

A stylized sunburst or starburst pattern in a lighter shade of blue, centered behind the text.


Living  2008

The Positive Leadership Summit

Summit report

Mexico City

31 July – 1 August 2008



Published by:
The Global Network of People Living with HIV/AIDS (GNP+)
P.O. Box 11726
1001 GS Amsterdam
The Netherlands

Website: <http://www.gnpplus.net>
Conference website: <http://www.LIVING2008.org>
E-mail: infognp@gnpplus.net

Some rights reserved: This document may be freely shared, copied, translated, reviewed and distributed, in part or in whole, but not for sale or use in conjunction with commercial purposes. Only authorised translation, adaptation and reprints may bear the emblems of LIVING2008 and/or individual partners in the LIVING2008 partnership. Enquiries should be addressed to GNP+, P.O.BOX 11726, 1001 GS, Amsterdam, The Netherlands, infognp@gnpplus.net.

© April 2009. The Global Network of People Living with HIV/AIDS (GNP+)

Suggested citation: LIVING 2008 Partnership: GNP+, IAS, ICASO, ICW, IFRC, International HIV/AIDS Alliance, IPPF, Mexican Network of People living with HIV, Sidaction, UNAIDS, WHO. 2009. *LIVING 2008: The Positive Leadership Summit, Summit report*. Amsterdam, GNP+.



Living 2008

The Positive Leadership Summit

Summit report

Mexico City

31 July – 1 August 2008

List of acronyms and abbreviations

ARVs	Antiretrovirals
CBO	Community-based organization
SW	Sex worker
GNP+	Global Network of People Living with HIV/AIDS
GIPA	Greater Involvement of People Living with HIV/AIDS
IAC	International AIDS Conference
ICW	International Community of Women Living with HIV/AIDS
IDU	Injecting drug user
IPPF	International Planned Parenthood Federation
MSM	Men who have sex with men
PLHIV	People living with HIV
RCRC+	Red Cross and Red Crescent PLHIV network
RedLa+	Latin American Network of People Living with HIV
SRHR	Sexual and reproductive health and rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

Table of contents

I. Introduction	4
II. Acknowledgements	5
III. Executive summary	6
IV. Background, meeting agenda and objectives	8
1. Background	8
1.1. Earlier PLHIV gatherings	8
1.2. The road to LIVING 2008 in Mexico	9
2. Context of the Summit	10
3. LIVING 2008: The Summit agenda and objectives	10
V. Meeting proceedings	11
1. Opening ceremony	11
2. Press conference	12
3. Opening plenary: The LIVING 2008 advocacy themes	13
3.1. Presentation of LIVING 2008 advocacy themes	13
3.2. Positive Leadership	14
4. Regional Reports Back	14
4.1. Anglophone Africa	14
4.2. Asia and Pacific	14
4.3. Caribbean	15
4.4. Eastern Europe and Central Asia	15
4.5. French speaking countries Africa, Caribbean and Europe	15
4.6. Latin America and the Caribbean	15
4.7. Middle East and Northern Africa	16
4.8. North America and Europe	16
5. Reports back by the thematic working groups	17
5.1. Access to treatment, care and support	17
5.2. Sexual and reproductive health and rights	18
5.3. Criminalization	19
5.4. Positive Prevention	20
6. Evaluation	22
7. Conclusions and next steps	22

I. Introduction

At present, there are more than 33 million people living with HIV (PLHIV) around the world¹. Living with HIV in the year 2008 is dramatically different for people depending on where they live, their gender, their sexual orientation, their income, their education, their access to information and health services and other factors. Nevertheless, in a unique exercise from September 2007 until July 2008, PLHIV from around the world came together to prioritize four key areas of interest to all members of the diverse community of PLHIV globally.

The four themes identified by the PLHIV community as its current main advocacy themes are:

- Universal access to HIV treatment, care and prevention
- Sexual and reproductive health and rights (SRHR) of PLHIV
- Criminalization of the transmission of HIV
- Prevention, with a focus on positive prevention

This report documents the LIVING 2008 proceedings and how each of these themes is crucial to the lives and survival of PLHIV. It also explores how PLHIV are continuing to advocate and develop programmes that meet the challenges in these four key areas.

¹ UNAIDS 2007 AIDS Epidemic Update.

http://data.unaids.org/pub/EPIslides/2007/2007_epiupdate_en.pdf

II. Acknowledgements

The LIVING 2008 Partnership wishes to acknowledge the generous financial support for LIVING 2008 by the following organizations:

AIDS 2008, Bill & Melinda Gates Foundation, Canadian International Development Agency, Ford Foundation, the French Ministry of Foreign Affairs, GlaxoSmithKline's Positive Action Programme, International HIV/AIDS Alliance, International Planned Parenthood Federation, Irish Aid, Norwegian Royal Ministry of Foreign Affairs, Sidaction, Tibotec, UNAIDS, The William and Flora Hewlett Foundation, and the World Health Organization.

In addition, the LIVING 2008 Partnership expresses its gratitude for the important contributions of all speakers, facilitators, working group rapporteurs and other contributors to the LIVING 2008 summit. Special thanks go to the AIDS 2008 volunteers who gracefully donated their time to support the Summit.

Without all of these contributions, LIVING 2008 would not have been possible.

III. Executive summary

*“There is life after HIV, there is hope. There is sex after HIV.
There is a lot of pride after HIV.”*

Jorge A. Saavedra López, Director General, National Centre for the Prevention
and Control of HIV/AIDS (CENSIDA), Mexico

LIVING 2008 – organized by the LIVING 2008 partnership - was a momentous event, the first gathering of positive leaders from around the world in five years. It was an opportunity to take stock of where the PLHIV movement stands, what its challenges are and how to react to them, and where to go from there. The preparations for LIVING 2008 included a gathering of 40 HIV positive leaders entitled “HIV+ Monaco” held in Monaco from 24-26 January 2008. One of the main achievements of the Monaco meeting was the identification of four key advocacy themes around which the deliberations of LIVING 2008 would be centered. These four themes are:

- Universal access to HIV treatment, care and prevention
- SRHR of PLHIV
- Criminalization of the transmission of HIV
- Prevention, with a focus on Positive Prevention

In addition, the LIVING 2008 partnership organized an e-consultation² between June and July 2008 that engaged a diverse group of PLHIV from different parts of the world to discuss issues pertinent to the four themes of the Leadership Summit.

The Summit gave delegates an opportunity to discuss the four advocacy themes in depth and issue recommendations for the way forward. With regard to **universal access to treatment, care and support**, the LIVING 2008 participants re-iterated that access to treatment is a fundamental right. In light of improved access of PLHIV to antiretro-

virals (ARVs), issues of care and support are gaining greater prominence and importance. LIVING 2008 participants requested better training of health care providers and called on national governments to establish sound standards regarding access to treatment, care and support. They also called on PLHIV to get actively involved in their care and become experts regarding their own health. LIVING 2008 delegates called on national governments to ensure expeditious and reliable procurement and distribution chains of ARVs and commodities throughout the national health systems.

In the area of **SRHR**, the LIVING 2008 delegates underscored that the needs of PLHIV are diverse. PLHIV need greater awareness regarding their SRHR and should be further empowered to advocate for them. Any promotion of the SRHR of PLHIV needs to be firmly anchored in the human rights approach. LIVING 2008 participants made concrete recommendations to improve the level of information and status of SRHR of PLHIV, such as the revision of discriminatory laws and creation of laws promoting SRHR of PLHIV, and the creation or strengthening of regional or local initiatives to fight stigma and discrimination. The LIVING 2008 participants issued a clear appeal to PLHIV around the world to be pro-active. PLHIV should resolutely claim their SRHR and get dynamically involved in their promotion and advocacy, e.g. by joining SRHR organizations.

