

**Report for NAPWHA/CHPNG
Psychology of HIV Treatments Workshop
Port Moresby May 20th 2015**

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Section A - Organisation and Project Information

Supporting Organisation: Collaboration for Health in Papua New Guinea

Project Implementer: National Association of People living with HIV Australia

Project Partner: Igat Hope Incorporated. (Rose Kunjip, a staff member of Igat Hope was the in-country coordinator of the activity, specialist local input was provided through co-facilitation by the PLHIV representative on the CCM Board Maura Eliriape and with assistance of Kapul Champions staff members Nic Evera and George Raubi)

Project Consultants: Dr John Rule, NAPWHA Consultant, Conjoint Associate Lecturer, School of Public Health and Community Medicine, Faculty of Medicine, University of New South Wales

Ruth Hennessy, BA(Hons), MPsych(Clin), Psychology Unit Manager, Senior Clinical Psychologist, The Albion Centre, Sydney

This is a report on the first component of the project only i.e. the 1st pilot workshop held in Port Moresby.

In this report the acronyms ARV and ART are used interchangeably as well as PLHIV and PLWH.

Project Background

The treatments-related challenges experienced by PLHIV in PNG can be summarised as:

- Low levels of treatments literacy among PLHIV, exacerbated by an absence of readily available and accessible treatments information
- Scarcity of health care practitioners with the knowledge and experience necessary for supporting PLHIV with treatments decisions
- Enduring and high levels of HIV-related prejudice and discrimination, which discourage PLHIV from seeking treatment and/or community and family support
- Scarcity of peer support opportunities for PLHIV
- Increasing anti-ARV rhetoric from a number of evangelical churches that actively discourages PLHIV from taking treatments
- A vibrant market in HIV ‘cures’ of both traditional and imported kinds
- Problems with interrupted drug supply, especially in areas outside Port Moresby.

Igat hope has recently started to talk about the psychology of HIV treatments information and NAPWHA has responded by proposing this workshop program. Igat Hope identified a number of crucial features being faced by PLHIV in PNG

- Absence of psycho-social supports for people taking treatments
- Frequency of death amongst the cohort –creating fear and misunderstanding
- Counselling in the PNG context needs to be understood from the point of view of people from PNG. Whilst there is pre and post-test counselling ongoing supports are very limited.
- Loss to follow up after testing is a generalised experience and no-one is collecting data on this information.

These are not Igat Hope problems alone but Igat Hope wishes to be part of a the critical response to the management of HIV in PNG and so addressing these complex issues is of crucial importance to the organisation.

Recent efforts to build up Igat Hope’s capacity to address these challenges as has met with mixed results. While Igat Hope has some impressive runs on the Board, including its 2010 treatments advocacy forum, the Waigani Statement of the same year and a 2012 brochure on treatments and side effects, its capacity to educate and advocate around treatments remains limited. This is significantly due to the recent deaths of three of its HIV-positive employees – out of a workforce of only six and the death of prominent Igat Hope Board founding members.

This workshop report is part of a broader project to address the particular needs that emerging as people living with HIV in PNG are on treatment for longer, with some still experiencing illness and death. The ‘psychology’ needs response at an individual and community level.

Section B – Workshop Aims

The treatments workshop is a proven model in PNG and NAPWHA has successfully conducted treatments workshops in years past. These workshops have been well received and evaluated positively. The need for accurate, up-to-date and accessible treatments information remains undiminished. Igat Hope remains the appropriate vehicle through which these workshops should be delivered. The workshop conducted in May was the first of two treatments workshops for PLHIV. With the agreement of Igat Hope it was decided to hold one workshop in Port Moresby and one other in an urban location, probably Lae. Information from the workshops may lead to the development of

an accessible, up-to-date treatments resource for PLHIV across PNG, although the question of whether more printed material is required will be discussed during the workshops.

