

Positive Health, Dignity and Prevention



Technical Consultation Report
27-28 April 2009, Hammamet, Tunisia



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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AHPN	African HIV Policy Network
ANRS	Agence Nationale de Recherches sur le Sida et les Hépatites Virales [(French) National Research Agency on AIDS and Viral Hepatitis]
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBO	Community-based Organisation
CDC	(United States) Centers for Disease Control and Prevention
FHI	Family Health International
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
IAS	International AIDS Society
ICASO	International Council of AIDS Service Organizations
ICW	International Community of Women Living with HIV/AIDS
INERELA+	International Network of Religious Leaders Living with or Personally Affected by HIV/AIDS
IRFC	International Federation of the Red Cross/Red Crescent Societies
IPPF	International Planned Parenthood Federation
m2m	Mothers2Mothers
MIPA	Meaningful Involvement of People Living with HIV and AIDS
NAP+N	National Association of People Living with HIV/AIDS in Nepal
NAPWA	National Association of People living with AIDS
NGO	Non-governmental Organisation
OI	Opportunistic Infection
PMTCT	Prevention of Mother To Child Transmission
RedLa+	Red Latinoamericana de Personas viviendo con VIH/SIDA [Latin American Network of People Living with HIV/AIDS]
SRHR	Sexual and Reproductive Health and Rights
STI	Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization
YCI-T	Youth Challenge International – Tanzania

Foreword

GNP+ and UNAIDS are proud of the outcomes of this technical consultation. We have moved the international agenda on HIV prevention forward by reshaping our thinking based on the perspectives and experiences of people living with HIV.

Until now, the understanding of HIV prevention as it relates to people living with HIV has been inconsistent or ill defined. Policies and programmes targeting people living with HIV have been designed, for the most part, without the involvement of people living with HIV.

The increasing availability of HIV treatment has enabled people living with HIV to lead longer and healthier lives and to engage in the issues that directly impact on their lives and those of their communities. More than ever, people living with HIV must be central to the HIV response.

At the technical consultation the term 'Positive Health, Dignity and Prevention' was agreed upon linking issues of HIV treatment, prevention, support and care within a human rights framework. People living with HIV worked with civil society, government agencies, international development agencies, UNAIDS Cosponsors and donor agencies to identify the components of Positive Health, Dignity and Prevention and to develop values and principles underpinning it.

In this process, we reached some important conclusions. We agreed that Positive Health, Dignity and Prevention requires a human rights approach based on legal protections and a policy environment free of stigma and discrimination for PLHIV. We agreed that programmes must promote holistic health and wellness, including access to HIV treatment, care and support services, and by doing so contributes to the health and wellbeing of their partners, families and communities. We also recommended that Positive Health, Dignity and Prevention efforts should be responsive to the needs of key affected populations.

GNP+ and UNAIDS will advocate for this more comprehensive understanding of HIV prevention informed by the perspectives and experiences of people living with HIV. We will also take the discussions on Positive Health, Dignity and Prevention forward in regional meetings in order to identify specific regional priorities. Through building an understanding and consensus of Positive Health, Dignity and Prevention, we have a new opportunity to bring about change that is driven by people living with HIV.

Kevin Moody
International Coordinator/CEO
GNP+

Michel Sidibé
Executive Director
UNAIDS

Executive Summary

This report presents the key points and recommendations that emerged over the course of a two-day international technical consultation on 'positive prevention' held in Hammamet, Tunisia on 27-28 April 2009. The consultation was co-organised by the Global Network of People Living with HIV (GNP+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), and aimed to:

- Gather experiences and knowledge of stakeholders, in particular people living with HIV at regional, national and local levels, at the technical consultation; and to develop a strategy to gather broader views and experiences following the technical consultation;
- Develop a set of initial principles on 'positive prevention'; and
- Develop recommendations to facilitate the scale up of programmes and the development of policies.

The meeting was attended by a range of stakeholders from twenty-eight countries on six continents, representing people living with HIV (PLHIV) networks, development agencies, civil society organisations, country implementers, multilateral and UN agencies, and donor agencies. More than half of the fifty participants were people living with HIV who are leading programmes and driving policies aimed at achieving better HIV responses and higher health and quality of life standards for HIV-positive individuals.

Consultation participants agreed that there are significant shortcomings to many current 'positive prevention' approaches and were concerned that many existing, donor-led 'positive prevention' interventions appear to focus almost entirely on preventing the onward transmission of HIV – which should not be the sole aim of any 'positive prevention' programme.

An important consensus emerged during the consultation that 'positive prevention' provides an opportunity to highlight the myriad health and prevention needs of HIV-positive individuals and is a useful lens through which to understand the important linkages between human rights and prevention, treatment, care and support.

Key elements identified include health promotion; treatment access; sexual and reproductive health and rights; prevention of transmission of HIV and other sexually transmitted infections (STIs); protection of human rights, including stigma and discrimination reduction; gender equality; social and economic support; and the empowerment of people living with HIV.

One of the most significant outcomes of the technical consultation was a new, working term that better describes this new paradigm: 'Positive Health, Dignity and Prevention'. Participants are eager to garner feedback on the new term during regional consultations, particularly as to how it might be translated to suit specific contexts.

Another important outcome was the consensus that Positive Health, Dignity and Prevention requires a human rights framework supported by protective laws to ensure non-discrimination, reduce stigma, and change harmful gender norms. It was agreed that the law must enable HIV-positive individuals to protect themselves and others; not through fear, but through empowerment and with dignity.

The technical consultation discussed how Positive Health, Dignity and Prevention could be integrated into the goal of universal access to HIV prevention, testing, treatment, care and support by 2010; current HIV prevention, treatment, care and support policies and programmes; and the integration of treatment and prevention and new perspectives on antiretroviral therapy (ART) as an element in prevention. The meeting recognised the continuing and persistent challenges in access to ART and endorsed the ongoing need for treatment decision-making to empower people living with HIV. In addition, participants highlighted the importance of ongoing community empowerment, access and behavioural issues attached to ART rollout.

Throughout the meeting, participants worked together to develop a set of elements, values and principles to guide the national, regional and international efforts of diverse stakeholders to implement Positive Health, Dignity and Prevention.

It was agreed that 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 populations¹ and should respect and be tailored to specific contexts and the diversity among people living with HIV.

Participants also developed some initial recommendations on partnerships, programmatic responses and advocacy responses for PLHIV networks, civil society, the public sector, donor agencies and multilateral and UN agencies.

Networks of People Living with HIV

- Develop an agenda through a consultative process for Positive Health, Dignity and Prevention;
- Identify key partners supporting advocacy work; and develop regional and local advocacy plans; and
- Build evidence of good practices in Positive Health, Dignity and Prevention and identify key indicators to monitor and evaluate programme implementation and policy development.

Civil Society

- Ensure inclusion of Positive Health, Dignity and Prevention in national strategic frameworks, resources, plans, policies, and monitoring and evaluation systems;
- Adapt and integrate Positive Health, Dignity and Prevention into existing programmes and services, and organisational plans; and
- Advocate for funding to provide further services and resources for Positive Health, Dignity and Prevention.

Public Sector

- Create and commit to multisectoral Positive Health, Dignity and Prevention programmes ensuring broad stakeholder involvement, including people living with HIV;
- Ensure that a national plan is in place that commits to funding and programming for Positive Health, Dignity and Prevention throughout the public sector; and
- Ensure fair allocation of funding for Positive Health, Dignity and Prevention programmes with full transparency, including monitoring and evaluation.

Donor Agencies

- Develop and fund multisectoral Positive Health, Dignity and Prevention programmes with a focus on health promotion and shared responsibility for prevention;
- Collaborate with people living with HIV networks, civil society and the public sector to ensure Positive Health, Dignity and Prevention is included in national, regional and local planning; and
- Create good practice guidelines through monitoring and evaluation to help build further evidence for Positive Health, Dignity and Prevention programmes.

Multilateral and UN Agencies

- Continue to consult on the definition, principles and components of Positive Health, Dignity and Prevention to produce and endorse policy and programming guidance;
- Ensure Positive Health, Dignity And Prevention is incorporated into national HIV strategic plans and recommend its inclusion in next and future rounds of Global Fund proposals; and
- Ensure Positive Health, Dignity And Prevention is included in UNGASS indicators, including monitoring of human rights, to guarantee its implementation.

This technical consultation is part of an ongoing process of reinforcing the leadership role of people living with HIV in Positive Health, Dignity and Prevention. Further consultations at regional level are planned in order to establish a common understanding of Positive Health, Dignity and Prevention and provide guidance in developing policies and programmes globally.

¹ Indigenous peoples, men who have sex with men, migrants, people who use drugs, prisoners, refugees, sexual minorities (including intersex and transgender people), sex workers, women, and young people.

Background to the Consultation

A brief history of 'positive prevention'

HIV prevention efforts aimed at people who know their HIV-positive status have existed in some form since the earliest days of the epidemic. Beri Hull, from the International Community of Women with HIV/AIDS (ICW), led the participants in an interactive timeline exercise to explore the history of the interaction between HIV prevention policies and programmes and people living with HIV. This exercise revealed that many of these messages were overwhelmingly negative and stigmatising.

Despite these messages, over the decades, many community based organisations and most organisations representing people living with HIV – for example, the California 'Breakfast Club'², Chile's Vivo Positivo³ and Canada's Ontario Gay Men's HIV Prevention Strategy⁴ – have developed 'positive prevention' policies and programmes. However, although HIV prevention aimed at people who know their HIV status has been part of the community response to HIV since the 1980s, these programmes have not necessarily been labelled as 'positive prevention'.