² For a summary of the e-consultation, refer to:

http://www.gnpplus.net/component/option,com_docman/task,doc_download/gid,288/Itemid,53/

LIVING 2008 participants were in complete consensus that **criminalization** of HIV transmission had a negative effect on the well-being and sexual and reproductive rights of PLHIV and was not a sound public health solution to HIV transmission. In order to change attitudes towards this issue, the PLHIV community needs to work closely with stakeholders such as lawmakers, representatives of the criminal justice system, media and health care providers, including medical doctors. PLHIV need more awareness of laws, regulations and practices and need to mobilize in order to respond to the global growth of criminalization legislation. LIVING 2008 participants recommended, among other things, to conduct a systematic review of laws criminalizing HIV transmission and the effect of these laws on the well-being and sexual and reproductive rights of PLHIV.

In the area of **positive prevention**, LIVING 2008 participants were not able to reach consensus. The main stumbling blocks were terminology and the fears of PLHIV that positive prevention as a concept might focus too much on the responsibility of PLHIV for transmitting HIV, and not their physical and mental well-being. There is no commonly shared and agreed on definition of the term positive prevention and significant work is necessary to define the term if it is to be used in the future. More discussions are needed for the PLHIV movement to take ownership of this concept and make it work. LIVING 2008 participants recommended, among other things, that the concept of positive prevention incorporates – as its central building stone – the element that prevention should always be a shared responsibility of all partners, irrespective of their status.

LIVING 2008 participants issued a clear call to action to all PLHIV around the world to become more involved, be it in becoming experts regarding their own health, actively requesting the enjoyment of their SRHR, or in making themselves knowledgeable regarding criminalization. This, however, will require further empowerment and capacity building for the PLHIV community.

In summary, LIVING 2008: The Positive Leadership Summit was a re-affirmation of PLHIV leadership. It successfully focused the attention on main issues of concern for PLHIV and created renewed momentum for the PLHIV movement. The challenge now will be to move forward and act on the recommendations issued by PLHIV from around the world.

IV. Background, meeting agenda and objectives

1. Background

1.1. Earlier PLHIV gatherings

International PLHIV conferences have been held regularly in various locations around the world since 1986, the latest ones in Poland (1999), Trinidad and Tobago (2001), and Uganda (2003). These meetings were seen as successful in terms of bringing together hundreds of PLHIV from around the world in a safe and empowering environment contributing to a strengthening of the PLHIV movement. However, the International PLHIV Conference that was planned for Lima/Peru in 2005 – and which was supposed to be merged with the Home and Community Care Conference – was postponed and then eventually cancelled due to financial constraints. To re-affirm the commitment to this kind of global gathering, several organizations convened by the Global Network of People Living with HIV/AIDS (GNP+) formed the **LIVING 2008 Partnership**. This Partnership – initiated in May 2007 – is a consortium of organizations committed to strengthening the PLHIV movement and its communities. It is composed of the following organizations:

- Global Network of People Living with HIV/AIDS (GNP+)
- International Community of Women Living with HIV/AIDS (ICW)
- International Council of AIDS Service Organizations (ICASO)
- International HIV/AIDS Alliance
- International AIDS Society (IAS)
- International Federation of Red Cross and Red Crescent Societies (IFRC)
- International Planned Parenthood Federation (IPPF)
- Mexican Network of People Living with HIV
- Sidaction
- Joint United Nations Program on HIV/AIDS (UNAIDS)
- World Health Organization (WHO)

Because it considers these regular PLHIV gatherings as a vital component of the global HIV response, the LIVING 2008 Partnership proposed that an international PLHIV gathering be held immediately prior to the International AIDS Conference (IAC) 2008. **LIVING 2008: The Positive Leadership Summit** was held in Mexico City, Mexico, from 31 July – 1 August 2008 as an official pre-conference of the IAC 2008. It brought together 267 PLHIV leaders from 82 countries around the world.

LIVING 2008 was a “stand-alone” Positive Leadership Summit but logistically and programmatically linked to the IAC 2008. Being a conference for PLHIV, all the delegates were PLHIV. The IAS joined the LIVING 2008 Partnership to facilitate open communication between all key organisations involved in planning for LIVING 2008 and the IAC 2008. GNP+ – as the only worldwide network of PLHIV – coordinated and facilitated the planning and operation of LIVING 2008. All other organisations in the LIVING 2008 Partnership were equally committed to making LIVING 2008 a success, especially in engaging their networks and partners at global, regional, country and community levels.

“When I look around me and see so many people with so much experience in this room I am amazed! Some of them have lived for over than 20 years with the virus in countries where treatments are not always available. They have fought against stigma and discrimination, lost their jobs, apartments, families, and yet, they’re here, experts!”

Dr. Kevin Moody, International Coordinator/Chief Executive Officer GNP+
Remarks during HIV+ Monaco conference

1.2. The road to LIVING 2008 in Mexico

In preparation for LIVING 2008, a gathering of 40 HIV positive leaders entitled “HIV+ Monaco” was held in Monaco from 24-26 January 2008³. HIV+ Monaco was hosted by Her Serene Highness Princess Stephanie of Monaco in her role of Founding President of Fight Aids Monaco (F.A.M.) and UNAIDS Special Representative. The motto of the meeting was “From Monaco to Mexico: Ignite the Passion”. It was the beginning of the LIVING 2008 pre-consultation process, and an important first step towards the development of a unified PLHIV advocacy agenda.

The conference’s main goal was to provide a unique and innovative opportunity for the PLHIV movement to reflect on how it can improve knowledge and information exchange, as well as enhance the collaboration among PLHIV groups at country, regional and global levels. It kicked off a process that would support the achievement of the LIVING 2008 outcomes.

HIV+ Monaco participants were selected by the LIVING 2008 partnership from international, national and community level networks and organizations of PLHIV. This conference provided a unique opportunity for key leaders within the PLHIV networks internationally to discuss relevant technical issues; devise mechanisms for implementing ongoing consultations around these issues; and to undertake preparations for LIVING 2008, including finalizing conference format and content, and select facilitators and speakers.

One of the main achievements of the Monaco meeting was the identification of **four key advocacy themes** around which the deliberations of LIVING 2008 would be centered. These four themes are:

- Universal access to HIV treatment, care and prevention
- SRHR of PLHIV
- Criminalization of the transmission of HIV
- Prevention, with a focus on positive prevention

In order to prepare LIVING 2008, HIV+ Monaco mapped out a process from Monaco leading up to the Mexico summit. This process comprised planning meetings as well as a parallel set of face-to-face consultations and a moderated e-consultation, which were organized by the LIVING 2008 Partnership and held between April and July 2008. The consultations engaged a diverse group of PLHIV in discussing issues pertinent to the four themes of the Leadership Summit. The face-to-face consultations were developed by the LIVING 2008 Partnership and by the thematic Working Groups. The e-consultation process – the first of its kind - revealed key lessons, success factors and challenges. Although the volume and depth of the e-consultations varied between thematic groups, it allowed PLHIV to shape the issues and agenda of LIVING 2008.⁴

Overall, both types of consultations provided valuable input from diverse PLHIV constituencies from around the world regarding their opinions and attitudes towards the four themes. This feedback was crucial in guiding the conference discussions at LIVING 2008. The consultations also laid the groundwork for a continuous and systematic consultative process by and for PLHIV on key existing and/or emerging issues. It is planned to use both consultation methods – with improvements - in the future for such purposes.