NAPWHA remains the appropriate agency to provide the technical support necessary for the implementation of the workshop program. NAPWHA proposes to work closely the health care practitioners with whom CHPNG has been collaborating in Australia and PNG, and including Catholic Health Services.

While the workshops will use some of the proven content from previous training events, they will also include a new focus on the psychology of taking treatments. This change reflects Igat Hope's developing understanding of treatments challenges for its constituents.

Aims:

- (1) The workshop will facilitate peer support opportunities for participating PLHIV
- (2) The workshop will be co-facilitated with local treatment advocates
- (3) The workshop will provide a space for other PNG professional level input regarding treatments management in PNG
- (4) The workshop will provide strategies for dealing with the many and varied challenges that taking treatments can generate.
- (5) The workshop will provide training on HIV, HIV treatments, compliance and managing side effects for PLHIV
- (6) The workshop will enable participants to develop their skills as peers in providing information to friends and PLHIV networks
- (7) The workshop will provide a space for PLHIV peers to explore the development of advocacy strategies as relevant to their interests and need.
- (8) The workshop will be an opportunity to generate ideas that inform the development of the proposed treatments information resource.

Section C – Workshop Activities

The in-country co-ordinating team and NAPWHA consultants reviewed the identified aims, objectives and outline of the workshop two days prior to the workshop. Conversations highlighted both questions and concerns around the effectiveness and efficacy of HIV ARV treatment, particularly first line treatment in light of recent losses of friends and staff due to AIDS related illnesses. It was noted that there may be various reasons as to why ARV treatment may have not been effected, including adherence, other health conditions and beliefs related to taking ARVs. Based on feedback the consultants made adjustments to the workshop content and on the day prior to the workshop reviewed again with the in-country team and local co-facilitators the program.

The workshop was opened by John West Tori (current acting Executive Director of Igat Hope) who spoke about the importance of starting the conversation around the psychology of HIV treatments. He acknowledged that people have questions about treatments, adherence, concerns related to recent

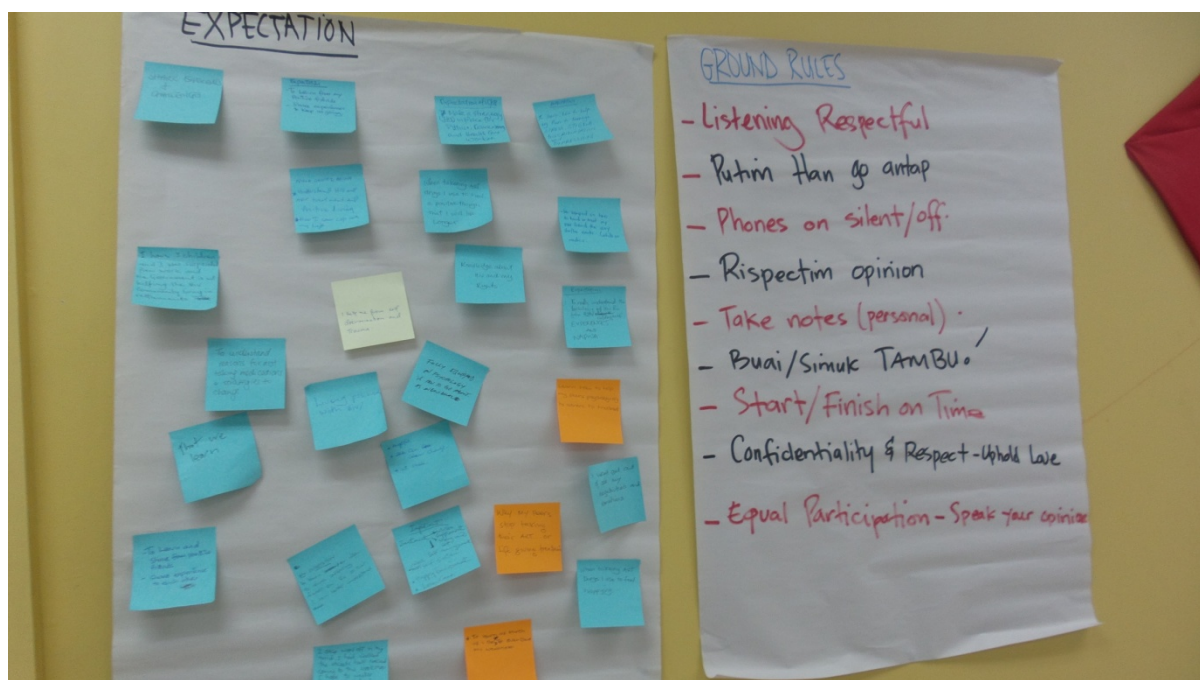
losses of Igat Hope key staff members who had become sick and died and the opportunity to educate and support each other around living with HIV. John related that he was patient number 17 at the Hedero clinic and that he wondered about the health outcomes of others who had also started on treatment around the same time as him, approximately 10 years ago. Each participant introduced themselves and many spoke of the length of time that they had been on treatment, some also identified if they were on second line treatments.



