

The Waigani statement on HIV Treatments Action

The participants of the Igat Hope National HIV Treatments Workshop held in March 2010 declare that they will work together to bring about urgent changes in the way that HIV treatments are provided and PLHIV on ART are monitored and supported in PNG. The workshop participants included PLHIV, community workers, policy makers, development partners, doctors, nurses and other health care providers. It was supported by a team of people from the National Association of People Living with HIV/AIDS (NAPWA), Australia.

We have identified the following set of key areas that we will focus on. We urge you to support us and join our coalition to bring about these important changes.

Support to people receiving ART

1. PLHIV employed as peer educators and supporters in clinics:

Experienced PLHIV can play a vital role in supporting their peers as they consider, commence and begin to adhere to ART. They can also support PLHIV in other areas such as HIV prevention, nutrition, emotional support, disclosure and PMTCT. Clinics are busy places and there is often limited time for adherence counselling and other forms of support including couple counselling and family support. We will work to have experienced PLHIV trained and employed as part of the clinical team.

There is sometimes a gap between the services that provide VCT, and the services that provide HIV treatments and monitoring. People diagnosed with HIV through VCT often do not find their way to treatment care and support services until they are sick, and they miss the opportunity for early access to ART and OI treatments. We will work to build stronger links between VCT and ongoing treatment, care and support, by advocating for the employment of PLHIV in VCT services to assist newly-diagnosed people to find their way to ongoing treatment, care and support.

We want to stress that access to meaningful work is a key factor in the health of PLHIV. ART make us well, and we need to find ways to be able to return to productive life. This improves health, quality of life and self-esteem and promotes HIV prevention by improving our general wellbeing. We will work with employers and support organisations to find ways for them to train and employ PLHIV to make GIPA real and identify and support innovative income-generating initiatives for PLHIV.

2. Clearer information about the needs of PLHIV in different places:

We need to more clearly understand what PLHIV in different parts of PNG need and what affects their ability to maintain their health, their treatments and their connection to community life. We need more information about the things that prevent PLHIV from accessing the services and the treatments they need. We will work with partners to gather and analyse information on:

- What do PLHIV know about the services that are available to them?
- What makes adherence and attendance at clinics and services difficult for individuals?
- What social supports are now available, or could be made available, and how would we improve them and connect PLHIV better with them?

Prescribing and monitoring of ART

1. Treatments access, awareness and literacy:

We want all PNG PLHIV to know their status and be able to access treatment and monitoring services.

We will work with our partners to remove the barriers to accessing HIV diagnosis and treatment. At the community level, we will advocate for a campaign to urgently make people aware of the need to access HIV diagnosis and effective treatment. We will also work with key health care workers - in TB clinics, in antenatal care and in other general health services - to ensure that they are in the best position to assist PLHIV to get access to HIV testing and treatments.

2. Antiretroviral treatment:

We will work with NDOH to produce materials and messages that promote the best possible treatment choices.

We will work to make clinics more accessible and user-friendly. This will include:

- Shortening waiting times by the use of trained triage nurses to carry out monitoring
- Relieving pressure on clinics by having paid treatments supporters in clinics
- Working with local PLHIV groups to make clinic procedures and practices more user-friendly

- Exploring the development of HIV management committees at major prescribing services (with strong PLHIV representation)

The evidence and the PNG National Treatment Guidelines state that D4T should be phased out, yet we remain concerned it is still being prescribed in some places. We will assist to monitor this phase out.

3. Monitoring:

We support improved access to monitoring tests. We are concerned that access to CD4, Hepatitis B and sputum AFB remains patchy. We support the need for new, cheap and effective viral load technologies and will seek a place for Igat Hope to provide input into the design and implementation of research into these technologies. We advocate for consistent access to urinalysis and pregnancy tests.

4. Follow up:

We will work with our partners to strengthen the continuum of treatment, care and support by introducing it into areas where it is not currently practiced. We will work together to include health maintenance and personal wellbeing issues into routine care and support - malaria prevention bed nets, alcohol and nicotine management strategies and health maintenance.

Like everyone else, PLHIV move from place to place. We need a nationally consistent and timely process for transferring our care from one clinic to another. We want our treatment doctors to transfer out medical histories quickly and efficiently to our new providers. We will develop a standardised transfer form and process to make this transfer more efficient.

