

Improving Coverage among Sex Worker Programmes in Jamaica

DEVELOPING A PLAN FOR A UNIQUE IDENTIFIER CODE PILOT TEST

UIC Pilot Test Report



**For the
National Family Planning Board**

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1. INTRODUCTION & BACKGROUND

As the lead entity in the implementation of the national HIV response in Jamaica, the National Family Planning Board (NFPB) monitors and evaluates the activities of the prevention response of HIV in Jamaica. The entity places special focus on key population groups – Sex Workers, homeless drug users, men who have sex with men and unattached youths. In assessing programme outcomes for these groups, the NFPB is required to estimate the coverage of these programmes as “estimating the programme coverage of key populations is a critical component of assessing the delivery of the preventative response.”

One key population group is Sex Workers. The National Response to the HIV/STI Epidemic Among Sex Workers Reports states that “sex work has been identified as one of the drivers of the HIV epidemic in Jamaica.”¹ One of the recommendations of this study is to “implement monitoring system to reduce double counting of sex workers, possibly including unique identifiers for those reached through programmes.”²

Establishing a UIC system for Sex Workers is part of the wider commitment to move toward universal access to HIV prevention, treatment, care and support for individuals. Consistent with this commitment, many countries are in the process of scaling up HIV services. This scale-up is resulting in the collection of an increasing amount of individual-level data. These data are being used to:

- 1) Improve the quality and coordination of service provision through the development of individual longitudinal service records, and
- 2) Improve the effectiveness, efficiency, equity and acceptability of these services through ongoing monitoring and evaluation.

Use of unique individual identifier for health services including HIV, for each individual will advance these aims. Unique identifiers enable all data collected within a facility to

¹ National Response to HIV/STI Epidemic among sex workers. Pg 1

² Ibid. Pg 3

be correctly attributed to a specific person. In addition, where persons receive services from a number of different facilities, relevant information can be more effectively and efficiently shared and linked across service sites to improve service coordination and strengthen monitoring and evaluation.

The use of a functional UIC typically enables removal of double counting and creation of more accurate coverage. A UIC also ensures confidentiality of patient's health records and information. The continuing prevalence of HIV-related stigma and discrimination in diverse settings underscores the imperative to protect the confidentiality and security of all personal data.

As proven in other developing countries, a functional UIC system should enable the NFPB to achieve its operational outcomes with regards to collecting accurate data on the sex worker population and in evaluating the impact of programmes. It will also make available to the NFPB, the information to compile and disseminate data that adequately meet national and international standards.

Against this background, The National Family Planning Board (NFPB) sought the services of an independent consultant to engage sex workers, to conduct a pilot test of UICs among Sex Workers.

As a precursor to the pilot testing, the Consultant conducted:

- 1) A review of the lessons learned from previous attempts at establishing a system for double counting and unique identifier codes among sex workers in Jamaica.
- 2) In-depth interviews with sex workers to establish how best to establish a system to address double counting. Also to find out from the sex worker what questions should be asked as the basis for the UIC. Based on the outcome of these interviews conducted in Montego Bay and Kingston, along with best practice

guidelines, ideas and suggestion from studies and workshops conducted on UICs, three UIC options were developed and approved for the pilot testing.

Reports were submitted for 1 and 2.

This report represents the final leg of the study. It documents the results of the pilot testing. The pilot was conducted in live sites among fifty sex workers in Kingston and Montego Bay.

The report includes the objectives of the pilot testing and methodology used. It also highlights considerations that the HIV Programme needs to be aware of for expanding the UIC to other key populations. Finally the report seeks to highlight some of the conditions that need to be present in order to expand the UIC to general health care environment.