³ For a detailed meeting report, please refer to <http://hivmonaco.living2008.org/>

⁴ For a summary of the e-consultation, refer to:

http://www.gnpplus.net/component/option,com_docman/task,doc_download/gid,288/Itemid,53/

2. Context of the Summit

LIVING 2008 took place at a crucial point in time for the PLHIV movement. Vibrant and globally present, the PLHIV movement needs to further build its capacities and is in search of new, fresh leadership. The current PLHIV leadership is confronted with the challenge of drawing in a new generation of positive leaders at the global, regional and country levels. It is crucial for the PLHIV movement to connect better with young people living with HIV, to find incentives for them to become involved in the PLHIV movement and to build their capacity to excel and inspire as positive leaders.

On the other hand, when it comes to HIV and AIDS, the epidemic is also at a momentous stage. For the first time, concrete progress and reverses in the epidemic have been recorded. Global funding for HIV and AIDS – albeit still insufficient – is at an all time high. With this, however, comes increased attention and demands on the HIV and AIDS response. There is a focus – not least among funders – on evidence-based programming, results, accountability and sustainability. The PLHIV movement has to react to this new environment. This means a further professionalization of the movement, greater capacity building for positive leaders and an effort to focus on measurable results and demonstrating accountability.

For a report on where the HIV and AIDS epidemic stands and suggestions for the way forward in the response, please refer to the Executive Summary of the 2008 Report on the global AIDS epidemic:

http://data.unaids.org/pub/GlobalReport/2008/JC1511_GRO8_ExecutiveSummary_en.pdf

3. LIVING 2008: The Summit agenda and objectives

The objectives of LIVING 2008 were:

- 1.** To identify and discuss current key issues for the PLHIV movement, including:
 - Universal access to HIV treatment, care and prevention
 - SRHR of PLHIV
 - Criminalization of the transmission of HIV
 - Prevention, with a focus on positive prevention
- 2.** To caucus and develop common positions and strategies on key priorities to take forward into AIDS 2008 and assist PLHIV to prepare for AIDS 2008.
- 3.** To develop technical and leadership skills in PLHIV as part of the ongoing effort to strengthen the PLHIV movement's ability to contribute to the AIDS response in countries.
- 4.** To ensure the issues, outputs and decisions identified during the conference that require attention and action are recorded and followed-up in a timely manner by the LIVING 2008 Partnership, and especially the international networks of PLHIV.

- 5.** To disseminate key messages developed by PLHIV on the four themes to and through the media.

Cross-cutting issues of LIVING 2008 were women and most at-risk groups. Overarching issues included:

- Addressing gender inequality.
- Increasing involvement of young people living with HIV.
- Stigma and discrimination.
- The greater involvement of people living with HIV (GIPA); and
- Creating effective partnerships.

The LIVING 2008 meeting agenda can be found in the annex.

The meeting format was a mixture of speeches and presentations, facilitated discussions in working groups, and reporting back by working groups.

V. Meeting proceedings

“Discrimination against PLHIV is not negotiable.”

Dr. Peter Piot, Executive Director, UNAIDS
Opening remarks at LIVING 2008

1. Opening ceremony

LIVING 2008 began with opening remarks by Eric Fleutelot, Anuar Luna, Deborah Williams and Dr. Peter Piot.

In his remarks, **Eric Fleutelot**, Deputy Chief Executive Officer, Sidaction, thanked the more than 300 participants from 88 countries for taking the (long) journeys to Mexico. Since this was the first PLHIV summit in 5 years, it was a tremendous opportunity to renew and strengthen the PLHIV movement, and confront new as well as old challenges, he said. Mr. Fleutelot stressed the importance of fostering new PLHIV leadership and the need to represent vulnerable communities, such as sex workers (SW), injecting drug users (IDUs), and young people. Guided by the four main areas developed during the Monaco meeting, LIVING 2008 would define what the PLHIV movement knows, where its knowledge gaps are, what the movement agrees on and not - and based on that develop new strategies.

Anuar Luna, Mexican Network of People Living with HIV and AIDS, and National Focal Point of the Latin American Network of People Living with HIV (RedLa+), opened his remarks by saying that his personal journey as a person living with HIV had been challenging but empowering. He stressed the crucial importance of working with the media for the PLHIV movement. Hosting the IAC was a great opportunity for Mexico and Latin America. As major issues in the response to HIV and AIDS in Latin America, Mr. Luna pointed out: men who have sex with men (MSM) and the lack of services for this group; the

fight against homophobia; gender-based violence; the feminization of HIV and AIDS; issues of young people and indigenous populations; and the continued fight for human rights. Mr. Luna stressed the challenge of keeping the political commitment for the HIV and AIDS response and the PLHIV movement sustained, and expressed the hope that LIVING 2008 would be a watershed in the PLHIV agenda.

The Chair of the GNP+ Board, **Deborah Williams**, speaking on behalf of the LIVING 2008 partnership, reminded the participants of the special importance of the LIVING 2008 summit since the summit planned for 2005 had to be postponed. She thanked UNAIDS for generously supporting the Monaco meeting as well as the LIVING 2008 partners for honouring the GIPA principle. She also acknowledged the great efforts of the host country Mexico in support of the LIVING 2008 summit. Ms. Williams underscored that the e-consultation that took place for the first time in preparation of LIVING 2008 made this summit unique. It allowed PLHIV to shape the issues and agenda of the summit and provide overall input. She expressed the hope that this kind of consultation would continue in the future and be expanded to include as many voices of PLHIV as possible, including rural women, SWs, and IDUs. She opined that LIVING 2008 might not be able to resolve all PLHIV issues or deliver consensus. However, the Summit would be a great opportunity for the PLHIV movement to create an environment of change and move the PLHIV agenda forward.

In his welcome note as VIP speaker, **Dr. Peter Piot**, Executive Director, UNAIDS, emphasized that the HIV and AIDS epidemic was not about statistics but about people. There was no effective response to HIV and AIDS without the involvement of PLHIV. The PLHIV involvement has transformed the response to HIV and AIDS but has also had a wider impact in many societies, e.g. in the struggle for democracy. It has given a voice to people without a voice or power. In light of recent progress in the response to HIV and AIDS, he reminded the PLHIV movement to continue with a daring, bold agenda and not to set its targets too low. As particular areas needing the contribution of PLHIV he highlighted access to treatment; prevention; and stigma and discrimination. Dr. Piot stressed that UNAIDS continued to be fully committed to the GIPA principle. He said that he was proud of the achievements of UNPLUS, a UN-internal staff representation group striving to ensure that the rights of UN staff living with HIV are respected. He mentioned that it was a meeting with UNPLUS representatives that touched the heart and brain of the present UN Secretary-General Ban Ki-moon and planted the seed of his AIDS activism. In terms of the future response to HIV and AIDS, he said it was important to keep HIV and AIDS on the political agenda and to ensure that new leaders are brought in. As critical issues

for the PLHIV movement he noted:

- Support of new leadership and involvement of young people living with HIV.
- Strengthening of PLHIV movements in the South, in particular regarding sexual minorities and women.
- Creation of new alliances, for example with the human rights movement, SWs and IDUs.
- Accountability of the PLHIV movement, e.g. by setting specific and measurable objectives, targets and timelines.

