Unique Identifier Codes

GUIDELINES FOR USE WITH KEY POPULATIONS

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MeSH Consortium
Measurement & Surveillance
of HIV Epidemics

LINKAGES
Across the Continuum of HIV
Services for Key Populations

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Acronyms

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
BCC	Behavioral change communication
CPR	Danish Central Person Registry
CRS	Danish Civil Registration System
DDRP	Drug Demand Reduction Program
HIV	Human immunodeficiency virus
KPHIV	Key populations living with HIV
LINKAGES	Linkages across the Continuum of HIV Services for Key Populations Affected by HIV
M&E	Monitoring and evaluation
MSM	Men who have sex with men
NGO	Nongovernmental organization
NSEP	Needle and syringe exchange program
PASMO	Pan American Social Marketing Organization
PLWHA	People living with HIV/AIDS
PNG	Papua New Guinea
PSI	Population Services International
PWID	People who inject drugs
SW	Sex worker
TL2	Tingim Laip Project 2
TG	Transgender
UIC	Unique identifier code
UNAIDS	Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development
VCT	Voluntary counseling and testing

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Acknowledgments

Overview and Purpose

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) announced the 90-90-90 targets for ending the AIDS epidemic by 2020. Under the new targets, 90 percent of all people living with HIV will know their HIV status by 2020; 90 percent of those diagnosed with HIV will be receiving sustained antiretroviral therapy (ART); and 90 percent of those receiving ART will be virally suppressed. In order to achieve these targets, UNAIDS emphasized the need to reach key populations with HIV services to reduce the treatment gap and provide equitable services to all communities.[1]

As a part of its commitment to ending the HIV/AIDS epidemic, the U.S. Agency for International Development (USAID), with funding from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), awarded its first global award targeting key populations.[2] The five-year agreement, Linkages across the Continuum of HIV Services for Key Populations Affected by HIV (LINKAGES), was awarded to FHI 360 and partners Pact, IntraHealth International, and the University of North Carolina at Chapel Hill. Under LINKAGES, FHI 360 and its partners will help countries develop and scale up evidence-based programs for key populations along the HIV care and treatment cascade.

This document serves as a guide for the LINKAGES program, partner governments, nongovernmental organizations, providers, and additional key population stakeholders on the use of unique identifier codes (UICs) for key populations receiving HIV services. A UIC is any set of numbers, letters, alphanumeric combination, or any unique property (e.g., fingerprints and other biomarkers) that can be used to identify one specific individual. UICs are frequently used to access health care services and other governmental and social benefits.

UICs are valuable tools in helping to protect the privacy of key population members, while also providing programs with valuable individual-level program data. Such data can assist organizations in ensuring program quality and retention of key populations along the HIV care and treatment cascade. In addition to the guidance document, the accompanying appendix includes a series of UIC case studies and suggested additional reading.

For questions or additional support, LINKAGES country teams are encouraged to contact their headquarters-based monitoring and evaluation (M&E) director.

I.   Introduction and Background

Individual identifiers are an important component of health care delivery. Not only are identifiers used in daily operations, such as administration and billing, but they are also necessary for maintaining personal health records. At single facilities, identifiers are used in clinical documentation to maintain longitudinal personal health records, and beyond the facility, identifiers assist in linking records clinicians may need for managing the health of their patients. Individual identifiers are also used to repeatedly and correctly identify individual-level health information to be used in conducting surveillance and program monitoring and evaluation.

At a national level, many forms of individual identification already exist. In the United States for example, social security numbers are used to access benefits from government-provided services. In Denmark, a central person registry (CPR) number is assigned to every citizen at birth. This number can be used to link information from various registries, such as birth, death, cancer, and HIV treatment service. More information on Denmark's CPR can be found in case studies included in Appendix 1. Kenya also issues a national identification number to all citizens older than 18 years. In Botswana, citizens are issued a national identification document called the Omang ID Card, which is used for accessing social services including health care and antiretroviral treatment. Malawi has a health passport in the form of a small, generic paper booklet, which can be obtained from the government and used to access health services. The health passport is used to record all diagnoses and treatments/interventions given. At facilities with access to an electronic medical record, books may be labeled with a unique health identification number and associated barcode. Residents may also choose not to label their passport with any personal identifiers, only write their name or carry multiple passports to protect their health information.

In many settings, however, additional protections must be added to individual identifiers to protect members of key populations. Key populations—sex workers (SWs), people who inject drugs (PWID), transgender (TG) persons, and men who have sex with men (MSM)—are often at higher risk of acquiring and transmitting HIV infections and are generally less served by existing health care services.[3,4] This is due, in part, to structural barriers such as criminalization, stigma, violence, and discrimination that lead to poor access and uptake of HIV services.[5-7] In 2010, 79 countries had laws prohibiting male-to-male sexual contact, including the death penalty.[8,9] Over 100 countries have laws that explicitly criminalize some aspect of sex work.[10] In many Eastern European and Central Asian countries, PWID are even recorded in national drug registries. Such punitive legislation makes it difficult for key populations to access social services and creates environments tolerant of key population abuse and discrimination. Therefore vertical, key-population-specific programs have been established in many contexts to provide services to members of key populations affected by HIV/AIDS.

One option for individual identification in key population programs is the use of confidential unique identifier codes (UICs). Since members of key populations encounter stigma in many countries and the lack of confidential care is a deterrent for seeking services, the use of UICs can help ensure anonymity when seeking care for stigmatized diseases or infections. In addition, some key population members are highly mobile (some travel across national borders to practice their trade) and thus access health care services in various locations. UICs can be used to link the health records from various facilities to provide longitudinal health care records for access by authorized providers at subsequent visits.

UICs are also valuable to programs in measuring the HIV cascade, a useful tool for tracking access to HIV preventive and treatment measures. The cascade can provide a "snapshot" of population size estimates, number of individuals that have access to a minimum package of HIV prevention services (including counseling and testing), HIV prevalence, number and proportion of those tested positive who are linked to care, number and proportion of those started on antiretroviral therapy (ART), and number and proportion of those on ART who have achieved viral suppression. When considered longitudinally, the cascade can also be used to measure time between steps, account for competing risks, and summarize the amount of time spent in each step. The cascade is useful both for planning and implementing interventions and serves as a valuable tool for monitoring and evaluating the effectiveness of programs and services (Figure 1). More information on the key population HIV cascade can be found in the *LINKAGES HIV Cascade Framework for Key Populations.*[11]