The notion of 'positive prevention' became more formalised in 2003, when the United States Centers for Disease Control and Prevention (CDC) announced a new national initiative, Advancing HIV Prevention (AHP): New Strategies for a Changing Epidemic, which focused on increasing uptake of and access to HIV testing and "prevent[ing] new infections by working with persons diagnosed with HIV and their partners, and further decreas[ing] perinatal HIV transmission."⁵ The CDC also published guidelines aimed at incorporating HIV prevention into the ongoing medical care of all HIV-positive persons in clinical settings. These guidelines recommended screening

Interactive Timeline: Prevention Messages that People Living with HIV have Heard in their Communities, 1981-2009

"HIV-positive people are guilty." (Africa)

"Positive people should not have sex." (Latin America)

"Positive people are responsible for HIV transmission." (North America)

"HIV-positive women cannot have children." (Africa)

"My doctor told me: 'Use condoms or go to prison.'" (Eastern Europe)

"I was arrested for providing needle-syringe exchange services." (North America)

"I was told to (overly) worry about superinfection." (North America)

"People in serodiscordant relationships should use condoms or split up." (Australasia)

"Some AIDS activists said: 'Barebackers are criminals.'" (Western Europe)

Source: Group activity session. *Developing a historical timeline of 'positive prevention'*. Technical consultation presentation, April 27, 2009.

for HIV transmission risk behaviours and STIs; providing brief behaviour risk-reduction interventions in the clinic setting with referrals for additional prevention and related services; and partner counselling and referral services.⁶

The CDC programme and guidelines were strongly criticised by the National Association of People living with AIDS (NAPWA), an organisation of people living with HIV in the USA, for their lack of consultation with people living with HIV, their narrow approach, and, specifically, for "placing

2 Statement and Proposal from the 'Breakfast Club' on Prevention and HIV-Positive Persons to the California Prevention Working Group, September 1998, in California HIV Planning Group. *Prevention with Positives: A Guide to Effective Programs*. State of California, Department of Health Services, Office of AIDS, 2003, Appendix A, pp 47-50. Available at ari.ucsf.edu/programs/policy/pwp_resources/Effective.PWP_Programs.doc

3 See: www.vivopositivo.org/portal/sitio/007.htm

4 *Poz Prevention Definition, Values and Principles*. Developed by the Poz Prevention Working Group and approved by the Provincial Advisory Body of the Ontario Gay Men's HIV Prevention Strategy, January 25, 2008.

5 CDC. *Advancing HIV Prevention: New Strategies for a Changing Epidemic – United States*, 2003. MMWR 2003; 52: 329-332.

6 CDC. *Incorporating HIV prevention into the medical care of persons living with HIV*. MMWR 2003; 52 (RR-12): 1-24.

the responsibility for avoiding infections on the shoulders of HIV-positive people”⁷

Since then, a number of organisations – including the CDC⁸, International HIV/AIDS Alliance⁹, UNAIDS^{10,11} and the World Health Organization (WHO)¹² – have developed more holistic programmatic guidance on ‘positive prevention’. Despite these activities and increasing funding levels directed towards ‘positive prevention’, there remains a lack of clear understanding regarding the concept, objectives and programmatic elements of ‘positive prevention’. This is as much the case within the community of people living with HIV and the organisations that represent them, as it is among multilateral and UN agencies, international funders and other stakeholders.

PLHIV consultation on ‘positive prevention’

Philippa Lawson, of Futures Group International, provided an introduction to the participants of the technical consultation on the seven-month consultative process involving more than 1000 people living with HIV worldwide prior to the Living 2008 Summit¹³ and well as the Summit itself. The results of this process and a literature review were published in a Living 2008 partnership discussion paper¹⁴, which concluded that a new, holistic health-needs approach defined and led by people living with HIV was necessary to ensure that ‘positive prevention’ policy and programming did not further exacerbate the stigma and discrimination already experienced by people living with HIV.

The consultation in the lead up to the Living 2008 Summit highlighted that although existing ‘positive prevention’ programmes

were welcomed by people living with HIV in certain regions – notably sub-Saharan Africa and Asia – in other areas – such as Latin America, North America and Europe – there was a great deal of misunderstanding and mistrust among people living with HIV around the concept. This was primarily due to the perception that ‘positive prevention’ was focused on preventing onward transmission by changing the behaviour of people living with HIV.

At the Living 2008 Summit, many participants objected to the fact that people living with HIV were not meaningfully involved with decisions to define ‘positive prevention’, nor in its policy and programmatic design, implementation, monitoring and evaluation, funding and research. They also objected to the idea that both the name and implied concept of ‘positive prevention’ may suggest that the sole responsibility for HIV transmission rests with the person living with HIV. Consequently, the main consensus to emerge from the Living 2008 Summit was that prevention should always be a shared responsibility of both partners, irrespective of their HIV status.



In response to the debate at the Living 2008 Summit, GNP+ and UNAIDS co-organised this technical consultation in order to move the discussion forward by considering how ‘positive prevention’ related to existing prevention and treatment policies and programmes, as well as the law and human rights. The overall objective of the technical consultation was to lay the ground for a common understanding of ‘positive prevention’ to guide the work of, and partnerships between people living with HIV networks, civil society organisations, and multilateral, bilateral, and governmental agencies.

7 Anderson T. *Expanding the Boundaries of Positive Prevention Programmes*. National Association of People with AIDS (NAPWA). Presented at 4th Annual CAPS Conference, San Francisco, 2004. Available at hivinsite.ucsf.edu/InSite?page=cfcaps2004-01

8 CDC. *HIV Prevention for People Living with HIV: an Intervention Toolkit for HIV Care and Treatment Settings*. Atlanta, Centers for Disease Control and Prevention, 2008.

9 *Positive Prevention: HIV Prevention for People with HIV*. Brighton, International HIV/AIDS Alliance, 2007.

10 *Intensifying HIV prevention: a UNAIDS policy position paper*. Geneva, UNAIDS, 2005.

11 *Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access*. Geneva, UNAIDS, 2007.

12 *Essential Prevention and Care Interventions for Adults and Adolescents Living with HIV in Resource-Limited Settings*. Geneva, World Health Organization, 2008.

13 The Living 2008 Summit, held in Mexico on July 31 and August 1, 2008, was a partnership of GNP+, IAS, ICASO, ICW, IRFC, International HIV/AIDS Alliance, IPPF, Mexican Network of People living with HIV, Sidaction, UNAIDS and WHO. It was the first gathering of HIV-positive leaders from around the world in five years. Prevention, with a focus on ‘positive prevention,’ was one of four key advocacy themes discussed at the meeting.

14 Living 2008 Partnership. *Draft discussion paper: Positive Prevention by and for People Living with HIV*. Amsterdam, GNP+, July 2008.

The specific objectives of the technical consultation were to:

- Gather experiences and knowledge of stakeholders, in particular people living with HIV at regional, national and local levels, at the technical consultation; and to develop a strategy to gather broader views and experiences following the technical consultation;
- Develop a set of initial values and principles on positive prevention; and
- Develop recommendations to facilitate the scale up of programmes and the development of policies.

Expected outcomes of the meeting included:

- A set of initial values and principles to undertake 'positive prevention' programmes;
- An action plan to increase the involvement of people living with HIV in developing a common understanding of 'positive prevention' for decision making around 'positive prevention' policies and programming; and
- Recommendations for priority actions specific to various stakeholders including UN agencies, civil society, people living with HIV networks, national authorities, and multilateral agencies, including specific advice for multilateral and donor agencies to guide their support for 'positive prevention' policies.

The meeting was attended by range of stakeholders from twenty-eight countries on six continents representing people living with HIV networks, development agencies, civil society organisations, country implementers, multilateral and UN agencies, and donor agencies. More than half of the fifty participants were people living with HIV who are leading programmes and driving policies aimed at achieving better HIV responses and higher health and quality of life standards for HIV-positive individuals.

Kevin Moody, representing GNP+, along with Rodrigo Pascal and Michael Bartos, representing UNAIDS, set the stage for the meeting by welcoming the participants and stressing that this joint effort between GNP+ and UNAIDS was part of an ongoing process that will continue with regional consultations throughout 2009 in order to achieve personal, national, regional, international and stakeholder understanding and ownership of 'positive prevention'.

Kevin Moody noted that this meeting, as well as the further consultations, provide an opportunity for people living with HIV to be central to HIV responses and to understand what 'positive prevention' means for people living with HIV, their

partners and those most at risk. "If we want to reclaim prevention," he told the participants, "we need to do the work."

Rodrigo Pascal explained that the meeting was about "dialogue and communication with people living with HIV sitting in the driving seat, to show that the components [of 'positive prevention'] are related to our needs." Michael Bartos also underlined the importance of the involvement of people living with HIV by stating that UNAIDS "needs more guidance from people living with HIV to shape this work."

Putting Positive Health, Dignity and Prevention into Practice

David Hoe, of the Poz Prevention Working Group of the Ontario Gay Men's Sexual Health Alliance, explained why people living with HIV should drive 'positive prevention' policy and programmes. He noted that few, if any, programmes exist to support people living with HIV with a lifetime of decisions on intensely personal issues such as sex and drug use, and that it is extremely rare for intentional infection to happen despite a worrying increase in prosecutions in Canada, and globally, for HIV non-disclosure, exposure and transmission. "We [PLHIV] care about HIV infections and our communities," he said, but "in the absence of health and social policy, society defaults to criminal law and stigma. But when we replace shame with empowerment, we can make conscious decisions." The involvement of people living with HIV – as definers, skill-builders, guides, and learners – can be the key to the success of Positive Health, Dignity and Prevention policy and programmes, he concluded.

Source: David Hoe. *Policy from PLHIV perspective: the story drives the policy*. Technical consultation presentation, April 28, 2009.

Towards a Name and Common Understanding

From 'positive prevention' to 'Positive Health, Dignity and Prevention'

During the Living 2008 Summit, it became clear that many people living with HIV were not willing to engage with the term 'positive prevention'. For many 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. Some stated that the term was "too broad, meaning nothing" while others said it could be "stigmatising". It was noted that in some Asian countries, the term 'positive prevention' translated into the local languages could imply or be reminiscent of quarantining HIV-positive individuals.

Many participants expressed similar opinions during this technical consultation. It was argued that the term does a disservice to both HIV prevention and people living with HIV, since many components agreed upon at the meeting are focused on 'health' in its broadest meaning – such as people going back to work and creating and maintaining families – rather than simply preventing disease or averting new infections. Those outcomes, one participant noted, are also "about human dignity and value." Another participant countered that there was a strategic value to adopting a different name now in order to reframe the issue, and focus on enabling environments. This would in turn give people living with HIV a chance to finally take control of the agenda.

Other participants, however, supported the ongoing use of the term. Some argued that since many donor agencies are already using the term, to change it might confuse them and may also appear as if people living with HIV were "creating a parallel programme [which] might further stigmatise us." One participant noted that it was important to value all the work done by people living with HIV to date in 'positive prevention' and was particularly concerned that changing the name might mean, "losing what we have gained in the past five years".

