

# Case Study 3: Introducing a Unique Identifier Code System to protect confidentiality and monitor outreach services to Tingim Laip peers

## Key Messages:

- Unique identifier code system is an essential tool for good monitoring and evaluation of key population groups
- Despite fears, an anonymous and reliable coding system was developed and accepted by key populations TL developed the unique coding system to maintain confidentiality of the Key Population (KP).

## Background

Unique Identifier Codes (UICs) provide an anonymous and reliable system for tracking members of key populations through prevention, treatment and care services. A unique code for each individual is created, based on a combination of answers to a set of questions that are relevant to the specific context and epidemic of the country.

Supported by a literature review of UICs, global best practice guidelines and consultation with technical advisors, Tingim Laip aimed to develop a UIC with the following key characteristics:

- client-generated: all information can be provided by the client
- non-identifying: by reading the code, another person is not able to learn who the client is (to maintain confidentiality)
- unique (<2% repeat): there is little risk of two individuals generating the same code
- acceptable to key populations: questions do not offend or alienate clients from service providers and account for local norms (for example, many people in PNG do not know their date of birth)
- not location specific: to accommodate for the high level of mobility of key populations.

Tingim Laip developed the following questions to generate the UIC:

GENERATION OF UNIQUE IDENTIFICATION CODE							
What is your first name? <small>(write last 2 letters only)</small>							
Are you left-handed or right-handed? <small>(write R for Right-hand, L for Left-handed)</small>							
Which is your district of birth? <small>(write first 2 letters only)</small>							
What is your gender? <small>(write 1 for Male, 2 for Female, 3 for Trans-gender)</small>							
What is your last name? <small>(write last 2 letters only)</small>							
Client's UIC Number <small>(Fill each box here with the letters above in their order)</small>							

TL designed UIC set of questions was tested among 128 staff, volunteers and peers in six project locations. The testing confirmed that this set of questions met all of the characteristics of an appropriate UIC and no duplicate codes were generated within the sample. At the time, 83% of respondents indicated that they would prefer to be identified through their UIC, rather than their names.

## Rationale

In a setting where stigma and discrimination against members of key populations is strong and often expressed through violence, it is important that outreach workers are able to protect the identity of the individuals with whom they work. Some behaviours and activities engaged in by key populations in PNG would be deemed as illegal and/or socially and culturally unacceptable.

This means that TL peers may be in danger of being questioned by local authorities, physical or sexual attack by members of the community, or be isolated from family and friends if their behaviour or activity is exposed. Therefore, protecting the identity and anonymity of TL peers was essential for the project.

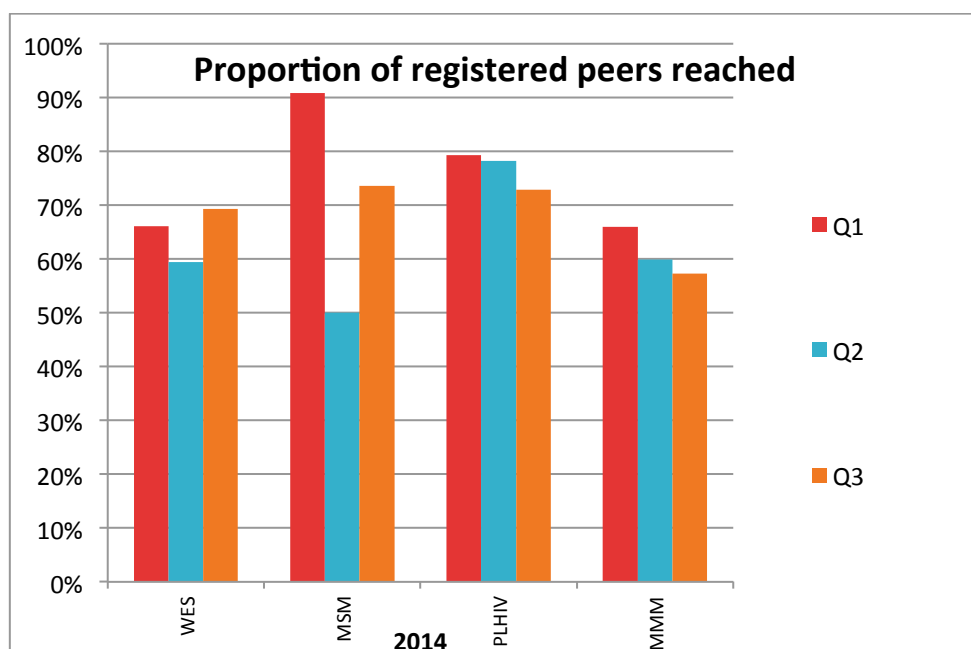
But the project also needs data collection, management, analysis for monitoring and evaluating the project expected outcomes. This data will also be used to plan and deliver more strategic service provision for the key populations.