Figure 1. HIV Continuum of Prevention, Care, and Treatment for Cascade Key Populations
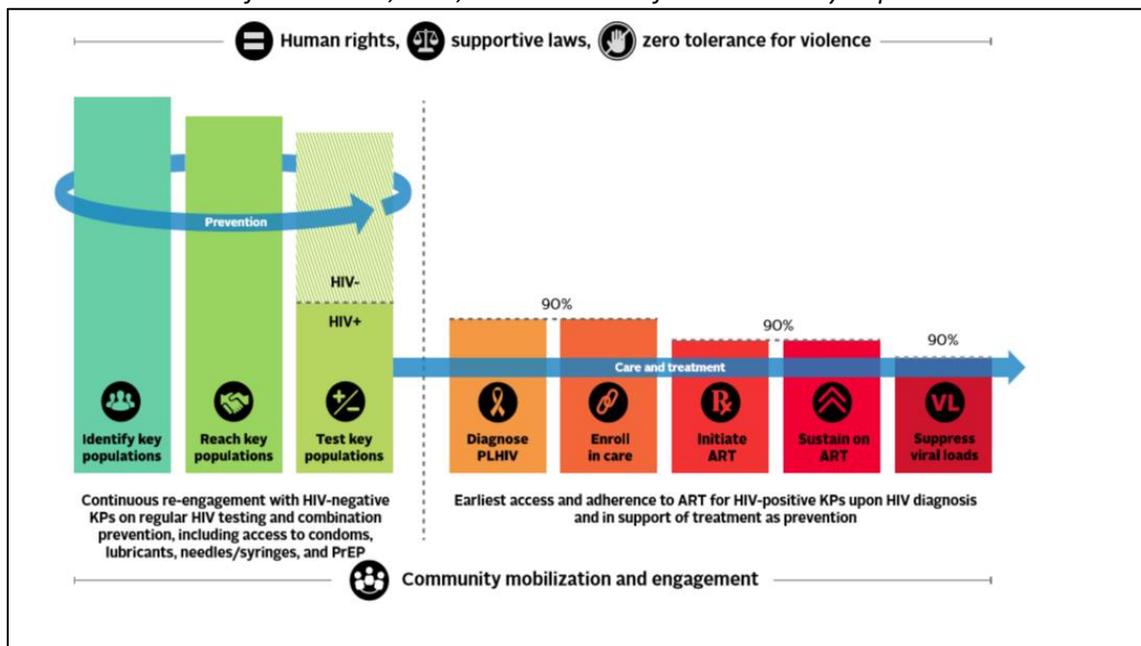
One of the major issues in tracking cascade indicators is that individuals sometimes access health care services at different facilities and no method exists to track them across service delivery outlets. This often leads to double-counting (counting client contacts rather than the total number of individual clients accessing a service) and produces unreliable cascade estimates. The use of UICs has helped improve the accuracy of HIV cascade indicators and helped identify new individuals who are engaging in prevention and treatment services.[12] In addition, programs can use UICs to estimate the frequency with which clients are reached to determine whether that frequency is adequate in improving outcomes, either in terms of behavior change or progress toward viral suppression.

Program implementers can also use UICs to assist in monitoring the progress of individuals through the entire continuum of HIV prevention and care. When done in this way, UICs can help programs follow up with patients who have missed referrals, are lost to follow-up, or who lack treatment adherence. Such approaches can be especially helpful where mobile data collection systems are in place. For example, LINKAGES programs in Thailand and Laos have begun collecting patient information using CommCare.

CommCare is an open-source, customizable platform that allows peer educators and other program staff to collect patient data through a mobile application, replacing the need for paper-based forms. The platform uses UICs to link both external and internal records. Program implementers can then follow clients through the cascade, and even send important messages and reminders to them about appointments, adherence, and upcoming events.

In summary, UICs can perform the following functions for key population members, program implementers, and M&E specialists:

1. Create a confidential service recognition system that uniquely identifies individuals without disclosing personal information
2. Improve health information management for highly migratory populations
3. Improve assessment of mobility of key populations through outreach services and health facilities
4. Avoid duplication in the counting of key populations attending services
5. Identify new individuals engaging with prevention through treatment services
6. Assist in the reorientation of services to meet the changing needs and attendance patterns of key populations
7. Conduct analysis of the HIV cascades through continuum of care indicator data
8. Help programs follow up with patients who have missed referrals, are lost to follow-up, or who lack treatment adherence

II.   UICs: Types, Generation, Assignment, and Record Linking

A.   What Various Forms of Unique Identifier Codes Exist?

Generally, UICs can be classified as biometrically associated and nonbiometrically associated (the more common type used for health care purposes). Biometrically associated UICs are commonly generated from fingerprint patterns, facial recognition patterns, or iris scans. Multimodal systems, which cross multiple biometric methods of identification, also exist.

Biometrically associated UICs have been used in the Kenyan Sex Worker Outreach Programme (SWOP), where a fingerprint reader is used to scan prints and enroll members of key populations in care, and in one large scale research project engaging MSM and PWID in India.[13] Upon registration, a unique identifier is generated from the scanned fingerprint, which eliminates the need to collect other identifiable information in the record-linking process. More information on this program can be found in the case studies in Appendix 1. Similar methods have also been used for PMTCT programs in South Africa.[14]

Nonbiometric UICs can be a set of codes, a physical card that stores encrypted data on it along with a UIC, or a form of national identification. For key population programs, UICs often consist of a code created through a series of individual prompts. An example of an alphanumeric code is a UIC used by Population Services International (PSI) for a Drug Demand Reduction Program (DDRP) in Tajikistan (discussed further in Appendix 1). The seven-digit alphanumeric code is generated as follows (fig. 2):

> -the first two letters of the client's mother's first name
> -the first two letters of the father's first name
> -gender (1=male and 2=female)
> -year of birth (last two digits)
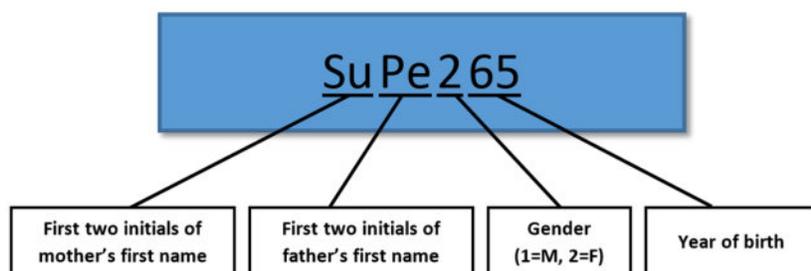
Figure 2. Example of alphanumeric UIC.

To choose a successful UIC, programs will need to consider local context. For example, in Vietnam, following pilot testing with databases from local universities, a nine-digit easily self-generated code was identified with a 0.9 percent duplication rate (i.e., different individuals creating the same UIC),[15] which was deemed not to be statistically significant in their M&E processes. The code was generated using:

> -the first two letters of father's familiar or common name
> -the first two letters of the mother's familiar or common name
> -the three-letter code for province of birth

-a code for identified gender (M=1, F=2)
-last two digits of the year of birth

(For example: a male born in 1976 in a province with the code 625 and a mother named Sarah and a father named Fred would have a UIC of FrSa625176.)

Other prompts are often necessary to generate a UIC and, again, are dependent on the local context. For example, naming practices may mean that many individuals have the same first few letters in their names, making duplicity more likely.

B. What Are the Properties of an Ideal UIC?

Regardless of context, certain properties constitute an ideal UIC (listed below). While it may not be possible to adhere to all these standards, ensure that any UIC meets at least the first two.

Confidential and secure: UICs should exclude privately identifiable information and can be encrypted, thus ensuring confidentiality and security. Should a data breach occur, codes cannot be used to identify individuals receiving services. This should be a priority for any program working with members of key populations, especially in locations where they are highly stigmatized or criminalized.

Nonstigmatizing: UIC generation and use should be sensitive enough to avoid further stigmatization of users. For example, in some contexts, fingerprint scanning may be associated with criminal activity and using a biometrically associated UIC may be further stigmatizing to individuals.

Client-generated: For a biometrically associated UIC, this is achieved using a unique physical property of the individual (such as a fingerprint or iris scan). For an alphanumeric UIC, prompts can be used with client-specific information to generate a code. Successful UICs will use prompts that can be easily answered.

Easy to recall: An ideal UIC will be simple enough to ensure easy client recall. Biometric UICs are often ideal since they only require a physical scan to recall the code. For alphanumeric UICs, prompts must be simple enough to ensure clients answer the prompts the same way each time.

Immutable over time: To capture the same UIC for an individual at each interaction, service providers should choose a code that is unchanging over time. For example, biometrically associated UICs are generally immutable (though certain exemptions do exist and are discussed in further detail later in this document). For alphanumeric UICs, prompts should seek answers that are immutable. For example, using a phone number may be challenging since these often change as individuals register new phones. A better prompt may be date of birth, as this is a fixed response.