Sister Tarcisia was invited to relate her own experience and she spoke of the importance of building a good relationship with health workers in management of HIV. Maura, on behalf of all present expressed her gratitude for the care and support that she had received from Sister Tarcisia and the services provided by Catholic Health.



Rose invited participants to establish the workshop's rules and each participant's expectations for the day. These were captured photographically. Workshop rules included ensuring confidentiality and respect for each participant's opinions (see below written in English and Tok-Pisin). Expectations included many participants wanting a better understanding of why they were on medication and the understanding more fully the nature of ARV treatments. There was an agreement that the workshop discussions and presentations could be a combination of English and Tok-Pisin with translation carried out with co-facilitators as required.



Nick was invited to speak of his support and the care he provided to his good friend Don who died in hospital late last year. Nick spoke of how he found himself providing both practical care and emotional support to his friend, at times performing tasks that arguably would be performed by nursing in other health settings. He acknowledged the importance of peer support, particularly for those who might be without family. He spoke of Don sharing his last meal with Nick as was a tradition within their shared village culture. Nick related that Don shared sensing others present

before he died. Nick was tearful and also acknowledged his own fears around dying and hope that he would be supported. Nick also acknowledged how important it was to be able to talk about this, especially to share his experience of caring for Don so that others would learn what was needed.



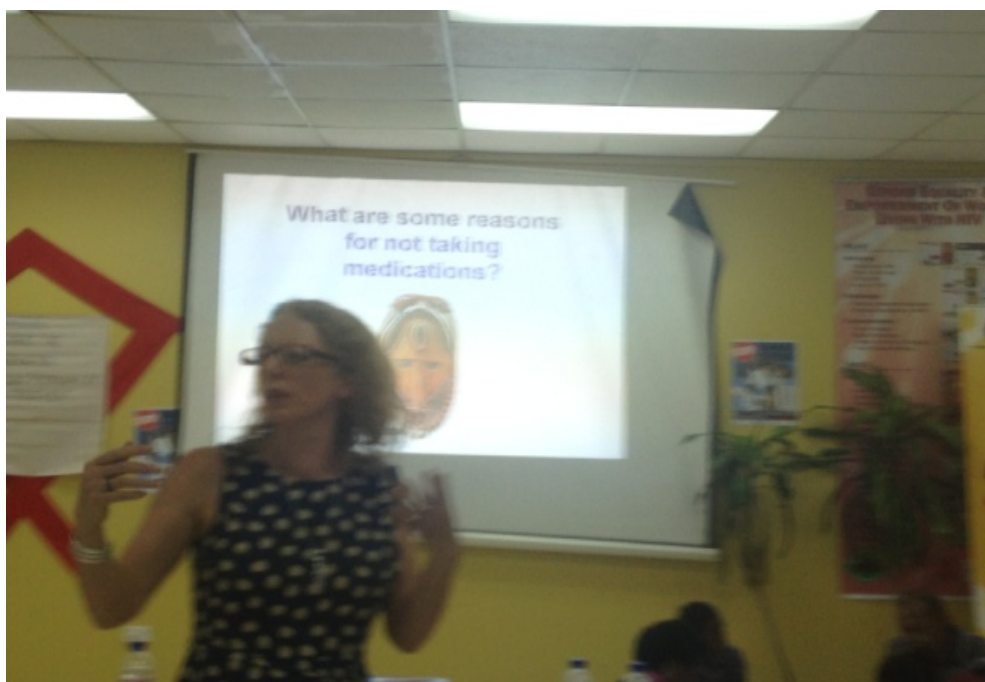
Dr John Rule (NAPWA consultant) provided a presentation entitled ‘**101 – ARVs and Adherence for ‘Psychology of HIV’ Treatments Workshops at Port Moresby May 2015**’ which covered the basics of HIV treatment ; ‘ HIV 101’ and an overview of adherence rates in both developed and developing countries contexts. His presentation provided both an overview of the biological impact on the immune system and the importance of 95% adherence. Participants expressed a great interest in understanding how particular treatments worked on the body and affected the HIV virus and what were the factors that may indicate treatment failure. A number of PLWH expressed that they would like to know if their treatment was effective and for how long were first line treatments thought to be effective. Some participants

