

**Report for NAPWHA/CHPNG  
Psychology of HIV Treatments Workshop  
Lae 13<sup>th</sup> & 14<sup>th</sup> Oct 2015**

**TAIM BILONG STORI - Starting the Conversation**



(Fishing boats in Lae Harbour)

Lae is the capital of the Morobe Province. The Province consists of nine districts and 33 Local Level Government areas, with an estimated population of 700,000. The Province has 49 functioning Health Centres and 300 Aidposts (only 50% of which are currently functioning). The Province is linked to the highlands region through the Highlands Highway, and to the northern coastal province of Madang through the Lae-Madang Highway. HIV prevalence in Morobe Province has been increasing over the last five years. <sup>1</sup> The first diagnosis of HIV recorded in the Morobe Province was at the Angau Memorial Hospital in Lae (the provincial capital) in 1989. There have now been 2,228 diagnoses: 917 male and 1,064 female. <sup>2</sup> Overall, Morobe Province accounts for 7.87% of the total number of HIV infections diagnosed in PNG since 1987.

<sup>1</sup> National Department of Health (2009). The 2008 STI, HIV and AIDS Annual Surveillance Report.

<sup>2</sup> The gender of the remaining 247 cases is unknown

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Based on feedback from the pilot Port Moresby workshop held in May, 2015 the workshop model was extended and conducted over two days.

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

**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 input was provided through co-facilitation by the President of Igat Hope Janet Sangopo.
- Lae PLHIV peer counsellors Elis Don and Mai Jack also acted as facilitators providing specific local input and translation as required.

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

### **Section B – Overall Project Goals and Objectives**

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 the response to the management of HIV in PNG and so addressing these complex issues is of crucial importance to the organisation.

### **Section C – Workshop Activities**

On the evening before the workshop commenced Rose Kunjip, Janet Sangopa, Dr John Rule and Ruth Hennessy reviewed the workshop aims and objectives. It was agreed to use a similar process to the Port Moresby workshop but that more time would have to be taken in translating material and allowing participant discussion.

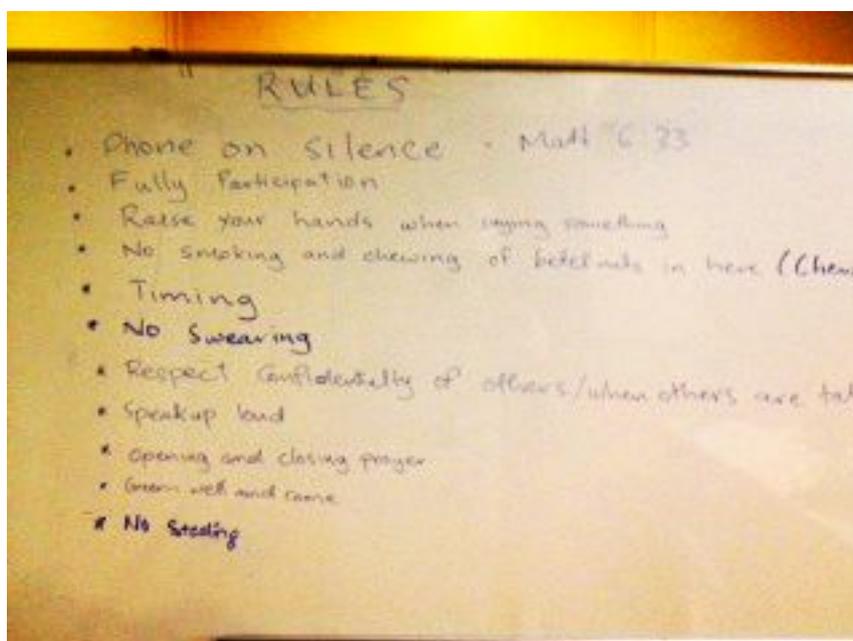
Janet Sangopa, President of Igat Hope welcomed all participants and noted that this was the first time an event like this had been held in Lae. Janet thanked the local organisers for bringing along PLHIV who might learn more and become peer leaders. Janet thanked the organisers.