Unique: Ideally UIC systems should aim to have a less than 2 percent chance of replication by separate individuals. Conducting statistical modelling for determining an alphanumeric UIC is discussed later in this document. For circumstances in which a UIC has been generated for two or more individuals, a system should be put in place to either split identifiers (mostly for retroactive use) or generate a new UIC for future use.

Allows for mobility: A successful UIC system allows patients to receive care at multiple sites. For highly mobile populations, the ability to access care in various locations is a major benefit. UICs should not be site-specific (i.e., include characters that specify the site where the individual is receiving services).

Can be linked: After allowing for mobility, an ideal UIC will have the ability to link data between sites when aggregated. Ensuring UICs are successfully linked can assist in both data collection as well as improving multidisciplinary coordination of care among different health providers. Successful linkage depends greatly on network infrastructure and collaboration between providers to support the UIC system. For individuals creating multiple UICs, systems should also support the merging of duplicate identifiers.

UNAIDS has developed additional recommendations for ideal health identifier codes which can be found in *Considerations and Guidance for Countries Adopting National Health Identifiers.*[16] These guidelines were developed to make health identification codes easy to recall, use, link, and to ensure confidentiality and data security.

C. Where Are UICs Used?

UIC systems are used at various levels of scale. When developing a system, consider short- and long-term goals. A short-term goal might be reaching key populations in an immediate service area. However, scaling up UICs for national health systems can strengthen services for residents, including key populations, and might be considered as a long-term goal. Ultimately UNAIDS recommends developing nationwide identifiers as they can link data across fragmented systems, allowing for better continuity of care and quality management.[16] For some programs though, this may not be feasible. The various levels of scale are explained below.

Single Site Provider: Measure unique number of KP individuals reached, frequency of reach, and type of contact — Level One

Multiple Sites, One Program: Linking data across sites in one program — Level Two

Multiple Programs: Measure KP patient outcomes across providers, (e.g., Linkages prevention and MOH treatment programs) — Level Three

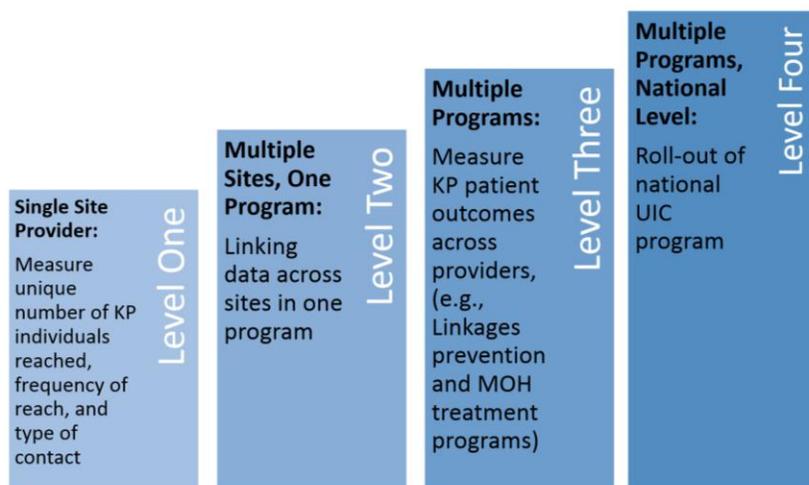**Multiple Programs, National Level:** Roll-out of national UIC program — Level Four

Figure 3. Levels of Scale

Level 4: National UIC
Level 4 is the highest level of UIC included in this guidance. At Level 4, UICs are used at the national level to track all people living with HIV/AIDS (PLWHA) or individuals receiving prevention outreach, not just

members of key populations. Ideally, these codes would also be useful across all care settings, not solely for HIV-positive prevention, care and treatment programs.

Goals for programs beyond Level 4 may include creating partnerships across national borders that allow for tracking of key population members that regularly cross borders. These populations may include long-distance truck drivers or sex workers that work along transportation corridors.

Advantages:
- Can help in assessing continuity and quality of care
- UICs can be used by all providers, even those not specific to key populations, allowing for measurement and tracking across the entire continuum of HIV prevention and care
- Since no longer key-population specific, ID cards can be issued to store longer UIC codes and ensure proper recall of codes

Challenges:
- Since UICs are no longer key-population specific, programs must determine how to carefully and safely identify members of key populations without compromising personally identifiable information or key population status to non-key-population specific providers. It will also be vital to work with key populations to establish trust and assure them of confidentiality and anonymity.
- Longer codes are most likely needed to reduce duplication rates
- May require significant additional financial and human resources in the beginning stages
- Requires robust technological infrastructure
- Strong security efforts need to be undertaken to protect privacy and personally identifiable information
- May be hard to reach individuals receiving services at private providers
- Transliteration may need to occur in countries with multiple languages
- Requires extensive political and community will and buy-in from multiple partners and stakeholders

Level 3: Multiple Programs
In Level 3, the UIC is used to measure key population patient outcomes in HIV services across multiple programs and providers. For example, the UIC would be used by multiple programs, such as those funded by LINKAGES, the Global Fund, and the government in country. Ideally, the UIC could be used across all HIV outreach and service providers within a nation to ensure that key population members are tracked no matter where they choose to receive services.

Advantages:
- Can ensure better continuity of care
- Allows for high quality analysis of patient outcomes across the entire HIV cascade and determining the number of individuals that are truly lost to follow-up

Challenges:
- Since the UIC is specific to key populations, programs must now determine how to safely and confidentially follow patients when they receive services provided by organizations that are not key-population specific. This has been done in some locations by linking UICs to separate IDs used by government or private health facilities.

Level 2: Multiple Sites, One Program
At Level 2, a single program uses the UIC to link key population members' data across multiple sites. For example, such a program might use a UIC for outreach as well as treatment and care activities. This would include most LINKAGES country programs, where services are provided by individual civil service organizations (CSOs) but funded or managed by LINKAGES within country. Since such programs will have multiple sites, it may be beneficial to first pilot a UIC at one site before expanding to all sites within the program.

Advantages:
- Accounts for patient mobility if patients access services within the same program
- Can track referrals and linkage of patients to different components of the HIV cascade

Challenges:
- Potential interoperability issues
- Must ensure staff at each site are generating codes identically
- Since not national, cannot determine whether clients are truly lost to follow-up or receiving services through other programs
- Must determine how to identify members of key populations if sites are not key-population specific

Level 1: Single Site Provider
While uncommon (and not applicable to LINKAGES programs), Level 1 represents programs using UICs at a single site, either a community-based organization or health facility, to measure the unique number of key population members reached. This may also include provisions to track the frequency and type of contact with each key population member. For example, at a care and treatment clinic, the UIC could be used to capture the number of individuals ever having attended the clinic, the frequency at which each key population member returns to the clinic, and the services provided to that client upon visitation.

Advantages
- Easier to generate a code with a less than 2 percent duplication rate
- Eliminates interoperability concerns
- Requires fewer resources
- Can conduct along with biobehavioral surveys to track progress against targets
- Can link with social media components of a program

Challenges
- Number of key population members reached may not be a true indicator of program success
- Unable to track patient outcomes if patients seek additional services outside of the site
- Does not account for patient mobility
- Potential failure of individual to recreate the same UIC

D. UICs May Be Generated Centrally or Peripherally

The generation of UICs can be done centrally or peripherally. Generating UICs centrally involves running checks with a central server or database to determine if a UIC already exists before creating a new one. This often requires internet or intranet connectivity. For central generation, programs will also need to

develop protocol on what should be done in the event a UIC already exists for a different client. Some options include creating an alternative code (which can be recorded on a client card) or flagging the UIC for later deduplication. In addition, programs should consider the additional amount of time needed to generate a UIC centrally as opposed to peripherally. Running checks against the existing database may take several additional minutes while the client waits, which may not be feasible in outreach settings or at large-scale events.