Some felt that that the term itself was not an issue but rather it was the concept, policies and programmes that mattered, while others felt very strongly that the name must be changed

in order to move forward. Consequently, participants agreed that a new working name should be created and agreed upon at the meeting since difficulties with the term were forestalling further discussions on the components, values and principles, and recommendations. A series of terms were proposed and discussed. These included:

- Essential Prevention by and for People living with HIV
- Health Promotion and Positive Living
- HIV Prevention for and by People living with HIV
- Positive Health and Rights
- Positive Health, Dignity and Prevention
- Positive Health, Wellbeing and Dignity
- Positive Life/Positive Living
- Positive Prevention for Health and Dignity
- Santé Plus/Health Plus

Through a process of careful consideration and debate, most of the suggestions were discarded. For example, most participants agreed that 'prevention' needed to remain in the name since prevention of illness, as well as transmission, was a major part of the concept, and not necessarily the same as 'health'.

Why People Living with HIV in Latin America reject the term 'positive prevention'

Anuar Luna, of the Mexican Network of People Living with HIV and RedLa+, highlighted Latin American concerns with the term 'positive prevention'. In his role as the people living with HIV representative on the UNAIDS HIV Prevention Reference Group – a working group of key actors from twenty-three countries involved in prevention around world, Anuar felt that in the Group's recent classification of HIV prevention activities, 'positive prevention' was considered to be an activity imposed upon people living with HIV and that the term suggests placing transmission prevention as the core activity. He argued that this distracts from other equally important issues such as access to the continuum of treatment and care, human rights, sexual health, reproductive rights and redressing gender imbalances.

Source: Anuar Luna. [*Positive prevention*] at UNAIDS Prevention Reference Group. Technical consultation presentation, April 28, 2009.

It was also noted that the term ‘rights’ “carries tremendous political baggage” and that ‘dignity’ – which encompasses the human rights-based aspects of the framework – may be preferable. One participant commented: “When you link prevention, health and dignity together you can’t abuse those terms.”

Following further discussion, participants reached consensus on a new, working term that better describes this new paradigm: ‘Positive Health, Dignity and Prevention.’ Participants are eager to garner feedback on the new term during regional consultations, particularly as to how it might be translated to suit specific contexts.



Towards an understanding of Positive Health, Dignity and Prevention

Consultation participants agreed that there are significant shortcomings to many current ‘positive prevention’ approaches and were concerned that many existing, donor-led interventions appear to focus almost entirely on preventing the onward transmission of HIV, which should not be the sole aim of any Positive Health, Dignity and Prevention programme.

It was agreed that Positive Health, Dignity and Prevention provides an opportunity to highlight the myriad health and prevention needs of people living with HIV, and a useful lens through which to understand the important linkages between human rights and prevention, treatment, care, and support. Throughout the technical consultation, participants worked

individually, in small groups, and collectively to list the components encompassed in this new paradigm.

The following list groups together individual components under programmatic headings. Many of these components achieve multiple programmatic aims and could also fit under other headings. Participants agreed that this list of components was neither exhaustive, nor binding, nor is presented in any particular order of importance, and welcomed further discussion from all stakeholders.

Components of Positive Health, Dignity, and Prevention include:

Health promotion and access

- Voluntary counselling and testing (VCT)
- Provider-initiated testing and counselling and community-based testing and counselling under conditions of informed consent, confidentiality and good counselling
- Antiretroviral therapy (ART), including clinical monitoring, adherence supporting, access, availability and quality assurance
- Health education for living well
- Treatment literacy
- Psychosocial wellbeing, including building self-esteem and confidence
- Mental health
- Preventing disease progression and further infections/prophylaxis for tuberculosis (TB) and opportunistic infections (OIs)
- Palliative care

Sexual and reproductive health and rights

- Sexual and reproductive health
- Maternal health
- Family planning
- Prevention and treatment of sexually transmitted infections (STIs), including hepatitis B and C
- Sex and sexuality education and services

Prevention of transmission

- Transmission literacy
- Harm reduction (drugs and alcohol)
- Prevention of parent to child transmission

Human rights, including stigma and discrimination reduction

- Ensuring confidentiality of status
- Safe and voluntary disclosure (“to create an environment of open communication and equality in relationships”)
- Autonomy of the individual (“i.e. choice as to when, and if, to initiate ART”)
- Legal literacy, advocacy and activism
- Enabling environment, including protective laws
- Shared responsibility

Gender equality

- Gender-based violence prevention and management
- Women’s rights
- Rights for men who have sex with men, and for lesbian, gay, bisexual, transgender and intersex people
- Economic empowerment

Social and economic support

- Social and economic support, including for caregivers
- Food and water security
- Health and social protection for children and adolescents living with HIV
- Education and awareness

Empowerment

- Meaningful involvement of people living with HIV, including positive leadership, participation and advocacy
- Social mobilisation and community engagement
- Linking to other social justice and development movements

Measuring impact

- Continued and/or increased funding for Positive Health, Dignity and Prevention programmes
- Building evidence and sharing lessons learned
- Indicators for monitoring and evaluation

Positive Health, Dignity and Prevention in Practice: Nepal

Since 2007, eight community-based organisations (CBOs) in Nepal have collaborated on a Family Health International (FHI) ‘positive prevention’ programme aimed at people living with HIV, their partners, families, and communities.

The programme has resulted in the following benefits for people living with HIV:

- Enhanced meaningful involvement and participation;
- Increased participation and ownership in the programme;
- Increased self-esteem and confidence;
- Improved positive and healthy lifestyles;
- Increased access to care, support and treatment services; and
- Decreased incidence of stigma and discrimination.

Individual interventions include:

- Counselling for serodiscordant and seroconcordant couples on disclosure and safer sexual and injecting behaviours, including condom promotion and distribution;
- Promotion of healthy lifestyles and positive thinking and living; and
- Referral to HIV counselling and testing and HIV care, support and treatment services.

Community interventions include:

- Education and outreach via a positive speakers’ bureau, community discussion forums that includes sensitisation around stigma and discrimination;
- Establishment of post-test clubs, and ‘HIV anonymous’ meetings; and
- Coordination and collaboration with stakeholders.

Source: Sudin Sherchan, NAP+N. *Practices and lessons learnt on PP: Designing and Implementing PP Programmes in Nepal*. Technical consultation presentation, April 28, 2009.

Linking Positive Health, Dignity and Prevention with Rights and Law

The strongest consensus to emerge from the meeting was that Positive Health, Dignity and Prevention requires a human rights framework (including rights-based approaches to HIV programming) supported by protective laws to ensure non-discrimination, reduce stigma, and change harmful gender norms. Participants unanimously agreed that the law must enable people living with HIV to protect themselves and others – not through fear, but through empowerment and with dignity.

Positive Health, Dignity and Prevention and Rights and Law

Susan Timberlake of UNAIDS provided an overview of the links between Positive Health, Dignity and Prevention, the legal environment and programmes to empower. She highlighted the many obstacles towards achieving this goal, notably due to punitive laws that criminalise behaviours that place people at risk of HIV – such as certain sexual practices, sex work, drug use, adultery and ‘fornication’; and the criminalisation of non-disclosure of HIV-positive status, HIV exposure and/or transmission of the virus.

Despite governments committing to enact protective laws, there is often a lack of consistency between policy and law. For example, discriminatory laws – such as restrictions on entry, stay and/or residence, or laws that require mandatory HIV testing – may exist alongside laws that protect people living with HIV.

She suggested three overarching strategies to improve the legal environment:

- Legal literacy: to empower people living with HIV and affected communities to know their rights and laws, to access the justice system and to advocate for change.
- Improve law enforcement: to train police, prison staff, lawyers and judges not to discriminate and to facilitate and uphold fair and equal access to the law.
- Legislate or reform law: although difficult, time-consuming, politically complex, and fraught with risks, we must prepare the ground to advocate for better laws, or, in some cases – such as non-disclosure and HIV exposure – no laws at all.

Laws that Criminalise Status: Civil and Sharia Law and Punishments Targeting Key Populations in Malaysia

Transgender (Offence: “indecent behaviour”)
Civil law (up to 3 months in prison, plus fine)
Sharia law (up to 1 year in prison, plus fine)

Sex between men (Offence: “carnal intercourse against the order of nature” or “Liwat”)
Civil law (up to 20 years in prison, plus whipping)
Sharia law (up to 3 years in prison, plus whipping, plus fine).

Sex work (Offence: “prostitution”)
Civil law (up to 3 months in prison, plus fine),
Sharia law (up to 3 years in prison, plus whipping, plus fine)

Source: Elisha Kor, PT Foundation, *Criminalization of Sexual Behaviour in Malaysia*. Technical consultation presentation, April 28, 2009.

Positive Health, Dignity and Prevention and Criminalisation of Status

Laws that criminalise certain key populations at risk of or disproportionately affected by HIV – such as people who use drugs, sex workers, men who have sex with men and other sexual minorities such as transgender and intersex people – significantly hamper HIV responses by hindering the dissemination of information; creating further stigma and discrimination; and increasing vulnerability to HIV and/or further illness.

According to UNAIDS’ 2008 *Report on the Global AIDS Epidemic*,¹⁵ 84 out of 136 reporting countries reported having laws and regulations that present obstacles to effective prevention, treatment, care and support for vulnerable populations.

During a parallel session on the impact of criminalisation of status on Positive Health, Dignity and Prevention, participants agreed it was important to make links between the

¹⁵ Available at: www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_GlobalReport.asp

Advancing the Sexual and Reproductive Health and Rights of People Living with HIV

The following national legislative reforms must take place:

- Create anti-discrimination laws (sexual orientation, gender identity, HIV status);
- Decriminalise HIV nondisclosure, exposure and transmission;
- Ensure the right to marry and found a family regardless of HIV status;
- Make HIV status irrelevant in divorce and child custody decisions;
- Ensure rights of young people to confidentiality, age-appropriate information and sexual and reproductive health care;
- Guarantee women's property rights;
- Recognise and prosecute sexual violence (e.g. incest, forced/early marriage, sexual assault or rape).

From 'Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV: A Guidance Package' published by EngenderHealth, GNP+, ICW, IPPF, UNAIDS and Young Positives.

