UNIQUE IDENTIFIER CODE FOR KP: ANONYMITY, PRECISION AND MOBILITY

"A desire for privacy does not imply shameful secrets" -- **Nick Harkaway, author.**

I. Importance of the UIC system

Research has repeatedly shown that Key Populations (KP) are fearful of using HIV-related health services because disclosure of their identities would increase social stigma, including rejection by their families.

Soon after it began, PACTE-VIH noticed that individuals from stigmatized groups saw lack of confidentiality in the provision of health services as a barrier for them to access the services and adhere to treatment subsequently. Key Populations try hard to keep their identity secret but there was no system to ensure anonymity and confidentiality. In 2013, PACTE-VIH started the process of developing the Unique Identifier Code (UIC) system in Togo and Burkina Faso.

The utility of UIC for KP stems from its simplicity, anonymity of client registration and precision in tracking service usage. It also addresses the programming and management needs of PACTE-VIH, while maintaining anonymity of KP receiving services and monitoring coverage of each KP. The individual KP can move freely because the code remains unchanged and allows access in any location regardless of the service provider.

The UIC system is now a central tool of PACTE-VIH's commitment to targeted interventions that are evidence-based, adaptable, replicable and transferrable across the West African region. It helps to consolidate gains made since the five-year PACTE-VIH project (2012-2017) was established to provide support for the HIV prevention efforts of government in Togo, Burkina Faso, and other West African countries.

PACTE-VIH addresses critical gaps in KP programming by strategically targeting interventions that build political will and resources to engage key stakeholders. The UIC system makes it easier for PACTE-VIH interventions to bring dignity and protection to KP who often feel defenseless and isolated in the face of prejudice and violence against them.

The governments of Burkina Faso and Togo have adopted the UIC system and want to implement it in all interventions targeting KP. It has been progressively adopted by all PACTE-VIH implementing partners.
However, PACTE-VIH does not rely on the UIC alone to protect the anonymity of KP. It is supplemented by other support measures, including advocacy with local police, media and government officials; confidential entry to health service centers; care with signage; and location of KP services separate from public dispensaries.

A UIC system is important because it protects anonymity even if patient-health care provider confidentiality is breached. Loss of anonymity can lead not only to prejudice-related violence but also harassment and arrest by the police. Hence, KP are very apprehensive about collection and storage of data that might identify them.

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II. Components of the UIC used in Togo and Burkina Faso

The UIC provides key data about the client, including age and gender, without including any information that could be easily used to identify that person. When a KP visits a health service provider, the request made is, "Without saying your name, please provide me the first letter of your last name". This discreet method builds trust and encourages the client to share information. At the first visit, the individual KP is given a UIC card for use at all subsequent consultations. The characteristics of the code are: Culturally acceptable, anonymous, confidential, easy to replicate, easy to obtain; decreasing likelihood of recall bias and is immutable over time.

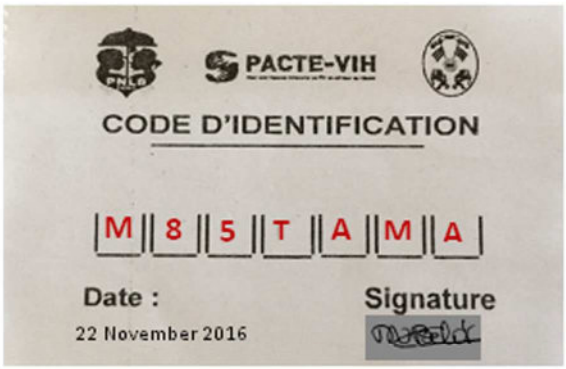
PACTE-VIH implementing partners in Togo and Burkina Faso report no duplication of the code or other significant problems.