When generated peripherally, UICs are not run against any central database and checks of duplication cannot occur until data aggregation. Real world constraints often dictate which method is more feasible. While centrally assigned UICs will reduce the occurrence of duplicate UICs, poor network infrastructure, connectivity issues, and lack of mobile devices or computers might make peripherally generated UICs the only feasible solution.

E. When Are UICs Assigned?

In countries where UICs are assigned by the government (such as the CPR number in Denmark or the social security number in the United States), UICs are often assigned at birth or when an individual reaches a certain age (for example, the unique identity card numbers might only be assigned to individuals over 18 years). Assignment at birth has obvious advantages, as early health and social records can easily be linked to this number. This is especially important as some health conditions in childhood often continue into adulthood, and childhood exposures have implications for adult health.

However, UIC assignment at birth is only possible for programs implementing a nationwide, non-key population-specific UIC. Thus, any programs below Level 4, should seek to assign a UIC at the inception of the program or at the individual's first contact with the health system.

F. Probabilistic and Deterministic Matching of Preexisting Health Records to UICs

When establishing new UIC systems, depending on the needs of the program, it may be useful to link preexisting health records (paper-based or electronic) from various service delivery points. For UIC programs attempting to link data retrospectively, systems will be required to define algorithms and convert paper records to electronic medical records. The two methods of record-linkage are: deterministic and probabilistic. Deterministic matching involves linking records based on the agreement, often exact, of characters in health records. While linking records based on perfect agreement often produces high rates of true linkage, it can often miss links due to spelling errors and variations or incomplete data.[17]

Probabilistic matching, on the other hand, is a method that can be used to link records based on the probability that characteristics in records are a true match. This method involves statistically weighting each matching characteristic. The weights reflect the degree of confidence in each as an identifier. The probability that different records are for the same individual is then computed, and if it falls within a previously determined acceptable range, those records are treated as belonging to the same individual.

The process of linking existing records is intensive and may need to be spread over several years, depending on program capacity. Also, verifying the accuracy of paper records places an additional demand on resources and manpower that may already be limited. Decisions on how many years of past records and which ones to convert and link to a UIC will need to be discussed by in-country stakeholders prior to implementation of a UIC system.

In some situations, it may be possible that information previously collected by programs can be used to retrospectively create UICs and link to data moving forward. This, however, will require programs to choose prompts based on these data elements previously collected.

If a name-based system was previously used, programs implementing new UIC systems may be able to go into retrospective records and replace the name with the new UIC. This, however, will require cooperation from the client (in that they must give their name again) and the use of important safeguards to ensure privacy and confidentiality (such as ensuring staff who look at records have had all necessary ethics training, have signed confidentiality agreements, and have obtained consent of the client).

III.   Ethical Considerations for UIC Development and Use

Many local, context-specific, ethical considerations need to be considered before developing a UIC system. As with any health program, the intended output should maximize benefits to the individual while minimizing the risk of harm. While UICs are valuable in reducing double-counting and producing accurate cascade estimates, programs must ensure the data gathered is used to inform and improve program and patient outcomes. Also, the benefit of such improvements must outweigh any risks to privacy at the individual level. It is vital for any program hoping to implement a UIC to first establish trust with members of the population groups with whom they work. Once trust is established, it may be easier to assure clients of confidentiality and garner their acceptance of the system.

A.   Data Confidentiality and Security

Regardless of whether a UIC is used or not, all programs should have a security protocol in place to protect patient confidentiality and ensure data security. To establish a security protocol, plans should include (1) mapping of all primary, secondary, and end users; (2) identification of data access privileges and security mechanisms for each level of user (e.g., passwords on tablets after a period of inactivity); (3) training to ensure users are trained and compliant with all patient confidentiality laws and/or procedures; (4) the length of time data will be kept and how it will be backed up; (5) procedure in the event of a security breach; and (6) an accountability structure.

For any country implementing UICs at the national level for key population members only (Level 3) or for all people accessing services (Level 4), one of the most important considerations will be determining how to share data across providers without revealing individuals as members of key populations, especially when data is being shared with organizations offering services that are not key population specific. In these situations, it will be important to develop guidelines in collaboration with all stakeholders as well as with members of key populations. Ultimately, guidelines should be clear, transparent, and readily available for review.

For more detailed information on data protection, see the guidelines under "Data Safety and Security" in Additional Resources.

B.   Models of Consent

Key populations are still stigmatized in many countries. Self-identification as a member of a key population exposes them to discrimination, threats, and the risk of violence from both law enforcement agents and other members of the community. Therefore, the public health benefits of UIC generation and use need to be balanced with the individual rights of human beings who may choose to identify or not identify as a key population member. Among the different levels of consent (fully explicit, opt-in, opt-out, and no consent), the cultural context in a country will dictate what consent model to adopt.

Fully explicit consent requires clear consent each time personally identifiable information will be used. While this respects individual autonomy, it is the costliest and most resource intensive for providers.

In the opt-in model, initial consent for use of personally identifiable information is sought and then an opt-in to allow additional information to be used by the health care provider or program. In contrast, the opt-out model assumes that consent is given unless the patient explicitly states otherwise.

Though not recommended, the no-consent model assumes that the patient's data will be held confidentially and does not require the patient's consent for analysis or record linkage. Despite this, patients should be informed that their data may be used for program planning, monitoring, evaluation, and other purposes but in a form in which personally identifiable information will be removed or encrypted.

A discussion with local in-country stakeholders, such as key population representatives, government officials, nonprofit health organizations, community leaders, religious leaders, and others, is necessary before the adoption of any model of consent in collecting data with UICs.

C. Special Biometric Considerations

Special considerations should also be given when using biometric UICs. In many countries fingerprinting is still associated with criminal law and implementing such a technology among key populations could lead to further stigmatization. In addition, since the purpose of UICs is to protect the privacy of key populations, biometric systems should aim to reduce the amount of necessary data needed for collection. For example, fingerprint scans can be used to generate a UIC but not store any actual fingerprint images. As with any system, programs using biometrically associated UICs need to ensure secure storage of the UIC and any associated data. Explaining the use of biometric methods and establishing patient trust will be vital to ensuring the success of the system.

IV. Technical Considerations for UIC Development and Use

A. General Considerations

Deciding on what type of UIC to use in context requires an assessment of the current identification system in the country, technical capacity, and infrastructural support available for a UIC system. Biometrically generated UICs might require expensive equipment that may need to be maintained (serviced or replaced frequently). In addition, the failure to accurately recognize and match biometrics are still a concern for biometric-based systems. Backup data servers where biometric information is stored need to have high standards of security (including password protection and encryption) and capacity. These may not be feasible for countries with a limited financial budget for developing a UIC system.

In addition, UICs need to be a certain length to guarantee uniqueness. Longer and difficult to remember UICs may require a physical card bearing that number, which increases the potential for card loss and subsequent data breach. Also, UICs that have elements with only two to three possible options (e.g., gender can only be male, female, or transgender) increase the possibility of duplication. The balance between the appropriate length and simplicity of a UIC for a country should be considered and, if possible, piloted before implementation nationwide.

Data security is a challenge in any situation where personal data is collected. Unauthorized data access and data breaches are always possible. Before implementing a UIC system, protocols must be created to protect the security and privacy of clients. Encryption systems, as well as the design of a system with

multiple levels of access control, can be invaluable, especially in communities where stigma toward members of key populations exists.