In concluding, Dr. Piot stressed that UNAIDS will be committed to positive leadership even after his departure as Executive Director but that it would be crucial for the new UNAIDS Executive Director to be connected early on into his tenure with the PLHIV movement.

2. Press conference

The LIVING 2008 press conference took place in the morning of the first day of LIVING 2008. The panel answering questions by journalists consisted of: Beri Hull, Global Advocacy Officer, ICW; Anuar Luna, Mexican Network of People Living with HIV and AIDS and National Focal Point for RedLa+; Peter Piot, Executive Director, UNAIDS; and Kokouvi Augustin Dokla, President of the Togo Network of People Living with HIV and AIDS and member of the Red Cross and Red Crescent PLHIV network (RCRC+).

The attendance of the press conference was considerable and included journalists from the following media organizations:

- Wire service: AFP, AP, EFE and Inter Press Service.
- Television: CNN Spanish and two local Mexican channels (Channel 22 and Channel 5).
- Written media: 14 journalists from local Mexican newspapers and specialized magazines, and 9 journalists from newspapers and magazines from countries in Latin America.
- Web media: 6 journalists from Mexican and regional e-media.

In terms of interviews, 12 interviews were conducted during LIVING 2008 with regional, i.e. Latin American, and local media from Mexico. These interviews provided

a good opportunity to share key messages and address issues of concern to the PLHIV community. In addition, 6 journalists living with HIV from Brazil, Canada, France and the United Kingdom covered LIVING 2008. Each of them wrote stories around the LIVING 2008 advocacy themes as well as the summit in general. These stories were disseminated to their media lists in their respective countries. 2 press releases highlighting LIVING 2008 and its topics were disseminated to mass media. In addition, 50 press kits in Spanish, 30 in English, and 20 in French were handed out to local and international journalists both at the summit and at the IAC LIVING 2008 Special Session. 5 international journalists attended the IAC Special Session.

3. Opening plenary: The LIVING 2008 advocacy themes

The deliberations at LIVING 2008 were centered on four advocacy themes that were defined at HIV+ Monaco in January 2008.

These four themes are:

- Universal access to HIV treatment, care and prevention.
- SRHR of PLHIV.
- Criminalization of the transmission of HIV.
- Prevention, with a focus on positive prevention.

In addition, the theme of Positive Leadership was discussed.

3.1. Presentation of LIVING 2008 advocacy themes

In an opening plenary, the four themes were introduced. The objectives of this opening plenary were:

- To raise awareness of the LIVING 2008 advocacy agenda.
- To broadly discuss the advocacy themes.
- To set the scene so that all delegates had a sense of where we came from, and where we want to go from here.
- To orientate delegates for the afternoon's regional breakouts.

The presentations were structured as follows: What we know (evidence); what we do not know (lack of evidence); where there is consensus; where there is disagreement (and more work needed to get to consensus); and the 5 key messages on the theme.

In his presentation on access to treatment, care and support, Alain Volny-Anne, Secretary, European AIDS Treatment Group, and Actions Traitement (France), emphasized that access to treatment works. It overcomes stress and depression, keeps families together and can ensure that babies of HIV positive mothers are born HIV negative.

As major current issues, he pointed out:

- Broadening the access to treatment, care and support agenda by not narrowly focusing on treatment issues.
- Reclaiming the access to treatment, care and support agenda by PLHIV.
- Procurement and distribution issues of ARVs and other medications for PLHIV.

As a question to the LIVING 2008 delegates he posed: Can there be universal access to treatment, prevention and care without universal standards?

Kevin Osborne, Senior HIV Advisor, IPPF, in his presentation regarding **SRHR of PLHIV**, posed the

following questions: Do we really know what SRHR for PLHIV means? Do we, as a community and at the personal level, own this term? What do SRHR exactly mean for everybody at the individual level? He said that SRHR should entail the right to information and services, and the right to choice. He stated that it was a positive development that SRHR of PLHIV had become part of the international HIV and AIDS agenda but that there was a need to make the issue more specific at the individual level. As key SRHR issues he underscored:

- Emphasize the importance of SRHR in light of greater access to treatment.
- Linking SRHR of PLHIV with other fields, such as criminalization.
- Ensure the principle of shared responsibility with regard to sexual health, and reject the notion that PLHIV are in charge of the health of others.

With regard to **criminalization**, Julian Hows, LIVING 2008 delegate, stated that PLHIV know the following:

- Prosecutions of PLHIV are increasing.
- In Europe, in particular, the situation has become more severe, and more countries in Africa are following.
- Even exposing an HIV negative partner without actual transmission is punishable in some places, e.g. Switzerland.
- The burden for preventing HIV transmission is laid solely on the person living with HIV.

He said there was existing evidence that criminalization adds an extra burden on the lives of PLHIV and that there was a huge knowledge and skills gap among PLHIV regarding this issue. PLHIV shared consensus that criminalizing HIV transmission sends the wrong message as PLHIV being "irresponsible" and that it creates a climate of fear and discrimination. There was also consensus that wilful HIV transmission should be punishable but no consensus on how that should occur.

As key issues for PLHIV regarding criminalization he pointed out:

- All PLHIV should become aware of the issue.
- Need to link criminalization with other areas, such as SRHR, positive prevention, access to care, treatment and support, and human rights.
- Discuss the vision of a world free of criminalizing HIV transmission.

In her discourse regarding **positive prevention**, Philippa Lawson, Senior HIV/AIDS Advisor, Constella Futures, stated that in basic terms "what we know about positive prevention is that we don't know a whole lot", meaning that there was no consensus in the PLHIV community regarding this concept. In order to provide more guidance

on positive prevention, she pointed out a recently written concept paper on positive prevention that contains, among other things, an extensive literature review, an advocacy brief, and case studies on positive prevention. In terms of what the PLHIV community knows, she pointed out:

- Prevention, treatment and care together form the comprehensive approach to HIV and AIDS.
- Positive prevention has been practiced for a long time but has been named like this only recently.
- Organizations like UNAIDS and WHO coined the term positive prevention.⁵

In terms of what the PLHIV community does not know, she pointed out:

- When on ARVs, can PLHV still transmit HIV?
- Under which circumstances can PLHIV be re-infected or super-infected with HIV?
- What role do new prevention technologies (NPTs) play in positive prevention?

3.2. Positive Leadership

Prior to the summit, an online survey was conducted with all LIVING 2008 delegates inviting them to contribute their views and perceptions on Positive Leadership.

4. Regional Reports Back

At the end of day one, representatives from each region reported back to the Summit from the regional discussions on a key point from each advocacy working paper.

This section summarizes the main points highlighted by the different regions.

4.1. Anglophone Africa

Regarding access to treatment, care and support:

- There is a lack of supportive legal frameworks.
- There is a need to improve procurement and stock systems at national level.

Regarding SRHR:

- How can vulnerable populations best be reached in Africa?
- There is a lack of services for young people.
- The lack of resources and poverty are great obstacles to the realization of SRHR in Africa.

Regarding criminalization:

- Criminalization is not a constructive solution.
- There is lack of clarity among PLHIV regarding the circumstances when they could be penalized.
- PLHIV need more information regarding their rights.

The results of the survey were presented at the opening plenary.