2. OBJECTIVES

According to an APM Report³, Unique Identifier Codes (UICs) provide an anonymous and reliable system for tracking of key populations through prevention, treatment and care services. The report suggests that a simple UIC is created based on a combination of answers to 4-8 questions that are relevant to the specific context and epidemic of the country. USAID funded DDRP Program developed a UIC that involved the use of a simple system of anonymous client registration of a 7-digit code composed of: First two letters of mother's first name, First two letters of father's first name, Gender (single letter M/F or number 1/2) Year of birth (last two digits) ⁴. Using these two examples, the Consultant, in collaboration with the NFPB developed three separate instruments each containing four to five questions. The questions were geared toward gathering information to create a unique code for sex workers in Jamaica.

³ Unique Identifier Code Systems Tracking Key Populations Confidentially and Comprehensively- Nikki Teggelove, Dave Burrows and Lou McCallum APMGlobal

⁴ Unique Identifier Code. USAID Funded Drug Demand Reduction Program in Uzbekistan, Tajikistan and Ferghana Valley DDRP Best Practice Collection pg6

In keeping with the terms of reference for the project, the objectives of the pilot testing were to:

- 1) Pilot the UIC system in at least one site using the three options suggested.
- 2) Compare pilot testing options in order to determine which option provides the most reliable, valid and acceptable UIC.
- 3) Observe and note any negatives feedback from the questions being asked.
- 4) Observe and note any positive feedback from the questions being asked.
- 5) Test sex workers general understanding of the need for the code to be introduced.
- 6) Test for reliability and validity of the information provided by the sex workers.
- 7) Solicit participants' opinion on the need/importance of reducing double counting among sex workers.
- 8) In the final analysis recommend a UIC that can be used as a monitoring and evaluation tool to reduce double counting among sex workers.

3. METHODOLOGY

The research methodology used to design and implement the pilot was qualitative. Due to the exploratory nature of the study, the methodology required combining primary data collected from focus group sessions conducted during the previous phase of the study with secondary data from desk research conducted.

In the previous phase of developing a plan for the UIC, focus groups were conducted with sex workers to find out what information they would be willing to share to develop the unique identifier for each person. Their suggestions were assessed and those questions that seemed to emerge mostly were contained in the pilot testing instruments.

Secondary research also played an important role in the design of the methodology for the pilot test. Best practices guidelines from UICs implemented, along with general guidelines from studied done on the subject was incorporated into the pilot test plan.

The Consultant explored ideas from countries that have successfully implemented UIC codes. For example, in 2003, Population Services International (PSI) developed a UIC system for monitoring the progress of their Demand Drug Reduction Program (DDRP) in Central Asia. They developed a simple system of anonymous client registration using a 7-digit code composed of: First two letters of mother's first name, First two letters of father's first name, Gender (single letter M/F or number 1/2) and Year of birth (last two digits) ⁵ The UIC was later implemented in Kyrgyzstan, Tajikistan and Uzbekistan.

Additional secondary research included a review of e UNAIDS workshop⁶ held in Switzerland in 2009 that recommended a similar approach. Similarly, the APM Global Report⁷ recommended using a combination 4-8 questions that are relevant to the specific context and epidemic of the country.

Qualitative research methodology was also used to conduct the fieldwork for the pilot. General interactive sessions along with in-depth interviews were used mainly because the process required hands on approach and required open communications with participants.

Fifty sex workers were recruited between Kingston and Montego Bay to participate in the pilot testing. They were recruited from clubs, workshops, massage parlours and the street. Approximately fifty percent of sex workers that agreed to participate in the pilot had been a part of the previous phase of the study. The other fifty percent were randomly selected by the outreach officers, club owners/operators and had not participated nor had any prior knowledge of the objectives of the pilot.

⁵ Unique Identifier Code. USAID Funded Drug Demand Reduction Program in Uzbekistan, Tajikistan and Ferghana Valley DDRP Best Practice Collection pg6

⁶ Developing and Using Individual Identifiers for the Provision of Health Services including HIV Proceedings from a Workshop, 24–26 February 2009 Montreux, Switzerland

⁷ Unique Identifier Code Systems Tracking Key Populations Confidentially and Comprehensively - Nikki Teggelove, Dave Burrows and Lou McCallum APMGlobal

Prior to conducting the in-depth interviews with individual sex workers, general sessions were held. They were told that the information being collected during the pilot would be used to develop a simple confidential code that would be given to them. The consultant explained that while the data is attributed to an individual, the information in the code cannot be linked a person. The code would be used as basis for a monitoring and evaluating of the HIV program and that, if implemented, would only be used by the HIV Program officers for reporting purposes. Once they understood the purpose of the UIC, and was given the guarantee by the outreach officers that their information would be kept confidential, all sex workers agreed to participate in the pilot exercise.