The UIC is a 7-digit code composed of:

- Gender (M or F)
- Last two digits of the year of birth
- First letter of the last name
- First letter of the first name
- First two letters of mother´s first name

Example: Mr. Traoré Ali, born in 1985, whose mother's name is Mariam

Gender	Year of birth	Last name	First name	Mother's name
M= Male F= Female	Last two letters of the year of birth.	The first letter of the last name	The first letter of the first name	The first two letters of the mother's name



This Unique Identifier Code coupon is given to the individual KP at the first visit

III. How PACTE-VIH partners motivate a beneficiary

The starting point is to build trust between the health care provider or PE and the beneficiary for the setting up the UIC.
Then,
• Clearly explain the reasons and use of a UIC to the client.
• Explain that the UIC is totally anonymous and that no one will be able to identify him/her.
• The health service provider or PE illustrates the code by using his/her own personal information. Thus, the client immediately sees that it is impossible to identify a person with the code.
• If a client does not remember the mother's first name, her nickname name is used (e.g. Chouchou = CH).
• If a client does not know his year of birth, his approximate age is used to establish it.
• If the client lacks clarity because of mental impairment or drug use, evidence from a friend is used to create the UIC.
• Explain to the client that the UIC must be kept secret to avoid identity theft. A personal code is like a fingerprint.
• Explain that the UIC is used to provide effective monitoring of all activities and services used by the KP.
• Explain that the codes are kept confidential in the organization but could be shared with other implementing partners.
• Ask if the client has other questions.

IV. The UIC system provides more than anonymity

The UIC system offers several vital advantages:

It ensures the necessary anonymity for KP to use health services provided by governments and others, without fear of being identified by persons in their neighborhoods who would do them harm.

For the first time, it allows data about each person with a UIC card to become mobile. The person can change health services without loss of continuity because the UIC identity allows any authorized health service provider to access all relevant data.

Also for the first time, the UIC system establishes a reliable and accurate database of usage statistics to monitor and evaluate the services used by KP and the performance of health services.

Importantly, the system permits precise monitoring of service use at each center.

It meets the needs of both donors and KP. It helps to improve efficacy by anonymously recording who are the users, what services they use, how they adhere to treatment, and how regularly they visit the health centers. At the same time, the data helps governments and donors to assess outcomes while keeping an eye on quality and costs.

The UIC's logic is easy to remember and even a less educated recipient can reconstitute it without help. At the first visit, the individual KP receives a small card with the code, which can be replaced if lost.

V. PACTE-VIH strategy emphasizes training and KP participation

The UIC component of PACTE-VIH strategy focuses on establishing trust by offering anonymity to each KP to encourage use of health services and better monitor coverage. The value added by the UIC system derives from the rigorous scientific studies that underpin the code's simplicity.

A simple seven-digit alphanumeric system comprises the UIC. It registers each client anonymously and generates the necessary data for tracking service usage. The UIC uses a structure that contains key data, including age and gender, without including any information that could identify the person by name.

Thus, the potentials for discrimination and related violence are eliminated.

Any system is only as good as its implementation. So, PACTE-VIH strongly emphasizes training for service providers to implement the UIC correctly and preclude information leaks that might cause jeopardy for KP who use the services. The UIC system helps to address two broad challenges faced by PACTE-VIH interventions.

• How to assess the effectiveness of health service interventions.
• How to monitor usage of services by KP clients.

From the start, the PACTE-VIH strategy has focused on thorough planning and preparation of the UIC system to lay the groundwork for successful implementation. Below are some of the strategic considerations:

• It developed performance indicators before starting the system's implementation.
• The UIC data collection was guided by appropriate user manuals.
• Staff providing services to clients were trained before starting work with clients, including peer educators and mediators.
• Staff training was repeated as needed to reemphasize the importance of the anonymity conferred by the UIC.
• Managers were given initial and follow-up training in UIC and supervision of staff involved in providing client services.
• Special attention was paid to developing methods to verify the quality of UIC data collection.

At a broader level, PACTE-VIH and its partners provide support for the UIC system with regular workshops to educate KP about HIV-related risks and train them for leadership in forming alliances with the media and police against KP-related stigma and violence.