Delegates affirmed that Positive Leadership was crucial to increasing PLHIV capacity to respond to the HIV epidemic. Specifically, Positive Leadership was perceived to be associated with passion, vision, courage, strength, knowledge and commitment, among other things.

Although Positive Leadership gave impetus to the response to the epidemic in marginalized communities, respondents raised concerns about the renewal process and the lack of sustainability planning for the next generation. They also wanted more attention given by the international leadership towards investing in capacity building, communications training and networking.

Overall, the survey made clear that positive leaders are community stakeholders and critical partners in the effort to prevent the spread of HIV. Strengthening their capacity and promoting their involvement is a crucial contribution in the response to HIV and AIDS.

Regarding positive prevention:

- Positive prevention should focus on prevention of infection, prevention of other STIs and prevention of premature death.
- There is a need to have a standardized approach to positive prevention at country level.
- Some messages are not relevant to Africa, e.g. health as a right.

4.2. Asia and Pacific

Regarding access to treatment, care and support:

- The areas of treatment, care and support are divided, not sufficiently connected with each other.
- Major procurement and supply issues continue to exist.
- There are serious reservations among PLHIV regarding provider-initiated testing policies, such as being implemented in China.

Regarding SRHR:

- The concept of human rights is still a sensitive one in most Asian and Pacific countries.
- PLHIV lack knowledge and skills with regard to SRHR.

⁵ According to WHO, the organization tends not to use the term positive prevention but rather the term "Prevention and Care for People Living with HIV/AIDS" to reflect a more comprehensive view of the concept.

Regarding criminalization:

- “The march of criminalization is increasing the silence”.
- Criminalization does not distinguish between accidental and willful transmission. There is a need to make this distinction.

Regarding positive prevention:

- The concept – as commonly interpreted – is too broad.
- The positive prevention agenda is driven by donors and governments.
- Positive prevention is not relevant in many countries since access to treatment is still the predominant issue.

4.3. Anglophone Caribbean

Regarding access to treatment, care and support:

- There is need for a holistic approach.
- There is a need for universal standards in access to treatment, care and support.
- All four themes are interrelated.

Regarding SRHR:

- There is a need to build links with other areas, such as criminalization.

Regarding positive prevention:

- The concept of positive prevention must be interpreted and owned by PLHIV.
- There is a need among PLHIV for more information and education regarding positive prevention.

4.4. Eastern Europe and Central Asia

Regarding access to treatment, care and support:

- Well trained, competent PLHIV need to be actively involved in all aspects of planning, design, implementation and monitoring and evaluation of access to treatment, care and support programmes.

Regarding SRHR:

- The enjoyment of SRHR is not a reality for most PLHIV in the region.
- HIV infection, however, should not be a reason to limit a person's SRHR.
- There is a need for more sex education programmes across the region.

Regarding criminalization:

- Criminalization directly contributes to the spread of HIV.

Regarding positive prevention:

- PLHIV need more information regarding the advantages of positive prevention.
- Positive prevention programmes should be developed by PLHIV for PLHIV in order to increase the quality of life of PLHIV.

4.5. French speaking countries in Africa, the Caribbean and Europe

Regarding access to treatment, care and support:

- Access to treatment is a human right.
- There is a need for universal quality standards.
- There is a need for greater involvement of community-based organizations (CBOs) in access to treatment, care and support issues.
- Attention must be paid to human resource issues.

Regarding SRHR:

- The rights of PLHIV need to be emphasized.
- Greater attention must be paid to the needs of African women.

Regarding criminalization:

- If there is criminalization, how about mothers transmitting HIV to their babies? Should they be criminalized?
- Criminalization is not in the public health interest as it creates a climate of fear and recrimination.

Regarding positive prevention:

- PLHIV need to strengthen their role and voices in positive prevention.
- Positive prevention needs to focus also on quality of life issues, not only transmission.
- PLHIV need to establish themselves as specialists in prevention.

4.6. Latin America and the Caribbean

Regarding access to treatment, care and support:

- Obstacles to access to treatment, care and support in the region are poverty and malnutrition.
- There are issues in the region with sustainability of access to treatment, care and support programmes.
- There are problems with pediatric ARV access.

Regarding SRHR:

- There is a lack of SRH services for PLHIV.
- There is a need to develop strategies to increase access to SRH services by PLHIV in the region.

Regarding criminalization:

- Criminalizing laws should become null and void.
- The creation of new criminalizing laws - where they are not yet in force – should be prevented.

Regarding positive prevention:

- There is a complete rejection of the concept of positive prevention in this regional group.
- Positive prevention should be integrated into regular prevention activities and programmes.
- Positive prevention can be misunderstood and open the doors to criminalization.

4.7. Middle East and Northern Africa

Regarding access to treatment, care and support:

- The group agrees with the key advocacy messages.
- More advocacy is needed for access to treatment in the region.
- Availability and access to HIV related tests (CD4, viral load, drug resistance) must be more wide-spread and consistent regionally.
- Standardization and full coverage for treatment, tests, hospitalization etc. must be achieved.
- Coverage of treatment necessary for co- infection must be provided.
- Trained physicians who can manage ARV treatment are needed.
- Trained health care providers with knowledge regarding the interaction of medications in co-infection cases are needed.

Regarding SRHR:

- For women in the MENA region, sex is a taboo subject. Women cannot even begin to talk about sex, let alone, sexual rights.
- Women do not have a say in:
 - a) Human Rights: This issue must be addressed first through very basic, first steps, i.e. awareness raising. If we do not know what human rights are, how can we advocate for them?
 - b) Education: There is no sex education in schools or in the homes. We need quality curricula to be integrated into regular school programming.
 - c) Child Bearing: If women are financially independent, it increases their ability to negotiate child bearing.
 - d) Negotiation skills: Many interventions assume that women have negotiating power in their relationships. In the MENA region this is rare. We need to address means to provide women more power in daily life. This includes education, awareness and access to free women-friendly services.

Regarding criminalization:

- Criminalization is not an issue in the MENA region.
- There should be attempts to avoid any efforts of trying to criminalize HIV transmission, if they should occur.

Regarding positive prevention:

- The group called for the training of more PLHIV leaders.
- There is a need to train healthcare providers under positive prevention programmes.
- Full coverage of HIV monitoring, medical tests and opportunistic infections should be provided.
- Psycho-social services to PLHIV and their families should be provided.
- In terms of terminology, the group suggested “Living Positively” instead of “positive prevention”.

4.8. North America and Europe

Regarding access to treatment, care and support:

- There is a need for universally high quality standards.
- More training and capacity building for health care providers is necessary.
- There is more attention needed for vulnerable groups within high-income societies. It is often forgotten that they are most often underserved too.
- The United States of America needs to pay more attention to domestic HIV and AIDS issues

Regarding SRHR:

- Research in areas such as alternative insemination and in-vitro fertilization needs to be increased.
- There is a need to address gender inequities with regard to sexual decisions, domestic violence and the economic status of women.

Regarding criminalization:

- The criminal justice system needs to be educated on HIV transmission issues and incorporate the “human element”.
- There should be an intensified search for alternatives to criminalization.
- Media sensationalism should be limited through education of media professionals.

Regarding positive prevention:

- Many find the term offensive, prevention should be for all, not narrowly focused on PLHIV.
- There is no consensus on whom positive prevention should target (PLHIV only or also HIV negative people?).
- Everybody should care about and be involved in prevention.

5. Reports back by the thematic working groups

After the presentation of the four advocacy themes and the regional reports back on day one, the LIVING 2008 delegates on day two developed key targets, recommendations and actions based on the LIVING 2008 advocacy themes (Part I), and developed draft thematic action plans (Part II).