B. Nonbiometric UICs

Most often, nonbiometrically associated UICs are created using alphanumeric codes generated by a set of prompts. While UICs can consist of public data (such as birth name, date of birth, and national ID number), ideally, alphanumeric prompts should also include one private data element. This makes make it harder for UICs to be reassociated with an individual. Private data elements will vary by context but can include such things as left- or right-handed and birth order. The following table provides a list of commonly used prompts, with potential issues and solutions for each. This is not, however, an exhaustive list. Create other prompts when necessary for a specific situation.

Potential Issue	Suggested Solutions
Client name/initials	
Clients, especially members of key populations, may be highly uncomfortable disclosing their names for UIC creation.	While it may be best to choose a different prompt, programs can also consider encrypting UICs to further ensure client confidentiality. Ask for client initials such as the first or first two letters of given and surnames rather than the full name.
Clients might go by various names or nicknames, making it difficult to create a matching UIC each time.	Have staff check IDs or NHS cards when generating UICs. To ensure quality, data forms can even contain a check box to signal verification occurred.
In some contexts, it is not uncommon for populations to have similar first and last names or to have names that start with common letters. Thus, creating a UIC with the first initial of the clients first and last name might not be unique enough to prevent duplication.	If this is a widespread problem, a different prompt should be used. If not, proxy codes can be created for these individuals.
Date or location of birth	
In many cultures, birthdays are not commonly celebrated. In some countries, poor record keeping leads to individuals who do not know their date of birth. Therefore, the client may not be able to identify their exact date of birth or location of birth.	Rather than using the entire date of birth, have the client estimate year of birth. For location of birth, create a code to represent wider geographic areas such as provinces or counties.
Gender	
Using either M/F or coding 1=M and 2=F can be exclusive of transgender (TG) or intersex individuals.	Rather than using M/F, program can use numeric code and extend to include other numbers to represent TG or intersex individuals (1=female, 2=male, 3=TG, 4=intersex)

Phone number	
While cell phone use is becoming increasingly widespread, some clients might not have their own cell phone or might share it with another individual. For those with cell phones, it might even be common to have constantly changing numbers.	If this is a widespread problem, a different prompt should be used. If not, proxy codes can be created for these individuals.
Parents names	
In areas that have experienced intense conflict, clients might not know their parents' names.	If this is a widespread problem, a different prompt should be used. If not, proxy codes can be created for these individuals.
Clients may feel uncomfortable sharing their parents' information. Especially for key populations, clients may believe their parents disapprove of their lifestyles.	Rather than asking for entire names, prompts can specify that those generating the UIC only need the first two letters of each parent's first and/or last name.
Service provider	
While some UICs contain digits representing the unique provider where the UIC was first generated, remembering the initial site of registration may not be easy for highly mobile populations. This makes replicating a correct match difficult.	If this is a widespread problem, a different prompt should be used. If not, proxy codes can be created for these individuals.

C. Biometric UICs

From an M&E standpoint, biometrically associated UICs may be preferable. They reduce the chance of creating duplicate UICs for different individuals or multiple UICs for the same individual. However, biometric systems generally have more expensive initial costs and may not be acceptable to the local population, government, or additional stakeholders. The safety of such systems is a concern, and any biometric system must put into place robust systems and protocols to protect client confidentiality and data.

When determining whether a biometric system is feasible, consider both direct and indirect costs. Direct costs include hardware (e.g., scanners) and software, processing power, system design, modifications, upgrades, installation, data storage, and licensing. Indirect costs include IT staff training, end user education, system maintenance, security administration, connectivity and/or internet hardware costs, and any back-up power systems for settings with unreliable electricity supply.

Below are issues and solutions associated with the most commonly used biometric modes. If considering an alternative biometric, programs may need to conduct further background research.

Potential Issue	Suggested Solutions
Fingerprint scanning	
Though fingerprint scanning generally has very high accuracy,	Minimize sun glare on screens; remove debris and smudges; enroll multiple fingers to improve recognition;

difficulties can still arise in fingerprint recognition.	for individuals with poor quality fingerprints (e.g., elderly people and manual workers), proxy methods (such as other biometrics or an alphanumeric UIC) should be developed.
Small changes may occur in fingerprints over time.	Again, multiple fingerprints can be used, or participants can be prompted periodically to re-register their fingerprint.
Iris recognition	
Though iris recognition is considered to have the highest degree of accuracy, initial costs might be prohibitive.	Consider developing public-private partnerships to share initial costs. Costing out long-term savings might also encourage donors to cover initial spending.
Scans may require large amounts of memory space.	Where possible and safe, programs can utilize cloud-based storage.
Iris scanning may not be possible for some members of the population.	Proxy methods (such as other biometrics or an alphanumeric UIC) should be used for these individuals.
Facial recognition	
Currently this technique has medium-low accuracy.	Though more expensive, 3D recognition systems have much a higher degree of accuracy.

After selecting a mode for biometric registration, consider the following:

Scanner: Determine the type of scanner to purchase. For example, fingerprint scanners come in a variety of weights and sizes. While heavier models tend to be more accurate (due to a larger sensing area), programs registering individuals through outreach may need a lighter weight, more mobile model.

Data storage: Determine how and where biometrically associated data will be stored. If stored locally, how will data be pushed to a central server or cloud for analysis? If pushing to a central server or cloud, what will be done when internet connectivity is lacking? What types of security and/or encryption will be used to protect local and central databases?

Software: Choose (or create) software for the system. Software should NOT capture and store images from scans. Rather it should generate a code that cannot be worked backwards to recreate an image. For example, the NCA program in India developed their own software using Visual Basic Platform, which then operated on Windows-based laptops and desktops. In NCA's program, images were converted to American Standard Code for Information Interchange (ASCII) characters (which consisted of 16 columns of code for each finger) and stored locally. All codes were then pushed to an encrypted cloud at the end of the day or when the internet became available.

Training: Program staff will likely require additional training on the use of both system software and hardware. Training should include practice to allow staff to become familiar with the software, to practice scanning, and ultimately to increase speed. Staff may need as many as 50 to 100 trial runs to become adequately familiar with software and hardware use.

Number of scans: Programs may want to use multiple scans when registering individuals. While single scans may require less time, multiple scans improve accuracy. For example, the NCA program decided to

register clients using all 10 fingers. While it took additional time (three minutes on average compared to 45 seconds for one finger), it ensured individuals could be identified if one finger was hurt or could not be recognized due to oil or dirt. In addition, it prevented individuals from registering more than once using different fingers.

To learn more about biometric programs for key populations, see the Kenyan Sex Workers Outreach Programme Case Study in Appendix 1.

APPENDIX 1   CASE STUDIES

This appendix provides details on specific UIC programs in Central America, Denmark, Papua New Guinea, Central Asia, Kenya, and Ghana including history, issues identified during use, and achievements.

Central America Case Study

Background

In 2010, the Pan American Social Marketing Organization (PASMO) began implementing the USAID-funded Central American Combination Prevention Program for HIV. The program targeted key populations in six countries: Panama, Nicaragua, Guatemala, El Salvador, Costa Rica, and Belize. Due to security and stigma concerns, the program determined that confidentiality was necessary to ensure uptake of available services. In addition, the combination prevention program consisted of three components (behavioral, biomedical, and structural) across which the organization wanted to be able to track individuals' access to each service.[18]

UIC Code

After conducting an initial pilot in 2011, PASMO settled on a code consisting of the following components:[18]

- First two letters of surname
- Gender (where M=male and F=female or TG)
- Date of birth
- Last two digits of year of birth

(For example, Samantha Ewing born on November 23, 1988, would have the UIC: EWF2388.)