Dr Mahboob Rahman (from UNAIDS) presentation entitled ‘**Fast tracking 90-90-90: Ending the HIV Epidemic**’ addressed the UNAIDS worldwide targets of ‘90x90x90’, where 90% of infections are identified, 90% PLWH are on treatment and 90% of PLWH on treatment have suppressed viral loads with these targets to achieved by the year 2020. This presentation highlighted the lack of available and reliable data for the PNG context. A number of participants advocated for PNG and PLWH in PNG to be provided with data related to PNG’s adherence and testing rates. Such data was proposed as providing meaningful direction for where they as individuals and as an organisation and advocates could direct efforts to ensure efficacy and address target gaps.

Ruth Hennessy’s session entitled ‘**Helping People Meet HIV treatment Needs**’ provided a summary of the benefits of adherence, a review of barriers and strategies for adherence and additional factors to build resilience and positive health outcomes. Participants worked in small groups and then reported to the wider group identifying both their experienced barriers to HIV adherence and then their strategies to achieve HIV adherence. The identified issues and solutions were consistent with the literature but also particular to the PNG context.

Some examples related to PNG included the impact of gender as both a potential burden and also a strength in PNG - mothers, for instance, may be responsible for the needs and care of all of the family and this could both be problematic when her own needs may be neglected, however, the family unit and community could also be a tremendous support to PLWH. People from diverse sexual backgrounds spoke of the need to have social and practical support, often from peers, as they were less likely to have family, spouses or children that were supportive of them. Alcohol and smoking were identified as key health factors by a number of members as a means of escaping stress and related to peer pressure.

Poverty factors, such as an inadequate diet or not having enough money for transport were highlighted as inhibiting access to treatment and health care. Negative beliefs about taking medications, fears of judgement, depressive symptoms or experienced discrimination from health care workers were also noted as factors that had affected people's adherence.





Potential ways to achieve good adherence, particular to PNG, included family support and using peers for support such as them reminding and checking on each other's adherence and ensuring that people were not isolated. The importance of having a good and open regular and communication with health workers and the mobilisation of peers to assist in addressing understanding of the importance of adherence were also highlighted. Some participants related an intention to use some of the strategies suggested, such as using phone alarm reminders, daily pill box and adopting a possible attitude to their health and pill taking.