Out of the above exercises, three testing instruments were developed and approved for pilot testing: Appendices I, II&III. These were developed from a combination of suggestions coming out of the focus groups sessions previously conducted, along with international benchmark standards from UIC studies and those implemented and discussed earlier.

The pilot was conducted by the Consultant along with the assistance of the outreach officers in Kingston and Montego Bay

Validity testing

As part of the general discussion and rapport, the ladies were asked to introduce themselves and provide some background. During the session, the Consultant asked the ladies their name, age, address/parish, mothers name etc. The information was recorded and noted. During the in-depth interviews the information was used to cross check to see whether the information given on both occasions were the same/not. This was one way of asking the same questions twice to test for validity.

4. FINDINGS OF THE PILOT

KEY FINDINGS

- Fifty sex workers participated in the pilot testing of the UIC. Fifty percent of these women had participated in the previous phase of the study and was aware of the objectives of the pilot. The other fifty percent was introduced to the UIC concept for the first time. Once the new participants understood the purpose of the UIC and had the guarantee that their information would be kept confidential and would be used ONLY by the HIV Program staff, everyone cooperated and had their UIC code generated. They all had praises for the HIV Program and the outreach staff. The trust placed in the outreach staff was underscored time and time again during the study. They committed to using the code if introduced in Jamaica.
- Feedback from all sex workers who participated throughout the project was positive. They thought the idea to introduce a code for sex workers as a means of minimizing double counting was a good idea and agreed that it could work once implemented and used consistently within the HIV Program.
- While participants were fully supportive of the pilot, the Montego Bay sex workers noted that they did not think all sex workers would support the initiative. However, they could not provide meaningful reasons why they thought that some persons would not want to participate.
- The pilot proved that for the data to be clean and consistent, data formats and standards would be required. For example if parish is going to be part of the data being collected, outreach officers would need to have a reference list of codes for the various parishes. Similarly date of birth needs to be standardized e.g. is it date/month/year and how it is to be written?

- Information being collected needs to be standardized. Failure to record the information in a specific standard could not only result in duplication of codes as has been in case in other UIC implementations but also incorrect reporting.
- Date should read Date of Registration.
- Outreach officers require technical and non technical training. They need to be trained with adequate knowledge to enable them to drive adoption of UIC among key population.
- A small scale validity test was employed among 20 participants that were selected as described in the methodology (pg 6). Specific information was gathered during the general discussion. The information was tested during the in depth interviews. In each instance where validity was tested, the information proved to be reliable. The same information that was provided during the general discussion and the in depth interview.
- There were no major issues experienced during the pilot testing.
- The approach used was well received. The Consultant took notes and noted any nuances that arose, while the outreach officers completed the UIC registration process.
- Generally, the pilot testing can be considered successful in both Kingston and Montego Bay.

An Aside: While presenting birth paper or national identification is currently not a goal/requirement of the prevention program, some participants said they were willing to produce same if and when required for the UIC.

Data Collection Instruments compared

Three data collection instruments were used as part of the pilot test to gather information for developing the code. While the content of all three instruments were similar, they were designed with different formats for testing purposes.

Outreach officers were briefed on the procedure for implementing the pilot and the form distributed. A schedule was developed to implement the pilot among sex workers at massage parlours, clubs and on the streets.