This section is a summary of the "recommendations by advocacy themes" presented by the thematic working groups at the end of day two.

5.1. Access to treatment, care and support

5.1.1. Working group proceedings

The access to treatment, care and support working group focused in its discussions mainly on what PLHIV know or should know about access to treatment, care and support issues, and which knowledge gaps exist among PLHIV regarding this area.

5.1.2. Main findings and opinions

In terms of what PLHIV know, the LIVING 2008 participants stressed that access to treatment is a fundamental human right and necessity of PLHIV. The current more favourable climate and overall greater access of PLHIV to treatment, however, allows a shift from an almost complete focus in earlier years on treatment alone to wider issues of access to treatment, care and support.

In terms of knowledge gaps, the participants requested more basic information with regard to treatment, such as what it means to be on treatment, issues of adherence, and myths and realities about generics. Other knowledge gaps existed in the areas of ARV registration procedures, the procurement and supply chain, the epidemiology of HIV and AIDS, and advocacy opportunities at country and regional levels. With regard to health care providers, in particular medical doctors, the LIVING 2008 participants noted that their levels of knowledge regarding access to treatment, care and support issues are mostly not

sufficient. There should be better training of health care providers. In this context, the LIVING 2008 participants also stressed the need for PLHIV to get more involved and knowledgeable in issues regarding their health care. PLHIV should become experts regarding their health care. When it comes to governments, the working group called on them to:

- Establish effective national legal frameworks in order to guarantee comprehensive, multidisciplinary and integrated care and services for PLHIV in full respect of their human rights.
- Ensure expeditious and reliable procurement and distribution chain of drugs and commodities throughout the national health systems, including treatment and care of infectious and opportunistic diseases; and
- Take the lead in ensuring availability of recourses for procurement and distribution of drugs and commodities throughout the national health systems.

With regard to international agencies, such as the World Health Organization (WHO), the working group did not reach a consensus on what their role should be vis-à-vis access to treatment, care and support issues. It was not clear how exactly international agencies could support this area. One possible recommendation was for international agencies to harmonize their own guidelines vis-à-vis access to treatment, care and support as they sometimes contradict each other.⁶

The working group made a specific request to the International Community of Women Living with HIV/AIDS (ICW) and GNP+ to:

- Advocate for equitable access to treatment.
- Provide knowledge and information regarding access to treatment, care and support, with a focus on gender issues; and
- Initiate research on microbicides, and effects of new and existing ARVs and other drugs on the body, fertility and libido.

"Doctors' knowledge regarding access to treatment, care and support is often low. They are mostly not very helpful. We as PLHIV need to educate ourselves regarding access to treatment, care and support issues."

LIVING 2008 delegate from Eastern Europe

⁶ According to WHO, the development and promotion of global norms and standards, including treatment and care guidelines is core WHO business and WHO has taken the lead in developing ART guidelines. There is increasing agreement across countries, donors and implementing agencies to use WHO treatment guidelines - e.g. from Global Fund, PEPFAR. However, it is recognized by WHO that other treatment guidelines have been produced.

LIVING 2008 participants' **recommendations**

regarding access to treatment, care and support:

- Train health care providers regarding the access to treatment, care and support needs of PLHIV.
- Provide more information to PLHIV on access to treatment, care and support issues, for example by offering capacity building workshops or widely disseminating information resources in different languages.
- Establish effective national legal frameworks with standards regarding access to treatment, care and support.
- Ensure expeditious and reliable procurement and distribution chain of ARVs and commodities throughout the national health systems, including treatment and care of infectious and opportunistic diseases.

Summary: LIVING 2008 participants reiterated that access to treatment is a fundamental right. In light of improved access of PLHIV to ARVs, issues other than treatment access are gaining greater prominence and importance. LIVING 2008 participants requested better training of health care providers and called on national governments to establish sound standards regarding access to treatment, care and support. They also called on PLHIV to get actively involved in their health care and become experts regarding their own health. For this to happen, however, PLHIV need more access to information and capacity building in the area of access to treatment, care and support.

5.2. Sexual and reproductive health and rights

5.2.1. Working group proceedings

The LIVING 2008 working group around SRHR reviewed five specific SRHR areas discussed in the morning session:

- a) Rights to reproduction, sexuality and desire.
- b) Articulating the SRHR dreams and desires of PLHIV.
- c) Better linking SRHR efforts and actors with each other.
- d) Emphasizing shared responsibility of PLHIV and HIV negative persons for SRH decisions; and
- e) Challenging the changing face of stigma and discrimination.

Breaking out into two groups, the working group prioritized these issues and attempted to outline strategies to address them. Some of the specific questions raised were: are there specific areas that need to be addressed through a global strategy? What are the cross-cutting, overarching

issues and concerns? Or are the issues at stake more of a regional nature? Which strategies can best benefit the SRHR of PLHIV given the great diversity of PLHIV and their SRHR needs?

5.2.2. Main working group findings and opinions

The main points the SRHR working group reached consensus on were as follows:

a) PLHIV are in need of empowerment regarding their SRHR

The level of knowledge and awareness regarding the SRHR of PLHIV is generally low. The provision of comprehensive sex education programmes is insufficient globally. PLHIV need more information with regard to what rights they have and how that translates into possible service provision. Participants strongly expressed that with regard to SRHR of PLHIV “knowledge means power”.

b) The SRHR discourse of PLHIV needs to be firmly anchored in the human rights approach

There are manifold violations of the SRHR of PLHIV occurring on a regular basis. In order to achieve greater awareness around SRHR of PLHIV, as stated under a), the work in this area needs to be based on the human rights approach. PLHIV themselves need to become advocates for their SRHR and develop a sense of “civil vigilance”. The LIVING 2008 participants called for greater PLHIV involvement in SRHR organizations and programmes worldwide.

c) There is great diversity in SRHR issues of PLHIV

Although there are overarching global issues that apply to all regions, such as the low level of awareness of PLHIV regarding their SRHR, the LIVING 2008 participants recognized and emphasized the diversity of SRHR issues across different regions. For instance, poverty and poor nutrition make the realization of SRHR particularly difficult in Africa and parts of Latin America and the Caribbean. Concurrently, LIVING 2008 participants called for programmes tailored to the needs of specific regions and in particular stressed the need for regional advocacy activities. In general, there are no “one size fits all” solutions to the SRHR needs of PLHIV. The SRHR needs of PLHIV are diverse. Or as one LIVING 2008 participant put it:

“The sexual and reproductive health needs and desires of PLHIV are as diverse as the epidemic itself.”

“We need to reclaim our body sovereignty.”

(LIVING 2008 delegate Celia Chung, San Francisco)

“I feel now that through this experience I am left feeling like a criminal for being HIV positive and my fear is now that people won’t be tested for fear of prosecution about being positive...”

Sarah, woman convicted and imprisoned for transmitting HIV
(Positively Women Magazine, fall 2006)

LIVING 2008 participants' **recommendations** regarding SRHR:

- Conduct a review of potentially discriminatory laws that have an impact on the SRHR of PLHIV and attempt to initiate new laws that positively promote the SRHR of PLHIV.
- Institute global comprehensive sex education programmes that include the specific SRHR needs of PLHIV.
- Encourage regional or local initiatives fighting stigma and discrimination of PLHIV.
- Promote a global media campaign – targeting PLHIV as well as the general public - to educate and advocate for the SRHR of PLHIV.
- Develop – or if an appropriate one already exists, widely disseminate – a toolkit regarding the SRHR of PLHIV.
- Develop and maintain a web site tracking SRHR abuses of PLHIV with the purpose of having data for SRHR advocacy for PLHIV.
- Increase the involvement of PLHIV in SRHR organizations, such as IPPF worldwide by providing information on such organizations and encouraging PLHIV to join them.