The above UIC was chosen as the information would not change over time and would thus reduce recall bias. In addition, after piloting the code, it was determined that the probability of duplication of UICs was less than 2 percent in each country.[18]

Linking Services

One goal of the program was ensuring that key population members receive the complete combination prevention package. The package required that individuals receive a minimum of (1) three behavioral change communication (BCC) interventions, (2) one referral for a biomedical service, such as sexually-transmitted infection screening, and (3) one referral to a set of complimentary structural services, such as treatment for substance abuse.[19]

To track exposure to all three components of the program, PASMO created a voucher system for referrals. A system for applied monitoring (SAM) was created and used to enter information regarding services and to track individuals (using UICs) accessing each service.[19]

Social Media

In addition to in-person BCC, PASMO also included a virtual education component for men who have sex with men (MSM) using social media. Due to stigma and discrimination, PASMO found it was difficult to reach MSM using traditional methods.[20] Using a trained peer outreach worker acting as a "cyber-

educator," PASMO provided one-on-one virtual BCC and VCT referrals. Outreach was conducted through existing chat rooms and social media websites.

Tracking of online interactions was achieved through the confidential UIC. UICs were also used to track the number of online referrals made to biomedical interventions. For example, virtual educators could generate a link for a referral voucher, which a client could then download by entering the necessary information needed to generate a UIC. A complementary website could then track (1) when/if the link was opened, (2) when/how many times the user accessed the site, and (3) whether the user downloaded the voucher.

Unfortunately, tracking the online vouchers was not as simple as the in-person issued ones, as improper training often led workers to not being able to differentiate between cyber and in-person referrals.[20]

Achievements
Between October 2012 and October 2013, PASMO reached 65,361 individuals, each of whom was given a UIC and tracked through the PASMO program.[18] With the help of the UIC, it was determined that 8,674 individuals received all three components of the combination prevention program.[18] In 2013, 7,219 UICs were created through the cyber BCC education program.[20] In Nicaragua, this helped the program not only reach its goal of 1,300 individuals, but to double its reach to 2,647 MSM.

Success was due, in part, to extensive training among partners on use of tools (such as the vouchers) and implementation. Trainers also emphasized the importance of the UIC in tracking activities, individuals, and in ensuring quality. PASMO also helped organizations develop plans to ensure services met minimum quality standards and then provided ongoing supervision and support.[18] Ultimately, quality assurance was achieved through the use of quality control reporting forms. While quality control was more complicated under the virtual BCC intervention, supervision was conducted using the three principles of observation, confirmation, and verification.[21] In addition, investment in SAM created a strong system for use. Following on PASMO's success, other partners in the region have begun to adopt the UIC system.[18]

Denmark Case Study

Background
In 1968, Denmark began using unique identification numbers to collect population data and maintain the national register, known as the Danish Civil Registration System (CRS). In addition to capturing an individual's unique identification number, the CRS also records information on the individual's name, gender, date of birth, location of birth, residence, citizenship, migration in and out of Denmark, regularly updated vital status, unique identification number of parents and spouses, and 150 additional variables. Since 1989, information in the CRS has been updated on a daily basis.[22]

UIC
The Danish UIC, known as a Centrale Person Register (CPR) number, consists of 10 digits. It is comprised of the following:[22]

- Date of birth
- Month of birth
- Last two digits in year of birth

- Three digits providing information on century of birth (created as a serial number to distinguish between individuals born on the same day)
- Final digit where odd indicates male and even indicates female

(For example, a male born on May 3, 1962, may have a CPR of 030562-4287.)

Individuals emigrating and re-entering the country retain the same CPR number, and only under rare occasions are individuals issued new numbers. Such instances include errors in the CPR-number (e.g., wrong date of birth) or sex-reassignment surgery. In these cases, new numbers are assigned, but the CRS keeps track of the previous CPR.[23]

The CPR number is considered to have high validity as individuals use the number on an almost daily basis.[24] In addition, the government uses the CPR for tax purposes, further encouraging residents to ensure that their CPR is valid and their information up-to-date.

Privacy Controls and Acceptability
In general, the CRS and CPR number have been well accepted among Danish residents,[23] of which several issues play a role. First, Denmark has a history of data collection and registration. The first Danish census was conducted in 1769, and the first registration occurred in 1924. From 1924 until the CRS system was initiated, residents registered their information manually on index cards, which was then updated regularly by the local municipality registration offices. Second, there is no history of misuse of CRS information. Lastly, Danish residents in general express confidence in their authorities.[23-25]

In Denmark, personal data is protected against abuse under the Danish Act on Processing Personal Data.[25] In order to gain access to the register or database data, researchers must receive approval from the Danish Data Protection Agency, and if relevant, the National Committee on Research Ethics.[25] Currently, only researchers living in Denmark or those affiliated with a Danish institution can gain access to individual level data.[24] The Data Protection Agency also sets safety standards for the use of data.[25]

Using CPR and Register Data in Research
The CPR allows linkage of individual level data across different registries including the Population's Education Register, in which it is estimated that education information is available for 97 percent of individuals born after 1945.[24] Other registries include the Income Statistics Register and a myriad of health registries such as the National Prescription Database, the Danish National Patient Registry, and the Pathology Database.[24,25] Though public health care is free to all Danish residents, some services have delayed waiting times, and residents opt for private treatment. However, since 2003, even private providers are required to report patient information to the National Patient Register.[24]

While national registries were originally established for administrative purposes, they have since been made available for research. In addition, clinical databases have been created and maintained by research units of hospitals to help monitor the quality of patient care.[24] In contrast to registers, clinical databases usually focus on specific diseases and contain further information regarding diagnostic evaluations, treatments, and outcomes.[24]

Besides being able to link data across registers, the CPR and CRS also ensure studies are representative of the entire population with no loss to follow-up and full longitudinal data.[24] Access to large sample sizes and complete data also allows for investigation of rare events. Unfortunately, a primary care

diagnostic database still does not exist, and those being treated solely at primary care facilities do not have data readily available on their diagnosis or treatment.[24]

Papua New Guinea Case Study

History

The Tingim Laip Project (TL2), under the direction of the Papua New Guinea (PNG) National AIDS Council, was implemented from September 2010 to June 2015. Funded by DFAT Australian Aid and managed by Cardno Emerging Markets and APMGlobal Health, TL2 was the second phase of the original Tingim Laip Project. TL2 focused on reducing HIV transmission and infection among key populations, mainly SWs, MSM, people living with HIV/AIDS (PLWHA), and mobile men with money. The project operated in more than 20 locations in 10 provinces.[26]

UIC Development

In 2013, partners determined the need for a UIC for key populations. The UIC could protect the identities of key population members while also providing stakeholders with valuable project information. In order to develop the unique code, partners conducted an initial literature review on international experiences and best practices.[27] In addition, the team consulted with APMGlobal, which had a wealth of experience in the creation of UIC systems.

The goal was to create a UIC that adhered to the following standards:[27]

- Client generated
- Nonidentifying
- Unique (less than 2 percent risk of duplication)
- Alphanumeric
- Simple/easy recall
- Immutable over time
- Can be created or recalled using simple prompts
- Does not have prompts that would alienate or offend clients
- Allows for mobility (not location specific)

The following prompts thus chosen:

- Last two letters of last name at birth
- First two letters of district of birth
- Right- or left-handed (R or L)
- Order of birth
- Gender (1=M, 2=F, 3=TG)
- Last two letters of first name at birth

(For example, a female who was born with the name Sandra Gold in Gumine District, was the third child born, is right-handed, would have a code of LDGUR032RA.)

The UIC was then piloted among 128 staff, volunteers, and clients in six project locations. Participants found the prompts to be acceptable, and 83 percent reported preferring using the UIC to their name.[27]

Following the pilot, tools and databases were developed to track the UICs, and initial rollout of training and tools to all sites was completed by mid-2014. Rollout of the UIC system was achieved through three-day trainings, in which staff were introduced to the new reporting tools and participated in role play practice sessions.[27]

Referrals

To link individuals' information across services, TL2 created referral cards utilizing UICs. On the front of the cards, referring volunteers could enter the client's UIC along with their own unique code. On the back of the card, spaces were printed for providers to enter the client's age, sex, and date of visit. The provider could also denote the type of service received and whether it was the client's first or repeat visit.