Source: Lynn Collins, UNFPA. *Addressing Sexual and Reproductive Health and Rights and HIV Prevention Linkages within Environments of Gender Inequality*. Technical consultation presentation, April 28, 2009.

criminalisation of different key populations (e.g. men who have sex with men, people who use drugs, sex workers) and to appreciate the differences – and similarities – between illegality and human rights violations. It was also agreed, however, that due to lack of country-specific data an international technical consultation specifically focused on the issue of criminalisation of status was necessary.

Initial recommendations include:

- Face challenges by working pragmatically towards assuring access of criminalised individuals to Positive Health, Dignity and Prevention.
- Improve legal literacy for people living with HIV.
- Establish better linkages between local level experts, people living with HIV networks, civil society, and multilateral and UN

agencies in order to obtain more data on specific laws and their impact.

- Lobby to ensure that the law follows human rights, while appreciating that changing the law is a slow process.

Positive Health, Dignity and Prevention and Criminalisation of Nondisclosure, Exposure and Transmission

During a parallel session on the criminalisation of HIV nondisclosure, exposure and transmission, participants heard that eighty-five countries have laws mandating the disclosure of HIV-positive status to sexual partners where there is a risk of transmission; and/or making it illegal for HIV-positive individuals to expose others to the risk of transmission; and/or to 'knowingly' or 'recklessly' transmit HIV to otherwise consenting sexual partners.¹⁶

Participants expressed concern about both the rise in the number of cases in which HIV-positive individuals have been criminally charged under these laws, and the drive towards new HIV-specific legislation, particularly in sub-Saharan Africa, where twenty countries have proposed or adopted such laws in the last four years.¹⁷

Susan Timberlake noted that while many legislators have good intentions, such laws are not an effective way of dealing with HIV transmission. She highlighted the tensions that exist between the criminal law's obligation to punish and deter blameworthy behaviour and the public health imperative to prevent new HIV infections. She stressed that while UNAIDS believes that there is no evidence demonstrating that broad application of the criminal law to HIV transmission achieves either criminal justice or prevents further infections, little is known about the impacts of criminalising HIV transmission.¹⁸

Participants expressed concern that criminal laws around HIV nondisclosure, exposure and transmission may risk undermining public health by having a negative impact on the uptake of HIV testing, raising unrealistic expectations of disclosure, and hindering access to HIV prevention, treatment and care services.

¹⁶ Susan Timberlake. *Criminalization of transmission: influencing legal frameworks with positive prevention*. Technical consultation presentation, April 28, 2009.

¹⁷ For detailed, up to date, information, see: www.gnpplus.net/criminalisation

¹⁸ See: www.unaids.org/en/PolicyAndPractice/HumanRights/humanrights.criminalization.asp

Skip Rosenthal, of GNP+ North America, asked participants to consider how and whether these concerns affected Positive Health, Dignity and Prevention policies and programmes. Participants felt strongly that by placing the burden of responsibility on people living with HIV these laws undermine one of the key principles of Positive Health, Dignity and Prevention: namely, that preventing HIV transmission is a shared responsibility of all individuals regardless of HIV status. “Criminalisation is the flipside of shared responsibility approaches,” noted one participant. “We have to teach the criminal justice system about this.”

Participants agreed that further consultation on this issue was necessary, including better clarification on what ‘shared responsibility’ means to people living with HIV, their partners and communities. Some initial recommendations include:

- Facing challenges pragmatically through a harm reduction approach¹⁹.
- Increasing awareness among HIV-positive individuals about existing laws.
- Ensuring that the law follows human rights lobbying, while appreciating that changing the law is a slow process.
- Creating better linkages between local level experts, people living with HIV networks, civil society, and multilateral and UN agencies to obtain more data on specific laws and their impact.
- Unpacking ‘shared responsibility’ in terms of the criminal justice system and building strategies to deal with that system proactively.

¹⁹ Such an approach might include engaging with key stakeholders in the criminal justice system to educate them about HIV exposure and transmission; and to work with at-risk communities to reduce the number of criminal complaints by highlighting shared responsibility, and suggesting alternative resolution methods, such as couples’ counselling or use of civil law.

Implications of Criminalisation of HIV Transmission for Positive Health, Dignity and Prevention: Some Recommendations

- Confront the realities of the legal world;
- Enter the debate in terms of legal arguments/ definitions;
- Keep the response in public health;
- Assess the nature of responsibility;
- Engage with law-makers; and
- Develop tools for education, empowerment, and challenge.

Source: Susan Timberlake. *Criminalization of transmission: influencing legal frameworks with positive prevention*. Technical consultation presentation, April 28, 2009.

Achieving the ‘Dignity’ in Positive Health, Dignity and Prevention: Some Recommendations

- Become more legally literate;
- Be outspoken and organised against bad laws and law enforcement and for good laws and law enforcement;
- Demand that Positive Health, Dignity and Prevention policy includes programmes that support human rights and legal literacy;
- Demand that donors fund and governments implement and scale-up these programmes;
- Support non-discrimination as the fourth pillar of universal access;
- Demand indicators of reduction in stigma and discrimination; and
- Call for operational research on the impact of bad law.

Source: Susan Timberlake, UNAIDS. *Links between positive prevention, the legal environment and programmes to empower*. Technical consultation presentation, April 28, 2009.

Treatment as Prevention

A new HIV prevention paradigm emerged from the XVII International AIDS Conference held in Mexico City in August 2008 that significantly blurred the lines between prevention and treatment, and greatly informed discussions at this technical consultation on how to move from 'positive prevention' towards Positive Health, Dignity and Prevention.

The first was the concept of 'combination prevention', which accepts that focusing primarily on behavioural change is overly simplistic. Combination prevention appreciates the realities of sexual dynamics, addresses societal and structural issues, and embraces biomedical interventions as prevention tools, including the experimental use of antiretrovirals (ARVs) – in the form of oral or topical pre-exposure prophylaxis – for people at risk of acquiring HIV.²⁰ The second was the increasing recognition – albeit with many reservations – of the potential of ART to greatly reduce HIV transmission risk on both an individual²¹ and population²² level.

Several presentations highlighted the challenges and opportunities of using treatment as a prevention tool. Kevin Moody, of GNP+, noted that some people living with HIV have been aware of the potential effect of treatment to lower the risk of transmission for many years and highlighted anecdotal evidence of "serodiscordant couples [who] have chosen not to use condoms because they know they are less infectious." He presented data from a small qualitative study of fifty-one long-term couples (of whom three were same-sex couples) in South Africa, Tanzania and Ukraine that highlighted the coping strategies and choices made in the context of long-term HIV discordant relationships. The study found that the HIV-positive partner was often afraid of infecting their HIV-negative partner; that, despite a high level of reported condom use, there was some reluctance on the part of the male partner to use condoms; that the heterosexual couples

were constantly balancing desire to have biological children with the risk of HIV transmission; and that these couples were not discussing their reproductive desires and intentions with health care providers because of anticipated negative reactions or lack of understanding.

A presentation by Portia Ngcaba of South Africa's Treatment Action Campaign (TAC), highlighted that treatment's role in prevention in resource-limited settings needs to focus primarily – and urgently – on the prevention of illness and death. She stressed that although 450,000 individuals currently receive ART in South Africa more than 500,000 adults and 27,000 children who are in urgent need of treatment – i.e. those who meet WHO's clinical definition of AIDS – do not have access to ART.



Participants from Africa highlighted that a multisectoral approach beyond treatment or prevention – that includes economic security, housing, and social service needs – is also required to support people living with HIV. A participant from Kenya added, "one of the biggest issues we face in sub-Saharan Africa is that around 40% of people living with HIV who start ART are no longer taking it after two years. The main reasons are economic – people can't afford the bus fare to get to the clinic, and they can't afford to pay for food."

Andrew Doupe, of the World Health Organization (WHO), noted that although WHO currently does not have a specific policy on ART for prevention, members of staff published a theoretical mathematical model in November 2008 in *The Lancet* that examined the potential impact of universal voluntary

20 See Pebody R, Cairns G. *Prevention – there will be no magic bullet, we need 'combination prevention'*. NAM, August 2008. Available at: www.aidsmap.com/en/news/851AA401-037F-44E8-8115-6320059C02D7.asp

21 See Bernard EJ. *Swiss statement that 'undetectable equals uninfected' creates more controversy in Mexico City*. NAM, August 2008. Available at: www.aidsmap.com/en/news/CB3AEAB0-8910-4B75-A6B1-3AE8B1413D2A.asp

22 See Alcorn K. *Treatment as prevention tool: enough evidence to say it works, says IAS president*. NAM, August 2008. Available at: www.aidsmap.com/en/news/30D49BD7-41FC-4E0D-AEBD-A210794D0533.asp

Positive Health, Dignity and Prevention in Practice: Zambia

Ruth Mukonde, of the International HIV/AIDS Alliance, provided an example of how Positive Health, Dignity and Prevention can make a difference to the lives of people living with HIV. Jane was a widow when she was diagnosed with HIV. In 2004, when she registered with the home-based Antiretroviral Community Education and Referrals (ACER) programme she had a CD4 count of 1 cell/mm³ and suffered from several OIs. She received Ministry of Health-funded ART via the ACER site, and healthcare workers supported Jane through a holistic approach that included:

- Home-based care visits;
- Transport support for clinic appointments;
- Nutritional support;
- Psychosocial counselling, including an ART support group; and
- Behaviour-change workshops.

Jane's latest CD4 count is 550 cells/mm³ and she is happy and well, supporting other people living with HIV at the University of Zambia ART Clinic.

Source: Ruth Mukonde. Personal communication following the technical consultation.

HIV testing followed by immediate ART irrespective of clinical stage of CD4 count. The model assumed that treatment in combination with current prevention methods would greatly reduce onward transmission, and concluded that this might reduce the number of new HIV infections by 95% within ten years in a generalised heterosexual epidemic of southern African severity, and might result in cost saving in the medium term²³. WHO is now calling for discussion and research on the implications of a policy of 'treatment as prevention', aware that ethical and human rights considerations must inform the debate, and ready to listen to the voices of people living with HIV.

Kane Race, of the University of Sydney, highlighted some of the potential benefits and pitfalls of such an approach if it were to become policy. A potential benefit was that many people living with HIV – both those who are currently

undiagnosed and those aware of their HIV-positive status – would have access to treatment, potentially saving millions of lives. However, a major pitfall is the concept of 'universal' voluntary HIV testing which cannot be achieved without major changes in both policy and social conditions. In addition, the scale-up of both testing and treatment would require a substantial and sustained scale-up of infrastructure and resources. Such an approach would also rely on a lifetime of ART adherence, which may not be sustainable for individuals, or for countries' healthcare systems.