One of the participants, a local Pastor said a prayer.

Dr John Rule spoke about the previous workshop held in Port Moresby and the idea coming from that workshop about the importance of starting the conversation around the psychology of HIV treatments. He acknowledged the previous work of CHPNG and Igat Hope and the journey to date.

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 first line treatments and a number of people were just starting medications and were newly diagnosed.

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. Expectations included many participants wanting a better understanding of why they were on medication and the understanding more fully the nature of ARV treatments.

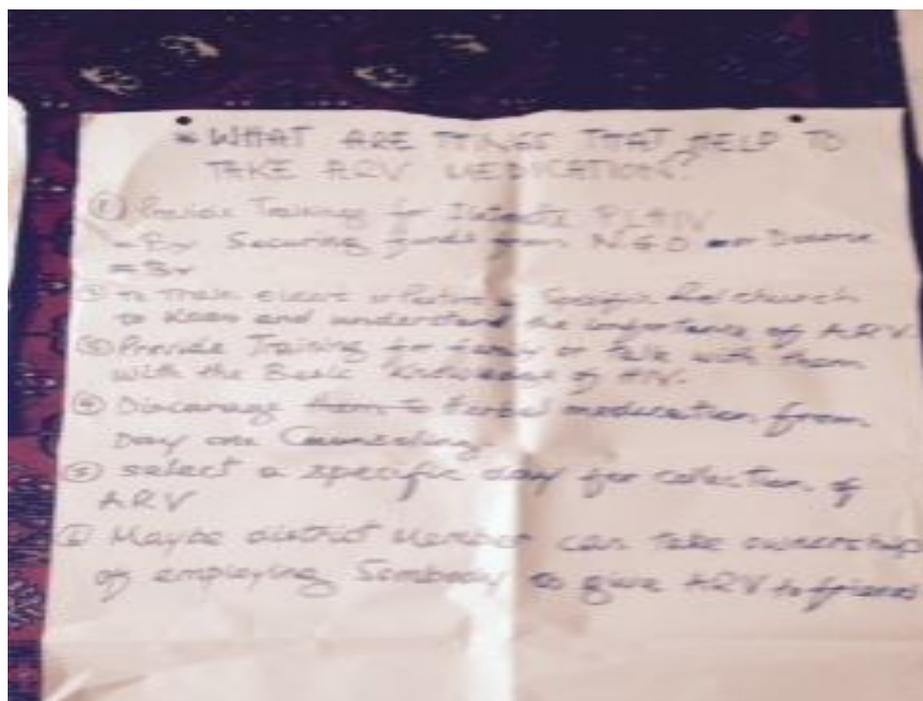
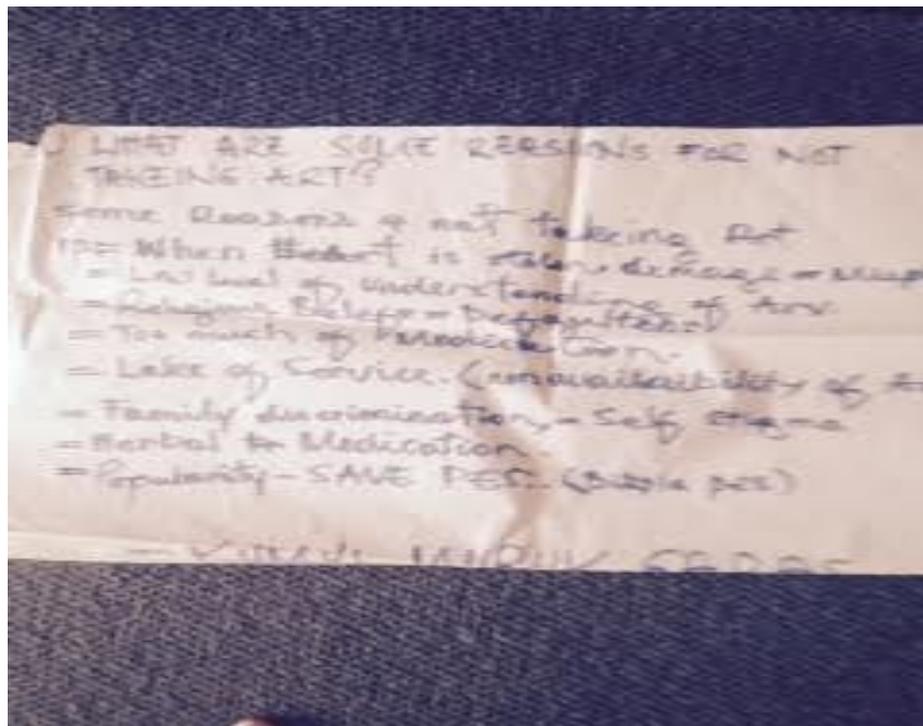
**Dr John Rule** (NAPWHA consultant) provided a presentation entitled '101 – ARVs and Adherence for 'Psychology of HIV' Treatments Workshops at Port Moresby May 2015' which covered the basics of HIV treatment ; ' HIV 101' and an overview of adherence rates in both developed and developing countries contexts. 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