We would also like more flexibility in the prescribing system so that if we run short of treatments in a place that is away from our normal treatment site, we can access temporary supplies using our registration card. We will advocate for this.

5. Rural access:

We need more ART prescribers in accredited rural sites in rural areas so that PLHIV can access treatment and care close to where they live. Until we can bring these services close to the people who need them, we will work to:

- Change supply policies and practices - ensuring longer supply (3 months) for people from isolated areas
- Secure financial and other assistance for people who need to travel long distances for treatment
- Advocate for accommodation and local transport services for people who need to stay overnight in the town or city in order to access their treatment.

Supply and distribution of medicines, test kits, reagents and equipment

Consistent access to ART and to monitoring and diagnostic tests is essential to effective treatment and care. It is also an important HIV prevention tool as it lowers the viral load across the entire PLHIV community and improves the health across PNG.

We agree to work on the following:

1. Transparent coordination of the approval, procurement and supply system:

There are significant problems across this system. Our members report inconsistent availability of medicines and diagnostics. We will work to assist the NDOH to convene a National ART Supply and Access Coordinating Committee comprising:

- NDOH staff involved in
 - pharmaceutical regulation
 - procurement and supply (ART, OI, reagents, tests, equipment)
 - ART prescribers and sites accreditation and training
 - Regional ART coordination
- Igat Hope
- Clinton Foundation, ADB, AusAID
- CCM representatives

A key concern is the threat to supply posed by the failure of Global Fund Round 9 application and the interim measures being proposed to maintain supply. This is a key concern of ours and should be a priority item on the agenda of this committee.

2. Ensuring that there is an adequate buffer supply of ART medications in all prescribing sites:

Whilst stock-outs are not officially acknowledged, Igat Hope members report that supply of ARV drugs, OI medications and test reagents is not consistent across prescribing and clinical care sites.

We will work to ensure that all sites maintain an adequate buffer of supplies and that this is regularly monitored by DOH regional ART teams.

3. Effective support of regional teams:

The establishment of HIV Regional Medical Officers (RMOs) to provide mentoring, support and monitoring of local prescribers is a good initiative and can contribute significantly to building more consistent access to and quality of care for PLHIV. We support the proposed inclusion of logistic or pharmacist support in this regional structure. We will work to ensure that these regional teams have the time and resources they need to carry out this important work. We are committed to supporting any decentralisation of the supply system and seek Igat Hope's participation in the development of any plans to decentralise this system.

HIV Treatments Advocacy

1. A Treatments Campaign:

We will advocate for the development and implementation of a campaign to reach PLHIV and inform them about the benefits of ART. This needs to be rolled out as a matter of urgency. This will focus on getting PLHIV back to clinics to be assessed for enrolment in ART and to ensure that they are on the right regime. This is an urgent priority, given the need to enrol as many PLHIV who need ART before end of August 2010.

The campaign will include easy-to-understand materials on HIV treatments in key languages.

2. Strengthening PLHIV personal advocacy

PLHIV who are armed with knowledge and skills can become effective advocates for their own care and for the care of the people around them. We will work to help PLHIV to become more treatments literate and to gain the skills they need to be effective treatments advocates. We will expand this to assist PLHIV to identify and access the full range of services they need for their continued health and wellbeing.

3. PLHIV participation in the response to HIV in PNG:

We want our voice to be heard in relation to HIV treatments. As the people taking these treatments, and expected to adhere to our treatment and monitoring regimes, we have a key role to play in improving the treatments program. We will seek Igat Hope representation on these committees and processes: The National

HIV Strategic Plan Steering Committee (NSP), National AIDS Council (NAC), Research Advisory Committee (RAC), HIV Prevention Task Force, and the Surveillance Technical Working Group.

We will seek formal partnerships with groups such as the Special Parliamentary HIV/AIDS Committee and the Business Coalition Against HIV/AIDS (BAHA).

Some of the issues we would bring to this participation include:

- Becoming partners in the national HIV research agenda, included in identifying what questions need to be answered, how research studies will be designed and conducted and analysed, and how the results of research will be disseminated to communities.
- Revising national treatments guidelines and other guidelines and policies that affect PLHIV
- Ensuring effective treatment, care and support for children with HIV
- Including PEP for sero-discordant couples into the PEP access policy
- Promoting stronger links between home and community care and clinical services