Participants were split between welcoming a policy of 'treatment as prevention' – due to its potential implications for universal access to testing, prevention, treatment, care and support – and being mindful of the possibilities of human rights abuses. Some expressed concern that the concept of the right to choose *if* and *when* to start treatment may get buried under the excitement and eagerness to expand access for those who currently do not have access to ART. "From a human rights point of view, 'treatment as prevention' is the perfect storm," stated one participant, who highlighted that throughout the HIV epidemic funding and political support have gone to easily measurable outcomes such as testing and treatment, and not to support social, legal and economic protection. Participants shared concerns that this may be repeated throughout the process of research, testing and rollout of 'treatment as prevention' unless people living with HIV demand policies that protect their human rights.

The technical consultation identified a number of priorities and challenges that require further attention. On an individual level these include:

- More research and programmatic action on the environmental elements and social conditions that enhance voluntary access to testing, treatment and care;
- Recognition that some people living with HIV already practice 'treatment as prevention' for a range of reasons, including a desire for intimacy and/or to reproduce;
- Greater understanding of the experiences of people living with HIV (including those in serodiscordant relationships) on:
 - Prevention strategies that are already being used and how introducing 'treatment as prevention' may impact on these strategies;
 - Outcomes that are sought from taking HIV treatment and how these outcomes relate to broader sexual and reproductive choices;
 - Barriers to taking HIV treatment;

²³ Granich RM, Gilks CF, Dye C, et al. *Universal voluntary HIV testing with immediate antiretroviral therapy as a strategy for elimination of HIV transmission: a mathematical model*. *Lancet* 373 (9657); 48 – 57, 2009.

- Accessibility of first-line and second-line regimens; and
- Fears and questions about taking HIV treatment for preventative measures;
- Clearer messages about the risks and benefits of using 'treatment as prevention';
- A greater understanding of how Positive Health, Dignity and Prevention impacts upon HIV-negative individuals who may become HIV-positive as a result of clinical trials for new prevention technologies.

Priorities and challenges for 'treatment as prevention' as a population level approach include understanding:

- How feasible and acceptable 'treatment as prevention' might be as a galvanising force towards universal access;
- What resources may be required to implement this approach, and what the role of civil society and people living with HIV networks should be;
- What the effect on people living with HIV might be of framing 'treatment as prevention' on issues such as autonomy, adherence and confidentiality;
- What is needed to prevent public health 'identify and contain' strategies from trumping 'community education, protection and empowerment' concepts;
- How 'treatment as prevention' may potentially be used coercively against key populations; and
- What the effect on individual and public health of treating early and for a lifetime might be in terms of drug toxicity and drug resistance.

Integrating Positive Health, Dignity and Prevention within Universal Access to Prevention, Treatment, Care and Support

WHO estimates that globally fewer than one in five people at risk of acquiring HIV have access to basic HIV prevention services; that more than 80% of the people living with HIV in low and middle-income countries do not know that they are infected; and that fewer than one in three people living with HIV clinically eligible for HIV treatment has access to ARTs.²⁴

Calls for universal access have boosted HIV responses around the world; focused countries' national responses; and galvanised civil society, people living with HIV and affected communities, governments and international organisations to work together towards a more coordinated approach.

The technical consultation discussed how Positive Health, Dignity and Prevention could be integrated not only into current HIV prevention, treatment, care and support programmes but also within the goal of universal access by 2010 to HIV prevention, treatment, care and support.

Positive Health, Dignity and Prevention and Universal Access

According to a presentation by WHO's Kevin O'Reilly, many of the values, principles and components of Positive Health, Dignity and Prevention go hand-in-hand with achieving universal access goals. In particular:

- It would help focus the attention of the health sector on an underserved population. He acknowledged that despite "encouragement", the health sector has not meaningfully engaged with civil society, non-governmental organisations (NGOs) and community-based organisations (CBOs) already providing services that support people living with HIV to live well.
- It may motivate earlier testing, achieve greater access for people living with HIV to supportive services, and give people living with HIV a reason to remain in contact with their clinic between testing HIV-positive and being eligible for ART. There are many people living with HIV for whom treatment is not currently indicated but for whom much

could be done, he said. "We know that people test too late and access services too late. We know that a lot of people test, get a result and then disappear until they are ill. We need to fill the gap between receiving a positive result and the initiation of treatment."

In discussing the recently released WHO guidelines, participants highlighted a number of challenges to both their implementation, and to linkages with important components of Positive Health, Dignity and Prevention:

- There is currently a lack of coherent implementation – whereas certain countries such as Zambia have embraced them, others have not.
- There is no specific funding earmarked for any of the recommended interventions.
- There are no current plans for monitoring and evaluation.
- The evidence-based nature of these guidelines constrained much of the guidance on reducing HIV transmission risk in the absence of condoms.
- No guidance was included on how to reduce the impact of the recently introduced criminal laws on HIV exposure and transmission throughout sub-Saharan Africa.
- Moral and political agendas often remain a barrier to implementing evidence-based interventions.

Participants unanimously agreed that linkages between Positive Health, Dignity and Prevention and universal access are essential. A number of priorities and challenges associated with integrating the values and principles of Positive Health, Dignity and Prevention into the various policy and programmatic elements of HIV prevention, treatment, care and support were highlighted, including:

- Tackling stigma and discrimination in healthcare settings;
- Mitigating the impact of a non-supportive legal and policy environment;
- Integrating proven harm reduction methods into treatment, care and support programmes;
- Creating stronger links and increasing collaboration between the health sector and civil society organisations already providing prevention, treatment and care services;
- Providing the resources required to train healthcare workers on the values, principles and programmatic elements of Positive Health, Dignity and Prevention and implement these elements within healthcare services; and
- Responding to the HIV-positive individual's needs but measuring the impact of the success of Positive Health, Dignity and Prevention on population health.

²⁴ WHO. *Towards universal access: scaling up priority HIV/AIDS interventions in the health sector*. Progress report, June 2008. Available at: www.who.int/hiv/pub/2008progressreport/en/index.html

Positive Health, Dignity and Prevention and HIV prevention

During a parallel session on placing Positive Health, Dignity and Prevention within broader HIV prevention efforts, participants identified a number of priority areas to consider. These include:

- Involving people living with HIV in all aspects of prevention, including design, programming, implementation, research, monitoring and evaluation;
- Broadening prevention programmes beyond focusing on the 'uninfected' and/or 'untested' and creating more discerning messages for individuals who are HIV-negative, -positive or -unaware;
- Focusing on serodiscordant couples and key populations;
- Incorporating and understanding the connections between an individual's capacity and the effects of the wider environment;
- Building skills-building programmes to address issues of confidence and assertiveness;
- Providing clear, up-to-date, evidence-based information in order to allow the individual to make choices; and
- Incorporating all aspects of sexual and reproductive health, including feelings and desires, into behavioural interventions, by acknowledging the complexities surrounding the moment of transmission/acquisition of HIV.

The technical consultation heard about prevention interventions aimed at people living with HIV that highlighted successes as well as a number of priorities and challenges. Angelina Namiba, of the UK's African HIV Policy Network (AHPN), explored these issues within the context of African migrants living with, and affected by, HIV in the UK. African migrants experience multiple challenges, notably around socio-economic and legal issues including the threat of deportation and prosecution for HIV transmission. In partnership with a range of broad stakeholders, AHPN developed a number of health promotion campaigns, which integrated messages that addressed HIV testing alongside access to services and focused on the shared responsibility of HIV transmission, rather than focusing primarily on people who were HIV-negative or untested.

Alan Brotherton, of the International HIV/AIDS Alliance, shared the Alliance's experiences – in particular, the challenges of linking the needs of people living with HIV with wider HIV prevention efforts. Using a 'real life' example from Thailand, he noted that individual prevention needs and messages are more effective when contextualised within internalised and externalised issues such as self-acceptance or community rejection.

Thirteen WHO-recommended Essential Interventions for People Living with HIV

WHO has recently published guidelines featuring a core set of thirteen effective, evidence-based interventions aimed at people living with HIV in resource-limited settings at all stages of HIV disease which are "simple, relatively inexpensive, and can improve the quality of life, prevent further transmission of HIV, and – for some interventions – delay progression of HIV disease and prevent mortality."

- Psychosocial counselling and support;
- Disclosure, partner notification and testing and counselling;
- Co-trimoxazole prophylaxis;
- Tuberculosis counselling, screening and prevention;
- Preventing fungal infections;
- Preventing sexually transmitted and other reproductive tract infections;
- Preventing malaria;
- Preventing selected vaccine preventable diseases (hepatitis B, pneumococcal, influenza and yellow fever);
- Nutrition;
- Family planning;
- Preventing mother-to-child transmission of HIV;
- Needle-syringe programmes and opioid substitution therapy; and
- Water, sanitation and hygiene.

Source: WHO. *Essential prevention and care interventions for adults and adolescents living with HIV in resource-limited settings*. Geneva, 2008.

Looking specifically at HIV prevention messages aimed at people living with HIV, he stressed that serostatus issues add further to the complexities of interpersonal issues. For example, should there always be disclosure with a new partner, and if so why, when, and how? What prevention messages are relevant if both partners are HIV-positive? Is it correct to focus on the continued use of condoms, based on limited data regarding the risk of re-infection and concerns over acquired resistance to ART?

Participants agreed that technical consultations should be convened to further discuss these issues and noted that there were significant challenges to overcome if there are to be successful linkages of Positive Health, Dignity and Prevention and broader HIV prevention efforts, and that these require further – and urgent – attention. Challenges include:

- Creating a common understanding of Positive Health, Dignity and Prevention across all stakeholders, including policymakers, funders and donors;
- Agreeing on the changing concept of Positive Health, Dignity and Prevention in the context of increasing access to and effectiveness of ARVs;
- Overcoming clinical constructions of people living with HIV as a “patient” rather than a sexual being;
- Advocating for better (or no) laws around criminal prosecution for HIV nondisclosure, HIV exposure and unintentional transmission, while balancing the need for justice for survivors of non-consensual sex;
- Understanding how to approach HIV-positive individuals who refuse to use condoms and/or have multiple concurrent partners, and how to ‘prove’ or endorse faithfulness;
- Assigning and agreeing on messages of responsibility rather than blame: are diagnosed HIV-positive individuals any more responsible for preventing onward HIV transmission than HIV-negative individuals for preventing HIV acquisition?