**Ruth Hennessy's** sessions were entitled **'Helping People Meet HIV treatment Needs'**. These sessions 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. Alcohol and smoking were identified as key health factors by a number of members as barriers to both good health and adherence. Poverty factors, such as an inadequate diet or not having enough money for transport were highlighted as inhibiting access to treatment and health care. Cultural beliefs about taking medications, including herbal and traditional medications and both internalised and externalised stigma, and the burden of other health conditions were also noted as factors that had affected people's adherence.

This session covered the afternoon and until lunch-time next day. It was a mix of presentation, discussions and feedback. **Some participants did not speak any English and some probably could not read English so a lot of time was spent in the translation of material and also in discussion of key concepts to do with HIV, treatments and adherence.**



“Ruth and workshop participants discussing HIV treatment needs”



A considerable amount of time was spent with groups discussing and talking about  
 (1) Reasons for not taking ARVs

Then participants were encouraged to discuss and come up with ideas about  
 (2) The things that help taking ARVs

### **Reasons given for not taking ARVs**

- When ARV is stolen, damaged or misplaced
- Low level of understanding of why ARV is to be used
- Religious beliefs that prevent people from taking medicine
- Sometime people are called defaulters and then not allowed to take ARVs
- Too many medicines to take and not understanding which medicine is for which (eg. what is the difference between TB medicine and ART)
- Lack of service or non-availability of ART
- Family discrimination \*\*\*\*\*
- Distance and transport costs \*\*\*\*\*
- Self-stigma
- People turn to herbal medications
- Losing medicines
- You won't be popular if people know you are taking ARV (Save pes, bikpla pes)
- Drugs and alcohol interfere and cause interruption\*\*\*\*\*
- Lack of proper counselling
- Discrimination \*\*\*\*\*
- Poverty\*\*\*\*\*
- Not enough food\*\*\*\*\*
- (If known) CD4 higher than 350-500 and don't qualify

Those marked with an asterisk \* were spoken about quite a lot

### **Things that help taking ARVs**

- Provide training for illiterate PLHIV by securing fund from NGO or donors
- To train Elders or Pastors of specific churches to know and understand the importance of ARV
- Provide training for family or talk with them about the basics of HIV
- Discourage herbal medicines from day 1 of counselling
- Select a specific day for collection of ARV
- Maybe district members can take ownership of employing somebody to take ARV to friends
- Advocate for the government to change the criteria of start ART with WHO guidelines and no waiting – simple for everyone
- Tell and counsel the person about the benefits of ART
- Education and training on the effects of alcohol in the body
- Make clear there is no cure to HIV
- Set the time using alarm clock to remind them of taking ARV on time
- Need training on drug and alcohol effects – drink lots of water, reduce alcohol, seek support from counselling services if they are available
- We need to have rest time, share ideas or opinions with other, seek advice from day care centre
- Transport services to deliver drugs to people or the people to clinic