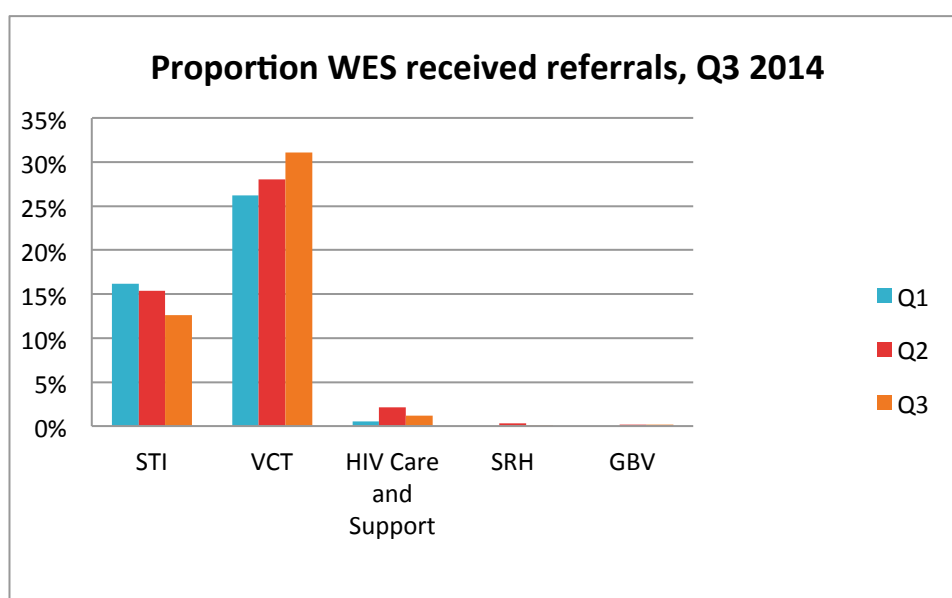
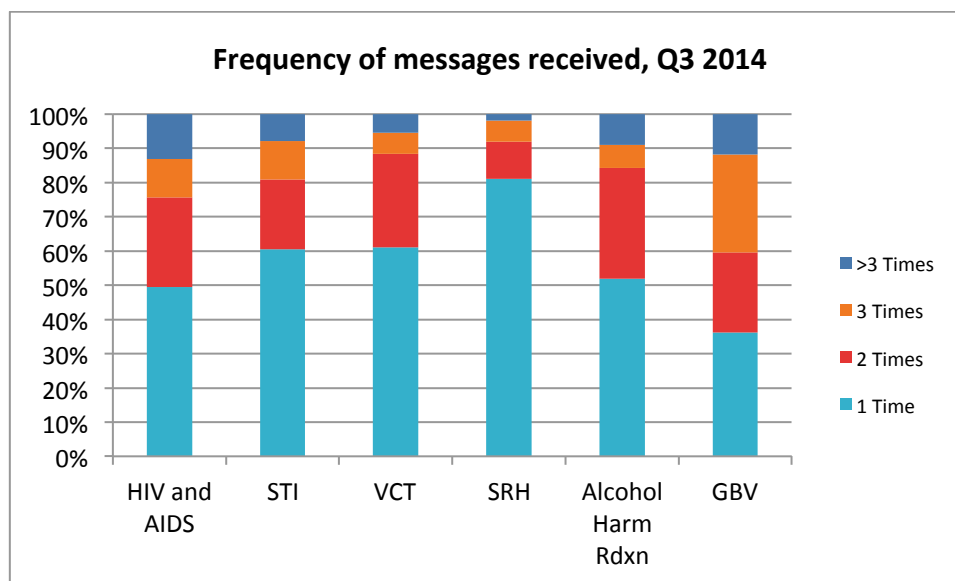
In the past, HIV prevention in PNG has been monitored by counting the number of trainings provided, number of outreach sessions, number of condoms distributed and number of referrals conducted.