Positive Health, Dignity and Prevention and Treatment, Care and Support

During a parallel session on placing Positive Health, Dignity and Prevention within the context of treatment, care and support, participants identified a number of priority areas to consider in clinical settings. These include:

- Ensuring sustainability of ART programmes. “In many settings, when funding stops, the programme ends,” stated one participant.
- Improving adherence to treatment and care. One of the participants highlighted a United Nations Development Programme (UNDP) study that found that 40% of people living with HIV on ART in sub-Saharan Africa are lost to follow-up after two years.
- Linking community-level activities with the healthcare sector and other sectors, and clarifying the roles of NGOs and CBOs and the public and healthcare sectors.
- Increasing awareness of the impact of STIs and co-infections among people living with HIV.

INERELA+: The SAVE Prevention Model

Dr Stephen Watiti, of International Network of Religious Leaders Living with or Personally Affected by HIV/AIDS (INERELA+) outlined the ‘SAVE’ approach to HIV, developed in reaction to the shortcomings of the existing ‘ABC’ method. This is a holistic prevention model that fits within the broader paradigm of Positive Health, Dignity and Prevention.

- **Safer practices**, including correct and consistent condom use; being faithful to your sexual partner(s); safe transfusions, needles, gloves; and the Basic Care package for people living with HIV, including clean water and hygiene, septrin prophylaxis, sleeping under insecticide treated mosquito nets, and good nutrition.
- **Available medications**, including ART, TB medicines, septrin, antifungals, antimalarials, antibiotics and other essential drugs; and food for a balanced diet.
- **Voluntary counselling and testing**.
- **Empowerment**. Knowledge is power. People who are empowered with knowledge can then make informed decisions concerning their lives and how to protect themselves and others.

Source: Stephen Watiti. *The S.A.V.E. Strategy*. Technical consultation presentation, April 27, 2009.

The technical consultation heard about the experiences of a number of diverse interventions aimed at people living with HIV within clinical settings that highlighted successes, as well as a number of priorities and challenges. Thomas Cai of AIDS Care China – an NGO that delivers around 30% of all ART to people living with HIV in China – highlighted one of the main challenges of integrating Positive Health, Dignity and Prevention into the clinical care of people living with HIV: “Donors only want to focus on [onward transmission prevention, such as] condom use and not injecting drugs, but don’t care how that is achieved,” he said.

AIDS Care China has managed to achieve much more than onward transmission prevention through an educational programme delivered at a community service centre situated next door to the HIV clinic. The two sites coordinate their work by sharing patient information linked via computer.

Positive Health, Dignity and Prevention in Practice: Tanzania

Makoti Edwin, Project Coordinator at YCI-T, shared his experiences of regularly participating in radio call-in shows providing information and education about HIV/AIDS and the sexual and reproductive health and rights of people living with HIV in a personal and accessible way. He acknowledged that sharing personal information in a public forum is not always easy, and that discussing complex issues such as 'positive prevention' is challenging but said that it was important to "help other people, especially young people, know the facts about [HIV] and take measures to protect oneself from acquiring infections, and how to take care of oneself if you are living with HIV." He recommended that people living with HIV networks work with the media to deliver advocacy messages, and that civil society, the public sector and donor and UN agencies commit resources to promote media training for people living with HIV to be able to respond to negative and inaccurate media coverage; to communicate positive health promotion messages; and to ensure that the voices of people living with HIV, including young people, are part of their communication messages on Positive Health, Dignity and Prevention.

Source: Makoti Edwin. *Communicating Messages on Positive Prevention*. Technical consultation presentation, April 28, 2009.

Two full time peer counsellors – one HIV-positive, one HIV-negative – sited within the community service centre provide information and interventions tailored to the individual. AIDS Care's Positive Health, Dignity and Prevention programme is built upon four building blocks:

- Self-education: In Chinese, the words used for HIV and AIDS are similar, and the most basic piece of education is explaining that AIDS can be avoided with treatment and care.
- Treatment literacy: Learning about ART, and establishing that with treatment comes an optimised life expectancy.
- Self-esteem: "Learning to love yourself takes you on a journey to positive living." As a consequence, this will have a positive impact on an individual's health and that of their partners and families.
- Preventing illness: Adopting prevention approaches – including preventing onward transmission, as well as

preventing STIs, TB, drug resistance, and hepatitis B and C – can ensure a better quality of life.

Innovative examples of how community-based Positive Health, Dignity and Prevention interventions delivered in collaboration with clinical treatment, care and support settings – and involving both community and private enterprise – can improve the health outcomes of people living with HIV, their partners and communities were provided Gail Goodridge, of FHI.

In 2006, a people living with HIV support group within the 'Roads to a Healthy Future' programme in Busia, a farming community in western Kenya, recognised that many were struggling with ART adherence due to the community norm of heavy social drinking. They established a non-denominational counselling group, styled on Alcoholics Anonymous, which was linked with the local ART treatment site and staffed by community volunteers. The technical consultation heard that the programme has been extremely successful, expanding from one group with 15 members in 2007 to over 100 groups with more than 1500 members in 2009. Positive outcomes include a greater willingness to discuss and address excessive drinking norms, leading to a decline in alcohol consumption for both the individual and family members, resulting in greater ART adherence. In addition, the programme has attracted untested members of the community and has been able to provide HIV testing to this hard-to-reach population.

A second programme in Busia provides income for volunteer home-based care providers, many of whom are young women living with HIV (75% of diagnoses in sub-Saharan Africa affect women aged 15-24). Based on a detailed marketing assessment, FHI identified a large and growing market for mushroom production in East Africa. In collaboration with private sector company, LifeWorks, they have established a mushroom production business that will provide job opportunities for over 200 volunteer home-based care providers living with HIV. By sharing in the production work, they will reap economic benefits that will allow them to continue their volunteer work.

Participants agreed that there were significant challenges to be overcome if there are to be successful linkages of Positive Health, Dignity and Prevention within HIV treatment, care and support, and that these require further – and urgent – attention. These include:

- Ensuring that health care workers respect and understand the holistic health needs of people living with HIV;

- Integrating proven harm reduction methods into treatment, care and support programmes identifying how best to respond to the individual's needs;
- Mitigating the impact of a non-supportive legal and policy environment (e.g. on people whose behaviours or status is criminalised, and criminal HIV transmission laws);
- Measuring the impact of the success of Positive Health, Dignity and Prevention on population health.

Positive Health, Dignity and Prevention in Practice: Kenya

Milker Simba, from mothers2mothers (m2m), explained how this peer education programme works to prevent mother-to-child transmission (PMTCT); keep HIV-positive mothers and their infants alive and healthy by increasing their access to health-sustaining medical care, and empower and enable mothers to live positively with HIV. m2m uses education, empowerment and support as PMTCT tools, and combats stigma within families and communities through individual and group education and support, including adherence to ART. The service provides priority linkages to care, including partner and family testing; CD4 counts for all pregnant women; family planning services; and STI prevention and treatment. Positive results include: an improvement in disclosure leading to more partner testing and better adherence to ART; improved demand for CD4 and viral loads tests leading to improved access to HIV care; and a reduction in stigma and a sense of positive living, with clients taking responsibility for their health, their relationships and their lives. High programme retention is achieved due to the use of peer educators ('mentor mothers') and active client follow-up via text/sms messages, phone calls and targeted home visits.

Source: Milker Simba. *Perspectives from mothers2mothers*. Technical consultation presentation, April 27, 2009.

Key lessons from the International HIV/AIDS Alliance on Integrating People Living with HIV in Prevention

A holistic approach that places people with HIV at its centre and addresses their reality is essential. This takes time, trust and honest engagement and debate. 'Proving' effectiveness is very hard and easily confounded – but we shouldn't trade access for methodological neatness.

Implementation bottlenecks, rushing things and poor co-ordination can all slow things down.

Inclusiveness and diversity are critical – and sometimes need to be balanced differently in prevention than in treatment and care.

Source: Alan Brotherton. *Positive Prevention – the Alliance Experience*. Technical consultation presentation, April 27, 2009.

West Africa's 'ADA Process'

Sylvere Bukiki, from the HIV Collaborative Fund, shared Positive Health, Dignity and Prevention experiences from Burkina Faso and Côte d'Ivoire in West Africa. Here, they utilise the ADA Process (from the name of the first PLHIV organisation set up via this approach), which works on three levels:

- Individual: building self-esteem, acceptance, knowledge, and skills that lead to people living with HIV experiencing validation, autonomy and empowerment, and moving from passive beneficiary to active partner.
- Organisational: providing capacity-building and mentoring.
- Environmental: addressing stigma through ambassador-of-hope missions, advocacy, and media.

Source: Sylvere Bukiki. *Placing 'positive prevention' within treatment, support and care*. Technical consultation presentation, April 27, 2009.

Positive Health, Dignity and Prevention: Values and Principles

Throughout the meeting, a small working group developed and refined a set of values and principles for Positive Health, Dignity and Prevention to guide the national, regional and international efforts of diverse stakeholders. Several drafts were presented at plenary sessions during the two-day meeting. These were discussed in great detail and further refined.

- **People living with HIV must be leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting us.** If the health and prevention needs of HIV-positive people are to be adequately addressed, people who know they are living with HIV must be meaningfully involved in all aspects of Positive Health, Dignity and Prevention.
 - **A human rights approach is the foundation of Positive Health, Dignity and Prevention.** Positive Health, Dignity and Prevention programmes and policies must recognise the inherent dignity and equal and inalienable rights of people living with HIV.
 - **Preventing HIV transmission is a shared responsibility of all individuals irrespective of HIV status.** Positive Health, Dignity and Prevention is about people living with HIV taking responsibility for their own health and wellbeing and not about making people living with HIV solely responsible for the health of others.
 - **Sexual and reproductive health and rights must be recognised and exercised by everyone regardless of HIV status.** Positive Health, Dignity and Prevention is about empowering people living with HIV with choices regarding whether, and how, to be sexually active and fulfilled, and whether, and how, to conceive and enjoy a family.
- To achieve these aims, Positive Health, Dignity and Prevention:
- **Requires a supportive and protective legal and policy environment to ensure freedom from 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, and particularly gender and sexuality.**
 - **Should be responsive to the needs of key populations²⁵ and should respect and be tailored to specific contexts and environments as well as to the diversity among people living with HIV.**

²⁵ Indigenous peoples, men who have sex with men, migrants, people who use drugs, prisoners, refugees, sexual minorities (including intersex and transgender people), sex workers, women, and young people.