As noted in previous workshops the importance of support from others, peers and family were highlighted as crucial to acceptance and good adherence. 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. Participants were encouraged to identify referral pathways and networks specific to the Lae region and it was evident that this information would be of benefit if formally documented. Some participants related an intention to use some of the strategies suggested, such as adopting a positive attitude to their health and lifestyle

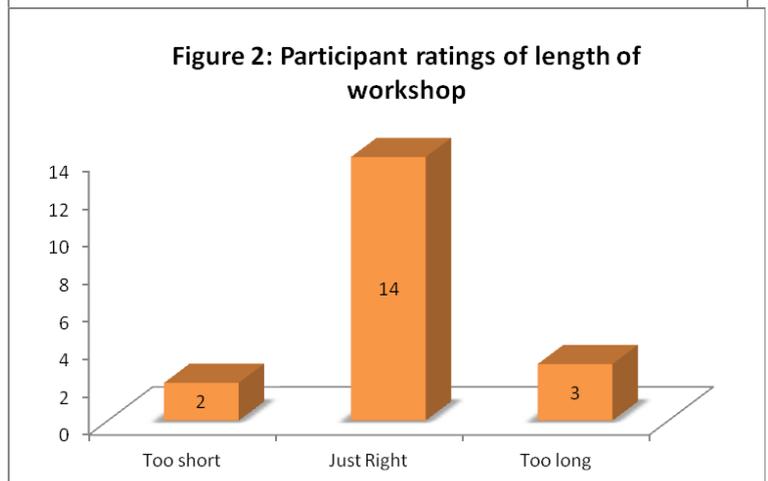
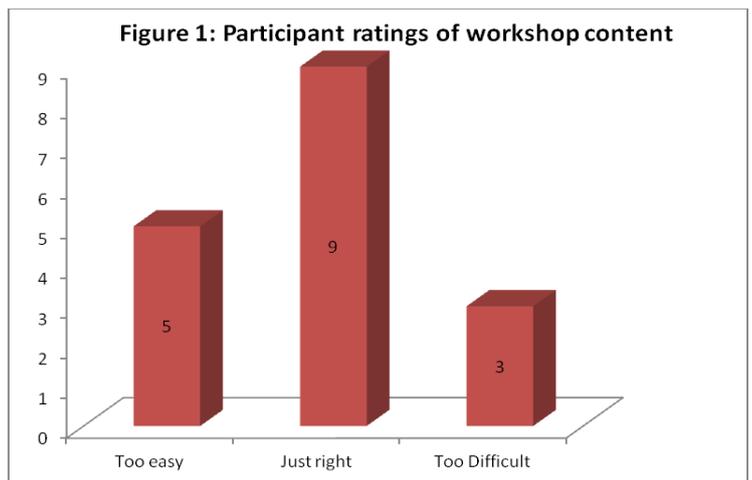


“Rose helping with translating and discussions”

### 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 this workshop was the first that they had attended of this kind. Of interest was an overall sense that the majority of PLH felt that they felt more informed and able to adhere to their medication as a result of their increase in knowledge and problem solving skills. As noted earlier a number of PLH voiced their intention to improve their adherence and adopt healthy lifestyles.

All participants completed anonymous evaluations pertaining to their experience of the workshop. The workshop’s: length, content, knowledge of facilitators and relevance of the workshop all rated positively (see Figures 1, 2, 3, 4). In general the feedback was generally positive but the variance in health literacy reflected the diversity in the room. Suggested future directions included provision of more information on nutritional advice and on ARVs and its impact on HIV and the body.



### Section E - Impact (Ruth/John)

The workshop appeared to have met both its aims and objectives and highlighted an interest from PLWH to explore more on this topic. Developing potential referral pathways and strengthening networks was raised as an area for development. The use of peers in supporting people who are newly diagnosed and/or struggling with adherence was raised repeatedly as an area where more

training and peer models could be developed.

### Section G – Recommendations for future activities (Ruth/John)

Future workshops should be other high prevalence areas or as recommended by Igat Hope.

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.