International best practice demonstrates that the most effective prevention interventions are those in which individuals are reached repeatedly with consistent messages. TL counted the number of times an individual received a message, or was referred to a service. This data was then compared to project targets to measure progress towards the project objectives.

## Outcomes

- The UIC system allows TL to more accurately monitor and report outreach work and improves the quality of the data collected. Until the establishment of a UIC system, Tingim Laip was unable to reliably count the number of individuals that the project reached, with peer education and other program activities. Examples are shown below.





- The introduction of the UIC system enabled Tingim Laip to measure the number of individuals receiving services, as well as the nature of the service and the frequency with which the service was received. The system allowed TL to identify when peers had not been reached in a month: this provided an opportunity for the project to look for the peer and to get a better understanding of their movement.
- The system helped monitor field staff performance, identify outreach patterns, challenges and opportunities for improvement and encouraged data feedback to field staff regarding performance against targets.
- No names were collected from peers as part of the UIC registration and only information required for monitoring purposes were collected.
- The UIC system allowed TL to register accompanied and unaccompanied referrals to health services and to track and monitor what services were actually accessed.

## Challenges

- TL conducted a follow-up 6-month evaluation of the appropriateness of the UIC and found that some peers did not answer the questions the same way they had when they first registered. The questions 'What is your first name?' and 'What is your last name?' can change and therefore the questions need to include a point in time such as 'What was your last name at birth?'. Time was needed to develop questions that would be answered consistently. Illiteracy among both clients and field staff was another major issue that required assistance from literate staff.
- UICs are not yet integrated into the health system in PNG, therefore TL was only able to track peers health service access through the referral system that was in place but unable to track or monitor peers accessing services across the country or outside of the referral system.
- Due to donor reporting requirements the TL project was unable to employ a system where UICs replaced peers names on all forms. Some finance and administration documents required names and signatures. TL made efforts to limit the number of documents with peer names and ensured these documents were safely stored at the national office.

## Lessons Learnt

- UIC registration cannot happen on the first interaction between a peer and an outreach worker. It is best to build a relationship with peers before the registration. Tingim Laip Field Officers and volunteers would begin work with peers and build trust before they asked if they would like to be registered. Language used and messages given by TL outreach workers is really important when registering new peers. Registration should be done between individuals – not in big groups and peers should understand how their information will be used. When registering new peers there is no need to ask information such as behaviour, sexual history or last condom use as asking these questions can create barriers.
- The Unique Identifier Code cannot be a barrier to Tingim Laip services. If a peer did not want to be registered but wanted to continue to participate in TL services then this was encouraged.
- Training field staff is very important. A good training system must be in place for newly recruited staff and volunteers and the importance of accurate data collection and recording must be stressed. Field staff with low literacy levels need additional support from superiors and peers to ensure accurate data collection.
- A good database must be designed prior the roll-out of a UIC system and data entry staff must be thoroughly trained and provided with ongoing support in the maintenance of this database. Revising M&E systems, tools and databases after a UIC system is in place, can be disruptive and can have an impact on the accuracy and quality of data collected.

Follow-up on some of these challenges and suggestions since the end of Tingim Laip project:

Challenges	Comments/Suggestions
<p>TL conducted a follow-up 6-month evaluation of the appropriateness of the UIC and found that some peers did not answer the questions the same way they had when they first registered. The questions ‘What is your first name?’ and ‘What is your last name?’ can change and therefore the questions need to include a point in time such as ‘What was your last name at birth?’. Time was needed to develop questions that would be answered consistently. Illiteracy among both clients and field staff was another major issue that required assistance from literate staff.</p>	<p>In PNG some people become confused when you ask “what is your last name or first name”. Many are more familiar with is “what is your <b>christian</b> name and what is your local or <b>father’s</b> (surname) name. So it is important to re-brand the question using words that they understand consistently is important.</p>
<p>UICs are not yet integrated into the health system in PNG, therefore TL was only able to track peers health service access through the referral system that was in place but unable to track or monitor peers accessing services across the country or outside of the referral system.</p>	<p>This problem will be overcome once the VSO current work on the UIC project progresses. NDoH is in the front line of the project so integration, setting up of national data base and integrating both clinical and program level data into the health system will improve the database system.</p>
<p>Due to donor reporting requirements the TL project was unable to employ a system where UICs replaced peers names on all forms.</p>	<p>Data security and maintaining KP members’ details in a non-disclosed manner is important. There needs to be discussions between partners and donors on how to manage that reporting requirement.</p>