Initial recommendations

Participants developed some initial recommendations on partnerships, programmatic responses and advocacy responses for people living with HIV networks, civil society, the public sector, donor agencies and multilateral and UN agencies.

People Living with HIV Networks

- Develop an agenda through a consultative process for Positive Health, Dignity and Prevention;
- Identify key partners supporting advocacy work and develop regional and local advocacy plans; and
- Build evidence of good practices in Positive Health, Dignity and Prevention and identify key indicators to monitor and evaluate programme implementation and policy development.

Civil Society

- Ensure inclusion of Positive Health, Dignity and Prevention in national strategic frameworks, resources, plans, policies, and monitoring and evaluation systems;
- Adapt and integrate Positive Health, Dignity and Prevention into existing programmes and services, and organisational plans; and
- Advocate for funding to provide further services and resources for Positive Health, Dignity and Prevention.

Public Sector

- Create and commit to multisectoral Positive Health, Dignity and Prevention programmes, ensuring broad stakeholder involvement including people living with HIV;
- Ensure that a national plan is in place that commits to funding and programming for Positive Health, Dignity and Prevention throughout the public sector; and
- Ensure fair allocation of funding for Positive Health, Dignity and Prevention programmes with full transparency, including monitoring and evaluation.

Donor Agencies

- Develop and fund multisectoral Positive Health, Dignity and Prevention programmes with a focus on health promotion and shared responsibility for HIV prevention;
- Collaborate with people living with HIV networks, civil society and the public sector to ensure Positive Health, Dignity and Prevention is included in national, regional and local planning; and
- Create good practice guidelines through monitoring and evaluation to help build further evidence for Positive Health, Dignity and Prevention programmes.

Multilateral and UN Agencies

- Continue to consult on Positive Health, Dignity and Prevention definition, principles and components to produce and endorse policy and programming guidance;
- Ensure Positive Health, Dignity And Prevention is incorporated into national strategic plans and recommend its inclusion in next and future rounds of Global Fund proposals; and
- Ensure Positive Health, Dignity and Prevention is included in UNGASS indicators, including monitoring of human rights, to guarantee its implementation.

Next steps

This technical consultation has shifted the debate on HIV prevention as it relates to people living with HIV. In particular, the meeting recognised the vital role of people living with HIV in defining and developing policies and programmes to achieve Positive Health, Dignity and Prevention.

GNP+ and UNAIDS will continue to advocate for a comprehensive understanding of Positive Health, Dignity and Prevention in policies and programmes.

With the support of participants and their organisations at the technical consultation, GNP+ and UNAIDS will also take the work forward through regional meetings. The regional meetings will be an opportunity to:

- Promote regional understanding of Positive Health, Dignity and Prevention;
- Collect evidence-based examples and case studies to inform the development of policies and programmes aimed at achieving Positive Health, Dignity and Prevention;
- Contribute to the field's ability to learn from local and national developments where there have been effective linkages in areas such as HIV treatment, sexual and reproductive health and rights, and human rights.

The regional meetings will continue to engage people living with HIV, civil society, international development agencies, governments and UN co-sponsors in a dialogue about Positive Health, Dignity and Prevention to identify regional priorities and to strengthen global advocacy and programmatic action.



Appendix 1: Consultation Agenda

Monday 27 April 2009

TIME	ACTIVITY
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8.30 – 9.00	Coffee and registration
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SETTING THE STAGE

OBJECTIVES	To meet one another, agree on objectives and the agenda of the meeting, and establish common knowledge of where we are coming from and where we are heading to.
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9.00 – 9.30	Welcome and introductions Kevin Moody, GNP+ Rodrigo Pascal, UNAIDS Michael Bartos, UNAIDS
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9.30 – 9.45	Participant introductions
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9.45 – 10.00	Objectives of the technical consultation, review of the agenda and how the meeting will work
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10.00 – 10.30	Group activity – Developing a historical timeline of positive prevention Beri Hull, ICW
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10.30 – 11.00	Coffee Break
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ADDRESSING THE LACK OF CONSENSUS ON THE TERM AND CONCEPT 'POSITIVE PREVENTION'

OBJECTIVES	To review discussions by PLHIV to date, to establish commonalities in our understanding of 'positive prevention', and to begin identifying guiding principles for positive prevention programmes.
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11.00 – 11.15	'Positive Prevention' by and for people living with HIV Philippa Lawson, Futures Group International
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11.15 – 11.30	Questions and discussion
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11.30 – 12.30	Group activity – Deconstruct 'positive prevention' and defining a common term Christoforos Mallouris, GNP+ Michael Bartos, UNAIDS
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12.30 – 13.30	Lunch
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FRAMING POSITIVE PREVENTION WITHIN UNIVERSAL ACCESS

OBJECTIVES	To develop a common understanding of how positive prevention efforts sit within broader universal access goals; and to identify priorities, challenges, and success factors in implementing positive prevention programmes with key populations within this context.
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13.30 – 13.45	'Positive prevention' within universal access (HIV prevention, treatment, care and support) Kevin O'Reilly, WHO
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13.45 – 14.00	Questions and discussion
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14.00 – 14.30	PARALLEL SESSION	PARALLEL SESSION
	Placing positive prevention within broader HIV prevention Facilitator: Tita Isaac, RAP+AC Rapporteur: Laetitia Rispel, University of the Witwatersrand Perspectives: INERELA+ – Dr. Stephen Watiti African HIV Policy Network – Angelina Namiba International HIV/AIDS Alliance – Alan Brotherton UNESCO – handout	Placing positive prevention within treatment, support and care Facilitator: Alejandra Trossero, IPPF Rapporteur: Robert Baldwin, APN+ Perspectives: AIDS Care China – Thomas Cai m2m – Milker Simba ITPC – Sylvere Bukiki FHI – Gail Goodridge
14.30 – 15.00	Group work	Group work
14.45 – 15.30	Report back from group work and discussion	
15.30 – 16.00	Coffee break	
LINKING POSITIVE PREVENTION WITH RIGHTS AND LAW, INCLUDING THE CRIMINALISATION OF HIV TRANSMISSION AND NONDISCLOSURE		
OBJECTIVES	To establish how legal environments impact on positive prevention efforts, especially with key populations; and to identify strategies and recommendations to overcome negative legal environments through policy-making, lobbying, campaigning, and the distribution of information.	
16.00 – 16.15	Introduction – Exploring the links between positive prevention, the legal environment and the programmes to improve the legal environment. Susan Timberlake, UNAIDS	
16.15 – 16.30	PARALLEL SESSION	PARALLEL SESSION
	‘Criminalisation of status’ Facilitator: Andrew Doupe, WHO Rapporteur: Anastasia Kamlyk, UNDP Criminalisation of sexual behaviours and impact on positive prevention Elisha Kor, PT Foundation Kuala Lumpur Addressing SRHR and HIV prevention linkages within environments of gender inequality Lynn Collins, UNFPA	‘Criminalisation of HIV transmission’ Facilitator: Beri Hull, ICW Rapporteur: Julian Hussey, GSK Positive Action Criminalisation of HIV exposure and transmission and impact on positive prevention Skip Rosenthal, GNP+NA Working with different legal frameworks Susan Timberlake, UNAIDS
16.30 – 17.00	Group work	Group work
17.00 – 17.30	Report back from group work and discussion	
17.30 – 17.45	Capturing key principles and recommendations & close	

Tuesday 28 April 2009

TIME	ACTIVITY
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9.00 – 9.30	Review of key issues
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TREATMENT AS PREVENTION

OBJECTIVES	To understand the implications of recent discussions on 'treatment as prevention' at both individual and population levels; and to develop recommendations for further research and action.
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9.30 – 10.15	Perspectives: GNP+ – Kevin Moody Treatment Action Campaign – Portia Ngcaba WHO – Andrew Doupe University of Sydney – Kane Race
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10.15 – 11.00	Questions and discussion
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11.00 – 11.30	Coffee Break
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EXAMPLES OF GOOD PRACTICE AND LESSONS LEARNT FROM PEOPLE LIVING WITH HIV NETWORKS

11.30 – 12.00	Perspectives: Designing and implementing positive prevention programmes Sudin Sherchan – Nepal Communicating messages on positive prevention Makoti Edwin – Tanzania Strategic partnerships on positive prevention – UNAIDS HIV Prevention Reference Group Anuar Luna – Mexico Driving a policy agenda David Hoe – Canada Advocating for HIV prevention services for people living with HIV Handout from Paula Samuels, Jamaica
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12.00 – 12.30	Questions and discussion
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IDENTIFYING A NEW WORKING NAME

OBJECTIVE	To explore a workable alternative to 'positive prevention'
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12.30 – 14.00	Plenary discussion
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14.00 – 15.00	Lunch
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FIRMING UP RECOMMENDATIONS SPECIFIC TO VARIOUS STAKEHOLDERS AND ISSUE AREAS

OBJECTIVE	To refine recommendations by stakeholder group and across issue areas; and to identify and agree on a way to take discussions forward at regional and national levels and with different key populations.
15.00 – 16.00	<p>Group work – Developing recommendations by stakeholders: people living with HIV networks, civil society, public sector, donor agencies, multilateral and UN agencies</p> <p>3 recommendations for each of the following issues:</p> <ul style="list-style-type: none">- Ownership- Communications and advocacy- National implementation- Resource mobilisation <p>For each issue, think about: What needs to be done? Who should lead? With which partners? Process?</p>
16.00 – 16.30	Report back from group work and discussion

REFINING VALUES, PRINCIPLES AND COMPONENTS

OBJECTIVES	To review values, principles and components identified throughout the technical consultation on how to undertake positive prevention programmes; and to establish areas of agreement, areas of disagreement and areas for further deliberation.
16.30 – 17.00	Plenary discussion

NEXT STEPS

17.00 – 17.30	Kevin Moody, GNP+ Susan Timberlake, UNAIDS
17.30	Close

Appendix 2: List of participants

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Appendix 3: Participant Feedback

A total of twenty-six participants provided detailed feedback following the meeting, highlights of which are summarised below.