The following reports the experience when each instrument was used:

Appendix I

- There were some issues associated with the **date format** in this form. The form requested "*Date of birth (Date, Month, Year)*". However the date format was not specified clearly. As such, while the outreach officer collected date of birth, they were not sure of the exact format. To correct this problem going forward, either an example of the format would be required when collecting date of birth or use the last two digits of the individual's year of birth.
- **Month** should be changed to **Date Registered**.
- Also **First and last initials** created a minor issue. Outreach officers were confused as were the sex workers. They recommended using just **Initials**.
- **Mother or Father initials** also has implications for double counting as the sex workers could give one officer mother's initials and another her fathers. To avoid this problem, it was recommended to record Mother's initials only.

- In the case of **current parish**, some officers spelt out the complete word of the parish e.g. Kingston. However, if parish is being used as part of the code, then short code would be more appropriate e.g. KSA for Kingston and St. Andrew. Collecting information on the parish where the sex worker registered could potentially track her movement subsequently.
- 20 persons were interviewed using this instrument (Appendix I). The information gathered turned out to be inconsistent in terms of length. UIC codes typically are between 8 to 12 digits. However the length of the codes generated using instrument 1 (Appendix I) were between 10 to 14 digits.

APPENDIX II

- First two letters of both mother and father's name may not necessarily add to the code as opposed to either mother or father's initials. This became apparent during the interviews when sex worker consistently made mistakes providing this piece of information. Some persons recalled their mother's initials but not the father's.
- **Month** should be changed to **Date Registered**.
- The last two digits of the date of birth worked well and was simple to understand, easy use and was well received by participants compared to the date of birth in Appendix I, that contained the lengthy format option (date, month, year)
- 18 persons participate using this instrument (Appendix II)
- UIC codes generated were 7 digits long

Appendix III

- This instrument gave the participant the opportunity to give first two letters of either mother or father's name. The first observation made was in some cases participant was uncertain whether they should use mother or father's name. The second observation made was that persons were confusing first two letters of the name with initials.
- **Month** should be changed to **Date Registered**.
- **Date of birth** format was left open for officers to record the information. As with the other instruments, the format for collecting date of birth ought to be made simpler or only the last two digits of year of birth. The latter has been used successfully implemented under the DDRP UIC solution in 2003 where Population Services International (PSI) developed a UIC system for monitoring the progress of their DDRP funded projects in Central Asia.
- 18 persons participated using this instrument (Appendix III)
- UIC coded generated were 8 digits long

LESSONS LEARNED FROM THE PILOT TESTING

- 1) While the second instrument appeared to be the simplest and easiest to generate the code, no one instrument on its own proved to be successful.
- 2) Given the limited time to record information and generate the UIC, for simplicity and ease it is being recommended that the code be made up of 4 simple questions:

1) Initials	RS
2) Year of birth (Last two digits)	67
3) Gender M/ F	F
4) First two letters of Mother's name	LU

UIC Code RS67FLU

This information provides key data about the client, including age and gender, without including any information that can be easily used to identify that person.

- 3) Bearing in mind that the UIC will be generated and used by outreach staff, typically on roadside, at clubs, massage parlors and workshop settings, the process involved in collecting and verification ought to be simple and straightforward to both outreach officers and sex workers.
- 4) Before introducing a UIC, in Jamaica, the NFPB should develop a plan supported by international agencies whose technical expertise can guide, conduct workshops and train NFPB and other agencies staff on best practices in introducing a UIC among key population in general. The plan should include technical guidance on how best to collect, store and retrieve the information for the purposes of monitoring and evaluating the program.
- 5) If implemented, a card containing the code should be generated and given to the sex worker. She should be asked to produce it at every encounter with the outreach officers.
- 6) A point made strongly was that when sex workers agreed to be issued a UIC, the decision is one based on trust and confidentiality in the outreach programs and outreach officers. In order for the UIC to be successful, the **confidentiality of the sex worker must be protected at all times.**

5. CONSIDERATIONS FOR EXPANDING UIC TO OTHER KEY POPULATION

A Unique Identifier Codes (UICs) provides an anonymous and reliable system for tracking of key populations through prevention, treatment and care services. The use of UICs has been highlighted in various reports by UN bodies, including the Technical Guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users(WHO, UNODC, & UNAIDS, 2012).

