

Positive Health

(Positive Health, Dignity and Prevention)

Moving the agenda forward in the Asia Pacific Region

Satellite meeting at the 9th International Congress on AIDS in Asia and the Pacific, Bali, Indonesia, August 2009

Consultation Report

Introduction

Consultations with people living with HIV on HIV prevention started in Monaco in January 2008 as a prelude to a summit entitled LIVING 2008, which took place before the International AIDS Conference in Mexico in July - August 2008. The sessions on 'positive prevention' at LIVING 2008 generated much debate and controversy. Subsequently, the Global Network of People Living with HIV (GNP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) co-organised an International Technical Consultation in Tunisia in April 2009 where participants agreed on a new concept: Positive Health, Dignity and Prevention. Later in June 2009, the Asia-Pacific Network of People Living with HIV (APN+) held consultations on Positive Health, Dignity and Prevention in Bangkok during their Annual General Meetings.

The series of consultations have been an opportunity to highlight the many health and prevention needs of HIV-positive individuals and to understand the important linkages between prevention, treatment, care, support and human rights. At the International Technical Consultation in April 2009, people living with HIV identified important principles and values for moving the agenda forward. This consultation in Indonesia during the 9th International Congress on AIDS in Asia and the Pacific was an opportunity to further discussions at regional level in a process led by people living with HIV and with key partners.

The meeting, convened by the Indonesian Network of People Living with HIV (JOTHI), APN+, GNP+ and UNAIDS, sought to explore programmatic, policy and research priorities within the Asia Pacific region and to agree on ways to move the issue of 'Positive Health' (the term used in the Asia Pacific region in place of 'Positive Health, Dignity and Prevention') forward through the work of different stakeholders invited to the meeting. The consultation brought together 37 participants representing networks of people living with HIV, civil society organisations, UNAIDS Secretariat and Co-sponsors, development agencies and donor agencies.

Background

Format of the meeting

The half-day meeting was held on 11 August 2009 at the Laguna Resort, Nusa Dua Bali in Indonesia as a satellite meeting of 9th International Congress on AIDS in Asia and the Pacific. It was facilitated by Robert Baldwin and Rico Gustav of APN+. After introductions by Robert Baldwin, Chris Mallouris of GNP+ and Shiba Phurailatpam of APN+, there was feedback from consultations held by APN+, GNP+ and UNAIDS on Positive Health, Dignity and Prevention and an opportunity for participants to clarify their understanding of processes that have occurred to date. Participants then self selected into three groups for specific discussions on prepared questions. Following feedback from each group, the four host organisations summarized the conclusions of the consultation. John Rock and Andrew Tan both from APN+ were rapporteurs for the session.

Introductions

Robert Baldwin welcomed participants and explained the format and the purpose of the meeting, which was to explore programmatic, policy and research priorities within the Asia Pacific region and to agree on ways to move the issue of 'Positive Health' forward through the work of stakeholders at the meeting. He emphasised the importance of advancing the agenda, further defining Positive Health, Dignity and Prevention, and ensuring the adoption and implementation of the concept in the region.

Chris Mallouris of GNP+ gave a short history of how discussions on 'positive prevention' started and have evolved. He described how the process has led to the need for an enlarged dialogue with partners on 'Positive Health, Dignity and Prevention', as well as the need to define what has to happen at operational level.

Shiba Phurailatpam of APN+ referred to concerns about the historical interpretation of 'positive prevention' and its links to issues such as HIV transmission and criminalisation. HIV prevention with people living with HIV must shift from focusing solely on stopping transmission from HIV-positive to HIV-negative people to promoting shared responsibility and the health and wellbeing of people living with HIV.

Previous Consultations

Robert Baldwin provided some background to the International Technical Consultation held in April 2009. The term and concept of 'Positive Health, Dignity and

Prevention’, which was agreed upon during the meeting, highlights the importance of HIV-positive people taking control of their own lives, of recognising human rights as expressed in the word ‘dignity’, and of understanding linkages between treatment and prevention. He explained the set of components, principles and recommendations that came out of the meeting. Participants at the International Technical Consultation were keen to further develop the concept through consultation at regional level and with key populations.

Principles and values of Positive Health, Dignity and Prevention

Positive Health, Dignity and Prevention is defined by people living with HIV and guided by the following values and principles:

- People living with HIV must be leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting us.
- A human rights approach is the foundation of Positive Health, Dignity and Prevention.
- Preventing HIV transmission is a shared responsibility of all individuals irrespective of HIV status.
- Sexual and reproductive health and rights must be recognised and exercised by everyone regardless of HIV status.