Summary: LIVING 2008 participants underscored that the SRHR needs of PLHIV are diverse. PLHIV need greater awareness regarding their SRHR and should be further empowered to advocate for them. Any promotion of the SRHR of PLHIV needs to be firmly anchored in the human rights approach. The LIVING 2008 participants made concrete recommendations to improve the level of information and status of SRHR of PLHIV, such as the revision of discriminatory laws and creation of laws promoting SRHR of PLHIV; and the creation or strengthening of regional or local initiatives to fight stigma and discrimination of PLHIV. The LIVING 2008 participants issued a clear appeal to PLHIV around the world to be pro-active. PLHIV should resolutely claim their SRHR and get dynamically involved in the promotion and advocacy of their SRHR, e.g. by joining organizations working in the area of SRHR.

5.3. Criminalization

5.3.1. Working group proceedings

The LIVING 2008 working group dedicated to issues of criminalization of the transmission of HIV broke into four working groups dealing with:

- a) How would (de)criminalization look in an ideal world?
- b) Media and criminalization.
- c) Alternatives to criminalization; and
- d) How to increase awareness regarding criminalization among PLHIV.

5.3.2. Main working group findings and opinions

Together, the four sub-groups identified the following key issues regarding criminalization:

- Ensure individuals are aware of how criminalization, i.e. laws and other regulations that affect the sexual and reproductive lives of PLHIV.
- Suggest alternatives to “criminal” remedies for non-intentional transmission.
- Ensure governments allow prosecution only where there is intention/malevolence in transmitting HIV.
- Assess whether decriminalization can occur in respective countries – or which parts of the law or criminalizing regulations can be modified.
- Ensure criminalization does not start where it has not yet been established; and
- Work with the media and hold them accountable for sensationalistic reporting of HIV transmission.

The LIVING 2008 participants emphasized the importance of increasing awareness of the impact of criminalization on the lives of PLHIV. Many PLHIV are not even aware of criminalization and under which specific circumstances they might become legally liable. The LIVING 2008 participants stated the need to identify existing laws through a systematic research effort, and develop appropriate strategies to increase the understanding of the effect these laws have on PLHIV. For this, much greater PLHIV community mobilisation is needed.

With regard to the “ideal world of (de)criminalization”, the working group voiced that in an ideal scenario there should be no criminalization of HIV transmission at all. There was complete consensus that transmission of HIV cannot be stopped via criminalization and that criminalization is not a solution. On the contrary, the

regional working group Eastern Europe and Central Asia clearly stated: “We agreed that criminalization directly contributes to the spread of HIV in our region.” However, blanket decriminalization might not be a realistic goal under the current circumstances. Therefore, the PLHIV community should focus on working with stakeholders, such as lawmakers, representatives of the criminal justice system, and medical doctors, to achieve constructive attitudes and realistic, practical change.

Should PLHIV target complete decriminalization of HIV transmission?

There was disagreement on whether the PLHIV community should aim for the complete decriminalization of HIV transmission. While the Latin America and the Caribbean regional group came out with a clear statement in support of this vision, there was a sentiment towards a less bold approach among the larger LIVING 2008 participant group, i.e. one that acknowledges that complete decriminalization might not be achievable in the short term. In order to unite the PLHIV community behind this issue, more discussions are needed in the future.

In this connection, the LIVING 2008 participants emphasized the important role of the media. There was consensus that the media play a crucial role in the attitudes towards criminalization. Often, unfortunately, they do contribute to a negative attitude by reporting in a sensationalistic way about HIV transmission. The LIVING 2008 participants expressed the need to work closely with media representatives and to educate and train them regarding issues of HIV criminalization and to look for allies among NGOs in working with media. According to the LIVING 2008 participants, the media, as well as NGOs, CBOs and health care providers, are all important stakeholders in the search for alternatives to criminalization.

LIVING 2008 participants' recommendations regarding criminalization:

- Conduct a systematic review of laws criminalizing HIV transmission and the effect of these laws on the well-being and SRHR of PLHIV.
- Increase community mobilisation by providing more information on criminalization to PLHIV and encourage the creation of advocacy groups and mechanisms regarding decriminalization.
- Educate media on balanced and objective ways of communicating issues of criminalization and HIV transmission in general.
- Educate stakeholders, such as lawmakers, representatives of the criminal justice system and health care providers, including medical doctors, on issues of criminalization and its harmful effect on PLHIV through workshops, seminars or similar awareness building activities

Summary: There is complete consensus among PLHIV that criminalization of HIV transmission has a negative effect on the well-being and SRHR of PLHIV and is not a solution to HIV transmission. In order to change attitudes towards this issue, the PLHIV community needs to work closely with stakeholders such as lawmakers, representatives of the criminal justice system, and health care providers, including medical doctors. In order to unite the PLHIV community behind this issue, more community awareness and mobilization is needed.

5.4. Positive prevention

5.4.1. Working group proceedings

The issue of positive prevention was discussed by four regional working groups: Africa; Asia and the Pacific; Eastern Europe and Central Asia; and North America and Europe.

5.4.2. Main findings and opinions

The discussions regarding positive prevention were particularly lively and controversial. Overall, LIVING 2008 participants could not reach a consensus on the concept of positive prevention. To begin with, the terminology turned out to be a bone of contention. Most LIVING 2008 participants were not content with the term “positive

“The responsibility for reducing transmission of HIV is a shared one and there should be no undue burden on people who are aware of their status. Safer and responsible sexual behaviour is the responsibility of all partners – irrespective of status.”

LIVING 2008 delegate Alejandra Trossero, IPPF

prevention". For most participants, the term had "negative connotations", implying an unjust and unrealistic burden of responsibility for transmitting HIV on the part of the person living with HIV. The term was "too broad, meaning nothing" or could be "stigmatizing". In some Asian countries, positive prevention – when translated into the local languages – could imply or be reminiscent of quarantining PLHIV. Some LIVING 2008 participants voiced that positive prevention was a donor or government driven concept and not owned by the PLHIV community. LIVING 2008 delegates also thought that positive prevention was not relevant in many countries where access to treatment was still the predominant theme. In addition, there was lack of clarity regarding the target group of positive prevention: is it targeting only PLHIV or also HIV-negative people?

LIVING 2008 participants objected most to the idea that positive prevention could imply a sole responsibility for HIV transmission on the part of the person living with HIV – and not a shared responsibility of both partners. As a matter of fact, regarding one positive prevention issue there was a clear consensus among LIVING 2008 participants: prevention should always be a shared responsibility of all partners, irrespective of their status.

Latin America and the Caribbean and positive prevention

The Latin America and the Caribbean working group – speaking for their region only – issued a complete rejection of the concept of positive prevention, as presently construed. They expressed that the concept was driven by agents outside the community of PLHIV and that the concept needed to be clearly re-defined, claimed and owned by PLHIV. The focus needed to be shifted from the present one that implied PLHIV had the sole responsibility for preventing HIV transmission. The concept of positive prevention should be fully integrated into overall government prevention services and not exist as a "stand alone" issue. The LAC working group proposed the creation of a regional working group to further discuss better and more clearly define positive prevention.

