 1 September 2016–31 August 2019. However, for analysis purposes, only data from the most recent clinic visit (or laboratory report) were retained.

Data Management

The project monitoring file and the clinical records files were then merged by the study team to create the analysis file and conduct range and consistency checks. The analysis file included 1,330 individual-level records for all children and youth ever enrolled in a Kids Club, 2014 through 2018. Several data management and data cleaning steps were employed beyond those typically required for well-designed primary data collection.

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1 Ethics review was granted by the Haiti *Comité National de Bioéthique* (CNB) (#1819-43) and the U.S.-based Health Media Lab (#617PAL19). CNB approval for all components except the secondary analysis of clinical data was granted on 16 May 2019; approval of the final component was given on 4 September 2019, following receipt of *Ministère de la Santé Publique et de la Population* approval to access the data for the study.

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First, many files had to be concatenated or merged to create the analysis file with a single record per case. This included a merge of the project data with the clinical records, comprising multiple types of forms. Further compounding the effort was the fact that five of the six clinic forms had two versions, one for children under age 15 and one for those age 15 and older. While the fields were comparable (with a few exceptions), they were stored separately on the UGP database and had to be reconciled prior to analysis.

Additionally, some recoding of the data was required. As others have noted, client care is the primary purpose of data capture in clinical records and, therefore, coding is often not standardized and fields often involve open-ended character strings that typically need cleaning due to misspellings, even when the responses are standardized (Gloyd, et al., 2016). This was the case for viral load test results, which had been recorded either as numeric laboratory readings, classified by range, or designated as suppression (or not). Using data sorting methods, these data were easily recoded, but required confirmation of the laboratory protocol for data reporting with the National AIDS Program.

Assessment of Usability and Quality of the Routine Data

Little documentation was directly available on data quality checks performed on these two routine data sources prior to data extraction for the study (however, see Puttkammer, et al. 2016, for a data quality assessment of the *iSanté* database). Internal consistency and range checks performed by the study team prior to merging the files showed only a handful of minor errors, such as spelling errors in character variables and one record with an incorrect date of birth that was subsequently corrected by program staff. Key fields common to both sources (i.e., sex and date of birth) were cross-checked in the merger of Kids Club and clinical records and inconsistencies were found in fewer than ten cases among those that had available data from both sources.

Clinical data from the client registration and initial visit forms were available for approximately three-quarters of all Kids Club enrollees. Complete clinical data (i.e., at least one record for all six forms) were available for 68 percent of Kids Club enrollees. Some 70 percent of Kids Club enrollees had data for at least one viral load test during the three-year period. Several factors were found to explain some of the "missing" clinical data. For example, five percent of missing clinical records were

from one health facility that had no data for Kids Club enrollees in the central server database (although the data were later verified to be available at the facility).

An additional five percent of missing clinical records were due to client transfers across facilities that resulted in assignment of new client IDs—a situation that prevented easy tracking of these clients over time. Comparison of cases with clinical data and without clinical data, however, showed no differences in sex, age distribution, and various measures of Kids Club participation. Thus, all available data were used in the analysis and no imputation was performed.

Initial examination of the clinical data also revealed that some of the clinical outcomes that we had intended to use in the analysis had high item nonresponse. For example, more than 40 percent of client records were missing data for the WHO disease stage classification and, thus, these data could not be used as had been planned.

Data Analysis Methods Used

Frequency counts and percentages were used to describe characteristics of Kids Club participants, enrolment by year, club type, and club participation. The latter was defined by three variables—(1) the individual participated for at least 12 months, (2) the individual was active in 2018 (i.e., had attended at least one meeting that year), and (3) was highly active in 2018 (did not miss more than three monthly club meetings). Chi-square and Fisher's Exact tests were used to test bivariate associations between participant characteristics, enrolment, and participation.

Two behavioral variables and one clinical outcome variable were derived from the clinical records data: (1) 100 percent of ART doses self-reported as taken in the past month, (2) self-report of no missed ART doses in the past four days, and (3) viral load suppression (defined as viral load laboratory result of less than 1,000 copies/ml.). Each of these outcomes was assessed at the most recent clinic visit (for adherence variables) and the most recent laboratory test (for viral load suppression). Similar to the program monitoring data, frequency counts and percentages were used to describe the prevalence of these outcomes; chi-square and Fisher's Exact tests were used to test bivariate associations between participant characteristics, club enrolment, club participation and behavioral and clinical outcomes. Additionally, associations between ART adherence measures and viral load suppression were similarly tested.

Limitations in Using Routine Data for Evaluation

We encountered several types of challenges and limitations in using routine data in this study, all of which were associated with use of the clinical records data. The first challenge was obtaining access to the data. A policy had recently been established to protect the privacy of individual medical records and—while the criteria for use and procedures for requesting access to these data had been outlined and our study was compliant—the process had not been fully operationalized at the time of our request. As a result, approval of the study protocol was delayed until the data request and approval processes were established and institutionalized. (See Beck, et al., 2011, and Beck, et al., 2016, for further discussion of confidentiality and security of clinical records data.)

In addition to the limitations noted regarding data quality, the study faced further limitations related to missing data. Specifically, we were unable to measure "loss-to-follow-up" at the facility because of the inability to distinguish whether the lapse was due to missing records in the information system or was because the client did not return to the health facility. Although clinical forms included a field for "date of next visit," which potentially could have provided information for tracking subsequent visits, this field often was not completed by the provider.

Additionally, we were unable to identify a comparison group, as was originally planned. This was because the structure of the central database in combination with data extraction limitations was unknown to us when we designed the study. Without a comparison sample, we lacked an important source of information for counterfactual causal inference.

What Worked Well?

Secondary analysis of routine data in this study served the intended purpose of corroborating our more in-depth qualitative primary data, which indicated that the Kids Club program had contributed in many positive ways to the well-being of children and youth in Haiti living with HIV. Although our decision to use routine data limited the rigor with which we could attribute observed outcomes to the program, it proved to be a cost-effective approach for strengthening the evidence case for program benefits.

An important note is that the process was highly efficient, although there were limitations in using clinical records data from the central database. While abstracting data directly from the health facilities would have allowed us to track missing cases and, perhaps, obtain missing data items, the cost of doing so would have far exceeded available time and resources for the study.

Inclusion of program monitoring data in the study was an important source of information about the evolution and implementation of the Kids Club program. And it, linked with the clinical data, lent further evidence to the association between program participation and behavioral and clinical outcomes. Analysis of the routine program data led to indirect benefits as well: Program managers gained greater appreciation of the data they had been collecting over the years as it demonstrated its power to reveal program insights, and managers vowed to expand their standardized reporting analyses to include more in-depth monitoring of program performance to aid the implementation of the next program phase.

Conclusion

Overall, the benefits of using routine data in our study outweighed the challenges. We found the use of routine data to be a cost-effective alternative to primary data collection. But we also learned the value of knowing to the fullest extent possible the specific limitations of routine data sources at the outset. Nevertheless, there are often challenges in obtaining this critical information. In our study, for example, documentation on data quality did not exist and we could not gain access to the routine data to verify quality until the study protocol had been approved. We were able to risk some limitations in routine data usability because these were not our only data sources. However, in other types of studies that may not be the case. Proper data documentation—including standardized metadata on quality—should be encouraged and made accessible, particularly for data sources with the potential for broader use, in order to optimize the use of routine data for evaluation.

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