VI. The UIC system's strengths

The UIC system has a strong evidence base supported by HIV surveillance literature. Rigorous scientific studies compared the effectiveness of names-based registration with anonymous UIC systems for attracting marginalized KP, especially MSM, for HIV testing during the 1990s.

Some U.S. states started implementing a system of HIV case reporting using UIC because of concerns that breaches in confidentiality, stigma and discrimination were deterring some individuals from being tested for HIV. There was evidence that names-based reporting was acting as a deterrent.

The UIC system involved creation of a code number used for reporting instead of an individual's name. The code was found to be unique enough to avoid duplicate records if all its elements were complete and accurate. It also facilitated gathering of follow-up information. Each code number was based on information specific to that individual.

UIC received support from U.S. Centers for Disease Control and Prevention (CDC), which recommends adherence to anonymous testing options and strict confidentiality of testing and surveillance data.

Successful research studying cross-border movement in China and Vietnam provided further validation of UIC systems.

Below are some strengths of the UIC system:

• The UIC is easy to remember. The KP client can recall the information easily and the prompt question from the service provider is always the same, regardless of which worker has direct contact with the client.
• The UIC is safe because it does not contain information that could identify the individual, e.g. name, date of birth or place of residence.
• Donors obtain accurate information for monitoring and evaluation, including regular inputs for management decision-making, monitoring activities and client numbers, and progress towards project objectives.
• KP clients need not fear using HIV prevention services because anonymity ensures that family, friends, coworkers or police cannot learn about them.
• Service providers receive more opportunities to measure how KP use various services and improve the linkages among services.

• Data from the UIC system also provides indications of trends in the pathways of service utilization. That could help to improve client referrals and coordination of service providers.
• The UIC system provides robust inputs towards achieving global goals like the 90-90-90 initiative of UNAIDS and the cascade framework of continuum of prevention, care and treatment (CoPCT) for KP, which underline the routes to healthy living with HIV and preventing new infections.
• The UIC system can help to improve cross-referral among service providers, thus giving individual KP greater access and choice. Elimination of stigma and discrimination against KP can be supported by risk behavior reduction and HIV prevention behavior within the cascade. A key population person can access a service provider to receive appropriate help and then move to other referral services with advice from the staff.
• Decision makers can use UIC data to assess performance, e.g. the percentage of KP using a service provider within a defined locality over a defined period. That can also help to improve services in response to emerging needs.

VII. Comments of KP, health care staff, counsellors and PE in Lomé in November 2016

"Now, I can say that the UIC is my most reliable friend. I feel reassured about visiting a health care services because I know that my identity will not be disclosed to anyone." – a FSW in Lomé.

"As MSM, we are happy that we now have access to health care services without disclosing our identities. My friends and I do not hesitate any longer to seek treatment if we have an STI. The UIC is a real protection." – MSM in

"The UIC and anonymity are real blessings. I am fully safe when I visit the health center because I do not have to disclose my name." – a FSW in

"I do not hesitate for a second to visit a health care services if I think I might have a STI because I feel protected with my secret code." – MSM in