UIC systems promote monitoring of key populations and accurate tracking against targets by:

- Creating a confidential service recognition system that minimises barriers to HIV services for Sex Workers, Men who have Sex with Men and People Who Inject Drugs
 - Avoiding duplication in the counting of clients attending services
- Identifying new individuals engaging with prevention through to treatment services
 - Enabling analysis of treatment cascades through continuum of care indicator data
- Assessing the mobility of key populations through outreach services and health facilities
- Assisting in reorienting of services to meet needs and attendance patterns of key populations⁸

While this study focused on pilot testing three UIC options for sex workers on a very small scale, there is no doubt that a UIC code can be successfully extended to other key populations.

According to the APM Global study on best practices, when introducing a UIC, some considerations include:

- Change management: a new way of thinking
- Setting realistic reach based targets
- Establishment of revised monitoring and evaluation systems and databases

⁸ Unique Identifier Code Systems Tracking Key Populations Confidentially and Comprehensively - Nikki Tegge love, Dave Burrows and Lou Mccallum APMGlobal

- Establishing trust with key populations and assurance of confidentiality & anonymity

The APM report further states that successful UIC systems can lead to:

- Increased engagement of key populations with health and outreach services
- Improved service focus on key populations
- Population size estimates
- Coverage data for individuals and populations

Given these requirements, to consider the introduction of UICs to other population would require having a national implementation plan in place. There would be need for collaboration between national, sub-national and local health authorities and program partners to be able to successfully implement UICs among key population.

6. RECOMMENDATIONS

The following recommendations should be considered by the NFPB if the UIC codes are to be introduced as a monitoring and evaluation tools among sex workers:

- Secure technical assistance from international donor agencies to assist with the development and roll out of a national plan to introduce UICs among sex workers.
- Develop a national sensitization campaign aimed at building trust and confidence in the system.
- Lobby support and from other key organizations involved in programs for sex workers program to strengthen the aims of the program.
- Secure technical training for staff on monitoring and evaluating reports UIC program.

- Another recommendation would be to bring together all the outreach officers across the island and conduct workshops that would be designed to educate them about the UIC. One of the goals of the workshop should be to train staff how to use the forms. They also need to be trained in database management so they can monitor, evaluate and report.
- Seek guidance with regard to legal precedence on confidentiality of information.
- Hold national training and sensitization workshops for sex workers staff and on UICs.
- Pilot the UIC in defined outreach sites
- Build databases that will generate M& E reports to meet requirements of the funding agencies
- At a later stage establish technology tools e.g. a handheld reader that is integrated with the database that can read and update the information real time.
- The code should be stored in an in house database and the appropriate software used for monitoring, management and general evaluation and reporting. The code should be produced by the sex workers for all engagements with outreach programs henceforth and recorded on each occasion. The information contained in this code can be verified from time to time if and when the sex workers need to produce identification.
- If a decision is made to introduce a card base system, in the event that the card is lost or misplaced, providing that the information is stored in a database, the sex worker would be required to produce their ID in order to generate a duplicate or a replacement card generated at the discretion of the outreach officer. In such

an instance, a notation must be made that the code generated was a duplicate and the reason for the duplication given. This process not only help to manage and control double counting, but also enables the NFPB to compile and disseminate data that adequately meets national and international standards. Information on the usage or lack thereof of the UIC will become apparent from early. This information will enable the NFPB to make further decisions on what measure or strategies they may need to put in place to encourage usage of the code.

7. LIMITATIONS OF THE RESEARCH

There were several limitations to the pilot.

- The scope and scale of the pilot was too small to draw generalized conclusions among the sex worker population
- The project cost was high to secure the assistance of sex workers over the duration of pilot
- There were major challenges securing/coordinating available time for the sex workers to participate in the pilot
- Limited secondary data available

8. CONCLUSIONS

Improving coverage estimates among sex workers programmes in Jamaica: Developing a plan for a UIC pilot testing is the first of its kind study to be conducted in Jamaica. With the support of the NFPB, the scope, objectives, data collection methodology and determination of sites for conducting the pilot study was developed and approved.