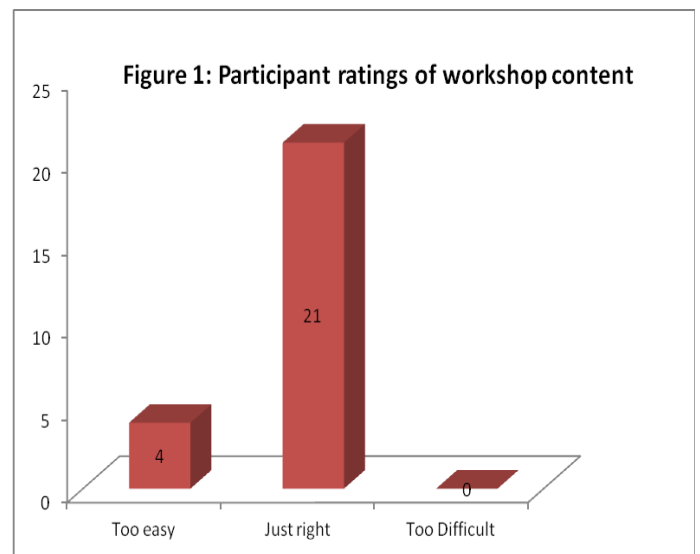
In a feedback session

- Carol Harbian from Anglicare Stop Aids related that there were support groups run for PLWH designed to assist with issues such as adherence and isolation.
- Helen Dabarotoa, and ART prescriber with Catholic Health Services said that she had learnt a lot about patient concerns from participating in the day and would take this information back into her work and discuss with colleagues ways to support ART adherence.
- John West Torie concluded with speaking of upcoming plans for Igat Hope, including the securing of a full-time Director and continuing with the Peer Support Project in Clinical Settings that will be funded through the Global Fund.

Section D – Workshop Evaluation

Overall both the verbal and written feedback from participants was overwhelmingly positive with many participants speaking of the importance of the topic of the Psychology of HIV adherence and that it was their understanding that this workshop was the first of its kind in PNG, at least that they were aware of had attended.

All participants completed anonymous evaluations pertaining to their experience of the workshop (see Appendix 1 for full transcriptions). The workshop: length; level of content; knowledge of facilitators; and relevance of the workshop all rated positively (see Figures 1, 2, 3, 4). The length was nominated as too short for a number of participants and many suggested in their comments that they would like a longer workshop, up to a week in length.



The workshop appeared to have met both its aims and objectives and highlighted an interest from PLWH to explore more on this topic. Most participants were from both Igat Hope but the inclusion of HCW from health facilities that were supporting PLHW was valued highly by participants.