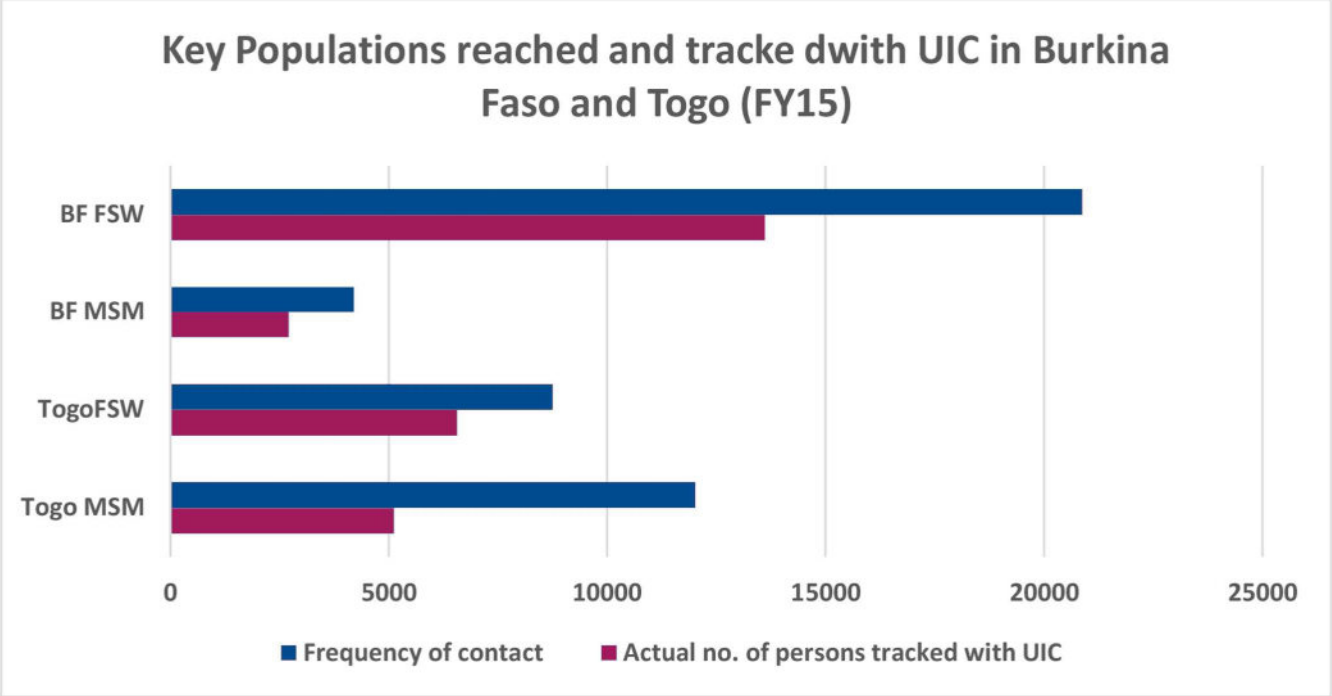
"The UIC is composed to information that is very easy to remember." – MSM in Lomé.

"It is not difficult to compose a UIC because it is very easy for people to give the necessary information." – a staff at Famme Drop-in Center (DIC) in Lomé.

"My HIV status will never be disclosed to anyone as my identity is totally protected with my personal code" – MSM in

VIII. Comments of KP, health care staff, counsellors and PE in Lomé in November 2016

The UIC system is an effective tool for keeping track of KP users of health services. Below is a basic presentation of numbers of contacts and number of people reached but information gathered can also be analyzed in other ways.



KP registered with the UIC system can be accurately tracked as they move through the eight-step cascade (CoPCT) from the needs to: identify the KP; reach the KP; perform a test; diagnose persons living with HIV (PLHIV); enroll in care; initiate antiretroviral therapy (ART); sustain on ART; and suppress viral loads.

• The UIC also allows analysis of adherence to treatment and follow up, including behavioral change counselling. Thus, the KP benefits not only from anonymity but a full range of services necessary for protection of human rights, especially the right to health.

• Data about each KP's commitment to treatment and regularity of visits to health services regardless of location allows program managers to improve efficacy of all elements of care provided to clients. It also helps to identify barriers to effectiveness and improve referrals to other relevant services.