Each month, someone from one of the referring partner service organizations would visit each provider and collect the referral cards. The program found that this was a good opportunity for partners and providers to meet one another and discuss the strengths and weaknesses of the referral process.[27] In addition, they shared data to strengthen the partnership.

Challenges

After six months of UIC system implementation, a follow-up survey revealed several challenges. While the UIC duplication rate was below the 2 percent standard, only 60 percent of those registered provided the same UIC each time they accessed services. This rate varied greatly across sites, with some showing 88 percent matching and others as low as 38 percent.[27] This emphasizes the importance of ensuring volunteers ask the prompts the same way each time and in a clear, easily understandable manner.

Overall, the program also had difficulty recruiting senior-level staff for M&E positions, as few individuals had previous experience working with UICs. This was compounded by the fact that changing the M&E system half way through the project made whole-project reporting difficult.[27] Reporting and collection differed under each system, with the original system reporting total contact numbers and the new system number of contacts per individual.

Program Successes

Regardless of challenges, by the close of the project in 2015, approximately 3,500 key population members had been registered using an UIC. The use of UICs allowed the program to report on the number of key population individuals contacted in a given period, as well as frequency of contact, type of contact, number of condoms received, and number of service referrals. This individualized data allowed the program to set targets and track progress against them. For example, staff found that in periods of increased initial registration, frequency of contact with those already registered decreased. They responded to this by increasing activities among existing clients after initial periods of registration and then expand time between further registrations. By the final quarter of 2014, this resulted in individuals being reached six times on average, which was higher than any other quarter.[27]

TL2 representatives have continued to share findings from the UIC system, sitting on the national strategic information working group. Here they have advocated for the rollout of a national system.[27]

Central Asia Case Study

Background

In 2001, Population Services International (PSI), with funding from USAID, began leading an HIV prevention program for PWID, SWs, and vulnerable youth in Kazakhstan, Kyrgyzstan, Tajikistan, and Uzbekistan. At the time, Eastern Europe/Central Asia had one of the fastest growing epidemics in the world with a 20-fold increase in the number of PLWHA. At least 70 percent of those were PWID, due in part to opiates being regularly trafficked from Afghanistan through the region, and drugs being readily available.[28]

Many of the regions' health systems also required patients to register for services by name, making it hard to attract clients from key populations. Thus, PSI set out to create an M&E system that would provide quality data while also protecting the confidentiality of clients. In 2004, in collaboration with Ekspert Fikri, PSI piloted an initial UIC system at the PSI Youth Power Center in Tashkent City.[29]

Pilot Program

After conducting reviews of existing codes in NSEP programs, PSI developed an initial UIC consisting of the following characteristics:[28]

- First two letters of mother's first name
- First two letters of father's first name
- Gender (1 for male, 2 for female)
- Last two digits of year of birth

(For example, a female who was born in 1965 with a mother named Susan and a father named Peter would have a code of SuPe265.)

Mathematical modelling determined that the likelihood of UIC code duplication was below 2 percent, which was considered acceptable.[28]

To track the new UICs, PSI also developed a simple Microsoft Access-based system. When a client completed one educational component of the prevention program, a UIC was assigned and the code entered into the new database. The database was set up to automatically create reports about client coverage. While the initial program goal was to reach 60 percent or more of youth at each site, behavioral surveys found that even when meeting these goals, behavior change was not occurring. Therefore, the database was updated to produce frequency of contact reports, making it simple for coordinators to track progress toward both coverage and frequency service targets.

Scale-up

One major success of the UIC in Central Asia was the extent to which the system was adopted and scaled up across the region. After the initial pilot, the UIC system was progressively adopted by additional PSI sites, partners in the Drug Demand Reduction Program (DDRP), and other groups working in HIV prevention. The government of Tajikistan even tested the use of UICs in one province before scaling up national use in 2007.[28]

Lessons Learned

Pre-project planning and the engagement of local social research companies was essential to the success of the UIC system. As local conditions varied greatly both within and across countries, social

research groups Panorama (Tajikistan and Kyrgystan) and Ekspert Fikri (Uzbekistan) were engaged in formative research and preparatory work.[29]

In countries where both Cyrillic and Latin script are used, partners determined that the ultimate database needed to be used with characters from both. Programs also needed to consider appropriate language on UIC registration forms. While Russian is the common language across Central Asia, many individuals in key population groups did not speak Russian. Thus, forms needed to be translated in multiple languages for different target groups.

Issues for UIC creation were also considered. While the final UIC included the letters from parents' names, conflict and migration meant that many members of key populations did not know these details. A proxy code was created for these individuals. While the majority had less than a 1.5 percent chance of sharing the same UIC, Afghan migrant populations, due to patronymic naming systems and polygamous marriage, were more likely to have UIC duplicates. Partners also developed a proxy code for these individuals.

Ghana Case Study

History
A UIC was used under FHI 360-Ghana's bilateral project SHARPER from 2009 to 2014. The code was used to prevent duplication in data in their prevention services for key populations while improving anonymity of data. The code consisted of the following components:

- Male (1)/Female (2)
- Last two digits of year of birth
- Initials of first and last name
- Last two digits of phone number

(For example, Ben Eveslage born in 1990 with phone number +12488948970, would have the following UIC: 190BE70.)

Limitations
The main limitation for SHARPER's UIC was its use of phone numbers, which in Ghana change commonly or people have more than one. Key population members who did not have a phone used their friend's phone number. This meant that records for key population members who could not remember their UIC could not be updated with services offered to them, or they would be entered twice (but with different UICs). The code was not unique and produced duplicates because the components were quite common (e.g., initials).

Larger Context under LINKAGES
The use of a UIC has taken on larger importance for LINKAGES globally because of the need to collect data across NGOs and government health services, which assume varied roles along the cascade of HIV services. Further, within Ghana, the Ghana Health Service (GHS) has prioritized the discussion of using a UIC or e-tracker to be able to streamline and synchronize patient records across GHS facilities. Since LINKAGES will need to develop their own UICs in various country contexts, the GHS is willing to consider and adopt the UIC system developed under LINKAGES-Ghana.

Due to the larger relevance and implications of the UIC developed for LINKAGES-Ghana, some additional limitations and concerns were discussed during an interagency trip in May 2015 to prepare for the key population implementation science (KEY POPULATIONIS) study of LINKAGES interventions in Ghana. These concerns included the large number of key population members who would be registered using UICs not only within LINKAGES, but also more broadly in Ghana.[9] This implied that the code should contain enough highly unique components to prevent duplications. Further, some MSM were known to provide fake names or unique nicknames for use with other MSM and therefore would not match with UICs generated at GHS. In Ghana, stigma and discrimination are high, and MSM (and other key population members) prefer to remain anonymous or discreet, which has implications for M&E data collection. It was discussed that providers offering the "reach" package of services should ask about UIC information at the end of the visit to give more time to build trust and increase the probability of obtaining accurate information.[3] Further, it was suggested that provider data forms should include a column next to each UIC with a check mark box to indicate whether a UIC has been verified by showing the provider an identity card or GHS card. This system would allow GHS nurses to also verify any un-verified UICs. Further, a script would need to be created for providers (and nurses) to use when collecting UIC information from key population members to describe why the information is needed and to assure them that full identifying information is not necessary, only the components necessary to construct a UIC (e.g., only initials, not full name).