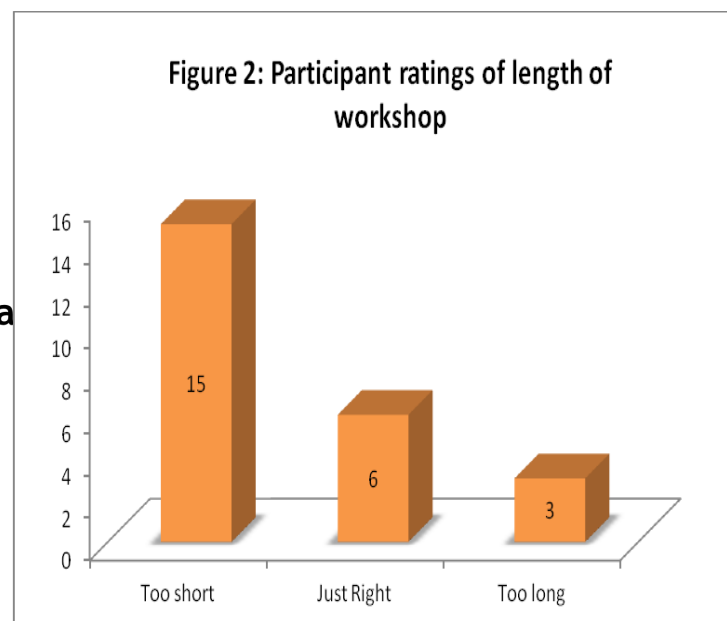


Figure 3: Participant rating of facilitator knowledge

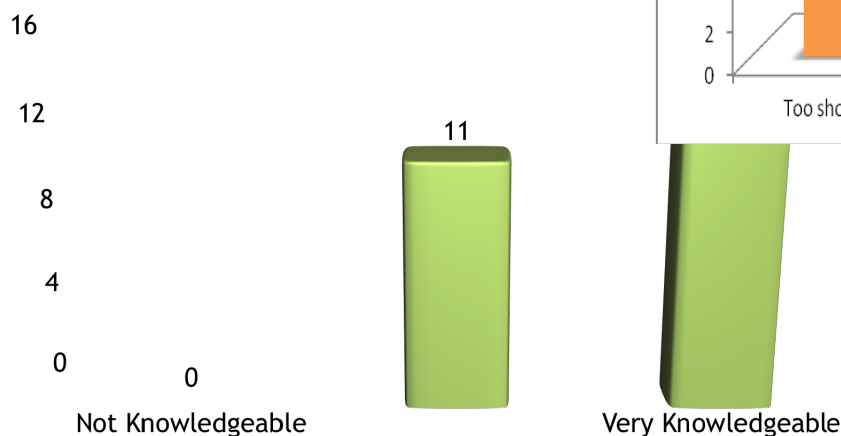
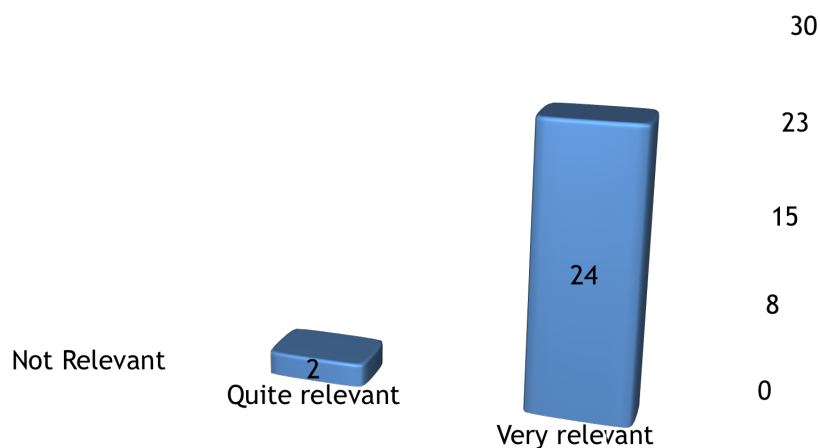


Figure 4: Participant rating of relevance of workshop



Section E – Recommendations for Future Activities

As noted there was expressed interest from PLWH to have future workshops to allow more in depth coverage of the areas the workshop addressed: more information about the HIV virus, its impact on the body and how treatment works, move toward data collection and monitoring of the PNG context and what means treatment failure can be monitored and further opportunities to build and develop psychological skills around resilience.

Igat Hope may investigate options around peer support models, such as PLWH led support groups that may provide an avenue for PLWH to gain both social and practical support in the management of HIV. Collaboration with other peer organisations and health clinic based groups and inviting health care workers to co-facilitate could also be explored. Training in self-management programs may also be viable given the limited resources available in PNG, such models may be peer-led and empower PLWH.

Appendix A – Participant Feedback

The most helpful thing I learnt today	What will I do differently in my life	I would like to learn more about	Other Comments
The important of taking ART medications	Taking different approach to being on ART and what I can do to help myself	Different effects of ART	More of these workshops to be conducted
To know and share experiences	Learn more about the ART	The Psychology and ART	To understand about the treatment and also know myself who I am