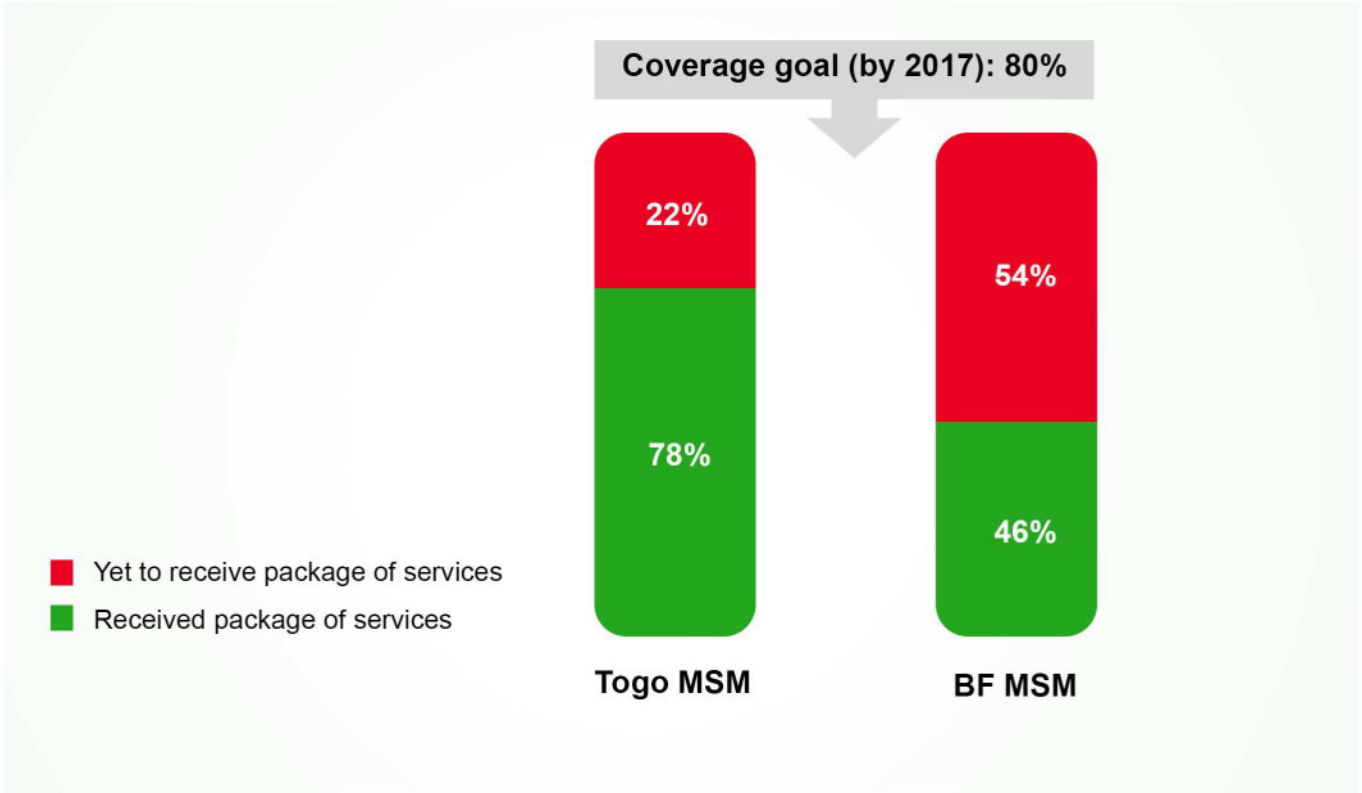
• The UIC´s active feedback monitors short-term progress towards longer term goals. Together with behavioral surveys, feedback from the UIC system helps program managers to quickly remedy weaknesses in program design and service delivery. It also helps to motivate staff to improve performance.

• The UIC system offers government service providers with a better alternative for managing confidential personal information. Government sector managers are provided with a tool that is easy to remember, meets client demands for confidentiality, and enhances government data collection and surveillance capacity.

• It also enables the government to fulfill its duty to protect KP human rights to privacy and access to health care.

Package of services offered by PACTE-VIH to KP are essentially related to: prevention, treatment & support, psycho social support and other specific services such as: peer education sessions, drop-in centers or KP adapted services, family planning, BCC activities etc.