Participants were asked four questions:

- What was your overall impression of the technical consultation?
- What did you find most useful for yourself and your organisation at the technical consultation?
- How could we improve similar future meetings?
- We would like to hold regional consultations to take the discussions forward. What areas of content would you like to have highlighted or emphasized at the regional level?

Overall impressions

Without exception, participants provided extremely positive general feedback about the organisation, facilitation, programme and outcome of the technical consultation. Participants described the meeting as “very relevant”, “courageous and productive” and “a very good consensus-building process.” One participant summed up much of the feedback regarding overall impressions by stating that the meeting was “very useful to me and has allowed me to share good practice and lessons learnt.”

Many comments highlighted the diversity of the participants, including the large numbers of people living with HIV, representing a range of cultures and backgrounds, with a good mix of genders and sexualities. Participants also welcomed the broad range of experiences brought to the meeting and noted that the meeting included those who were skilled in policy-making and those new to policy but with hands-on, grassroots experience. One participant noted that the “representation was diverse, and it was good to have players from the different fields and levels.” Another participant highlighted that the focused and skillful facilitation allowed everyone’s voice to be heard: “It was a very good meeting whereby it involved participants from all parts of the world and everyone’s thoughts and perspectives were respected.”

However, the length of the meeting was the subject of several comments. Some noted that since the programme was extremely full, the meeting could have lasted longer, with many suggesting “an extra day”. Another noted that the meeting “tried to do too much in such a short time” and that in particular, the parallel sessions on criminalisation “were too

big to be dealt with in such a short time.” Several participants also felt that the meeting did not talk enough about transmission prevention, with one feeling that the discussions were “not close enough to the moment when HIV jumps from one to the other.” Participants provided further constructive criticism when they answered question three.

Most useful

It was clear from the breadth of responses to this question that the meeting provided something for everyone. Almost every aspect of the technical consultation was alluded to in this part of the feedback. Many participants highlighted that the meeting had challenged and confounded their expectations around what ‘positive prevention’ meant, and its programmatic features, and that they now felt “clarity” about “the way forward” due to the “consensus about the name of the approach: Positive Health, Dignity and Prevention.”

Many participants stated that they learned a great deal about the content and programmatic features of Positive Health, Dignity and Prevention from other regions as well as their challenges and concerns. Participants from well-resourced and resource-limited settings alike appreciated the similarities and differences in Positive Health, Dignity and Prevention priorities, with one noting, “it is vital we are in relation with others on this issue for mutual learning.”

For some, it was the values and principles of Positive Health, Dignity and Prevention that stood out; for others it was the initial recommendations on partnerships, programmatic responses and advocacy responses for people living with HIV networks, civil society, the public sector, donor agencies and multilateral and UN agencies. Others were struck by the importance of global people living with HIV leadership in Positive Health, Dignity and Prevention’s programmatic design and “not just the country networks alone as we have done in the past.” This was summed up by one participant who welcomed “the opportunity to open discussions about how to involve communities of people living with HIV in shaping the type of services offered at the ground level, in applying pressure to the health sector to make that happen...I feel hopeful and without this consultation, I am not sure when or if things would ever get moving.”

Improving future meetings

Participants provided a range of constructive criticisms, highlighting how future meetings could further be improved. The technical consultation took place in English, and several participants for whom English was not their first – or even second – language suggested that future meetings should consider addressing the issue of language.

Although the meeting's logistics were generally praised, some participants were frustrated by the short lead-in time to the meeting. This also frustrated some potential participants who were unable to travel so far at relatively short notice. It was also suggested that participants who had travelled from different continents, and who either arrived late the night before, and/or were suffering from jet lag during the meeting, might be better accommodated in future.

Many participants would have liked the meeting to have lasted longer, but suggested that the number of presentations could be reduced to allow for more small-group work and more discussion time in general if future meetings also lasted two days. One participant suggested: "Drop the presentations and spend more time in the trenches of 'what is important' and 'why is it important'."

Finally, although participants generally appreciated the broad range of stakeholders at the meeting, it was suggested that participants from similar backgrounds in terms of access to resources might have been able to work better together during small-group work rather than mixing participants from well-resourced and resource-limited settings. This, noted one participant, "would add deeper context and more targeted recommendations for the document that is to follow." Another participant from sub-Saharan Africa put it more bluntly: "At one point I felt like I was attending a meeting where people were discussing how to get to Mars while we in Africa have not yet started walking at all!"

Suggestions for regional level meetings

A broad variety of suggestions were received, with many participants highlighting issues particularly relevant to their region, setting or stakeholder group. "I think we need to look at the most pressing issues or priorities for the different regions," stated one participant. One participant highlighted the "need to address intra-community dynamics between

HIV-positive and HIV-negative people – for all communities, and especially those which are marginalised." Another suggested that what was needed now was a "regional dialogue on how best to integrate community-based Positive Health, Dignity and Prevention activities with what services are available in the facilities to ensure sustainable programmes."

It was anticipated that regional level meetings will differ dramatically according to setting. "In Africa, we first need to prioritise universal access to ART and then as the quality of the lives of people living with HIV improves, we stress Positive Health, Dignity and Prevention." Another participant from sub-Saharan Africa suggested focusing on how Positive Health, Dignity and Prevention can help people living with HIV move from being undervalued volunteers within the healthcare system to earn a living from their work.

Many participants highlighted discussing the values, principles and components identified at this meeting, and asking the question: "What does and does not resonate for you?" Others suggested discussing the creation of regional guidelines, and addressing resource mobilisation and advocacy plans for Positive Health, Dignity and Prevention. Several suggested that further discussion around the issues of criminalisation of status and of non-disclosure, exposure and transmission were necessary, with a focus on human rights: "I would like to suggest 'dignity' to be highlighted or emphasised."

Finally, but importantly, several participants highlighted the need to continue to focus on GIPA and MIPA principles in regional Positive Health, Dignity and Prevention discussions.

Appendix 4: Further reading

All of the presentations from the technical consultation are available for download from the GNP+ website:

www.gnpplus.net/component/option,com_docman/task,cat_view/gid,257/Itemid,53/

Anderson T. *Expanding the Boundaries of Positive Prevention Programmes*. National Association of People with AIDS, Presented at Broadening the HIV Prevention Landscape: 4th Annual CAPS Conference San Francisco 2004. hivinsite.ucsf.edu/InSite?page=cfcaps2004-01

Betteridge G., Thaczuk D. *Poz Prevention: Knowledge and Practice Guidance for providing Sexual Health Services to Gay Men living with HIV in Ontario*. Toronto, Toronto People With AIDS Foundation, 2008. www.pwatoronto.org/pdfs/Poz%20Service%20Manual.pdf

Brighton, International HIV/AIDS Alliance, 2007. www.aidsalliance.org/graphics/secretariat/publications/Positive_prevention.pdf

Centers for Disease Control and Prevention. *Advancing HIV Prevention: New Strategies for a Changing Epidemic – United States*, 2003. MMWR 52: 329-332, 2003.

Centers for Disease Control and Prevention. *HIV Prevention for People Living with HIV: an Intervention Toolkit for HIV Care and Treatment Settings*. Atlanta, Centers for Disease Control and Prevention, 2008.

Centers for Disease Control and Prevention. *Incorporating HIV Prevention into the Medical Care of Persons living with HIV*. MMWR 52 (RR-12): 1-24, 2003. www.cdc.gov/mmwr/Preview/mmwrhtml/rr5212a1.htm

EngenderHealth, GNP+, ICW, IPPF, UNAIDS, Young Positives. *Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV: A Guidance Package*. 2009. www.gnpplus.net/component/option,com_docman/task,doc_download/gid,334/Itemid,53/ (in English)
www.gnpplus.net/component/option,com_docman/task,doc_download/gid,336/Itemid,53/ (en français)

Global HIV Prevention Working Group. *HIV Prevention in the Era of Expanded Treatment Access*. Gates Foundation and Kaiser Family Foundation, 2004. www.kff.org/hivaids/upload/HIV-Prevention-in-the-Era-of-Expanded-Treatment-Access.pdf

International HIV/AIDS Alliance. *Positive Prevention: HIV Prevention with People living with HIV – A guide for NGOs and Service Providers*. 2007.

Living 2008 Partnership. *Draft Discussion Paper: Positive Prevention by and for People Living with HIV*. Amsterdam, GNP+, July 2008. www.gnpplus.net/component/option,com_docman/task,cat_view/gid,260/Itemid,116/

Living 2008 Partnership. *Living 2008 Summit Theme: Positive Prevention*. www.living2008.org/images/stories/positive%20prevention%20en.pdf

Living 2008 Partnership. *Living 2008: The Positive Leadership Summit Report*. Amsterdam, GNP+, April 2009. www.gnpplus.net/content/view/1507/34/

Moody K. *Positive Prevention: Opportunity or Threat*. HealthDev, 2007. eforums.healthdev.org/read/messages?id=18479

Poz Prevention Definition, Values and Principles. Developed by the Poz Prevention Working Group and approved by the Provincial Advisory Body of the Ontario Gay Men's HIV Prevention Strategy, January 25, 2008. www.health.gov.on.ca/english/providers/pub/aids/reports/poz_prevention_definition_values_principles_j.pdf

UNAIDS. *HIV prevention focused on people living with HIV* (p 118) in *2008 Report on the Global AIDS Epidemic*. Geneva, UNAIDS, August 2008. www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp

UNAIDS. *Intensifying HIV Prevention. UNAIDS Policy Position Paper*. Geneva, UNAIDS, August 2005. data.unaids.org/Publications/IRC-pub06/jct165-intensif_hiv-newstyle_en.pdf

UNAIDS. *Practical Guidelines for Intensifying HIV Prevention: Towards Universal Access*. Geneva, UNAIDS, 2007. data.unaids.org/pub/Manual/2007/20070306_Prevention_Guidelines_Towards_Universal_Access_en.pdf

WHO. *Essential Prevention and Care Interventions for Adults and Adolescents living with HIV in Resource-limited Settings*. Geneva, WHO, 2008. www.who.int/hiv/pub/prev_care/OMS_EPP_AFF_en.pdf

WHO, UNAIDS, UNICEF. *Towards Universal Access: Scaling up priority HIV/AIDS Interventions in the Health Sector*. Geneva and New York: World Health Organization, UNAIDS and UNICEF, 2008. www.who.int/hiv/mediacentre/2008progressreport/en/index.html



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