Three instruments were developed and used as the main tool for gathering data, used to generate the codes. The questions used as the framework for conducting the pilot were evaluated and based on feedback from the outreach officers, the Consultant has recommended a combination of questions from the three instruments to be used for the UIC for sex workers. The recommendation is based on 4 questions that are simple, straightforward, while at the same time meeting international standards best practices guidelines for developing UICs.

The pilot was conducted in live sites in Kingston and Montego Bay. Fifty sex workers were interviewed for the purposes of the pilot. Outreach officers in Kingston and Montego fully supported the initiative and provided assistance where needed. Given that upon introduction, the UIC would be generated and used for reporting by the outreach officers, it was important to have full participation of the officers. The outreach officers' relationship with sex workers played a critical role in gaining confidence and building rapport and support for the pilot testing.

While participants understood the purpose of the UIC to be strictly for monitoring and evaluation of the program, there were concerns raised about incidences of breach of confidentiality and whether there were any implications if breaches occurred. Throughout the pilot, sex workers were mostly concerned about protecting their privacy and identity. The Kingston based sex workers especially cautious with providing information and admitted that they had confidence in the officers hence their willingness to participate in the pilot study.

While the study was limited in size and scope, there were several positives of the pilot. One of which is the fact that the pilot was conducted in live environments where the sex workers operate: clubs, roadsides, and massage parlours. This gave the project team the opportunity to experience firsthand, what potentially could occur in a live implementation. The second positive associated with the pilot was that the sex workers were fully engaged and actively participated in the pilot.

While the size and scope of the engagement was limited, an attempt was made to test the reliability of the information provided by the sex workers. In the instances where they were approached twice to validate information provided, the outcomes were all positive. In other words, the information that they gave was verified as the same when asked a second time around.

Generally, the pilot was a success as all fifty sex workers assisted by providing information needed to generate UIC codes from three different instruments.

Outreach officers were trained by the consultant to use the forms and they executed the pilot while being observed and the outcomes recorded.

In the end, while no one instruments worked perfectly, a combination of four simple questions is being recommended.

Next Steps: Having completed the pilot successfully, the Consultant suggests that NFPB along with key stakeholder groups and organization place emphasis on seeking technical assistance to develop a comprehensive UIC system with established procedures that follow best practice guidelines. Once established, HIV Prevention officers should be fully trained to implement the UIC.

APPENDIX I -
PLEASE COMPLETE REGISTRATION IN ALL CAPITAL LETTERS

Month

*First and last initials

*Gender Female () Male ()

*Date of birth (Date, Month, Year)

*Mother or Father initials

Tick whether Mother () Father ()

*Current Parish

Please tick which method was used to verify date of birth

(a) National ID ()

(b) Birth Paper ()

(c) Other () Please name the document.....

TO CREATE THE UIC CODE PUT ALL INFORMATION TOGETHER THAT HAS THE *

.....

Comments

APPENDIX II

PLEASE COMPLETE REGISTRATION IN ALL CAPITAL LETTER

Month

*First two letters of mother's first name

*First two letters of father's first name

*Gender Female () Male ()

*Last two digits of Year of birth

Please tick which method was used to verify date of birth

(a) National ID ()

(b) Birth Paper ()

(c) Other () Please name the document.....

TO CREATE THE UIC CODE PUT ALL INFORMATION THAT HAS THE *

.....

Comments

APPENDIX III
PLEASE COMPLETE REGISTRATION IN ALL CAPITAL LETTER

Month

*First two letters if of Mother of Father's name

*Gender Female () Male ()

*Date of Birth

*Current Parish

Please tick which method was used to verify date of birth

(a) National ID ()

(b) Birth Paper ()

(c) Other () Please name the document.....

TO CREATE THE UIC CODE PUT ALL INFORMATION THAT HAS THE * IN ORDER:

.....

Comments