Proportion of MSM who have received PACTE-VIH package of services at project sites (FY15)



IX. UIC and current KP-related surveillance in Togo and Burkina Faso

Below are some elements that can be obtained with the UIC-related data base system of PACTE-VIH (adaptation of Microsoft Access data base software)

Please see the annexes of some screen shots (In French):

- Number of HIV tests performed.
- Number of HIV positive and HIV negative persons.
- Number of pretest and posttest counselling sessions conducted.
- Number of KP screened for an STI.
- Number of persons referred to a specific service (example: Referral for a suspected STI or TB etc.).
- Number of people who accessed referral services and received treatment.
- Number of KP HIV+ receiving ART.
- Stocks of materials, ARV medicines needed in DIC or other health care centers.
- Number of KP participating in various prevention activities.
- Activities of Peer Educators (PE) and Mediators.
- Number of male condoms, female condoms, and lubricants distributed to KP.
- Number of leaflets, brochures or other IEC materials distributed to KP.
- Stocks of materials needed by PE.
- Monitoring of staff (field officers) so that supervisors of PE might easily follow up on their activities.
- Reports can rapidly be generated within the selected period (monthly, and by project). This helps tracking of KP as they move through the continuum of prevention, treatment and care services (CoPCT)

X. Some elements emerging from UIC-related data

Important elements emerging from the UIC-related data include the needs to keep trust with clients and show understanding when low literacy levels become a problem. Other elements include:

- The importance of training staff in using the UIC. It is important to note that the turnover of medical providers, PE etc. require new training sessions.
- The importance of maintaining the data base in perfect working order.
- Motivating engagement of KP in outreach activities so that their friends can also have the benefits of the UIC system.
- Promoting project partnerships and advocacy at the regional level.

XI. Replicating the PACTE-VIH model of a UIC system focused on KP

The PACTE-VIH experience offers some pointers for scaling up in the region and replication in other locations. It could serve three purposes:

1. Provide a broad protocol for others seeking to establish UIC systems, including how to motivate KP to access health services and
2. Capture the best practices observed so far, which might help to guide others in the region.
3. Demonstrate the utility of UIC as an instrument that facilitates cooperation among all partners and stakeholders involved with KP concerns.

Below are some steps for a UIC system based on the PACTE-VIH experience:

Step 1:

Careful planning before starting a UIC system.

- Ensuring anonymity is the foundation of a UIC system for KP, who suffer daily from prejudice and violence because of the social stigma and adverse reactions of their communities, friends and families.
- This is particularly important in health service locations outside national capitals and large urban centers. Discrimination and marginalization are often more virulent in more parochial communities.
- All UIC registration forms should be in a language or languages spoken and understood by KP. Often FSW come from poorer backgrounds and may not have much education. MSM are often better educated and more self-confident persons.

• Age, ethnicity and migration can affect patterns of language use and literacy. For example, cities may have younger and more educated MSM alongside almost illiterate unskilled migrants from rural areas. The official government language needs to be balanced against the sensitivities of KP who use other languages.

• This may mean planning for appropriate staff and materials available in more than one language. Younger MSM from rural areas might also fall into at-risk but low-literacy groups.

• Sometimes a KP seeking health services may not know his/her exact year of birth or the mother's name. Persons dislocated by war and refugees sometimes do not have all the details required for the UIC. In such cases, the health worker should ensure that the KP memories which ever birth year and mother's name are used for the UIC registration card.

Step 2:

Preparations for service delivery

• Once KP are convinced of the UIC system's anonymity, they tend to cooperate with health service staff, peer educators and mediators. But this trust must be maintained by continuing to ensure confidentiality.

• The UIC is just one component albeit a major one of a series of measures to ensure anonymity. Other measures include avoiding entry points or signage and labels that might disclose the client's status as MSM or FSW even when the identity is kept confidential. Regular advocacy with local police, government officials and media are also helpful.

• Everyone involved in service delivery, including stakeholders and partners, should be appropriately briefed and trained to use a UIC system. They should also understand that a KP deserves care because of not only public health and HIV prevention imperatives endorsed by the government but also human rights, including the right to health and equal treatment with other citizens guaranteed by the national Constitution. These are particularly important in smaller towns because local communities are more tightly knit and prejudices may be sharper.