In conclusion, there is a need for more discussion to reach agreement on the concept of positive prevention. PLHIV need to claim ownership of positive prevention if it is meant to work in the future. It is a positive development, however, that *"PLHIV are in the process of re-taking ownership of positive prevention"*, as Christoforos Mallouris, Director of Programmes, GNP+, stated during LIVING 2008.

As "food for thought" and to structure future discussions with regard to positive prevention, the IPPF guidelines on positive prevention might be insightful. This definition of positive prevention is used by a number of organisations in the context of sexual and reproductive health.

IPPF defines positive prevention as:

"Positive Prevention encompasses a set of actions that helps people living with HIV/AIDS to:

- **Protect their sexual health**
- **Avoid other STIs**
- **Delay HIV and AIDS disease progression, and**
- **Avoid passing the infection to others.**⁷

IPPF's guiding principles for positive prevention are:

1. Promotion of human rights
2. Involvement of PLHIV
3. Embracing shared ownership and responsibility
4. Recognition of diversity

LIVING 2008 participants' **recommendations** regarding positive prevention:

- The concept of positive prevention needs to incorporate – as a central building block – the element that prevention should always be a shared responsibility of all partners, irrespective of their status.
- Positive prevention as a concept should stress the well-being and health of PLHIV, not focus (solely) on preventing the transmission of HIV.
- WHO, UNAIDS and other international organisations, as appropriate, should work together with the PLHIV community to develop and agree on a commonly shared vision and definition of positive prevention.
- Establish a LAC working group – and possibly other regional ones - to further discuss and more clearly define positive prevention.

Summary: In the area of positive prevention, LIVING 2008 participants were not able to reach consensus. The main stumbling blocks were the terminology and the fears of PLHIV that positive prevention as a concept might focus too much on the responsibility of PLHIV for transmitting HIV, and not their physical and mental well-being. More discussions are needed for the PLHIV movement to take ownership of this concept and eventually make it work.

⁷ See "A Framework for Priority Linkages", 2005, WHO – IPPF – UNFPA – UNAIDS.
http://www.who.int/reproductive-health/stis/docs/framework_priority_linkages.pdf

6. Evaluation

LIVING 2008 will be formally evaluated between December 2008 and March 2009. The three main areas of examination will be:

- Pre-consultations
- LIVING 2008 Partnership
- LIVING 2008 the Positive Leadership Summit

The methodology for each part of the evaluation will be developed and tailored individually to analyze and answer specific key questions and issues related to each area. The overall aim of the evaluation will be to determine the effectiveness of the LIVING processes and to make recommendations for future summits. The future of LIVING: The Positive Leadership Summit and the LIVING Partnership will be determined based on the evaluation report, which will be ready by April 2009.

7. Conclusions and next steps

LIVING 2008 has resulted in the development of thought among PLHIV in the four main theme areas: access to treatment, care and support; sexual and reproductive health and rights; criminalization of HIV transmission; and positive prevention.

Each theme area has been developed differently and to different degrees. Summary results of the consultations – both before and during the Summit – will be captured on one-pagers that will be available in English, French and Spanish, as well as one or two other languages should funds be available. This, along with supporting documents that have already been produced separately by LIVING partners, will become the basis for moving ahead.

For example, the positive prevention theme area clearly highlighted the need for more consultation on this issue. It is anticipated that regional (or sub-regional) consultations will need to take place in order to:

- (1) Define what positive prevention means for PLHIV;
- (2) Agree on components of positive prevention;
- (3) Agree on an advocacy agenda for positive prevention, including a research agenda for unanswered questions; and
- (4) Agree on consultation and reporting methodologies in order to ensure optimal participation of PLHIV and transparency.

For each theme area, a work plan will be devised and the appropriate interested partners will move the plan forward. The plans may include advocacy opportunities, research priorities, programme development and implementation, consultation, and other relevant issues. In addition, each recommendation will be flashed out

to specify the responsible party, resources required and time line for completion. The work will be led by PLHIV networks, with technical support from partners. Because of regional differences, any global work conducted will be conducted in direct collaboration with representatives from regional networks.

Meanwhile, PLHIV networks will be encouraged to further develop consultation modalities, including face-to-face and electronic consultations, in order to continue developing the thoughts of PLHIV around the four topics. Additional themes will be identified in 2009 and 2010 in order for PLHIV networks to be able to proactively seek out, collect and analyze evidence and opinions on topics that are important for PLHIV. This will result in a library of theme areas for which PLHIV have been consulted and will contribute to an ever-growing database that can be consulted when advocating for changes in policies and programming at country, regional or international levels.

The LIVING 2008 Positive Leadership Summit was the beginning of a process to systematize interactions among PLHIV for sharing information about specific topics. In the future, conferences and summits will remain an important space for dialogue for PLHIV networks to explore and exchange ideas. However, the systematic sharing of information and evidence will lead to more readily available ammunition for advocacy in order to improve the lives of PLHIV; fight injustices; and promote the inclusion of PLHIV in decision-making, programme and service implementation and evaluation.

Annex

1. The LIVING 2008 Summit agenda

31st July 2008

- 09:00** Opening Ceremony
- 10:30** Press Conference and Tea Break
- 11:00** Plenary: The LIVING 2008 Advocacy Themes
- 12:30** Networking Lunch
- 14:30** Regional discussions and feedback on the LIVING 2008 advocacy working papers
- 16:30** Regional Report Back
- 17:00** Close

1st August 2008

- 09:00** Talk Show: Meet the Positive Plenary Speakers at AIDS 2008
- 10:30** Tea Break
- 11:00** Thematic Breakout: Developing recommendations for key targets for action on the LIVING advocacy themes
- 12:30** Networking Lunch
- 14:30** Action planning: Planning and implementing the LIVING advocacy themes
- 16:00** Report Back: Recommendations by Advocacy Themes
- 17:00** Plenary: Moving forward with the LIVING advocacy agenda
- 18:00** Close
- 20:00** Reception (Museo de la Ciudad de Mexico)

2. List of organizers and funders of LIVING 2008

LIVING 2008: The Positive Leadership Summit was organized by the LIVING 2008 Partnership, a consortium of organizations committed to strengthening the movement of people living with HIV and their communities. The consortium consists of the following partners:

- Global Network of People Living with HIV/AIDS (GNP+)
- International Community of Women Living with HIV/AIDS (ICW)
- International Council of AIDS Service Organizations (ICASO)
- International HIV/AIDS Alliance
- International AIDS Society (IAS)
- International Federation of Red Cross and Red Crescent Societies (IFRC)
- International Planned Parenthood Federation (IPPF)
- Mexican Network of People Living with HIV
- Sidaction
- United Nations Joint Program on HIV/AIDS (UNAIDS)
- World Health Organization (WHO)

LIVING 2008: The Positive Leadership Summit was supported financially by AIDS2008, Canadian International Development Agency, Dutch Ministry of Foreign Affairs, Ford Foundation, French Ministry of Foreign Affairs, Bill & Melinda Gates Foundation, GlaxoSmithKline's Positive Action programme, International HIV/AIDS Alliance, International Planned Parenthood Federation, Irish Aid, Norwegian Royal Ministry of Foreign Affairs, Sidaction, Tibotec, UNAIDS, The William and Flora Hewlett Foundation, and the World Health Organization.

Notes