LINKAGES-Ghana UIC
The LINKAGES-Ghana team and interagency trip members have defined a revised UIC for use under LINKAGES. Below are the components:

- Male (1) or female (2)
- Year of birth (last two digits)
- Date of birth
- First two letters of first and last name
- Hyphen and then NGO code

(For example, Ben Eveslage born on date 24 in 1990 being referred by WAPCAS would have the UIC 19024BeEv-WAP.)

In Ghana, the UIC system that will be used by LINKAGES activities in is one that remains possible for individuals who are familiar to key populations and key populations living with HIV (KPLHIV) with a UIC to decipher their code themselves and access their outcomes along the continuum of HIV services (notably their HIV status). While this aspect will allow linking records over space and time, this insecure aspect of the UIC highlights the importance of having close relationships between nurses and KPLHIV to prevent persons fraudulently impersonating someone else and their UIC to gain access to sensitive information. This also denotes the importance of limiting access to UIC-linked data on KPLHIV care and support and treatment services to only M&E officers at the NGO-level.

Kenya Case Study

Background
In 1980, the University of Manitoba and the University of Nairobi began collaborating on an innovative research program involving the study of sexually transmitted infections (STIs). Recognizing the need to

include key populations in their HIV prevention work, they also concentrated efforts on reaching FSWs with peer education and counseling. In August 2008, this initiative expanded to the establishment of a Sex Workers Outreach Programme (SWOP) care and treatment clinic. SWOP has grown to include11 full-service clinics (with seven sites specific to FSWs and one specific to PWID). An estimated 30,000 FSWs (about 60 percent of the FSW population in Nairobi County) and 2,500 MSWs are receiving services through SWOP. Though MSM are a relatively new population for SWOP, approximately 935 are currently enrolled in services, of whom 735 (81 percent) have enrolled using the biometric system (as of Sept. 30, 2015).

Because SWOP's populations are highly mobile, often change their names, and would previously share clinic ID cards, the program began piloting a biometrically associated UIC in 2010 using fingerprint identification to track clients.

Community Engagement
Recognizing the need for community buy-in, the program has been proactive in engaging key population community representatives since the pilot. One key component was gaining support from peer-educators. Since peer educators are used by SWOP as gatekeepers to the community, 300 were sensitized on the use of the biometric UIC, system advantages, and ensured that the fingerprint scans would not be used to gain access to personal information. In addition, staff began using biometrics to encourage clients to register as well.

Acceptability
By using a biometrically associated UIC (through fingerprint scanning), clients can attend any of the SWOP clinics and have their records easily accessible. Due in part to the confidential nature of the UIC and this potential for mobility, the UIC has had a high level of acceptance among FSWs. While initially some clients were concerned that the fingerprints would be used to access bank accounts or turned over to the police, sensitization activities and ongoing enrollment have led to approximately 71 percent registering a UIC (though registration varies across clinics with one clinic having a registration rate of only 30 percent). In addition, refusal rate is currently only 10 percent. Those refusing the biometric UIC are captured with ID numbers and should they choose to register with a UIC later, they can be linked through the ID.

The biometric UIC is also still linked to a name and a clinic ID for ease of service delivery in the absence of biometric registration. Depending on the access level, name and other personal information can be blinded to the service provider who would be able to retrieve medical and other records using only the biometric identification.

Functionality
The program was designed so that the actual patient fingerprint would not need to be stored. Rather, a binary code is created from the scan and then encrypted. To store the UICs, the program used an open-source software to create a customized UIC database. An open-source platform, rather than a

proprietary system, was chosen since it was not only more affordable but also allows a quicker search of existing records. When registering an individual with fingerprint, the health care worker can search through the database in only three minutes to see if the associated UIC already exists. So far, the program has experienced a failure rate of less than 1 percent.

The UIC database is updated once daily using point-to-point connections between the clinics on a virtual private network. Each facility also keeps its own master database. Due to connectivity issues, the UIC application is also installed on laptops that can be used for fingerprint verification when power or internet is unavailable. Once power and internet are restored, the stored UIC and dataset are matched with any existing data.

As a backup and due to fluctuating electricity and blackouts, paper records are also maintained with the main file held at the initial facility of enrollment. In the event of a client attending another clinic, only details of that particular visit are captured at the visiting clinic. This paper record is transferred to the mother clinic or maintained at the visiting clinic. Clients are encouraged to make ARV treatment and care quarterly visits at the clinic of registration while they can access services such as condom pickups, post-exposure prophylaxis (PEP), and STI screening at any facility. This data is later synchronized and updated across all clinics for future reference and retrieval.

Outreach
SWOP is also beginning to use the biometric UIC in outreach activities. The goal is to reach and register members of key populations with UICs where they are. For outreach activities, laptops (rather than mobile devices) will be used so that staff can continue to search existing records to avoid double registration. The laptop is already preloaded with skeleton up-to-date encrypted biometric and client enrollment data to reduce the turnaround time and increase efficiency. Upon connection to the network, the data is synchronized to the master and shared across the network. Ultimately, program implementers hope to use outreach to identify KPs in each of four categories (1) already enrolled with the biometric UIC and active in prevention, care, and treatment; (2) already enrolled with the biometric UIC and not active in prevention, care, and treatment; (3) enrolled, but not with a biometric UIC, and active in prevention, care, and treatment; and (4) not enrolled and not active.

Success
The biometric UIC has been largely successful in the SWOP program. Clients appreciate the confidentiality allowed by the UIC and the ability to access records easily at multiple clinics. For SWOP, the UIC allows the program to view patients' records both prospectively and retrospectively. The use of the fingerprint has also simplified data cleaning, as it is easy to track multiple registrations. SWOP can also use the data to generate an HIV prevention, care, and treatment cascade and identify HIV prevalence and retention rates.

Appendix 2 Additional resources

HIV Cascade

> *HIV Cascade Framework for Key Populations*
> USAID, PEPFAR, LINKAGES, FHI360, 2015

Legal Environment Assessment

> *Legal Environment Assessment for HIV*
> United Nations Development Programme, 2014

> *Patient Privacy in a Mobile World: A Framework to Address Privacy Law Issues in Mobile Health*
> TrustLaw, mHealth Alliance, Baker & McKenzie, Merck, 2013

Monitoring and Evaluation

> *Operational Guidelines for Monitoring and Evaluation of HIV Programmes for Sex Workers, Men Who Have Sex with Men, and Transgender People: Volume I for National and Sub-National Levels*
> MEASURE Evaluation, 2013

> *Operational Guidelines for Monitoring and Evaluation of HIV Programmes for Sex Workers, Men Who Have Sex with Men, and Transgender People: Volume II for Service Providers*
> MEASURE Evaluation, 2013

> *Referral Systems Assessment and Monitoring Toolkit*
> MEASURE Evaluation, 2013

Conducting Stakeholder Outreach

> *Tools for Data Demand and Use in the Health Sector: Stakeholder Engagement Tool*
> MEASURE Evaluation, 2011

> *Tools for Steering Committees*
> Collective Impact Forum, 2013

Data Safety and Security

> *Guidelines on Protecting the Confidentiality and Security of HIV Information: Proceedings from a Workshop, 15-17 May 2006*
> UNAIDS, 2007

> *Data Security and Confidentiality Guidelines for HIV, Viral Hepatitis, Sexually Transmitted Disease, and Tuberculosis Programs: Standards to Facilitate Sharing and Use of Surveillance Data for Public Health Action*
> CDC, 2011

Additional Resources on Health Identifiers

> *Considerations and Guidance for Countries Adopting National Health Identifiers*
> UNAIDS, 2014

Developing and Using Individual Identifiers for the Provision of Health Services including HIV: Proceedings from a Workshop, 24-26 February 2009
UNAIDS, 2009

Unique Identifier Code: DDRP Best Practice Collection
Alliance for Open Society, 2007

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