Positive Health, Dignity and Prevention:

- Requires a supportive and protective legal and policy environment free of stigma and discrimination.
- Should promote holistic health and wellness, including equitable access to voluntary HIV testing, treatment, care and support services.
- Must improve and maintain the health and wellbeing of people living with HIV, which, in turn, contributes to the health and wellbeing of their partners, families and communities.
- Should include addressing psychosocial, economic, educational and socio-cultural vulnerabilities, gender and sexuality.
- Should be responsive to the needs of key populations and should respect and be tailored to specific contexts and the diversity among people living with HIV.

Components of Positive Health, Dignity and Prevention

- Health promotion and access

- Sexual and reproductive health and rights
- Prevention of transmission
- Human rights, including stigma and discrimination reduction
- Gender equality
- Social and economic support
- Empowerment
- Measuring impact

GNP+ and UNAIDS International Technical Consultation, Tunisia, April 2009

Robert Baldwin also reported on subsequent consultations with the APN+ Positive MSM Working Group and at the APN+ AGM in June 2009. Responses were collected from 16 participants at the Positive MSM Working Group meeting and 15 Board members of APN+ at their AGM. Overall participants embraced a change away from 'positive prevention', which was viewed in a negative light. There was considerable debate about the wording of 'Positive Health, Dignity and Prevention'. It was suggested that when translated into other languages, the words 'Positive Health' would be clearer. Participants also chose to exclude the term 'prevention', which is seen as negative. Following these consultations, the Board of APN+ unanimously passed a motion to ask the APN+ Secretariat to contact GNP+ requesting that consideration be given to using the term 'Positive Health' rather than 'Positive Health, Dignity and Prevention' in the Asia-Pacific region.

Discussions

In order to explore Positive Health, Dignity and Prevention within the Asia Pacific context, three groups were formed with participants self selecting an area of focus:

Group 1: Programmes – how we operationalise Positive Health?

Group 2: Policies – how do we overcome barriers than hinder progress on Positive Health?

Group 3: Research – what more do we need to know to advocate for evidence- based Positive Health programmes and policies?

Programmes – how do we operationalise Positive Health?

Examples of existing programmes and good practice in the area of Positive Health

Participants highlighted a preference for programmes to be community owned and led. They emphasised the role of peer groups in providing social and psychological support. These encourage people living with HIV to take control of their own health. The Thai network of people living with HIV was put forward as an example of good practice in this area.

The following examples were put forward highlighting good practice in service provision: STI and TB screening, hepatitis C treatment, removing barriers to the provision of anti-retrovirals, promoting condom use, and decentralised secondary needle exchange distribution centres. India's 'Test and Treat campaign' was suggested as good practice because of the comprehensive health services available to communities (with the limitation that there was a reported 70% drop out rate). Participants gave the example of MMM in Cambodia, which provides a continuum of care including counselling and adherence through home visits and other support. Participants highlighted the opportunity to advocate for integrated and appropriate services through the framework of Positive Health.

Education and access to information were identified as important elements of HIV programmes. Participants shared examples of promoting 'know your rights' campaigns through an entertaining approach that takes into consideration language and gender-related issues, and conveys messages through film. They felt that current examples of good practice also include empowering people living with HIV to demand for health services and community monitoring of access to HIV treatment.

Promoting and documenting good practice

Participants emphasised the importance of monitoring both activities and outcomes when documenting good practice. There are some areas of good practice that are poorly documented, including programmes that enhance knowledge of human rights, and programmes that empower men who have sex with men, sex workers and people who use drugs to access necessary services. Case studies of good practice on training for healthcare providers would be useful in monitoring the provision of appropriate services.

Policies – how do we overcome barriers that hinder progress on Positive Health?

Challenges in implementing Positive Health programmes

Participants in Group 2 identified unsupportive legal environments and the criminalisation of sex work, homosexuality and drug use as issues that affect all key populations and that challenge the implementation of Positive Health programmes. Additionally, cultural and religious beliefs and practices can influence policy, which then creates challenges for implementing comprehensive programmes. Other challenges include insurance policy exclusions, the non-standardisation of guidelines and policies, and a lack of policies that address Positive Health holistically, in other words policies that focus on the transmission of the virus rather than the health and well-being of the person living with HIV.

Implementing Positive Health requires an understanding of the GIPA principle (the greater involvement of people living with HIV at all levels of the HIV response). When this is not applied uniformly or meaningfully, people living with HIV do not own and drive the programmes and the HIV response is less effective. The GIPA principle also needs to be extended to include the meaningful participation of key populations.

Actions that can be taken to address them

Several actions to address unsupportive environments and criminalisation were defined:

- Mapping existing guidelines, policies and laws in place to support people living with HIV to maintain their health and promote their dignity;
- Researching and documenting impeding laws, cases of criminalisation and their impact, and violations of existing laws; and
- Building partnerships and developing advocacy plans to promote holistic Positive Health programmes.