• Central emphasis is required on maintaining accurate UIC records and regular updates. Service delivery, monitoring and evaluation are parts of the same flow and program planning should try to promote their integration.

• All partners and stake holders should receive capacity-building training regularly on how to get the most out of a UIC system. That would ensure that everyone works from the same page and avoids duplication of efforts or wastage of resources.

• Sometimes, KP are reluctant to engage with outreach workers in locations outside the health services center if they look too official, e.g. they are carrying too many papers, ticking off boxes etc. The less literate may also feel intimidated and avoid asking for help.

Step 3:

Training to implement the UIC-based services system

- Each clinic should have a point person trained to receive referrals.
- The training plan ensures that all Peer Educators are trained to accurately fill out the UIC coupons, including referral coupons. Trainings are regular because of turnover of PE.
- Training on the use of data-tracking systems is also necessary for Peer Educators and clinic staff members.
- If feasible, recruit PEs who are not only members of key populations, but also trained in the provision of PE services because of work in previous projects.
- Conduct a landscape analysis to map existing clinics.
- Use tools and materials for project implementation that have worked successfully in similar projects to save time and resources.

Step 4:

Management, monitoring and evaluation

- Evaluation reviews should be conducted regularly to improve service delivery and obtain better outcomes. The UIC system can help to assess the minimum exposure to services required to obtain lasting behavior changes in favor of HIV prevention and to reduce stigma.
- Random audits of service delivery staff could be conducted to ensure the accuracy of UIC data collected. The wider benefits for program management and service improvement depend on the quality of that data.
- Management practices could include clarity on hierarchy and accountability, ongoing training, technical support to staff, and coordination among health service centers. Smaller centers may struggle without sufficient support.
- Despite anonymity, KP may prefer to use health centers distant from their usual neighborhoods to avoid being seen going in or coming out. Accurate reporting of UIC data could help to discern patterns of who goes where to use what, and thus equip the health center accordingly. It could also help to decide geographical coverage and where to open new centers.
- Ensure that a staff member at each referral clinic or other health services acts as a point person for referrals from PEs, and is also trained in data-tracking systems and processes.
- Train PEs to use tracking tools, including referral coupons, mapping sheets, and inventory sheets.
- Supervisors should check-in with PEs on a regular basis to ensure they are filling out all forms accurately and completely.

Step 5:

Project partnerships with donors and experts

- Donors supported establishment of the UIC system and its extension to all KP-related projects in the region.
- The UIC system's simplicity and anonymity were desirable also because it offers possibilities for bringing other activities in favor of KP and HIV prevention together to exploit synergies.
- The scaling up UIC across the region would also help to prevent resource wastage by attempts to re-invent monitoring and evaluation systems. The UIC system should be the preferred mechanism.
- All government and NGOs would gain from using the PACTE-VIH system of UIC by agreeing to use one code structure and one set of prompt questions. That would improve data quality and reduce errors. It would also make data and outcomes comparable to assess performance.

XII. Taking the PACTE-VIH model to scale

The PACTE-VIH model of a UIC system was developed specifically in response to stigma and violence against KP. In this sense, it is unique although UIC are being used in other contexts, e.g. drug addiction.

As a key component of the wider PACTE-VIH program of targeted interventions, the UIC system offers much promise of positive outcomes.
In Togo and Burkina Faso all implementing partners are using the UIC system and each organization has its own password.

The scaling up at national level has started in both countries with the integration of UIC to national platforms of treatment and prevention.

The scaling up at national level will help reaching the 90-90-90 UNAIDS targets because the anonymity and the confidentiality offer the reduction of fears to visit health services for voluntary HIV testing and related ARV treatment leading to suppression of viral load.
Taking the system to scale at national and regional levels involves establishing operational capabilities and training service providers, which entails some administrative and financial costs.

At a later stage, it might be worthwhile to consider replacing the UIC card and code with biometric identification of KP clients, e.g. an electronic fingerprint. That would preclude anyone from stealing a UIC card and using the anonymous identity to receive services.

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