I always have a question in my mind ? Why is all my peers are already dead even though they are on treatments	Now I think I know the reason or answer. Change some bad behaviour that effects my health issues and look on the positive side to live a healthy life	What the first line drugs and second line drugs do in my immune system	I think the psychology of HIV treatment workshop is the first of it's kind , so please next make it more than one day.
I learnt that how you think effects how you feel and how you behave	I will always think positive and be happy about myself.	Psychology trainings in the future	Please organise more psychology training for peer counsellors and nurses
Things that help me to take my treatment	Develop training sessions for newly diagnosed clients for my ART site	ARV interruption to HIV mutation	In future trainings I would like to see professionals like Professor McBride from Cairns University providing more information on HIV mutation and ARV interruption in HIV.
Attitudes and beliefs effect my life	Being and think positive	Psychological counselling	We need this workshop again for 2 full days.
The ending of AIDS epidemic presentation by UNAIDS	Build a friendly relationship with my peers and help others with their treatments	ARV medication	Would like to learn more on HIV and ARV treatment and positive living
My strengths and weaknesses in adherence	Keep up and maintain my adherence.	PNG data needs to be presented so I will know my strengths, weakness, options and threats.	Such workshops must be organised for 3 days or more.
The importance of taking ART and the positive impact on the lives of people living with HIV/AIDS	I will always take my ART with compliance as this is my lifeline	The virus it's mutations and changes in cells	Need more workshop and counselling for PLWH with nurses and doctors to elaborate on the ART in detail
How the virus replicates	Encourage the dissemination of information to all my peers about the importance of treatment	Treatments and what will happen to me for treatments in the long run	Want Igat Hope to see what's happening in other ART sites. Want Igat Hope to organise workshops like this in the future and engage more PLHIV in ART clinics.
I must be in control of my thinking, feeling and behaviour.	Think positive, be positive and adhere to my treatments	How the treatment works on the virus. Cycle of how first and second line works on the virus.	Have more of the psychology of HIV treatments workshop.
I have learnt more on the psychology of HIV treatments and the difficulties faced	Better understand my friends and clients	Psychology of HIV treatment.	Too short.
Understanding why people think and do	Understanding my peers and how they think, try not to be judgmental	More of this specific training.	More of this special training.

I am real happy to learnt new things about my status	Now I will take care of my status and help my friends	Yes to learn more	Really enjoyed today
Treatment adherence and treatment of opportunistic infections	HIV, TB, Malaria are killer diseases and I would like to do systematic check ups for TB and Malaria	Want to learn more about HIV, TB and malaria	I'm able to teach others what I learnt today
HIV without ARV affects the whole body system	Advocate for ARV treatments	ARV treatments	The workshop should take on week training
All new and want to learn more please	Reduce alcohol and drugs, take by drugs on time and adherence	The psychological needs of PLHIV on ART	I need constructive training like this, this needs more time.
How the virus and the ART works	Always remember to take my medications	Why does the therapy fail in our body?	Maybe next time we have to have enough time to run this workshop
The psychology of HIV treatment and management	To help PLWH to educate them in the psychology of HIV treatment so they can take ownership in their own lives to live positively	To understand the skills and information and how to develop my own strategies for management.	Very well presented.
The 1 st line and 2 nd line drug and how it works	Taking my life seriously and take my drugs and live for my children and family	A holistic approach of my being to my drug taking and living a happy life	To have more of this meeting to create better environment for peer counselling
Sharing experiences on treatment and learning how to maintain adherence	Do not miss a dose. Need 95% important to take medication that much	Missing a dose is risky	Engage more positive men who have sex with men and transgender. It is most important for Friends Frangipani and Kapul Champions to be involved in supporting peers.
Strategies for dealing with challenges	To continue to take my ART treatment no matter what it takes.	Replication of the HIV virus and how it works	It was just refreshing and I feel just good. Thanks NAPWA and Igat Hope.
How to take ART and live longer	Quite some activities in my life such as smoking and reduce alcohol and have a healthy diet and regular exercises.	Objectives and expectations and also more of such workshops to be conducted so that more positive people in rural areas can have access without stigma	I personally appreciate the sponsors and facilitators of this workshop to continue in workshops like this to help those in the settlements and mostly the rural areas where there is no health services.
The training will help improve my daily life	Will change some of my life after this training to improve my life-style	Request for more than one day training in the future.	In the future this training should be conducted for one week so that every one of us can understand well.