To address the lack of standardisation of guidelines and policies there needs to be a review and analysis of existing policies and guidelines and an identification of good policy and best practice.

In implementing and extending the GIPA principle, it is important to empower people living with HIV to articulate the needs and experiences of communities in a way which informs the development of appropriate and effective programmes and policies. This should be extended to other community groups, including networks of men who have sex with men and people who use drugs. Promoting networks of people living with HIV and mobilising resources for community development is essential if this is to succeed.

Partners we work with to assist us

Effectively addressing legal barriers involves working with coalitions of legal experts and UN and development agencies and funders. Partnerships with parliamentarians are essential in promoting Positive Health in political fora.

Important partners in addressing the lack of standardisation of guidelines and policy include international law organisations, technical agencies such as the WHO and UNAID, national authorities, research organisations, and national expert and stakeholder organisations. Country to country collaboration is useful in developing guidelines and processes.

Partners in promoting the application of the GIPA principle include civil society, key populations, organisations and networks of people living with HIV and donor agencies.

Research – what more do we need to know to advocate for evidence-based Positive Health programmes and policies?

Missing evidence

Participants in Group 3 felt there remains a lack of evidence about the real experiences of people living with HIV. Tools, such as the Stigma Index, are useful in capturing individual testimonies in a systematic way. These tools should be rolled out across the Asia Pacific region and over time to monitor trends and the impact of interventions.

Participants also felt that further research needed to be conducted into access to services, particularly for people living with HIV who identify with key populations such as sex workers, men who have sex with men or people who use drugs.

Operational research into environmental barriers to Positive Health must be conducted in order to inform the development of appropriate interventions. As part of this research, it is important to review the involvement of people living with in decision-making in the national HIV response.

Partners we work with to address gaps in research

Networks of people living with HIV and key population groups should contribute to setting the research agenda and should lead community-based research. Existing research methodologies and tools, such as the Stigma Index (global), should be resourced and rolled out in more countries by people living with HIV and key populations, in collaboration with local research institutions and development agencies.

How we do it

Networks of people living with HIV must demand operational research driven by people living with HIV. UN and development agencies and national implementers have a role to play in promoting and supporting this research.

The findings from operational research can be used as advocacy tools with the reports and advocacy material tailored to different audiences. The results should be used in designing and improving programmes, which improve the quality of life of people living with HIV and enable an environment conducive to achieving Positive Health.

Outcomes of the discussion

The key messages from the discussions were summarised by spokespeople from each of the hosting organisations – JOTHI, APN+, GNP+ and UNAIDS.

Yogie Wirastra stated that for JOTHI and in the Indonesian context, Positive Health was a new way of looking at HIV prevention as it relates to people living with HIV and it will be a challenge to change people's thinking in operationalising it. However, they welcome the shift in thinking and look forward to identifying practical ways of implementing it through their countries' policies and programmes.

Robert Baldwin spoke on behalf of APN+ pointing to the need for more research to be conducted, building on that already undertaken by APN+ in the areas of access to services and treatment for people living with HIV, and stigma and discrimination. He said that a global effort was required for such research and the results need to be used effectively for advocacy. Existing programmes need to be evaluated and Positive Health must be the basis of future programmes. He referred to the importance of an enabling environment for implementing Positive Health.

Chris Mallouris of GNP+ said that Positive Health is a framework, which we need to articulate and incorporate into all policies and programmes that relate to people living with HIV. Through consultation with partners, such as UNAIDS, we need to advocate at global, regional and national levels for the framework to be universally adopted.

Andrew Doupe of WHO spoke on behalf of UNAIDS and pointed out that Positive Health is a two way dialogue. There is strong support from UNAIDS for a rights-based approach to HIV programming. Additionally, people living with HIV must demand that

their rights are recognized. Positive Health is meant to be inclusive of all the aspects that affect the health and well being of people living with HIV.

Conclusion

Positive Health is a useful framework, which can inform the development and implementation of HIV policies and programmes. Participants at the consultation overwhelmingly endorsed a shift away from the focus on HIV transmission to a holistic interpretation of health and wellbeing. They embraced the change of terminology and the principles and components of Positive Health, Dignity and Prevention, as identified at the International Technical Consultation in April 2009. This consultation was the beginning of a dialogue driven by people living with HIV. APN+, in collaboration with national networks of people living with HIV, GNP+, UNAIDS and other partners, will continue consultation to identify concrete strategies to move the agenda of Positive Health forward in the Asia Pacific region.

The consultation report was written by John Rock and Andrew Tan, with support from Robert Baldwin, Georgina Caswell, Rico Gustav, Chris Mallouris and Shiba Phurailatpam.

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