Case Study 7: Working with People Living with HIV

Key Messages:

- PLHIV staff enable the project to reach and work with substantial numbers of PLHIV, despite ongoing stigma and discrimination
- PLHIV services in PNG need to include follow-up of patients by outreach workers as clinic staff often do not have the time or resources to do this type of work.
- NGOs and health services can work effectively together to provide PLHIV with the range of services they need.

Background

At the beginning of Phase 2, Tingim Laip undertook a review of Volunteer Activity. Findings from this review were published in The Price of Wok Sol Report and included TL's work with PLHIV. The review found that working with PLHIV was a significant, though often under-reported area of work of many TL staff and volunteers and that support being provided to individual PLHIV included home visiting, accompaniment to medical appointments and provision of food and household goods.

In 2011 the Tingim Laip team developed the TL STEPs model (step-wise improvements in the range of interventions offered at site – see briefing note in Guidance section) to assist Site Committees to better tailor their interventions towards key populations at risk of and affected by HIV. TL's work with People Living with HIV (PLHIV) is addressed in Level 4: working with HIV treatment and care services on HIV support, ART adherence and community care. Activities undertaken in this STEP include:

- Providing advice and information on how to take HIV treatments properly
- Helping PLHIV to access reliable supplies of Anti-retroviral medication
- Working with health services to help them improve the way they work with PLHIV
- Supporting PLHIV groups so that they can offer peer support and other services to their members
- Providing or supporting home-based care for PLHIV who are unwell
- Working with communities so that PLHIV are properly supported.

Rationale

The 2014 WHO Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment and Care for Key Populations recommends that 'key populations living with HIV should have the same access to ART and care and the same ART management as other populations'. The NDOH 2013 PNG HIV Epidemic Estimation Report (Unpublished Workshop Presentation, UNAIDS PNG, 2013), presented the following 2013 HIV Estimations for PNG:

HIV Estimation	Total	Men	Women
People with HIV	22,389	9,550	12,839
People with HIV needing ART	16,846	7,057	9,789
PLHIV who died in 2012	1138	575	563
Children with HIV	3387		

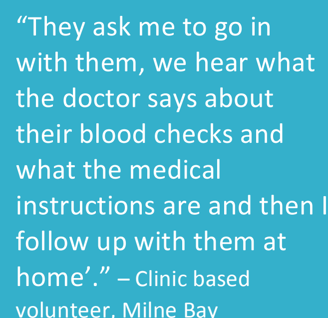
Although the numbers look less daunting than previous estimates, PNG still faces a considerable challenge to provide quality care and support to the 3,387 children and the 22,389 adults who are currently living with HIV throughout the country[1]. TL worked with PLHIV in many locations across PNG, focusing on working with key populations living with HIV to provide links to treatment and support services and ongoing care.

Outcomes

- During late 2013, Tingim Laip Project (TL) commissioned the services of a Short Term Advisor (STA) to provide technical advice on improving Tingim Laip's support for people living with HIV (PLHIV) and for the people who care for them. The consultation found that TL was implementing Greater Involvement of People Living with HIV (GIPA) principles, such as, having PLHIV as volunteers for peer education with other PLHIV and HIV negative or as yet untested key population members; providing accompanied referrals for testing and treatment; conducting home visits to those who were unwell; providing adherence support and ART promotion. By the end of 2014 TL had recruited 16 PLHIV as either field officers (FOs) or volunteers. These 16 members of the workforce worked with 95 active registered PLHIV peers.

- TL's work with PLHIV included linking peers to ART and non-ART services; supporting regular 'positive living' support visits; forming support groups driven and managed by PLHIV and connecting these support groups to the PNG national umbrella body for PLHIV, Igat Hope. Working relationships were established with local branches of Igat Hope in five project location. In some locations the project had a designated clinic based field worker who worked in the VCT clinics supporting the clinic staff and TL peers. This FO or volunteer was often a positive advocate living with HIV and provided pre and post-test support for TL peers. When peers received a positive result the staff was there to ensure they understood the scope of support that was available to them through TL. In some locations registered PLHIV peers would request and consent to having the clinic staff present during appointments which was especially helpful when the peer spoke no english and the staff could translate into Tok Ples. The below graph demonstrates the type of referrals provided to PLHIV peers in 2014.

  As the project increased its work with PLHIV over 2014 the number of peers who were referred to VCT services decreased, while the number who received referrals for HIV care and support increased. This supports TL's commitment to providing ongoing outreach to PLHIV and tailoring this outreach to the actual needs of peers.



[1] Joanne Robinson, Understanding the PNG HIV Epidemic, UNAIDS 2013; Port Moresby PNG.

Challenges

- In some locations stigma and discrimination against PLHIV made it difficult to get PLHIV to become registered peers of TL because many people were not open about their status due to actual or perceived risk to their safety. Staff reported being happy with the home visits which involved them going into the community to discuss HIV. However, treatment adherence was an issue in locations with high levels of stigma. A desire to do more was expressed and one suggestion was having a shelter that provided a space for TL to provide ART support and monitoring.

> "Most of the PLHIV in Jiwaka don't really open up, stigma and discrimination is still strong there. Rosa (a PLHIV FO) does field visits and I keep asking her, 'how do you see some of your friends, are they opening up? Can they join our team?' , she says 'no', so it is really hard. I tell her she has to do more of these home visits. It's a challenge we're facing."
>
> *- Project Officer, Jiwaka*

- Clinics have limited resources and most reported not having the capacity to undertake outreach or follow-up for PLHIV patients. TL was able to assist with follow-up in locations where the project worked with PLHIV peers, however, the clinics expressed a need to follow-up with all patients, not just those registered to TL. TL did not have the resources to provide follow-up for non-TL PLHIV patients.

Lessons Learnt

- PLHIV staff enables the project to reach and work with substantial numbers of PLHIV, despite ongoing stigma and discrimination. By actively seeking to employ PLHIV and making GIPA a core part of TL's work, PLHIV became actively involved in all parts of TL's work.
- PLHIV services in PNG need to include follow-up of patients by outreach workers as clinics do not have the time or resources to do this type of work. NGOs and health services can work effectively together to provide PLHIV with the range of services they need: in particular, outreach workers can follow up on PLHIV in the community, encouraging their adherence to ART and their attendance at clinics for ongoing medical help.